

IMPACT OF FAMILY CAREGIVING UPON CAREGIVERS OF ELDERLY WITH  
DEMENTIA IN CHINA

by

Yu Liu

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SIGNED: Yu Liu

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## DEDICATION

This dissertation is dedicated to family caregivers and their elders with dementia in China.

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## ABSTRACT

Caring for an elder with dementia at home is considered a challenging and complex process. The purpose of this study was to describe the impact of family caregiving upon caregivers of elders with dementia on caregiver's health in the context of Chinese family caregiving. The investigation also describes the roles of caregiving appraisal, coping, familism, and perceived social support on the relationship between caregiving stressors and caregiver outcomes.

A cross-sectional correlational design was used to examine relationships among the variables. Ninety-six family caregivers of elders with dementia in China were recruited. Self-reported questionnaires were utilized to measure the variables.

Results from bivariate correlational analysis found that ADL impairments had no any significant relationship with other variables and was not used in model testing.. Path analysis indicated that the proposed Dementia Caregiving Model did not fit the data well. Model modifications were performed based on AMOS 5.0 output and the theoretical rationale for the potential modifications. The modified final model fit the data perfectly. It explained 21.1% and 39.7% of the variance in caregiver physical health and psychological health respectively. In the final models, behavioral problems of care-recipients and perceived social support of caregivers had direct and indirect effects on caregiver physical health and psychological health. Familism and caregiving satisfaction only had indirect effects on caregiver psychological health and no effects on caregiver physical health. Conversely, caregiving subjective burden and coping had direct effects on caregiver health; burden had direct effects on both physical and psychological health of caregivers, whereas coping had a direct effect on caregiver psychological health.

The findings enrich knowledge of dementia family caregiving in the context of China and Chinese culture and add the important variables of caregiver appraisal of caregiving satisfaction and familism to existing theories and models of stress and coping on family caregiving cross culturally. This study not only contributes to Chinese nursing research by introducing a conceptual model for family caregiving of elders with dementia, but also can be a basis for formulating interventions to help family caregivers of elders with dementia cope with their caregiving situations.

## CHAPTER I STATEMENT OF THE PROBLEM

Growing older is inevitable. Currently, we are facing a disproportionate increase in the percentage of elderly. The increased percentage of elderly will challenge social, economic, and family resources, and is a major challenge for most countries in the world. In 2000, 35.0 million people 65 years of age and over were counted in the United States (Hetzl & Smith, 2001). In China, 109.56 million people were 65 years of age or older and accounted for 8.3% of the population in 2008 (Ministry of Civil Affairs of the People's Republic of China, 2008). It is predicted that by 2020 there will be 67 million people who are 65 years of age or older in China, or 24% of the older people in the world (Xu, 2005).

As the population grows and lifespan expectancy increases, there is a co-occurring increased incidence of dementia. Because dementia results in progressive deterioration leading to disability and dependence, more care is required. Although formal home health services will be a factor in health care systems of the future, most of the care of aged and ill persons will be provided by family members (Schumacher, Stewart, & Archbold, 1998; Tian, 2003). In China, care of those with dementia typically occurs within the context of the family. Cultural norms and sociopolitical contexts directly and indirectly influence family caregiving, and caregivers with different cultural backgrounds are likely to perceive and react to caregiving in different ways (Connell & Gibson, 1997; Haley et al., 1996; Kim, Knight, & Longmire, 2007; Knight & Sayegh, 2010; Purnell & Paulanka, 2008). Hence, nurses need to consider the context of cultural, social, and historical processes when trying to understand and interpret caregiving behaviors and effects. This study explores how caring for elders with dementia at home affects family caregivers and whether the

context of familism in the Chinese culture influences the impact of caring upon caregivers.

### Background

Dementia occurs most often in older adults. In the United States, the first national population-based prevalence study of dementia found that nearly 14% of those aged 71 and older suffer from some form of dementia and almost 10% suffer from Alzheimer Disease (AD) (Plassman et al., 2007). In China, the prevalence of dementia varies among different cities, generally affecting 2.7% to 7.3% of people aged 60 and over (Tang et al., 2007; Tian et al., 2009). The incidence of dementia in China is around 5% and, as life expectancy increases, the incidence of dementia will continue to increase (Tian, 2003). The progressive degeneration of dementia leads to multiple cognitive deficits and results in disability and dependency. As the disease advances, individuals with dementia require more and more care.

In China, care of family members with dementia at home occurs commonly and is a reflection of Chinese culture. Chinese people live in a society strongly influenced by the traditions of filial piety and familism (Lou, 2007; Purnell & Paulanka, 2008). Filial piety is the responsibility of an adult child to care for his/her parent and to meet the needs of the parent (Lou, 2007; Park & Chesla, 2007). Familism describes strong identification, attachment and loyalty of individuals to their families (Park & Chesla, 2007). Under these traditional values, families try to take care of patients with dementia at home as long as possible. In addition, a shortage of formal long-term care for elders with dementia in China has made families the main caregiving source for patients. Despite the recognition that informal caregiving represents the main source of care for elders with dementia in China, studies related to

family caregiving are not extensive. However, this research area has grown dramatically in Western countries over the past 3 decades.

The negative impact of caregiving upon caregivers is the focus of most of this research. Taking care of a family member with AD or other dementia at home is widely recognized as challenging and stressful. "Caregiver burden" is a common concept in the literature on family care of dementia patients that reflects the negative impact of caregiving (Hunt, 2003). It was introduced into the literature by Grad and Sainsbury (1966) in an examination of community care for the mentally ill. They defined burden as any cost (negative impact) to the family of which the patient is a member.

Many studies indicate that long-term stressful caregiving negatively affects the caregiver's health. Relatives caring for a family member with dementia have poorer physical and psychological health than people without such tasks or responsibilities (Ducharme et al., 2007; Gallagher-Thompson et al., 2006; Gonzalez-Salvador et al., 1999; Schulz et al., 1995). These relatives have elevated symptoms of anxiety and depression compared to other caregivers in age-matched controls or populations means (Schulz et al., 1995; Losada et al., 2006), decreased immunity (Vedhara et al., 1999; De Vugt et al., 2005), and increased biologic vulnerabilities (Aschbacher et al., 2006). Taking care of dementia patients at home can also result in the decreased use of health services, role conflict (Heru & Ryan, 2006), social isolation, and decreased quality of life (Davis & Tremont, 2007; Given & Given, 1991; Serrano-Aguilar, Lopez-Bastida, & Yanes-Lopez, 2006). Caregivers also have an important influence on the course of AD and other dementias. A higher burden on the caregiver and the deterioration of caregivers' health usually result in institutionalization of the patient

and rapid deterioration of the illness (Dunkin & Anderson-Hanley, 1998; Gaugler et al., 2005; Kim et al., 2002; Torti et al., 2004). Though there are only a few studies from China, the findings are consistent with reports from Western countries that family caregivers of dementia patients experience burden and deteriorated health when they are taking care of family members with dementia at home (Fu et al., 2007; Meng et al., 2006; Yue et al., 2007; Zhang et al., 2003).

In addition, studies from Western countries and Asia including China found that both care-recipient factors and caregiver factors can affect the negative impact of caregiving on caregivers. The findings are consistent even though caregiving happens within a different cultural and ethnic context.

For the care-recipient characteristics, consistent findings are found between Western countries and Asia including China. Severe behavioral problems is the most consistent factor to negatively influence caregiver health ( Arai & Washio, 1999; Farran et al., 1993; Fu et al., 2007; Gallicchio et al., 2002; Harwood et al., 2000; Heok & Swee, 1997; Holley & Mast, 2009; McKeith & Cummings, 2005; Meng et al., 2007; Rymer et al., 2002; Thomas et al., 2006; Yue et al., 2007; Zhang et al., 2003). Severity of cognitive impairment and ADL function are found to negatively impact caregiver health in some studies (Aguglia et al., 2004;Chappell & Reid, 2002; Gonzalez-Salvador et al., 1999; Meng et al., 2006; Schulz et al., 1995; Zhang et al., 2003), but not in others (Schulz et al., 1995; Sussman & Regehr, 2009; Yue et al., 2007). Consistent findings on the influence of caregiver characteristics are also reported. For instance, being female (Chou, LaMontagen, & Hepworth, 1999; Fu et al., 2007; Gallicchio et al., 2002; Youn et al., 1999), children (Arai et al., 2000; Andren &

Elmstahl, 2007), and younger caregivers (Kim et al., 2002; Schneider et al., 1999; Yue et al., 2007) all predicted a higher burden of caregiving.

Compared with care-recipient factors, caregiver factors are repeatedly demonstrated as having profound influence on the negative impact of caregiving on caregivers. Caregiver variables have typically been thought of as mediating or moderating (Dilworth-Anderson, Williams, & Gibson, 2002; Dunkin & Anderson-Hanley, 1998; George & Gwyther, 1986). In other words, they are variables that alter the relationship between stressors and consequent outcomes. In addition to caregiver demographic characteristics, the pre-morbid relationship history with the care-recipient, coping strategies caregiver used and perceived social support by of the caregiver are three important caregiver factors, which are getting more attention in the study of caregiving. The influences of these factors on caregiving processes are also considered embedded within the context of different ethnicities and cultures (see reviews from Aranda & Knight, 1997; Janevic & Connell, 2001; Knight & Sayegh, 2010).

Notably, some studies from Western countries reported that caregivers appear to adapt to the challenges of caregiving over time even as the patient continues to deteriorate, whereas others report continuing and increasing strain and burden (Dunkin & Anderson-Hanley, 1998). These observed individual differences in stress response and outcomes have been theoretically explained as the result of people's cognitive appraisal and coping strategies (Haley et al., 1996; Lazarus & Folkman, 1984; Lawton et al., 1989). It is believed that the perception and interpretation of a significant encounter and how people cope with it, rather than the encounter itself, are paramount to these differences.

Congruent with theoretical explanations, some studies have found that providing care to relatives with dementia can also be perceived as a positive experience by family caregivers. This positive experience has been conceptualized in different ways such as satisfaction (Kramer, 1993; Lawton et al., 1989), rewards (Picot, 1995), meaning through caregiving (Farran et al., 1991), and uplifts (Kinney & Stephens, 1989; Pruchno, Michaels, & Potashnik, 1990). This positive experience of caregiving perceived by caregivers is found to be inversely related to their depression (Cohen, Colantonio, & Vernich, 2002; Talkington-Boyer & Snyder, 1994; Yee & Schulz, 2000) and subjective burden (Cohen et al., 1994; Cohen, Colantonio, & Vernich, 2002; Lawton et al., 1992). However, the relationship between the positive and negative aspects of providing care is moderate or modest, which means they may coexist and be related to different aspects of the caregiver situation (Andren & Elmstahl, 2005; Rapp & Chao, 2000). It indicates that caregivers may not only have adverse experiences, but also positive feelings when they provide care (Kramer, 1997).

During the complex process of family caregiving, coping also plays a key role with caregiving appraisal influencing the effect of stressors on caregiver outcomes. Coping is defined as a person's ongoing cognitive and behavioral efforts to manage stressful demands (Lazarus & Folkman, 1984). Specifically in the situation of caregiving, coping is the way one deals with stressful situations. The relationship between emotion-focused coping (e.g., avoidance, wishfulness, and emotional discharge) and depression has been found in several studies (Fingerman et al., 1996; Knussen et al., 2008; Powers, Gallagher-Thompson, & Kraemer, 2002; Pruchno & Resch, 1989; Sanders-Dewey, Mullins, & Chaney, 2001; Vitaliano et al., 1985; Williamson & Schulz, 1993) which indicates that caregivers who utilized more

emotion-focused coping were more likely to be depressed. On the other hand, the association between problem-focused coping and depression is not consistently found. Some studies show a relationship between problem-focused coping strategies and lower levels of depressive symptoms (Haley, Levine, Brown, & Bartolucci, 1987; Kneebone & Martin, 2003; Vitaliano et al., 1985), although other studies have found no such relationship (Fingerman et al., 1996; Pruchno & Resch, 1989; Williamson & Schulz, 1993). Inconsistencies in the current literature suggest a need for further exploration.

Lazarus and Folkman (1984) believe that personal and environmental factors can influence his or her appraisal of stressors and the choice of coping strategies. One of these factors, perceived social support, has been defined as “the nature of the interactions occurring in social relationships, especially how these are evaluated by the person as to their supportiveness” (Lazarus & Folkman, 1984, p.249). Perceived social support reflects the support that is believed to be available by caregivers at any moment. It is considered a more consistent predictor of caregiver well-being than actual support or network size (Williams & Dilworth-Anderson, 2002; Roth et al., 2005). Some studies also report important influence of perceived social support on caregiving appraisal and coping. For instance, caregivers with higher levels of perceived support were less emotionally reactive to a stressor occurring in their environments compared to caregivers with lower levels of perceived support (Atienza et al., 2001; Thoits, 1995). This was explained as the feeling of controlling the situation was increased among caregivers who had higher levels of perceived social support. This control belief may influence the caregiving appraisal, and in turn, protect psychological well-being. However, whether perceived social support

influences both caregiving subjective burden and caregiving satisfaction is still not clear. In addition, perceived social support can be considered a coping resource, which influences the way someone copes with a situation as well as the outcome of these coping efforts (Lazarus & Folkman, 1984; Pierce, Sarason, & Sarason, 1996). However, there are few studies that have explored the effects of perceived social support on coping of caregivers, and more research evidence is needed especially within different cultural contexts.

Values and beliefs of caregiving are personal factors and can influence a person's appraisal of stressors and the selection of coping strategies (Lazarus & Folkman, 1984). Thus, cultural factors play important roles on constructing a person's values and beliefs and could influence caregiving appraisal as well as selected coping strategies. Several studies reported greater satisfaction with caregiving among African-American caregivers compared to Caucasians (Lawton et al., 1992; Rapp & Chao, 2000). Other studies found that African American caregivers used more avoidant coping strategies than White caregivers (for a review, see Dilworth-Anderson, Williams, & Gibson, 2002). This suggests that caregiving appraisal and the selection of coping strategies may operate differently across ethnic groups who have different cultural backgrounds.

Familism is a central concept in Asian culture affecting people's beliefs and values and hence family caregiving. Several studies have examined the relationships of familism to the negative aspects of caregiving, but the results are not consistent. Youn and colleagues (1999) found that familism did not protect against caregiving distress, but may actually increase it. Conversely, other studies (Coon et al., 2004; Shurgot & Knight, 2004) suggest that familism can be a protective factor against

negative caregiving outcomes such as burden. Unfortunately, there were no studies found that explore how familism influences the choice of coping strategies among family caregivers of elders with dementia in Asian countries.

It has been suggested that the influence of cultural variables on caregiver outcomes may not be direct and may operate by influencing both caregiving appraisal and choice of specific coping strategies (Aranda & Knight, 1997; Dilworth-Anderson, Williams, & Gibson, 2002; Haley et al., 1996; Knight & Sayegh, 2010). Further studies should measure these variables in order to more fully explain this possibility. In China, there are no studies that address the influence of culture on caregiving appraisal and coping strategies. Studies in this area are needed.

In summary, past research documents the negative impact of caregiving on caregivers, while recent research has tried to elaborate the meaning of caregiving by examining not only the negative impact of caregiving upon caregivers but also those seen as positive by the caregivers themselves. However, literature on the investigation of both the positive and negative impact is underdeveloped not only in western countries, but also in Asia. In addition, care of elders with dementia at home has been considered a complex process in which caregiving appraisal and caregiver coping work together to affect the relationship between caregiving stressors and caregiver outcomes. Thus, caregiving research for dementia care at home should pay equal attention to caregiving appraisal as well as coping. Even though family care for elderly with dementia is becoming an important social issue in China, few studies systematically explore the complex caregiving process. Chinese culture emphasizes the key role family plays in coping when a member becomes sick, and it also highly values the efforts that each family member contributes in order to re-achieve family

harmony. Therefore, how caring for elders with dementia at home affects family caregivers and whether perceived social support and Chinese culture, especially the belief of familism significantly influence coping and the positive and negative aspects of caring as perceived by caregivers, and in turn, affect caregiver outcomes, are questions that need to be addressed.

### Conceptual Framework of the Study

Based on the Stress and Coping Model (Lazarus & Folkman, 1984) and the Two-factor Model of Caregiving (Lawton et al., 1991), the Dementia Caregiving Model (DCM) was developed and used as the conceptual framework in the study. In the following, the Stress and Coping Model and the Two-factor Model of Caregiving are presented, followed by the Dementia Caregiving Model.

#### *The Stress and Coping Model*

The stress paradigm has played a dominant role in the field of psychology with regard to the perception of life stress as it pertains to health and well-being. Much of this literature is anchored within the Stress and Coping Model (also named the transaction model of stress and coping) developed by Lazarus and Folkman (1984).

In the model, environmental situations that could be harmful (the stressors) are appraised by the person in terms of whether they are in fact a threat to the person (primary appraisal). If judged to be threatening, challenging, or harmful, a process of secondary appraisal begins whereby the person judges whether the methods available for dealing with the potential stress are adequate. In this model, stress is regarded as a relational concept. Stress is not defined as a specific kind of external stimulation or a specific pattern of physiological, behavioral, or subjective reaction. Instead, stress is viewed as a relationship (transaction) between individuals and their environment.

“Stress refers to a relationship with the environment that the person appraises as significant for his or her well being and in which the demands tax or exceed available coping resources” (Lazarus & Folkman, 1984, p.21). This definition points to two processes as central mediators within the person-environment transaction: cognitive appraisal and coping.

The concept of cognitive appraisal is a key factor for understanding stress-relevant transactions. According to Lazarus and Folkman (1984), “cognitive appraisal can be most readily understood as the process of categorizing an encounter, and its various facets, with respect to its significance for well-being...it is largely evaluative, focused on meaning, or significance, and takes place continuously during waking life” (p.31). Thus, the perception and interpretation of a significant encounter, rather than the encounter itself, is paramount to observe individual differences in stress response and outcomes. This concept is necessary to explain individual differences in quality, intensity, and duration of an elicited emotion in environments that are objectively equal for different individuals. In Lazarus and Folkman’s model, there are two basic forms of appraisal, which are primary and secondary appraisal. Primary appraisal concerns whether something of relevance to the individual’s well being occurs, whereas secondary appraisal concerns coping options. The appraisals, in turn, are determined by a number of personal and situational factors. The most important personal factors are motivational dispositions, goals, values, and generalized expectancies. Relevant situational parameters are predictability, controllability, and imminence of a potentially stressful event.

Cognitive appraisal associated with demands in the environment engenders coping responses by the individual. Coping is defined as “the 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” (Lazarus & Folkman, 1984, p.141). Coping serves two major functions: to regulate distress (emotion-focused coping) and to do something to change for the better the stressful encounter (problem-focused coping). Either emotion-focused or problem-focused forms of coping are superior in terms of their adaptive values. However, when an encounter is appraised as unchangeable, emotion-focused coping strategies are likely to be predominantly used. In contrast, when an encounter is appraised as changeable, problem-focused coping strategies are likely to be predominantly selected over emotion-focused ones (Folkman, 1997). Lazarus and Folkman (1984) propose that coping is a process that evolves from resources, and the way people actually cope also depends heavily on the resources that are available to them.

Ultimately, an individual’s cognitive appraisal and coping efforts affect adaptation outcomes. The three basic kinds of outcomes are functioning in work and social living, morale or life satisfaction, and somatic health (Lazarus & Folkman, 1984). Simply put, mental and physical health and quality of life are combined together when people evaluate and cope with the stress of living (Lazarus & Folkman, 1984). They are intertwined and compose a general trait of good or poor adaptation. That is, if the person functions well, he or she has good morale and somatic health (Lazarus & Folkman, 1984).

In summary, the Stress and Coping Model proposes a multidimensional conceptualization of the stress process and highlights the influences of the person’s cognitive appraisal and coping on the stressor-adaptational outcome relationship. It also emphasizes the importance of contextual factors (including personal and

situational factors) on the stress process, and the significance of considering the adaptation outcome as good morale and somatic health with normal social functioning.

### *The Two-factor Model of Caregiving*

Based on the Stress and Coping Model (Lazarus & Folkman, 1984) and the conceptualization of psychological well-being as constituting the two orthogonal dimensions of positive and negative affect (Bradburn, 1969, cited in Lawton et al., 1991), Lawton and colleagues (1991) developed a two-factor model of caregiving appraisal and psychological well-being that addressed the positive and negative aspects of the caregiving experience. They view the caregiver's subjective responses to caregiving as secondary appraisal. That is, the person's evaluation of the ongoing quality of his or her caregiving experience is seen as a mediator between the demand of caregiving and the outcome of psychological well-being. They propose that "the central feature of this caregiving model is that parallel processes occur in which the two types of appraisal differentially affect the two types of psychological well-being in ways that are congruent with their valence: satisfactions led to positive affect and burdens to negative affect" (p.182). The effects of caregiver resources (physical health and informal assistance) on both caregiving appraisals and psychological well-being are also specified in the model.

The Two-factor Model of caregiving draws upon stress related research and thus includes several key constructs, which are stressors, caregiving appraisal, resources, and psychological well-being.

Stressors represent environmental demands specific to the caregiving experience that may be perceived through the process of primary appraisal as potential threats to the person (Lawton et al., 1989, 1991). They point out that the

stressor has frequently been represented by the degree of disability of the person being cared for (Lawton et al., 1989, 1991).

In this model, Lawton and colleagues (1991, 1992) agree with the meaning of primary appraisal and secondary appraisal from the Stress and Coping Model (Lazarus & Folkman, 1984). Primary appraisal is defined as the process of appraisal when an environmental situation (the stressor) is appraised by the person in terms of whether it is in fact a threat to the person. If judged to be threatening, challenging, or harmful, a process of secondary appraisal begins (Lawton et al., 1989, 1991). Within the caregiving context, secondary appraisal represents an evaluative process of the quality of the caregiving experience as well as the cognitive and affective responses that mediate the relationship between caregiving stressors and psychological well-being (Lawton et al., 1991).

Upon the definitions of primary appraisal and secondary appraisal, Lawton and colleagues eventually developed the term “caregiving appraisal” to describe the evaluation of any part of the caregiving process (Lawton et al., 1991). Within the evaluation, caregiving satisfaction and caregiving subjective burden are the two most important parts. Caregiving satisfaction represents “subjectively perceived gains from desirable aspects of, or positive affective returns from, caregiving” (Lawton et al., 1991, p.182); caregiving subjective burden is the perception of psychological distress, anxiety, demoralization, and generalized loss of personal freedom attributed directly to caregiving.

Resources are seen as sources of strength within the person or in the external environment that mitigate the influence of caregiver stressors. Examples include

caregiver's physical health, income, education, occupational status, and social support (Lawton et al., 1991).

Psychological well-being is viewed as an outcome of caregiving (Lawton et al., 1991, p.182). It is viewed as the distinct dimensions of positive and negative affect (Lawton et al., 1991).

In summary, the Two-factor Model of Caregiving is a concrete utilization of the stress and Coping Model in caregiving research. It highlights the influence of positive and negative appraisals on psychological outcomes and emphasizes the importance to study both positive and negative impact of providing care on family caregivers. However, in this model, coping strategies and some contextual factors (e.g., caregiver's age, gender, relationship history to the patient, and beliefs on providing care), which have actually been found as important influencing factors in caregiving research are paid less attention with limited explanations, and caregiver's outcome is only represented by psychological well-being, which can not give a whole picture on caregiver's health.

#### *Dementia Caregiving Model*

Based on the Stress and Coping Model and the Two-factor Model of Caregiving, the Dementia Caregiving Model (DCM) was developed to overcome the limitations of the Two-factor Model of Caregiving and was utilized for this study, which investigated the impact of caregiving on family caregivers of elders with dementia in China (see Figure 1).

This model describes the complexity of the caregiving process and covers the following 5 constructs which include multiple components. The five constructs are stressors, caregiving appraisal, coping, caregiver outcomes (caregiver's health), and

contextual factors (caregiver's characteristics, beliefs on providing care, and perceived social support). The five constructs and related concepts in this model are also detailed in Figure 1.

According to the two-factor model of caregiving (Lawton, 1991), caregiving is considered an activity of mixed valence involving positive and negative aspects that are independent of one another yet all related to the experience of caregiving. Family caregivers are defined as relatives of an older person who provide, arrange, or oversee services that the older person needs because of dementia.

#### *Caregiving Stressors*

According to the two-factor model of caregiving (Lawton, 1991), caregiving stressors are defined as environmental demands specific to the caregiving experience that may be perceived through the process of primary appraisal as potential threats to the person. Within the family caregiving situation, the stressors have frequently been represented by the degree of disability of the person being cared for (Lawton, 1991). In this study, the degree of disability of the elders with dementia is evaluated by functional impairment and dementia related behavior problems, which resulted from the deterioration of cognitive function of an older person.

#### *Caregiving Appraisal*

The definition of caregiving appraisal in the DCM is consistent with the one from the Two-factor Model of Caregiving. It has a similar meaning with the term of "secondary appraisal" from Lazarus and Folkman's (1984) Stress and Coping Model. Caregiving appraisal describes the evaluation of any part of the caregiving process. It mediates the relationship between caregiving stressors and caregiver outcomes. There

are two important parts within caregiving appraisal, which are caregiving satisfaction and caregiving subjective burden.

Caregiving satisfaction represents “subjectively perceived gains from desirable aspects of, or positive affective returns from, caregiving” (Lawton et al., 1991, p.182); caregiving subjective burden is the perception of psychological distress, anxiety, demoralization, and generalized loss of personal freedom that are attributed directly to caregiving (Lawton et al., 1991).

### *Coping*

In this model, coping is defined as “the 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” (Lazarus & Folkman, 1984, p.141). Coping also mediates the relationship between caregiving stressors and caregiver outcomes.

From Lazarus and Folkman (1984), there are two forms of coping, which are problem-focused coping and emotion-focused coping. Problem-focused coping is to do something to change for the better of the stressful encounter, and emotion-focused coping is to regulate distress. However, since these coping strategies were not culturally appropriate for Chinese population (Xie, 1989), this study utilized Xie’s category for coping strategies, which were grouped into 2 categories. One was positive coping strategies, and the other one was negative coping strategies. For the positive coping strategies, they reflected the ways that people seek help and tried different ways to solve the problems (i.e., getting help and advice from other people; trying to see it in a different light), whereas the negative strategies reflected that people avoided facts and did not actively solve the problems (i.e., using alcohol or

other drugs to make myself feel better; saying to myself “this isn’t real”). The type of coping chosen depended partly on an individual’s appraisal of the situation’s amenability to change and his or her resources, and there were not absolute good or bad coping strategies (Xie, 1989).

### *Contextual Factors*

Contextual factors are elements that make up the history of the caregiving career and have a potential impact on the caregiving stress process. Contextual factors usually include:

1. Caregiver characteristics, such as age, gender, educational level, occupational, economic attainments, duration of caregiving, relationship of the caregiver to the care-recipient (i.e., son, daughter, daughter in law, or spouse), and the pre-morbid relationship history.

In this study, even though caregiver characteristics were included in the Dementia Caregiving Model, they were used to provide a description of caregivers and care-recipients and their background without further exploration. They do need to be investigated in-depth in the future because some of them have been verified as having consistent influences on caregiver outcomes with studies from Western countries.

2. Beliefs on providing care. According to Lazarus and Folkman’s (1984) model, commitments and beliefs are important personal factors affecting cognitive appraisal and coping. Commitments are an expression of what is important to people, and they underlie the choices people make. Beliefs also determine how a person evaluates what is happening or is about to happen, and the ways they cope.

In this model, beliefs on providing care are considered values and beliefs that influence caregiver's commitments and beliefs on providing care. It is considered as being strongly influenced by familism, a highly valued Chinese cultural norm especially when family members get sick. It describes strong identification, attachment, and loyalty of individuals to their families (Park & Chesla, 2007).

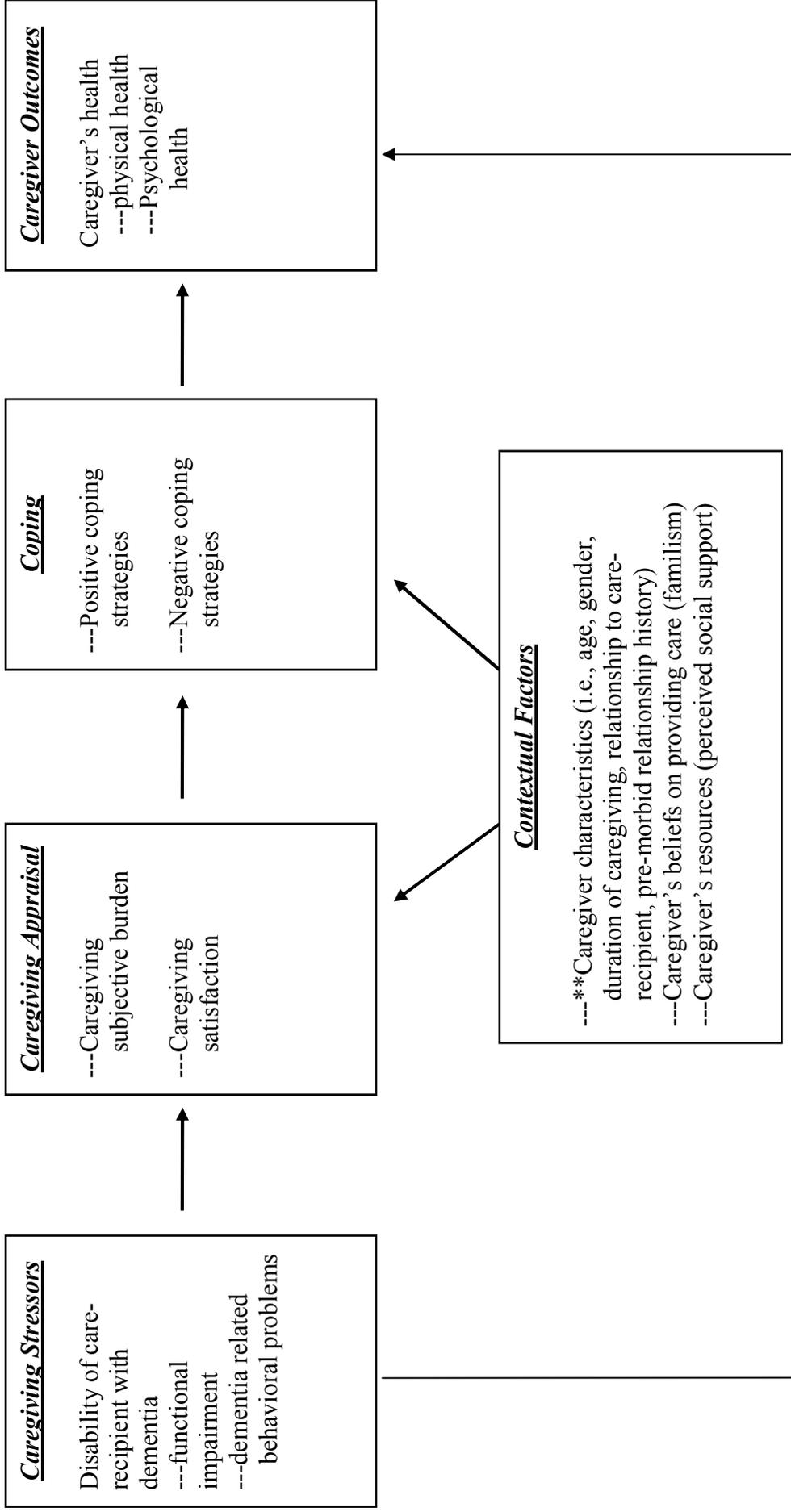
3. Resources. According to Lazarus and Folkman (1984) and Lawton and his colleagues (1989, 1991), person's appraisal and the way a person copes are all influenced by his or her resources that may be within the person or in the external environment. For instance, the caregiver's energy, existential beliefs (e.g., about God), commitments, social skills, and social support. In the DCM, resources are especially represented by perceived social support referring to "the nature of the interactions occurring in social relationships, especially how these are evaluated by the person as to their supportiveness (Lazarus & Folkman, 1984, p.249)".

#### *Caregiver Outcomes*

According to Lazarus & Folkman (1984), good morale and somatic health reflect good adaptation outcomes to stressors. Thus, in the DCM, the outcome is observed by caregiver's health which is composed of physical and psychological health.

In summary, the Dementia Caregiving Model emphasizes the multidimensional aspects of the complex caregiving process. This model provides useful insights as to what constructs should be assessed when determining the impact of caregiving. The Dementia Caregiving Model suggests that caregiving stressors do not affect caregiver health directly, but rather through the processes of caregiving appraisal and coping mediate them. More specifically, it is not the mere presence of

stressors that affects caregiver's outcome, but the caregiver's appraisal of burden and appraisal of satisfaction, as well as coping that will impact the outcomes of caregivers. Contextual factors in terms of caregiver characteristics, beliefs on providing care, and perceived social support also have influences on the relationship of caregiving stressors to caregiver outcomes via caregiving appraisal and coping.



Note: \*\*= variables which were not explored in this study

FIGURE 1. Dementia Caregiving Model

### Purposes of the Study and Research Questions

The purpose of this study was to describe the impact of family caregiving upon caregivers of elders with dementia in terms of caregiver's health in the context of Chinese family caregiving, and investigate the role of caregiving appraisal, coping, familism, and perceived social support on the relationship between caregiving stressors and caregiver outcomes.

The specific research questions and related hypotheses were as follows:

1. What are the associations among caregiving stressors (functional impairment and behavior problems), familism, perceived social support, caregiving appraisal (caregiving subjective burden and caregiving satisfaction), the coping composite (the composite variable for positive and negative coping), and caregiver outcomes (physical health and psychological) among family caregivers of elders with dementia in China?

2. What are the effects of caregiving stressors, familism, perceived social support, caregiving subjective burden, caregiving satisfaction, and the coping composite on the caregiver outcomes?

*Hypothesis (1)* The hypothesized associations in the causal model fit the collected data.

*Hypothesis (2)* There is a direct effect of caregiving stressors and the direct effect is inversely associated with the caregiver outcomes.

*Hypothesis (3)* There is an indirect effect of caregiving stressors on the caregiver outcomes through its relationships with caregiving satisfaction and the coping composite.

Hypothesis (4) There is an indirect effect of caregiving stressors on the caregiver outcomes through its relationships with caregiving subjective burden and the coping composite.

Hypothesis (5) There is an indirect effect of familism on the caregiver outcomes through its relationships with caregiving satisfaction and the coping composite.

Hypothesis (6) There is an indirect effect of familism on the caregiver outcomes through its relationships with caregiving subjective burden and the coping composite.

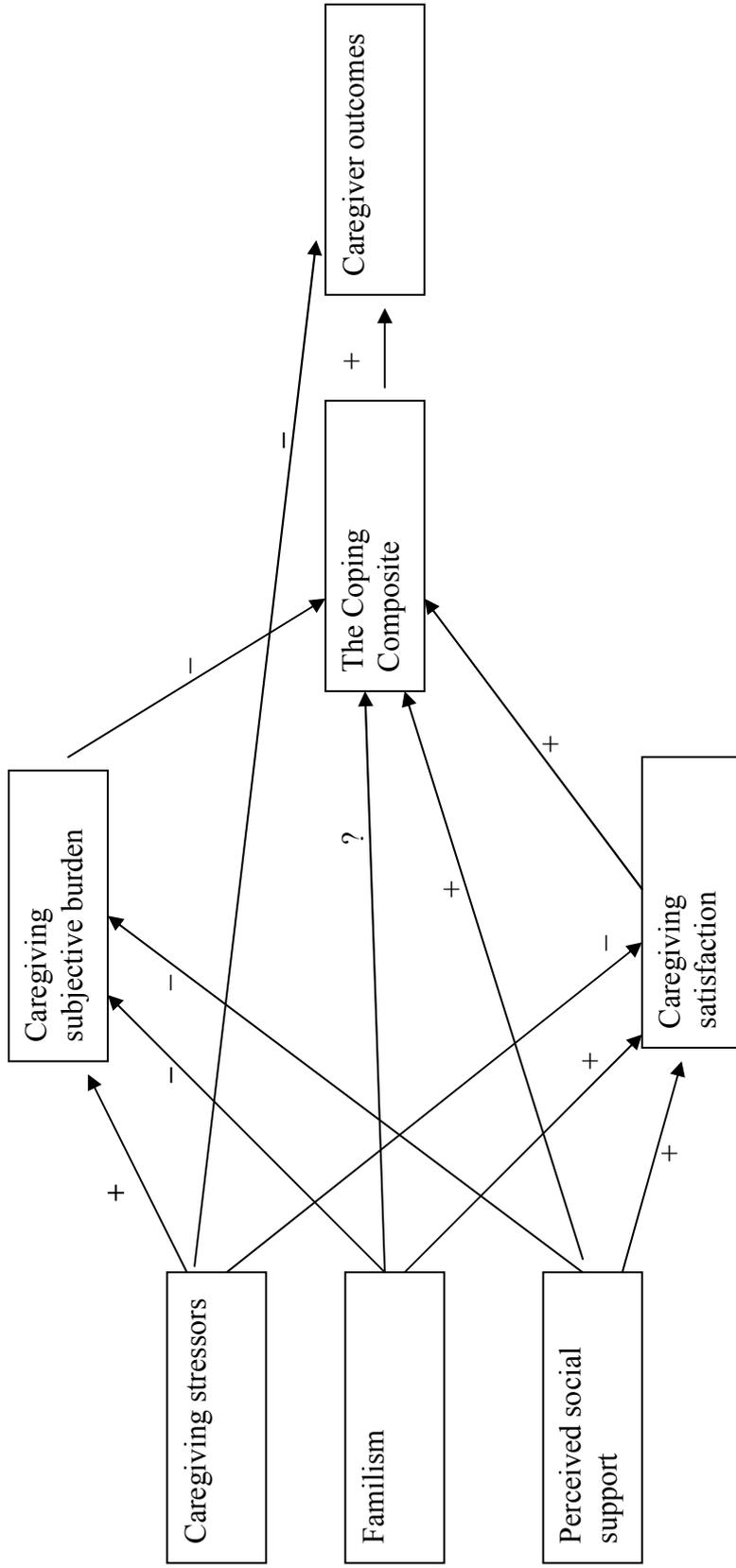
Hypothesis (7) There is an indirect effect of familism on the caregiver outcomes through its relationships with the coping composite.

Hypothesis (8) There is an indirect effect of perceived social support on the caregiver outcomes through its relationships with caregiving satisfaction and the coping composite.

Hypothesis (9) There is an indirect effect of perceived social support on the caregiver outcomes through its relationships with caregiving subjective burden and the coping composite.

Hypothesis (10) There is an indirect effect of perceived social support on the caregiver outcomes through its relationships with the coping composite.

All the hypotheses are depicted in Figure 2 as well as the hypothesized paths.



**FIGURE 2. Path Model for Dementia Caregiving Model**

## Significance of the Study

### *Help Understand the Complex Process of Family Caregiving*

The evidence of relationships among caregiving stressors, caregiving appraisal, coping, and caregiver outcomes supports the complexity of the processes of caregiving and gives scientific explanations about how caregiver health is affected by providing care to a family member with dementia. The findings may ensure the important roles of caregiving appraisal and coping on the relationship between caregiving stressors and caregiver outcomes and enrich the reasons that different caregivers have different adaptational outcomes when they provide care to elders with dementia.

In addition, knowledge in family caregiving of dementia patients has revealed that caregivers not only have adverse experiences, but also positive feelings related to their caregiver role. The findings of this study will enrich knowledge addressing this new critical point within the Chinese culture and help nurses see the total picture of family caregiving. Lack of attention to the positive dimension of caregiving seriously skews perceptions of the caregiving experience and limits the ability to help family caregivers adapt to the challenging caregiving context (Kramer, 1997).

### *Explore a Cultural Effect on Family Caregiving*

As a marked increase in the migration of people within and between countries worldwide, there has been a rise in multicultural identities, with people expecting their cultural beliefs, values, and life ways to be understood and respected by nurses and other health care providers (Andrews & Boyle, 2003; Purnell & Paulanka, 2008). The findings of the influence of familism on the relationship between caregiving stressors and

caregiver's outcomes via caregiving appraisal and coping will help nurses explore a cultural effect on family caregiving and get better understanding on how it works. The findings will not only be helpful for nurses in China but also for nurses who are working worldwide and have the chance to take care patients with dementia and their family members with similar cultural background with China, which also places high values on the belief of familism. The findings of this study will enable nurses to better understand and communicate more effectively with families of dementia patients from Chinese cultural background and other similar cultural background.

*Provide Research-based Directions for Future Nursing Interventions*

The evidence of mediated roles of caregiving appraisal and coping, and the influencing effects of familism and perceived social support will help nurses design some research-based nursing interventions for families with dementia. The findings of this study will also enable nurses to provide more culturally appropriate interventions to families in order to help them cope with the caregiving challenges smoothly and successfully. For instance, under the present societal norms in China, institutionalization of impaired elderly is discouraged, and family members who do this may be treated with contempt. Child caregivers also experience feelings of guilt about institutionalizing their elderly parents. Therefore, to diminish or prevent negative effects associated with family caregiving, culturally acceptable and accessible formal support programs are necessary, such as programs of home health care, respite care for caregivers, and adult day care centers. In addition, the findings of this study may influence health care personnel in China to provide effective support for families with dementia patients, which in turn, help

caregivers choose more positive coping strategies to deal with those challenging caregiving situations.

## CHAPTER II LITERATURE REVIEW

Following the main constructs in the Dementia Caregiving Model, which was used as the conceptual model in the study (see Figure 1), this chapter is organized into 5 sections: (a) dementia and family caregiving; (b) caregiver outcomes; (c) caregiving appraisal; (d) coping; (e) contextual factors which include beliefs on providing care (familism) and caregiver resources (perceived social support). The review includes studies from Western countries as well as Asian countries and China.

### Dementia and Family Caregiving

#### *Prevalence of Dementia and its Clinical Manifestations*

Dementia is a syndrome, not a disease. It is characterized by dysfunction or loss of memory, orientation, attention, language, judgment and reasoning. It also results in changes in the patient's behavior. Ultimately, these problems result in alterations in the individual's ability to work, take care of social and family responsibilities, and maintain activities of daily living (Heitkemper, Hansen, & Lewis, 2004; Zarit & Zarit, 2007).

Dementia can be caused by many different disorders. Among these causes, Alzheimer's Disease (AD) is the most frequent cause of dementia in the United States and Europe (Zarit & Zarit, 2007; Morris, 2005; O'Connor, 2005). Based on postmortem examinations, about three-quarters of cases of dementia involve Alzheimer-type pathologies-amyloid plaques and neurofibrillary tangles (Barker et al., 2002; Knopman et al., 2003). Vascular dementia (VaD) is the second most common cause of dementia because the cerebrovascular damage can disrupt neural systems important for cognition and increase the frequency of stroke with age (Morris, 2005; O'Connor, 2005; Zarit &

Zarit, 2007). The prevalence of VaD accounts for an estimated 15% to 20% of dementia cases (Mendez & Cummings, 2003; Morris, 2005; O'Brien et al., 2003; Peisah, Sachdev, & Brodaty, 1993). VaD and AD often coincide and appear to have additive effects. Between 8% and 30% of cases of dementia have been found to have mixed vascular and Alzheimer's pathologies (Gearing et al., 1995; Knopman et al., 2003). In China, AD and VaD also are the major causes for dementia, though the prevalence rate of VaD is lower than that of AD (Lai et al., 2000; Qu et al., 2001; Tang et al., 2007; Tian et al., 2009; Zhou et al., 2001; Zhang et al., 2001).

The typical pathological changes of AD include the degeneration and loss of nerve cells (neurons), particularly in those regions essential for memory and cognition, and the presence of amyloid plaques and neurofibrillary tangles (Master, 2005; Zarit & Zarit, 2007). Amyloid plaques are accumulations of degenerative nerve endings and other material, with a core of the peptide beta amyloid. Located near synapses, plaques probably interfere with communication between neurons and may also be toxic to healthy cells. Neurofibrillary tangles are twisted strands of protein found within the bodies of nerve cells. Tangles probably interfere with the cells' energy metabolism and the movement of chemicals to cell endings, eventually leading to cell death. This loss of neurons can result in atrophy. Cell loss is most pronounced in the temporolimbic region, particularly the hippocampus, entorhinal cortex, and amygdala, as well as in frontal and temporoparietal areas of the brain (Master, 2005; Mendez & Cummings, 2003). Sensorimotor areas are relatively spared. These patterns of cell loss correspond to typical neuropsychological performance found in AD patients. Accompanying the loss of cells is

a decrease of certain neurotransmitters, the chemicals that permit communication across the synapses between neurons. Among the affected neurotransmitters are acetylcholine, serotonin, and norepinephrine (Master, 2005; Mendez & Cummings, 2003).

Vascular Dementia is a heterogeneous category of disorders in which the common feature is vascular pathology (O'Brien et al., 2003; Zarit & Zarit, 2007). The most widely known type of VaD, multi-infarct dementia, involves the occurrence of multiple strokes or "infarcts" in the cerebral cortex. Infarcts result in the death of surrounding tissue due to insufficient blood supply (Mendez & Cummings, 2003; Morris, 2005; Zarit & Zarit, 2007). The most common forms, however, are characterized by small-vessel ischemic changes, or lacunas, and extensive white-matter lesions (Mendez & Cummings; Morris; Zarit & Zarit). Lacunar states are caused by occlusion in small vessels in the frontal lobes, basal ganglia, and other areas. White-matter lesions are found among both healthy older people and those with dementia; however, dementia is found when white-matter lesions are more extensive (Pantoni et al., 1999) and when they occur in combination with other vascular and nonvascular pathology, including AD and Lewy body dementia (Peisah et al., 1993).

All these abnormal physiological changes for AD and VaD have resulted in impairments of patient cognition and function, and eventually result in loss of self-care ability and total dependence on care provided by others (Zarit & Zarit, 2007).

For individuals with dementia, because of the special pathological changes, there are several kinds of symptoms. These symptoms also are the reason why taking care of dementia patients is very challenging. Three broad domains for the impairments in

dementia patients have been utilized by many studies. These domains are cognitive function, functional capacity, and behavioral problems (Dunkin & Anderson-Hanley, 1998; Given & Given, 1991; Tian, 2003; Zarit & Zarit, 2007). More specifically, functional impairment and behavioral problems are consequences of cognitive decline among patients with dementia. Impairments in these three domains reflect needed care and affect the caregiving process. The care needs are appraised as stressors by caregivers.

### *Cognitive Function*

Cognitive function is critical to an individual's performance in every aspect of life (Hooyman & Kiyak, 1991; Langley, 2000). It is commonly broken down into several domains: attention, memory (calculation/working memory, episodic and semantic memory, implicit and procedural memory), orientation, language, visual-spatial abilities, psychomotor speed, executive/problem solving, and intelligence (Langley, 2000). Dementia, in contrast to normal age-related cognitive changes, leads to severe, irreversible, and global deterioration of cognitive function (Hooyman & Kiyak, 1991; Zarit & Zarit, 2007).

In the early stage of dementia, the pattern of cognitive impairments varies depending on the site of brain damage and the type of dementia. For example, AD is characterized with insidious onset and gradual decline in memory and is typically noticed first. Initially the patient has difficulty recalling new information such as names or details of conversation (short-term memory), while remote memories are relatively preserved. With progression, the memory loss worsens to include remote memory (Corey-Bloom & Fleisher, 2005; Zarit & Zarit, 2007).

In contrast, for VaD patients, impaired memory is not as prominent a symptom as in AD, while frontal lobe executive abilities and language deficits may be prominent at the early stage. Vascular Dementia reflects sudden onset and stepwise progression. In all kinds of dementia, as the dementia progresses, global deterioration of cognitive function is revealed.

There are several well used measures to examine cognitive function in dementia patients: Mini-Mental State Examination, Global Deterioration Scale, and Clinical Dementia Rating Scale (Langley, 2000; Zarit & Zarit, 2007). Each of these measures can reflect the level of cognitive impairment for dementia patients and provide information on patients care needs and treatment effects. .

### *Functional Capacity*

Over the years, functional capacity has come to mean a person's ability to perform activities of daily living deemed necessary to survive adequately in modern society (Pearson, 2000). Functional capacity assessment includes three major domains: activities of daily living (ADLs) (e.g., dressing, bathing, eating, grooming, toileting, bladder/bowel continence), instrumental activities of daily living (IADLs) (e.g., cooking, cleaning, shopping, money management, use of transportation, use of telephone, medication administration), and mobility (e.g., walking, stairs, balance, transferring). During the normal aging process, even with 50 percent deterioration in many organ systems, an individual can still function adequately because the elder has the ability to compensate for age-related changes (Zarit & Zarit, 2007). However, for individuals with dementia and the resulting progressive cognitive decline, a gradual loss of the ability to

perform everyday tasks occurs. Early on, the ability to carry out complex activities (such as work-related tasks or managing finances) is impaired. Later in the disease, people can no longer perform basic activities of daily living, such as dressing and bathing. Many studies related to dementia care have addressed the importance of determining individual levels of independence in meeting ADL and IADL which can aid in understanding the patient's severity of dementia and care needs (Eliopoulos, 2005; Pearson, 2000; Zarit & Zarit, 2007).

### *Behavioral Problems*

In addition to cognitive and functional impairment, behavioral problems are another prominent manifestation of dementia (Teri et al., 1992; Volicer & Hurley, 2003; Zarit & Zarit, 2007). It is estimated that about 90% of patients with dementia will develop significant behavioral problems at some point in the course of their illness (Zarit & Zarit). These problems include, but are not limited to, difficulties with personal hygiene and care, depression, agitation, and aggression (Teri et al., 1992). Because of the nature of behavioral problems, they are more burdensome to caregivers than are physical impairments (Ory et al., 1999; Pinquart & Sørensen, 2003; Zarit & Zarit, 2007).

Agitation is the term used to describe all behavioral symptoms of dementia (Cohen-Mansfield, 1988). It is defined as inappropriate verbal, vocal, or motor activity that is not explained by needs or confusion per se. Agitated behaviors have been divided into three major syndromes: physically aggressive behavior (hitting, kicking); physically non-aggressive behavior (pacing, disrobing, wandering); and verbally agitated behavior (constant repetitions of words). A more complex taxonomy can be based on a

multimethod assessment approach: verbal aggression/vocal agitation (screaming, moaning, complaining), physical aggression (inflicting self-harm or harm to others), affective behavioral disorder (crying, seeking reassurance, rejecting others, coldness), psychotic behavior (delusions, hallucinations, confusion), wandering, and asocial behavior (disrupting others, disrobing, sloppy eating) (Cohen-Mansfield, Marx, & Rosenthal, 1989).

Alzheimer's Disease and Vascular Dementia can increase the likelihood of agitated behavior in several ways. Neurons are lost in key regions of the brain, leading to corresponding deficits in neurotransmitters involved in the regulation of mood and behavior (Kirby & Lawlor, 1995).

Cognitive deficits associated with dementia also make problem behavior more likely. Patients may misunderstand what other people say to them, be unable to communicate effectively, or become frightened by their inability to recognize people, places, or things. They also may have more difficulty initiating activities and keeping occupied. These changes create an increased probability of behavior problems (Zarit & Zarit, 2007).

In summary, individuals with dementia have special pathological changes in the brain compared with others who are aging normally. These pathological changes result in abnormal symptoms of dementia in the cognitive, functional, and behavior domains. The abnormal symptoms result in care demands and make caring for a family member with dementia especially difficult (Ory et al., 1999; Pinquart & Sørensen, 2003; Pinquart & Sørensen, 2007). These unique cognitive, functional, and behavioral impairments can

contribute substantially to the psychological and physical morbidity of the caregiver as well as caregiver's social function (Hooker et al., 2002; Pearlin et al., 1990; Pinquart & Sörensen, 2003).

### *Family Caregiving of Dementia Patients*

Family members provide the majority of care provided to older adults with functional impairment (Robertson et al., 2007). According to the Alzheimer's Association and National Alliance of Caregiving (2004), more than 22 million households in the United States are involved in caregiving for someone older than 50 years. Many of these family caregivers provide care for older adults with progressive memory impairments; approximately 4 million older adults have Alzheimer's disease alone, which does not take into account those suffering from related dementias. Because age is the primary risk factor for AD, the number of people with the disease is expected to reach 11.3-16 million as early as 2050 (Hebert et al., 2003). Population aging, increases in life expectancy, and social policy further underscore the importance of family caregiving networks (Robertson et al., 2007).

In China, care of a family member with dementia also typically occurs within the context of the family (The 10/66 Dementia Research Group, 2004; Tian, 2003; Tian et al., 2009). It is estimated that about 95% of patients with dementia are taken care of by their family members at home (Tian, 2003). Chinese people live in a society strongly influenced by the traditions of filial piety and familism (Lou, 2007; Purnell & Paulanka, 2008). Filial piety is the responsibility of an adult child to care for his/her parent and to meet the needs of the parent (Park & Chesla, 2007; Lou, 2007). Familism in Asia is

reflected by strong identification, attachment and loyalty of individuals to their families (Park & Chesla, 2007). With these traditional values, families try to take care of elders with dementia at home as long as possible.

Several studies from China have shown that more than half of family caregivers were older than 60 years, which is the cut-off age for being called elderly in China, and more than half of family caregivers are spouses (Li, Chen, & Luo, 1990; Meng, et al., 2006; The 10/66 Dementia Research Group, 2004; Wang, et al., 2004; Zhang, et al., 2003). Sixty-seven point five percent of the family caregivers of dementia patients had chronic illnesses, and 30% of caregivers had two or more chronic illnesses (Meng et al., 2006). Studies from China also reveal that over 60% of the family caregivers of dementia patients are female (Li, Chen, & Luo, 1990; Meng, et al., 2006; The 10/66 Dementia Research Group, 2004; Wang, et al., 2004; Zhang, et al., 2003) and is a reflection of the Chinese cultural norm that women are expected to be the primary caregivers of dependent family members (Lou, 2007; Purnell & Paulanka, 2008).

In China, the community health care system has only been developed for 2 decades, and the emphases is more on the management of patients with chronic illness, disease prevention and health promotion for children, women and elderly in communities (Liang, 2002; Yu, 2005). Caregivers of dementia patients in the community have not gotten much attention. Even though there are some nursing homes and daily care centers for the elderly, most of them are open only to the elderly who do not have adult children to care for them. The nursing homes do not always provide highly qualified health care to dementia patients because of there is a lack of professional personnel (Liang, 2002;

Tian, 2003; Zhang, et al., 2008). There are also several support groups for caregivers run by some hospitals, but the effectiveness of them still needs to be explored

As governmental education related to dementia has improved, Chinese people are recognizing dementia as a common condition for elderly. However, some behavioral problems (e.g., abnormal sexual behavior, aggressive behavior) that happen in elderly with dementia still can not be correctly understood by some neighbors and caregivers (Elliot et al., 1996; Lou, 2007; Tian, 2003; Wang et al., 2004). For instance, Wang and colleagues (2004) found that 59.7% family caregivers stopped patients' aggressive behavior by using scolding or physical restraints, and family caregivers did not seek much help from the community or society because they looked at these kinds of behavior as a family stigma.

All the descriptions above reveal that family caregivers of dementia patients in China is a social group and vulnerable to adverse health outcomes because of limited resources and increased exposure to risks that contribute to poor health. This group needs more attention and help as they deal with caregiving situations. Unfortunately, not many studies have been done in China on family caregiving of dementia patients. In addition, there is no study on the influence of Chinese culture especially familism on family caregiving of dementia patient. This is a research area that does need deep exploration now and in the future.

### Caregiver Outcomes

Caregiving for an elderly family member with dementia is recognized as bringing high risks for a number of negative outcomes to caregivers. A number of studies also

demonstrated negative biopsychosocial effects of caregiving on the caregivers (Dunkin & Anderson-Hanley, 1998; George & Gwyther, 1986; Roepke, Brent, & Mausbach, 2008; Thomas et al., 2006; Torti et al., 2004; Zarit, Reever, & Bach-Peterson, 1980). Caregivers who experience strain in their roles have higher rates of mortality than age-matched controls who are not caregivers (Schulz & Beach, 1999).

### *Psychological Health*

Relatives caring for a family member with dementia have poor psychological health (e.g., anxiety, depression) compared to people without such tasks (Pruchno, Burant, & Peters, 1997; Schulz et al., 1995, 2003). One of the most commonly examined psychological problems of caregiving is depression. It is estimated that between 10% and 34% of caregivers experience significant symptoms of depression (Cooper, Balamurali, & Livingston, 2007; Zarit & Zarit, 2007). Many studies report elevated rates of symptoms of depression in caregivers compared to age-matched controls or population means (Alspaugh et al., 1999; Gallicchio et al. 2002; Malone-Beach, Zarit, & Spore, 1992; Russo, Vitaliano, Brewer, Katon, & Becker, 1995; Schulz et al., 1995, 2003; Schulz, Visintainer, & Williamson, 1990; Teri et al., 1997), whether symptoms were measured by self-report or by structured diagnostic interviews. The symptoms of depression remain even after the institutionalization of the patient (Aneshensel et al. 1995; Gallagher-Thompson et al. 2006; Novak & Guest, 1992; Wright et al. 1999; Zarit & Whitlach 1992). For example, family caregivers feel helpless and out of place when they come to visit their relatives with dementia who are institutionalized. Feelings of helplessness can lead to apathy, guilt, and depressed (Novak & Guest, 1989).

### *Physical Health*

Family caregivers of patients with dementia experience increased physical morbidity (Clyburn et al. 2000; Connell, Janavic, & Gallant, 2001; Vitaliano et al., 1997), and may develop hyperlipidemia, hyperglycemia (Davies 1996; Vitaliano, Russo, & Niaura, 1995) and insufficiency of the cellular immune system (Davies 1996; Irwin et al. 1997; Kiecolt-Glaser et al. 1995; Mills et al. 2004; Thomson et al. 2004; Vendhara et al. 1999). In addition to depression, other reactions may increase the risks of caregiver illness. They include sleep problems, poor diets, and the decreased use of health service (Fuller-Jonap & Haley, 1995; Gallant & Connell, 1997; Vitaliano et al., 2002). In Vitaliano and colleagues' meta-analysis (2003), it was reported that there were two pathways, which might be relevant in relationship of illness and chronic stressors, which result from caregiving. One pathway appears to flow from chronic stressors to psychosocial distress and then to stress hormones. This primarily occurs via the hypothalamic-pituitary-adrenal axis, from which corticotrophin releasing hormone- ACTH-cortisol is secreted, and the sympathetic adrenomedullary axis, from which norepinephrine and epinephrine are secreted. These hormones stimulate peripheral activity, which can lead to allostatic load, or wear-and-tear from repeated arousal and inefficient control of physiological responses. In a second pathway, distress may trigger risky health behaviors, such as poor diet, sedentary behavior, and substance abuse. Vitaliano and colleagues also estimate that caregivers had a 23% higher level of stress hormones and a 15% lower level of antibody responses than did noncaregivers.

### *Social Functioning Health*

Caregivers also report significant negative social consequences related to caregiving of elders with dementia (Aneshensel et al., 1995; George & Gwyther, 1986). Taking care of dementia patients at home can result in role conflict (Heru & Ryan, 2006), social isolation (Zarit, Reever, & Bach-Peterson, 1980), poor communication (Morris, Morris, & Britton, 1988), and decreased quality of life (Davis & Tremont, 2007; Given & Given, 1991; Serrano-Aguilar et al., 2006). The impact of caregiving on social contact appears to be related to the extent of the care recipient's memory and behavior problems as well as his/her functional impairment. For example, Deimling and Bass (1986) found that demented elders with greater ADL limitations and disruptive behaviors were more likely to have caregivers with decreased levels of social participation. In another study, it was found that disoriented and disruptive behaviors were related to fewer caregiver social activities (Pruchuno & Resch, 1989).

Caregivers also have an important influence on the course of AD and other dementias. A higher burden on the caregiver and the deterioration of caregivers' health usually result in institutionalization of the patient and rapid deterioration of the illness (Dunkin & Anderson-Hanley, 1998; Cohen et al., 1993; Gaugler et al., 2005; Kim et al., 2002; Torti et al., 2004).

Though there are only a few studies from China, the findings are consistent with reports from Western countries that family caregivers of dementia patients experience burden and deteriorated health when they are taking care of family members with dementia at home (Fu et al., 2007; Meng et al., 2006; Yue et al., 2007; Zhang et al., 2003).

For instance, Fu and colleagues (2007) investigated the prevalence of depressed symptoms in 42 spouse caregivers of dementia patients and found that 42.9% of spouse caregivers had depressive symptoms, and the rate is higher than the general community populations (6.0%). Caregivers also reported deteriorated health as well as limited social activities and social interactions (Meng et al., 2006; Yue et al., 2007; Zhang et al., 2003).

Many research studies have consistently shown that care-recipient impairments are associated with caregiver outcomes in term of health (Pinquart & Sörensen, 2003; Schulz, 1995; Zarit & Zarit, 2007). Studies from Asia including China also revealed similar findings. Severe behavioral problems ( Arai & Washio, 1999; Farran et al., 1993; Fu et al., 2007; Gallicchio et al., 2002; Harwood et al., 2000; Heok & Swee, 1997; Meng et al., 2006; Rymer et al., 2002; Thomas et al., 2006; Yue et al., 2007; Zhang et al., 2003), and more severe cognitive impairment and decreased ADL functioning (Aguglia et al., 2004;Chappell & Reid, 2002; Gonzalez-Salvador et al., 1999; Meng et al., 2006; Schulz et al., 1995; Zhang et al., 2003) predicted higher levels of caregiver burden and negative caregiver outcomes. In addition, behavioral problems of care-recipients are consistently associated with caregiver depression, and they play a larger role in caregiving outcomes than do functional and cognitive impairments (Fu et al., 2007; Schluz et al., 1990, 1995; Pinquart & Sörensen, 2003).

Inconsistent findings between Western countries and Asian countries do exist. Studies from Western countries found that more severe dementia was related to higher levels of burden and caregiver distress (Aguglia et al., 2004; Gaugler et al, 2005;

Harwood et al., 2000; Rymer et al., 2006; Thomas et al., 2006), while the finding was opposite in studies from Asian countries that report less severe illness predicts higher caregiver stress (Arai, Washio, & Kudo, 2000; Yue et al., 2007). The authors from Asia speculate that less severe dementia is associated with less predictable clinical behavior and thus higher caregiver burden and distress.

In summary, taking care of demented elders at home is stressful. Many research studies from Western countries as well as China reveal deteriorated biopsychosocial caregivers health after they take on the caregiver role. Care-recipient impairments are associated with caregiver outcomes, and care-recipient characteristics of dementia are mostly reported as having consistent influences on caregiver outcomes compared to Western countries. Negative consequences on caregiver outcomes after they provide care to demented care-recipients emphasizes the importance of conducting studies in this area, as the explorations from the studies will guide health care personnel to help family caregivers of demented elders deal with the stressful caregiving situations and take good care of elders at home as well as themselves.

### Caregiving Appraisal

Caring for a family member with dementia is challenging. Noticeably, some studies from Western countries have reported that caregivers appear to adapt to the challenges of caregiving over time even as the patient continues to deteriorate, whereas others report continuous and increasing strain and burden (Dunkin & Anderson-Hanley, 1998). These findings suggest that caregiving stressors might not affect caregiver outcomes directly, but rather the processes of cognitive appraisal and coping mediate

them (Lazarus & Folkman, 1984; Lawton et al., 1989, 1991). Two theoretical models are supporting this explanation. They are the Stress and Coping Model (Lazarus & Folkman, 1984) and the Two-factor Model of Caregiving (Lawton et al., 1989, 1991).

Lazarus and Folkman's Stress and Coping Model (1984) has been utilized as a conceptual framework for most of the empirical research on caregiving (Dilworth-Anderson, Williams, & Gibson, 2002; Kneebone & Martin, 2003). Based on its theoretical constructs, Lawton and colleagues (1989, 1991) developed the Two-factor Model of Caregiving. Both of the models suggest that whether an environmental situation is stressful, is determined by the person's appraisal and coping strategies. Thus, within the caregiving situation, whether the caring demands of dementia patients are stressful is based on the caregiver's appraisal and how the caregiver copes with the situation. Therefore, appraisal involves the assessment of both the nature of the stressor itself (e.g., caregiving demands) and the individual's resources for coping. Once coping responses are put in motion, subsequent appraisals include the evaluation of their effectiveness.

Appraisal is identified as a mediating psychological process involving evaluation and judgment and is cognitive in nature. Its role as a mediator is verified in many research studies (Haley et al., 1987, 1996; Lawton et al., 1989; Knight et al., 2000; Knight & Sayegh, 2010). It imbues a situation or event with meaning (Lazarus & Folkman, 1984). As a perceptual process, cognitive appraisal also reflects one's attributions of the stressors experienced. It is how people make sense of their experiences. Lawton and colleagues (1989) pointed out that "burden" could not refer to all appraisals of caregiving stress because not all appraisals and experiences are necessarily interpreted

as burdensome. They suggested using the term “caregiving appraisal” to refer to the largest category that includes all cognitive and affective appraisals and reappraisals of the potential stressor and the efficacy of one’s coping efforts (Lawton et al., 1989). Based on the prior empirical research evidences, Lawton and colleagues (1989) explained that the caregiving appraisal should reflect all degrees of subjective response to the caregiving situation. Commonly, it includes caregiving subjective burden and caregiving satisfaction (Lawton et al., 1989, 1991). Both caregiving satisfaction and caregiving subjective burden have the potential to bring meaning to the caregiving situation. Thus, in the Dementia Caregiving Model (see Figure 1), caregiving appraisal, which is composed of caregiving satisfaction and caregiving subjective burden, is conceptualized as mediators which mediate the relationship between caregiving stressors and caregiver outcomes.

Caregiving subjective burden is the perception of psychological distress, anxiety, demoralization, and generalized loss of personal freedom attributed directly to caregiving (Lawton et al., 1991). Actually, the concept of burden was first introduced into the literature by Grad and Sainsbury (1966) in an examination of community care for the mentally ill. They described burden as any cost (negative consequences) to the family of which the patient is a member. Further, Zarit and colleagues (1980), who first introduced the concept of burden into family caregiving for dementia patients, defined burden as “the extent to which caregivers perceived their emotional, physical health, social life, and financial status as a result of caring for their relative” (p.261). They viewed burden as the product of specific, subjective, interpretive process. Later on, Montgomery, Gonyea, & Hooyma (1985) dichotomized burden into subjective and objective burden. They

described that “subjective burden refers to the caregivers’ attitude toward or emotional reactions to the caregiving experience, while objective burden is the extent of disruptions or changes in various aspects of the caregiver’s life and household” (p.21). It is noticeable that all definitions emphasize the person’s perceptions and subjective interpretation of the caregiving.

The positive aspects of caregiving for dementia patients have received far less attention than the negative. In the review from Kramer (1997), it was found that the vast majority of studies that relate to the positive aspects of caregiving have been done since 1988 and is far behind the published studies on the negative aspects of caregiving. Fortunately, the positive aspect of family caregiving is getting more attention by researchers. Caregivers of persons with dementia do perceive their caregiving provides them with a variety of positive and satisfying experiences. In a qualitative study (Farran et al., 1991), 90% of the 94 caregivers reported that they valued positive aspects in caregiving. Caregivers frequently reported that caregiving made them feel needed, useful, and good about themselves. Most caregivers also report that caregiving enabled them to appreciate life more, to develop a more positive attitude toward life, and strengthened their relationships with others. These findings are generally consistent with what is reported in the caregiving literature (Farran et al. 1999; Lawton et al. 1989; Pinquart & Sörensen, 2004). In China, even though there are only few studies (Zhan, 2004, 2006; Zhang & Li, 2007; Zhang et al., 2008) which addressed positive experience of caregiving for dementia patients, the findings verified the existence of positive experience. For example, Zhang and her colleagues (2008) conducted a qualitative study to describe the

caring experiences of 10 Chinese caregivers of demented elders in Beijing. They found that caregivers considered providing care to their elders was one way to reflect their self-value, and they were becoming adjusted to the life changes due to caregiving. In another quantitative study (Zhang & Li, 2007), it was also reported that more than half of caregivers of demented elders had positive experience during the caregiving process, such as self-affirmation and positive outlook on life.

There are several terms to describe the positive experience of caregiving, such as uplift (Kinney & Stephens, 1989; Pruchno, Michaels, & Potashnik, 1990), rewards (Picot, 1995), and caregiving satisfaction (Lawton et al., 1989). Caregiving satisfaction is one of the most common terms used to address the positive aspects of caregiving (Kramer, 1997). It was first introduced as one of the major dimensions of caregiving appraisal by Lawton and colleagues according to the result of factor analytic techniques (Lawton et al., 1989). An early definition of caregiving satisfaction was defined as “the benefits accruing to the caregiver through his or her own efforts” (Lawton et al., 1989, p. P64). This research group later defined satisfaction as, “subjectively perceived gains from desirable aspects of or positive affective returns from caregiving” (Lawton et al., 1991, p. P182).

Some studies have shown that the relationship between negative (caregiving subjective burden) and positive (caregiving satisfaction) aspects of caregiving are moderate or modest, and the findings mean that they may coexist and be related to different aspects of caregiving situation (Andren & Elmstahl, 2005; Lawton et al., 1989; Rapp & Chao, 2000). Caregivers who perceive more burden may also experience positive aspect of caregiving. Both caregiving subjective burden and caregiving satisfaction have

influence on the relationship between caregiving demands of care-recipient with dementia and caregiver outcomes (Knight et al., 2000; Lawton et al., 1989, 1990; Pinquart & Sörensen, 2003).

Caregiving subjective burden is shown to be a strong predictor of strain and distress (Brodaty et al., 1997; Zarit & Zarit, 2007). For example, increased burden was found to be associated with declining physical health (Vitaliano et al., 2003; Winslow, 1997) and psychological morbidity (Brodaty & Hadzi-Pavlovic, 1990). Caregiving satisfaction is known to be associated with increased positive affect (Lawton et al., 1991; Robertson et al., 2007), lower levels of depression (Pinquart & Sörensen, 2003), higher self-esteem (Noonan & Tennstedt, 1997), and improved caregiver well-being (Levesque et al., 1995; Pinquart & Sörensen, 2004). Much empirical evidence suggests that positive feelings sustain coping efforts during periods of distress (Folkman, 1997; Folkman & Moskowitz, 2000; Fredrickson & Joiner, 2002; Tugade & Fredrickson, 2004). The evidence also reflects that positive feelings may have indirect effects on outcomes through coping.

Many studies have consistently revealed that caregiving subjective burden mediated the relation between stressors and health (Haley et al., 1996; Knight et al., 2000; Schulz & Beach, 1999; Son et al., 2007). For example, Son and colleagues (2007) found that more behavior problems and high levels of perceived role overload were associated with poorer self-reported health, more negative health behaviors, and greater use of health care services among caregivers of demented patients. The association between care

receivers' behavior problems and caregivers' health was mediated by caregivers' feelings of overload. Lawton and coworkers (1991) also reported that caregiving subjective burden was the central element of caregiving appraisal that strongly determined both positive and negative psychological well-being in the caregiver group of adult children. On the other hand, there are not many studies to test the mediator role of caregiving satisfaction on the relationship of caregiving stressors to caregiver's outcomes. Thus, the mediator role of caregiving satisfaction is still not verified consistently. Some studies reveal that caregiving satisfaction works as a mediator between caregiving stressors and caregiver outcomes (Knight & McCallum, 1998; Picot, 1995), but some not (Lawton et al., 1991; Haley et al., 1996). For example, in Lawton and colleagues' study (1991), caregiving satisfaction was reported as a mediator between AD patients' behavior and caregiver's psychological well-being in the caregiver group of spouse, but this mediator role of caregiving satisfaction were not found in the caregiver group of adult children. Therefore, future study is needed to verify the role of caregiving satisfaction in the caregiving process.

In summary, it has been demonstrated that positive and negative appraisals of caregiving coexist among family caregivers of relatives with dementia. However, the role of positive caregiving appraisal such as caregiving satisfaction has not been confirmed and awaits further evidence.

### Coping

Caregiving to a family member affected by dementia is usually a chronic stressful experience that poses significant adaptive challenges. Some studies indicate that

caregivers vary in their ability to cope successfully even though most caregivers endure great stress resulting from providing care to demented care-recipients (Dilworth-Anderson, Williams, & Gibson, 2002; Haley et al., 1987; Janevic & Connell, 2001). The findings reveal that stress is not simply an external force that automatically leads to negative effects in all caregivers who experience it, but is in relationship to the individual and his or her environment, and coping is one of important factors in predicting the outcome of stress. Similarly mentioned by Lazarus and Folkman (1984) in their Stress and Coping Model, the impact of a stressful situation (stressors) is mediated by the appraisal of the situation and the ability to cope with it.

In the Dementia Caregiving Model of this study, coping is considered one of two important mediators (another one is caregiving appraisal), each of which play roles as mediators between caregiving stressors and caregiver outcomes. The effect of caregiving stressors on caregiver outcomes in terms of health is mediated through caregiver appraisals and coping styles, so caregiving can result in negative mental and physical health outcomes when caregivers appraise the caregiving situation as burdensome and use ineffective coping strategies (Kim, Knight, & Longmire, 2007).

Coping refers to a person's ongoing cognitive and behavioral efforts to manage stressful demands (Lazarus & Folkman, 1984). Specifically in the situation of caregiving, coping is the way one deals with stressful situations. There are several classification systems that have been used to categorize different strategies of coping. Lazarus and Folkman (1984) categorized coping strategies as being either problem-focused or emotion-focused. Problem-focused coping focuses on the potential that something will

change for the better because of the stressful encounter, and emotion-focused coping is to regulate distress. On the other hand, Billings and Moos (1984) proposed three methods of coping: active cognitive coping, active behavioral coping, and avoidance coping. Active cognitive coping involves thinking about and analyzing the stressful situation (e.g., look for something good in it), whereas active behavioral coping involves some sort of activity on behalf of the individual (e.g., seeking information). Avoidance coping is directed at ignoring or avoiding the emotional consequences of the stressor cognitively (e.g., refusing to believe a situation exists), or behaviorally (e.g., keeping feelings to oneself).

The relationship between different strategies of coping and caregiver outcomes especially psychological distress has been examined in caregivers of dementia patients. Consistently, the inverse relationship between emotion-focused coping and depression was found in several studies. The use of different emotion-focused coping strategies such as avoidance (Fingerman et al., 1996; Powers, Gallagher-Thompson, & Kraemer, 2002; Vitaliano et al., 1985), wishfulness (Kneebone & Martin, 2003; Pruchno & Resch, 1989; Williamson & Schulz, 1993), and emotional discharge (Haley et al., 1987) are associated with an increase in depression for caregivers. However, one emotion-focused strategy, acceptance, has been found to be associated with decreases in negative affect in caregivers (Kneebone & Martin, 2003; Pruchno & Resch, 1989). On the other hand, the relationship between problem-focused coping and depression has not been found as consistently. Some studies show a relationship between problem-focused coping strategies and lower levels of depressive symptoms (Haley et al., 1987; Vitaliano et al.,

1985), though other studies found no such relationship (Fingerman et al., 1996; Pruchno & Resch, 1989; Williamson & Schulz, 1993). The inconsistencies call for further studies.

However, the relationship between coping and caregiver physical health has not been well studied, and findings from the limited studies are also inconsistent. Goode and colleagues (1998) report in their study that the use of more problem-focused coping was significantly associated with the better physical health of caregivers of AD individuals, but they did not provide an explanation for the reason. The opposite of this finding, that is, it was reported that coping did not function as a mediator between caregiver status and caregiver physical health among Korean American caregivers of demented patients (Kim & Knight, 2008). They explain that self-report of physical health may not accurately reflect the actual physical health of the caregiver and biomarkers might more accurately reflect the changes in physical health even before the caregiver perceives the health changes. Therefore, the relationship between coping and caregiver physical health is still not clear and needs further exploration.

Since there are many different classification systems on coping strategies, many measurements are also used in caregiving studies. The original or revised Ways of Coping (WOC) Checklist developed by Lazarus and Folkman (1984) is the most prevalent measure (Gottlieb & Wolfe, 2002). However, when WCQ was translated into Chinese and tested among Chinese population, it was found that it was not particularly culturally appropriate (Xie, 1989). Based on the Stress and Coping Model (Lazarus & Folkman, 1984) and the items from WCQ, Xie developed the Simplified Coping Style Questionnaire (SCSQ) in order to test the ways of coping with daily life events for

Chinese population under Chinese culture. The validity and reliability of SCSQ are satisfied. Factor analysis found that coping ways were classified into positive and negative strategies, which consisted of 12 and 8 items respectively. For the positive coping strategies, the items reflect the way that people seek help and try to solve or view the problems (e.g., getting help and advice from other people; looking for something good in it), whereas the negative strategies reflect that people avoided facts and were not actively engaged in solving the problems (e.g., using alcohol or other drugs to make myself feel better; saying to myself “this isn’t real”). Following Lazarus and Folkman’s (1984) work, Xie (1989) also emphasized that the type of coping chosen depended partly on an individual’s appraisal of the situation’s amenability to change and his or her resources, and there is no absolute good or bad coping strategies. Also, Lazarus (2000) does mention that people often use both problem-focused and emotion-focused coping strategies in the course of a stressful encounter. The most effective overall strategy may lie in obtaining a balance between problem-focused and emotion-focused coping.

The mediator role of coping has been found in research studies (see reviews from Dilworth-Anderson, Williams, & Gibson, 2002; Gottlieb & Wolfe, 2002; Kneebone & Martin, 2003). For example, Huang (2004) found that avoidance coping had a mediating effect between care recipient’s behavioral problems and depressive symptoms of caregivers, with no moderating effects. When a mediating effect of avoidance coping occurred, the care recipient’s behavioral problems no longer were significantly associated with depressive symptoms. Except for caregiving appraisal, coping is reported as another mediator between the relationship of caregiving stressors to caregiver outcomes in many

research studies, and the combined effects of caregiving appraisal and coping do need more attention (Haley et al., 1996; Dilworth-Anderson, Williams, & Gibson, 2002; Janevic & Connell, 2001). For example, Knight and associates (2000) found that the African American caregivers in their study perceived less burdensome in caregiving, which might induce to lower emotional distress than the White sample in their study. But the result of overall distress scores were similar between these two groups because the African American caregivers used more emotion-focused coping (similar to avoidance coping), which served as a “counterbalance”. Therefore, it might be appropriate to include both caregiving appraisal and coping in a caregiving study in order to get more accurate results and explanations.

In China, there are no prior investigations testing the mediating role of coping for family caregivers. Meng and her colleagues (2006) tested the relationship between caregiving subjective burden (measured by Zarit Burden Interview) and coping strategies (measured by Xie’s SCSQ) among 40 caregivers of demented elders. It was reported that caregiver burden was negatively related to positive coping strategies ( $r = -.330, p < .05$ ). Several other studies from China, which utilized SCSQ to assess the coping strategies used by family caregivers of patients with other diseases (i.e., cancer, chronic illness) instead of dementia, consistently found that positive coping strategies were inversely associated with negative consequences of caregiving (i.e., caregiver burden, level of anxiety of caregivers) (Chen et al., 2006; Zhang et al., 2008), and negative coping strategies were positively associated with caregiver burden and anxiety as well (Chen et al., 2006; Li, Jiang, & Zhu, 2007).

In summary, even though some studies from Western countries have revealed the mediating role of coping in the effect of caregiving stressors to caregiver outcomes, there are no studies in China that test the mediated role of coping among family caregivers of demented elders. In addition, there were not many studies to describe how caregiving appraisal and coping work together as important mediators in the caregiving process. Research studies in this area are necessary to fully comprehend the impact of caregiving processes on caregivers.

#### Contextual Factors

Based on the Dementia Caregiving Model (see Figure 1), contextual factors are elements that make up the history of the caregiving career and have a potential impact on the stress process. Contextual factors usually include caregiver characteristics, beliefs on providing care specifically how culture (e.g., familism) influences beliefs of caregiving, and resources especially perceived social support from both informal resources (e.g., other family members, relatives, and friends) and formal resources (e.g., health care personnel, health care agencies).

#### *Caregiver Characteristics*

A number of investigations have repeatedly demonstrated that characteristics of the caregiver profoundly influence the negative impact of caregiving on caregivers. Caregiver variables have typically been thought of as mediating or moderating (Dunkin & Anderson-Hanley, 1998; George & Gwyther, 1986). In other words, they are variables that alter the relationship between stressors that affect the individual and that individual's outcomes. These include demographic variables, such as the caregiver's age, gender,

ethnicity, level of education, coping strategies, and other variables, such as duration of caregiving, relationship to the patient and relationship history between the patient and caregiver. These characteristics are also influenced by ethnic and cultural characteristics. For instance, being female (Chou, LaMontagen, & Hepworth, 1999; Fu et al., 2007; Gallicchio et al., 2002; Youn et al., 1999), children (Arai et al., 2000; Andren & Elmstahl, 2007), and younger caregivers (Kim et al., 2002; Schneider et al., 1999; Yue et al., 2007) all predicted higher burden of caregiving.

However, the history of the relationship to the person with dementia resulted in different findings in a Korean study and a study from Western countries. The study from Korea (Youn et al., 1999) found that a good relationship history to the care-recipient predicted higher caregiver burden, while the study from a Western country (Steadman et al., 2007) found the opposite. Steadman and colleagues (2007) found that caregivers with less pre-morbid relationship satisfaction were more likely to negatively react to the care-recipient's behaviors and had strained communication and problem-solving skills, which could result in higher caregiver burden ( $r=-0.38$ ,  $p=.001$ ) (Steadman et al., 2007).

The history of the relationship between caregivers and care-recipients is a factor in the motivation to continue providing care (Lawrence et al., 1998), and it has emerged as an important aspect to caregiver's appraisal of the caregiving situation (Lawrence et al., 1998; Lopez, Lopez-Arrieta, & Crespo, 2005; Pearlin et al., 1990). A moderator hypothesis is assumed that the high quality of the relationship history may make the caregiver feel close to care-recipient, and this closeness may "act like a coping mechanism by providing a lens or perspective through which the situation is appraised in

a less stress-inducing manner” (p.151). Thus, the caregiver with a strong or better relationship quality may feel less burdened or stressed relative to someone with a poorer relationship quality, even though they are in similar situations (Lawrence et al., 1998). Lawrence and colleagues’ study (1998) found that the current relationship quality was significantly related to a decreased sense of role captivity and lower levels of depression, but it did not offset the linkages among caregiving stressors and caregiving appraisal of the stress process. This result calls for further exploration on the influence of the history of the relationship to caregiving appraisal as well as caregiver outcomes.

In China, there is no study to explore the influence of history relationship on the caregiving process. From Chinese culture, talking about something like the relationship with others is a very private topic, so it is difficult to get a valid response from caregivers if the researcher meets them only once or twice, which was the procedure used in this study. Therefore, this variable was not explored in this study because the concern of getting invalid responses from caregivers. Future studies will test the effects of this variable after the researcher has established a trustful relationship with family caregivers.

#### *Perceived Social Support*

Pinquart and Sørensen’s meta-analysis (2003) found that the association between care-recipient impairments and caregiver outcomes is only small to moderate, so they concluded that moderator variables such as social support may influence the strength of the relationship between caregiving stressors and caregiver outcomes.

Social support is a “multi-faceted concept that has been difficult to conceptualize, define and measure” (Hupcey, 1998, p. 1231). In the mid 1970s to early 1980s, the

literature most often described social support in concrete terms, such as an interaction, person, or relationship (Schaffer, 2004). However, the concept of social support has become more abstract in recent years and includes perceptions, quality and quantity of support, behaviors, and social systems (Schaffer, 2004).

Perceived social support is support that is believed to be available at any given moment (Zimet et al., 1988). This does not mean that the perceived social support is actually there, but rather that the individual holds a firm belief and conviction that it is available, no matter what. Lazarus and Folkman (1984) also mentioned that if people believed they would receive social support when it is needed, they would have better moral and somatic health, and function better when others things are equal. In the Stress and Coping model and the Two-factor Model of Caregiving, perceived social support is considered a resource, which can influence caregiving appraisal and coping. Thus, for a person in a caregiving role, perceived social support is an important variable for understanding how that individual appraises stressors and copes with stress.

In general, higher levels of social support are related to better caregiver outcomes, particularly life satisfaction and health (Haley et al., 1987; Kaufman et al., 2010; McCabe et al., 2003). It was found that caregiver depression was significantly related to perceived adequacy of social support; caregivers with less social support were more depressed (Wijngaart et al., 2007). More recently studies also support that perceived social support was a more consistent predictor of caregiver well-being than actual support or network size (Williams & Dilworth-Anderson, 2002; Roth et al., 2005). Simply this support allows for the individual to be connected to others in the belief that when needed the

others will be available, and when needed, that the others will in fact be present without fail, and without excuse. Perceived social support was viewed by the researcher as beneficial because it provides caregivers with consistent positive experiences and a resource for stability in spite of the illness.

Research suggests that perceived social support can ameliorate or reduce the detrimental effects of stress on psychological well-being (see reviews by Dunkel-Schetter & Bennett, 1990; Thoits, 1995). Atienza, Collins, and King (2001) conducted a study to examine the relationship between perceived social support and dementia caregiver's mood. Findings indicate that believing support would be available if needed reduced the deleterious impact of stress on the negative mood of caregivers. Caregivers with higher levels of perceived support were less emotionally reactive to a stressor occurring in their natural environments compared to caregivers with lower levels of perceived support. One of the proposed mechanisms is that high levels of perceived support may bolster or sustain a sense of control during the time of stress (Thoits, 1995). Atienza and colleagues' study (2001) also demonstrates that the feeling of controlling the environment was increased among caregivers who had higher levels of perceived social support. This control belief may influence caregiving appraisal to be viewed as less burdensome, and in turn, protect psychological well-being. Cohen (2004) summarized evidence that high levels of social support buffer against the effects of stress by increasing the perception that resources are available to handle stress, and thereby decreasing appraisals that stressors are potentially harmful. However, whether the

perceived social support influences both caregiving subjective burden and caregiving satisfaction is still not answered clearly.

Social support has been studied widely as a coping resource that might mitigate the adverse psychological effects of stress (Cohen, 2004; Picot, 1995; Zimet et al., 1988). Theoretically, perceived social support can be considered a coping resource which includes the supportive provisions potentially available within the individual's social network (Lazarus & Folkman, 1984; Pierce, Sarason, & Sarason, 1996). Therefore, perceived social support may influence the way someone copes with a situation as well as the outcome of these coping efforts (Lazarus & Folkman, 1984; Pierce, Sarason, & Sarason, 1996). However, to the researcher's knowledge, there is no study that investigates the relationship between perceived social support and coping strategies among family caregivers of demented care-recipients. Young and McCubbin (2002) conducted a study to explore the relationships of family stress, perceived social support, and coping for families who have a child with chronic illness. The findings indicate that perceived social support appeared to be an important predictor of parent's coping. Thus, if a parent perceived more social support, the individual might also be likely to report a higher level of coping ( $\beta=0.39$  for mother, and  $\beta=0.28$  for father,  $p<.01$  for both mother and father). However, neither the moderating or mediating model was supported in the study. Even though there is no related study on perceived social support and coping in the research area of dementia care, the findings from Young and McCubbin's study gives a concrete example about the influence of perceived social support on coping. Whether

these findings will be obtained from family caregivers of demented care-recipients needs to be addressed in the future.

Zimet and colleagues (1988) mentioned that there might be additional sources of support for a variety of subject groups that need to be taken into consideration when studying perceived social support with unique populations. For family caregivers, perceived social support can be evaluated from both informal resources (e.g., other family members, relatives, and friends) and formal resources (e.g., health care personnel, health care agencies) (Zarit & Zarit, 2007). In China, nurses and other health-care professionals are becoming involved in providing formal support services to family caregivers of demented elders (Tian et al., 2009). Therefore, the interface between family caregiving and the formal support system has received more attention. However, there are no studies in China currently that explore if family caregivers truly perceive that they can get support from health care professionals when they need them, and if perceived social support from health care professionals could be helpful. Thus, a related study about perceived social support is needed.

#### *Culture and Familism*

Recent research reveals an increased interest in how the caregiving experience varies between different ethnic and cultural groups. However, the findings are not consistent. Several studies found that African American caregivers suffer from less depression and report less burden than do non-Hispanic Whites (NHWs), even given similar or more demanding caregiving roles for a relative with dementia (Connell & Gibson, 1997; Fredman, Daly, & Lazur, 1995; Haley et al., 1996). Conversely, Aranda

and Knight (1997) reviewed the literature on Latinos caring for family members with dementia and concluded that although studies are equivocal, there is some evidence that Latinos experience as much or more burden than do NHWs.

In addition, Shaw and associates (1997) reported that U.S. caregivers of relatives with dementia were found to experience more distress than caregivers in Shanghai, China compared to non-caregiving controls from their respective countries. Researchers suggested that the normative nature of caregiving in more collectivistic cultures (e.g., Chinese culture) may be protective against distress (Guarnaccia & Parra, 1996; Shaw et al., 1997). Conversely, Youn and colleagues (1999) found similar levels of burden among Korean resident, Korean American, and non-Hispanic Whites American caregivers, despite higher levels of familism among both Korean groups.

Even though research findings are not consistent, they do suggest that cultural factors and ethnic group status are related to beliefs about dementia, caregiving, and caregiving outcomes (Connell & Gibson, 1997; Dilworth-Anderson et al., 2005; Dilworth-Anderson, Williams, & Gibson, 2002; Gallagher-Thompson et al., 2003; Janevic & Connell, 2001; Knight & Sayegh, 2010). Dilworth-Anderson and colleagues (2002) suggested that investigations into cultural differences in caregiving should study the effects of cultural mechanisms – such as the values, customs, beliefs, and attitudes held by individuals – rather than simply relying on race as an explanation for difference.

Cultural values and norms influence attitude, decisions, and actions regarding family caregiving. Appraisal of the caregiving experience is strongly influenced by these values, as are the strategies employed by individuals in coping with the caregiving

experience (Gottlieb & Wolfe, 2002; Knight & Sayegh, 2010; Wallace et al., 1998). Thus, including both caregiving appraisal and coping strategies in the studies is very important because those combinations help understanding the more integrated indirect effect of caregiving stressors on caregiver outcomes within different culture. For example, Knight and colleagues (2000) reported that positive effects of African American ethnicity on mental health outcomes were mediated by reduced burden. However, these positive effects were counterbalanced by the effects of African American ethnicity on increased use of avoidant coping styles, resulting in equivalent levels of emotional distress between groups in their study. This exemplifies the complicated effects of culture on the caregiving appraisal and coping strategies, and in turn, caregiver outcomes.

Familism is one of the central values of Chinese culture (Lou, 2007; Purnell & Paulanka, 2008). It describes strong identification, attachment, and loyalty of individuals to their families (Park & Chesla, 2007). Generally, the concept of familism refers to the precedence of family needs over the needs of the individual, as well as the reliance on and obligation that one relegates to the nuclear and extended family (Park & Chesla, 2007). Heller (1976) describes familism as interrelated at three conceptual levels. First, as social organization, familism describes the members of the family, and the values governing the rights and behaviors of members toward one another. Second, as behavior, it represents actions to be fulfilled as role obligations. Third, it refers to attitudes regarding one's obligations towards other family members (Heller, 1976). A further examination of familism, measured and conceptualized by Triandis, Marin, Betancourt, Lisansky and Chang (1982), describes the concept as consisting of "strong familial

identification, the sharing of strong feelings of loyalty, reciprocity, and solidarity among the family members, the structures of mutual help and obligations held by family members, and belief in the high value assigned to both the nuclear and the extended family” (p.1). Based on prior work, Steidel and Contreras (2003) developed the Attitudinal Familism Scale to measure familism among Spanish-speaking Latinos in the United States who were with low levels of acculturation. The measure consisted of 18 items assessing familial support (the belief that family members have a duty to support immediate or extended family members not only in times of need but also in everyday life), familial interconnectedness (the belief that all family members must be both physically and emotionally close to each other, and relatives must spend and cherish time together), familial honor (the belief that an individual has a responsibility not to tarnish the family name and a duty to defend any attacks against the family integrity), and subjugation of self to family (the belief that a person must be submissive and respect the family rules).

To the researcher’s knowledge, there is no systematic study to explore the influence of familism on caregiving of elders with dementia among the Chinese population, even though a few studies have utilized the term “familism” to explain their research findings (Shaw et al., 1997; Zhan, 2004). Thus, the literature review here is based on the findings from Western countries and other Asian countries (e.g., Korean).

Pyke and Bengtson (1996) mention that caregivers who have a strong value of familism attempted to see the caregiving experience as a chance to strengthen the bonds between themselves and the elders being cared for. Some studies also verified this

opinion that those holding a strong value of familism perceive the caregiving process as a natural extension of family life – even a positive aspect – rather than necessarily appraising the experience as a burdensome interruption of their lives and their health (McCallum, 2002; McCallum, Longmire, & Knight, 2007; Pyke & Bengtson, 1996). Furthermore, more familistic individuals would justify the caregiving role and caregiving responsibilities as expressions of held cultural values and expected commitment.

A number of studies have been conducted to explore the subjective appraisal of African American caregivers of the stressfulness of caregiving. However, the findings from research studies are not consistent.

Many of these studies were done among African American caregivers who are considered as having significantly higher familism values than European Americans (Knight et al., 2002). Researchers explain that African Americans have been taught that they are expected to provide care to older family members, irrespective of their own situations or levels of dependency. Research findings from these studies show that African Americans appraise caregiving as less burdensome, in comparison to other ethnic groups (Fredman, Daly, & Lazur, 1995; Morycz, Malloy, Bozich, & Martz, 1987; Lawton, Rajagopal, Broday, & Kleban, 1992; Haley et al., 1996; Knight, Silverstein, McCallum, & Fox, 2000), reported more benefits from caregiving, and described less subjective burden and intrusion on their lives (Lawton et al., 1992; White, Townsend, & Stevphens, 2000).

On the other hand, one study (Kim et al., 2007) did not find a similar result. Kim and colleagues (2007) explored how familism, burden, and coping styles mediate the

relationships between ethnicity (African American and White American) and the mental and physical health of caregivers. From the meaning of familism, it is assumed that caregivers with higher familism were thought to view caregiving as less burdensome (Segall et al., 1998). However, the interesting findings were that familism had no significant relationship with burden.

In addition, another study (Youn et al., 1999) from Korean caregivers also found that familism did not have a protect effect for caregivers. In that study, Youn and colleagues (1999) reported that familism was highest in Korean caregivers and lowest in non-Hispanic White caregivers, with Korean Americans in the middle. However, Koreans and Korean Americans reported higher levels of burden; Korean showed higher levels of depression and of anxiety than white American caregivers, with Koreans and Korean Americans higher than non-Hispanic White caregivers on anxiety. The authors discuss that greater adherence to familism values does not protect Korean caregivers from burden, and familism may not protect against caregiving distress but may actually increase it.

Familism is also considered as having influence on the selection of coping strategies by caregivers. From the meaning of familism, it has been assumed that caregivers with higher familism would use more effective coping styles such as more use of active coping and less use of avoidant coping (Segall et al., 1998). However, the research findings did not support this assumption. For example, Kim and colleagues' study (2007) explored how familism, burden, and coping styles mediate the relationships between ethnicity (African American and White American) and the mental and physical

health of caregivers. The researchers found that African American who had higher levels of familism used more avoidant coping strategies than White caregivers, which in turn led to worse outcomes for mental health and self-reported physical health. The researchers explained that the familism, which was measured by the Bardis (1959) scale may represent obligation more than positive feelings about family support, and in turn would affect the results on coping strategies. On the other hand, the stronger connection of familism to coping strategies rather than to perception of burden suggests that familism might influence stress and coping among caregivers through coping styles rather than through burden (Kim, Knight, & Longmire, 2007).

Since there are not many studies that explore the influence of familism on caregiving appraisal and coping, it remains unclear of the relationship of familism to caregiver outcomes via the positive aspect of caregiving (e.g., caregiving satisfaction) and coping. These areas need to be explored in the future. In addition, more culturally appropriate measures are needed to further probe into the role of cultural value of familism in the caregiving stress process (Dilworth-Anderson, Williams, & Gilbson, 2002; McCallum, Longmire, & Knight, 2007).

### Conclusion

In summary, the literature review demonstrates that caring for an elder with dementia is a complex and demanding process. Family members who provide care for their elders with dementia at home often experience stress-related physical and psychological health problems. These outcomes also depend on the caregivers' appraisal of their caregiving experiences and should include both positive and negative aspects of

caregiving and selection of coping strategies. Contextual factors that include the pre-morbid relationship satisfaction, culture influence on the belief of providing care, and perceived social support do have influences on caregiving appraisal and coping strategies, and in turn, affect caregiver outcomes. However, the relationships among these key constructs in the stress-coping process are still not answered clearly by research. Further studies exploring the relationships are essential. In addition, the literature review also revealed a shortage of systematic studies related to family caregiving of dementia elders in China. Therefore, there is a need to explore how caregiving appraisal, coping, and culture relate to contextual factors (familism and perceived social support) and influence the relationship of caregiving stressors to caregiver outcomes among family caregivers of demented elders in China.

## CHAPTER III METHODOLOGY

This study was designed to examine the impact of family caregiving upon Chinese caregivers of elders with dementia in China. This chapter describes the methodology of this study, which includes research design, sample, setting, measurement, data collection procedures, data analysis as well as the procedures for protection of human subjects.

### Research Design

A cross-sectional correlational design was used to examine the impact of family caregiving upon Chinese caregivers of elders with dementia in China. Path analysis with structural equation modeling was used to test the linear structural relations in the proposed Dementia Caregiving Model among family caregivers of demented elders in China. Two composite variables were developed to measure caregiving stressors and coping. While latent factors could be used to obtain information on the cumulative roles of caregiving stressors and coping and then effects on caregiver outcomes, using composite measures decreased the number of subjects that would be needed for the current study. Structural Equation Models involve specification of the model, identification, estimation methods, interpretation and model modification. Model specification is the process of describing the relationships that are hypothesized to exist among all variables. Model identification examines whether or not the model can be tested. That is, there are unique estimates for the parameters of interest given the number of known parameters. The model was specified when there are fewer parameters to be estimated than exist among the possible parameters

## Methods

### *Sample*

This study used a convenience sample of 96 Chinese family caregivers of elders with dementia in China. In structural equation modeling, power is a function of the number of parameters that are constrained versus those that can be estimated. A good model fit is when the difference between the collected data and the proposed model is minimized; that is, the residual between the estimated parameters and those that remain fixed, is minimized. Therefore, small sample sizes may overestimate the fit of the data to the model and a large sample size may overestimate the discrepancies between the data and the model. Nunnally and Bernstein (1994) use a rule of thumb suggesting 30 subjects per independent variable in the model will increase the likelihood that findings can be replicated and are not mere artifact. In this study, there were 3 independent variables, the composite of caregiving stressors, familism, and perceived social support. Therefore, the minimum required sample size is 90. In this study, 96 research participants were recruited who met the selection criteria.

The target population in this study was family caregivers of elders with dementia in China. The inclusion criteria for family caregivers were: (1) primary family caregivers of elders ( $\geq 60$  years of age) with dementia; (2) functioning as a caregiver for at least 6 months; (3) caring for the elder at least 4 hours/day; (4) able to read Chinese and speak Mandarin; (5) co-residing with elders with dementia; and (6) willing to participate in the study.

Family caregivers who were currently providing care to another family member with a chronic physical or mental illness were excluded from the study.

#### *Data Collection Procedures*

Ninety-six research participants were recruited from three outpatient clinics of hospitals in Shenyang and Beijing, China. The researcher contacted the nursing directors of selected hospitals and explained the purpose of the study and sought permission to access potential participants from the outpatient clinics. Nurses who were working in the outpatient clinics asked potential participants if it would be all right for a graduate student in nursing to talk with them about her study by phone. If yes, then the researcher approached the potential participants by phone with information about the study and arrangements were made for in-home visits. During the home visit, the researcher read the content of the disclosure (see Appendix A) to the potential participant, and answered any questions. The potential participant was given time to decide if he/she wanted to participate. Oral agreement to participate in this study was obtained from participants.

After obtaining the caregiver's oral permission, the researcher asked the participants to complete 1 demographic form and 8 questionnaires (see Appendix A). It usually took the participant 35-45 minutes to finish. After participants finished the questionnaires, all questionnaires were kept by the researcher and locked in a personal file in China. All questionnaires were coded with a number. The de-identified data on the questionnaires were entered on the researcher's personal computer with password protection.

### *Measurements*

Conceptually, 3 independent variables (the composite of caregiving stressors, familism, and perceived social support) and 3 mediating variables (caregiving subjective burden, caregiving satisfaction, and coping) were hypothesized to influence family caregivers outcomes (physical and psychological health). The measurements include: (1) demographic information forms of care-recipients and family caregivers; (2) Activities of Daily Living scale (ADL); (3) Revised Memory and Behavior Problems Checklist (RMBPC); (4) Attitudinal Familism Scale (AFC); (5) Multidimensional Scale of Perceived Social Support (MSPSS); (6) Zarit Burden Interview (ZBI); (7) Positive Aspect of Caregiving instrument (PAC); (8) Simplified Coping Style Questionnaire (SCTQ); (9) Medical Outcomes Study 36 Item Short Form Health Survey (SF-36). All items for the measurements are listed in Appendix A. Except AFC, all other measurements (ADL, RMBPC, MPSSS, ZBI, PAC, SCTQ, and SF-36) have corresponding Chinese versions. The familism scale was translated from English into Chinese using Brislin's (1980) guidelines for cross-cultural research. Each of these measurements is discussed in this section, including validity and reliability.

### *Demographic Characteristics*

Demographic information forms were designed by the researcher to collect demographic characteristics from caregivers as well as care-recipients. Demographic data collected from caregivers include their age, gender, educational level, marital status, duration of caregiving, and relationship with the care-recipient.

The demographic data collected from care-recipients included their age, gender, educational level, type and duration of diagnosis, and type of medical insurance payment.

### *Caregiving Stressors*

Caregiving stressors were defined as environmental demands specific to the caregiving experience that may be perceived through the process of primary appraisal as potential threats to the person. Stressors were represented by the degree of disability of the person being cared for (Lawton et al., 1992). In this study, the degree of disability of the elders with dementia was evaluated based on both functional capabilities and dementia related behavior problems.

*Functional Capacities.* Care-recipient's functional capacities were assessed by using the Chinese version of Activities of Daily Living Scale (ADL-C; He, 1990). ADL-C was translated and revised based on the ADL, which was developed by Lawton and Brody (1969). The ADL-C was demonstrated to have good reliability and validity when it was used in a study including 5,055 community-dwelling elders (He, 1990). The test-retest reliability (stability) of ADL-C was 0.502, and convergent validity was shown by the association between the score of ADL-C and MMSE ( $r=0.45$ ,  $p<0.01$ ).

In ADL-C, there are 6 items to assess how much assistance the care-recipient requires with bathing, dressing, eating, toileting, grooming, and transferring out of a bed or a chair, and another 8 items to assess how much assistance is required for higher-level self-care abilities including help needed to take medications, shop, travel, manage finances, use the telephone, prepare meals, do housework, and do laundry. On each item, the caregivers were asked whether or not their care-recipients require assistance with

those 14 tasks. Caregivers rate items on a Likert scale ranging from 1 to 4, with 1=performs without difficulty or help, 2=performs with difficulty, 3=performs with assistance, 4=unable to perform. The possible scores for the entire scale are ranging from 14 to 66. For the entire scale, the cut-off point of ADL-C is 16, and scores greater than 16 indicate decreased functional capabilities. Scores over 22 indicate an obvious functional impairment (He, 1990).

*Dementia Related Behavior Problems.* The Revised Memory and Behavior Problems Checklist (RMBPC; Teri et al., 1992) was used as the measure of care-recipient's behavior problems. This scale estimates care-recipient's current behavior and cognitive disruptions, but not the severity of dementia. There were 24 items in RMBPC, which rated three domains of care-recipient's problems: behavior, memory, and depression. Each behavior is rated on two scales that is the frequency of behavior and the caregiver's reaction to each behavior. In this study, only the subscale on the frequency of behavior was used. The frequency of each behavior is rated from 0 to 4: 0=never occurs, 1=occurs infrequently and not in the last week, 2=occurred 1-2 times in the last week, 3=occurred 3-6 times in the last week, and 4= occurs daily or more often. The final score is the sum of all scores. Therefore, the possible score ranges from 0 to 96. Higher scores mean more frequent behavior problems.

Internal consistency of the subscale for frequency of behavioral problems was acceptable ( $\alpha = .75$ ). Validity was established by conducting correlations between the RMBPC dimensions and several established measures: the Hamilton Depression Rating Scale (HDRS); the Center for Epidemiological Studies Depression Scale (CES-D); the

Caregiver Stress Scale (CSC); and the Mini-mental Status Examination (MMSE). Teri and colleagues (1992) found that the depression subscale was significantly associated with the HDRS and the CES-D (demonstrating concurrent validity); the frequency of memory problems was reliably correlated with the MMSE and dementia diagnosis (demonstrating concurrent validity); the frequency of behavior problems was significantly related to the HDRS (demonstrating construct validity).

The Revised Memory and Behavior Problems Checklist has been translated into Chinese by Fuh and coworkers (1999) and tested among 76 AD patients and their caregivers in Taiwan. The results showed that RMBPC-C was a reliable tool as used among Chinese population (Fuh et al., 1999). The Cronbach's alpha was 0.82 for the subscale on frequency of problems. The test-retest reliability (3-day) was 0.89.

### *Caregiving Appraisal*

Caregiving appraisal describes the evaluation of the caregiving process. Caregiving appraisal is thought to mediate the relationship between caregiving stressors and caregiver outcomes. There are two important parts within the caregiving appraisal, which are caregiving subjective burden and caregiving satisfaction.

*Caregiving Subjective Burden.* The Zarit Burden Interview (ZBI) was used to measure appraised caregiving subjective burden. There are 22 items in the scale. It was originally developed to assess perceived stressors among caregivers of individuals with dementia (Zarit, Reever, & Bach-Peterson, 1980). Item response options range from "never" (0) to "nearly always" (4), with a total score ranging from 0 to 88, higher scores

indicate greater perceived burden. Internal reliability for ZBI is generally higher (e.g., 0.88), and construct validity is good (Zarit, Anthony, & Boutselis, 1987).

The ZBI was translated into Chinese by Ko and colleagues (2008) and examined reliability and validity. The Chinese version of ZBI (ZBI-C) was administered to 181 Chinese patient-caregiver dyads. The Cronbach's alpha was 0.89, and test-retest reliability for 2 weeks interval was 0.88. Concurrent validity was established by examining the correlation of the ZBI-C with Chinese Health Questionnaire. It was reported that high levels of perceived burden were associated with high levels of psychological distress ( $r=0.54$ ,  $p<0.0001$ ).

*Caregiving Satisfaction.* Caregiving satisfaction was measured using the Positive Aspect of Caregiving instrument (PAC; Tarlow et al., 2004). Based on the original work of Lawton and colleagues (1989, 1991), the PAC was originally developed to assess the positive aspects of caregiving using a sample of dementia caregivers. It was administered to 1,229 participants in a national collaborative Alzheimer's disease caregiver study and tested on psychometric qualities. PAS has 9 items and has two components, Self-affirmation (6 items) and Outlook on Life (3 items). Each item was rated on a 5-point ordinal scale ranging from 1 (disagree a lot) through 5 (agree a lot). Possible scores for the entire scale range from 9 to 45. Higher scores mean high levels of caregiving satisfaction (Tarlow et al., 2004). Cronbach's alpha was 0.89 for the entire scale, and 0.86 and 0.80 for the subscales of Self-affirmation and Outlook on Life, respectively. Discriminate validity was verified by examining the correlation between the overall score and the Somatic subscale of the CES-D ( $r=-.17$ ,  $p<.05$ ).

The PAC has been translated into Chinese by Zhang and Li (2007), and the Chinese version of PAC (PAC-C) was tested with reliability and validity among 82 Chinese dementia caregivers. The Cronbach's alphas for the entire scale, Self-affirmation subscale, and Outlook on Life subscale were 0.90, 0.89 and 0.83, respectively. Factor analysis also provided evidence for the construct validity of the two subscales of PAC.

### *Coping*

In the Dementia Caregiving Model, coping is one of the important mediators between caregiving stressors and caregiver outcomes. Coping is defined as “the 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” (Lazarus & Folkman, 1984, p.141).

In this study, coping was measured by using the Simplified Coping Style Questionnaire (SCTQ), which was developed in China by Xie (Xie, 1998). Based on Lazarus and Folkman's Way of Coping Questionnaire, Xie developed SCTQ considered appropriate for the Chinese population under Chinese culture. The psychometric properties of SCPQ were tested among 846 male and female Chinese adults (aged 20-65 yrs) (various occupations). SCTQ consisted of 20 items referring to different ways of coping with daily life events with 4 choices (0=not use, 1=use occasionally, 2=use sometimes, 3=use frequently).

Factor analysis found that coping ways were classified into positive and negative styles that consisted of 12 and 8 items respectively. The positive coping styles reflected the ways that people seek help trying different ways to solve problems (e.g., try to come

up with several strategies to solve problems; look for something good in it; see it in a different light), whereas the negative styles reflected that people avoided facts and did not actively solve problems (e.g., using alcohol or other drugs to make myself feel better; trying to forget the whole situation). The result from the study (Xie, 1998) also showed that positive styles of coping were associated with less psychological symptoms, and negative styles of coping were associated with more psychological symptoms.

Two-week test-retest reliability for 20 subjects was 0.89. Cronbach's alpha for the entire questionnaire was 0.90, and the Cronbach's alpha for positive style subscale and negative style subscale were 0.89 and 0.78, respectively.

Following Lazarus and Folkman's (1984) work, Xie (1989) also emphasized that the type of coping chosen depended partly on the individual's appraisal of the situation's amenability to change and his or her resources, and there are no absolute good or bad coping styles.

After the indicators from SCTQ for each care-recipient were obtained, the coping composite was calculated. More details about the procedure of making the composite are described as part of the data analysis section.

### *Contextual Factors*

In the Dementia Caregiving Model, two contextual factors were explored in this study. They were familism, which could affect beliefs about providing care, and perceived social support.

*Familism.* Familism is considered a core value of the Chinese culture. It describes strong identification, attachment and loyalty of individuals to their families (Park &

Chesla, 2007). It is the value that influences family caregivers to provide care to their demented elders. In this study, the Attitudinal Familism Scale (Steidel & Contreras, 2003) was used to assess familism among Chinese family caregivers of elders with dementia. This scale was originally developed to measure familism among Spanish-speaking Latinos in the United States who had low levels of acculturation. The measure consisted of 18 items assessing familial support (the belief that family members have a duty to support immediate or extended family members not only in times of need but also in everyday life; 6 items), familial interconnectedness (the belief that all family members must be both physically and emotionally close to each other, and relatives must spend and cherish time together; 5 items), familial honor (the belief that an individual has a responsibility not to tarnish the family name and a duty to defend any attacks against the family integrity; 4 items), and subjugation of self to family (the belief that a person must be submissive and respect the family rules; 3 items).

The scale was scored on a 10-point Likert-type scale ranging from 1 (strongly disagree) to 10 (strongly agree). Responses on all the items were summed to create an overall familism score. Total scores for responses on this scale ranged from 18 to 180 with higher scores indicating stronger values toward familism. In addition, participants' responses on each subscale were summed to create a score for each subscale. For this study, the researcher used the total familism score.

The internal consistency reliability for the overall scale is 0.83, and 0.72 for Familial Support, 0.69 for Familial Interconnectedness, 0.68 for Familial Honor, and 0.56 for Subjugation of Self for Family. All subscales were significantly intercorrelated.

Factor analysis also confirmed the construct validity of the scale, which was composed of four factors. In addition, validity analyses also showed that this scale negatively correlates with acculturative status ( $r=-.26, p<.01$ ) (Steidel & Contreras, 2003).

*Perceived Social Support.* In this study, perceived social support referred to the support that is believed to be available at any given moment. Perceived social support was evaluated by caregivers from their informal resource (e.g., other family members, relatives, and friends).

Perceived social support was measured by the Multidimensional Scale of Perceived Social Support (MSPSS; Zimet, Dahlem, Zimet, & Farley, 1988), which was a 12-item self-report questionnaire designed to measure the perception of individuals' social support sufficiency. Factor analysis demonstrated three subscales: family, friends, and significant other. The response format is based on a 7-point Likert scale ranging from 1 (*very strongly disagree*) to 7 (*very strongly agree*). The range for the total scale is 12 to 84. Zimet and colleagues (1988) have reported excellent psychometric properties, especially considering the number of items in the scale. Cronbach's coefficient alpha is 0.88 for the total scale, and 0.81, 0.85, and 0.91 were reported for Family, Friend, and Significant Other subscales, respectively. In addition, test-retest reliability for the total scale was .85, and ranged from .72 to .85 on the subscales. Construct validity has been established by an inverse correlation with depression scores ( $r=-0.25, P<0.01$ ). It was also found that factor structure of the MSPSS was stable in cross-cultural studies in Turkey and Italy (Zhang & Norvilitis, 2002). The measure had good internal consistency as well as construct validity.

The MSPSS was translated into Chinese by Chou (2000) and applied to high school students in China. The Chinese version of MSPSS (MSPSS-C) was reported to have good reliability and validity (Chou, 2000). The internal consistency coefficient (Cronbach's alpha) for the MSPSS-C scale was 0.89. However, factor analysis did not provide evidence for construct validity of the three social support subscales for the sample from Chou's study (2000). It reflected that the Family subscale of the original three-factor solution is retained, whereas the original Friend and Significant Others subscales were combined into one Friend subscale in Chou's sample. Chou (2000) explained that the reason of the two-factor solution may be due to the sample he used in his study. In his study, respondents were Chinese adolescents in Hong Kong high schools. The samples were university undergraduate students in the original MSPSS validation study. In Chou's study, significant others of adolescents were more likely to be their peers. Therefore, items related to support from friends and significant others were highly associated. However, in the sample of the original MSPSS validation study, respondents might also engage in romantic relationships. Therefore, their close friends in romantic relationships would most likely be their significant others.

#### *Caregiver Outcomes*

The Medical Outcomes Study 36 Item Short Form Health Survey (SF-36; Ware & Sherbourne, 1992) was used to evaluate caregiver health-related quality of life in terms of physical and psychological health. The SF-36 is a short questionnaire with 36 items that measured 8 multi-item variables: physical functioning (PF), social functioning (SF), role limitations due to physical problems (RP), role limitations due to emotional problems

(RE), general mental health (MH), vitality (VT), pain (BP), and general perception of health (GH). A question about changes in overall health status over the past year was also asked in SF-36 but is not included in the eight categories. Questions related to the eight categories cover respondents' behaviors as well as feeling states in the past 4 weeks. Items in each category can be aggregated without score standardization or item weighting. High values represent good health. Previous factor analyses suggest two composites in the SF-36, which are physical and psychological health. Physical health is scored as the average from four categories (PF, RP, BP, GH), and psychological health is scored as the average from the other four categories (VT, SF, RE, MH). The possible score for physical and psychological health is from 0 to 100. In this study, the each total score for physical and psychological health were utilized in the model test. The reliability and validity of the SF-36 have been tested and verified as acceptable (McHorney, Lee, & Raczek, 1993; McHorney, Ware, Lee, & Sherbourne, 1994; Ware, 1995).

The SF-36 was translated into Chinese through a rigorous scientific process of forward and backward translation, and tested among 1,688 community-dwelling general adult population from mainland China (Li, Wang, & Shen, 2003). It was found that the Chinese version of the SF-36 functioned in the general population of Hangzhou, mainland China similarly to the original tested American population. Reliability and validity were acceptable for the Chinese version of SF-36. In addition, Yu and colleagues (2003) tested the Chinese version of the SF-36 among 309 bilingual Chinese in Tucson, Arizona. The majority of the subjects were international students, visiting scholars, and their dependents. Cronbach's alpha for the Chinese version of the SF-36 ranged from

0.64 to 0.85 with the highest value for the bodily pain scale and the lowest for the social functioning scale. All but one (social functioning) of the reliability estimates for the SF-36 scale exceeded 0.70, the minimum internal consistency reliability recommended for group comparisons. One-week test-retest correlation coefficients for the SF-36 scales ranged from 0.67 to 0.90 for the Chinese version. Equivalent-forms reliability for the English and Chinese versions was analyzed in both the English-Chinese administration order and the Chinese-English administration order in the study. The equivalent-forms reliability estimates were excellent, ranging from 0.81 to 0.98 for the English-Chinese administration order and 0.82 to 0.99 for the Chinese-English administration order. There was no systematic effect of administration of the English and the Chinese version on the reliability estimates. These findings provided general support for the equivalence of the Chinese and English versions of the SF-36.

#### Instrument Translation

In order to ensure cultural equivalence of the Attitudinal Familism Scale (AFS) that was developed in English and had not been used for the Chinese population, the AFS was translated using Brislin's (1970, 1986, cited in Jones et al., 2001) guidelines for cross-cultural research for this study. First, the researcher translated the AFS into Chinese. Next, the Chinese version of AFS was translated back to English by two independent bilingual translators who were blind to the original English version of AFS. Then, the original and the back-translated version were compared. If there were inconsistencies between these two English versions, the researcher and the bilingual experts discussed the differences until consensus of meaning was obtained. Finally, face validity was

obtained by two clinical gerontology nurses who have been working with dementia patients and their family caregivers for more than 10 years.

### Data Analysis

Data analysis procedures involved univariate analysis, bivariate relationship analysis, and path analysis under SEM. All data were entered and analyzed with computerized statistical programs. Statistical Package for Social Science, version 16 (SPSS 16) was used to conduct univariate analysis and bivariate correlation analysis. Analysis of Moment Structures software 5.0 version (AMOS 5.0) was used in this study for path analysis. To answer the research questions, the following analyses were conducted:

1. Calculating the coping composite. The procedure for computing the composite was equivalent to the estimation of unit-weighted factor scores. The unit weighting of multivariate constructs had the additional advantage of increasing the stability (and thus interpretability) of results across independent samples (Gorsuch, 1983), and it also could overcome any potential difficulties associated with the estimation of actor scores with missing data and with smaller sample sizes (Figueredo, McKnight, McKnight, & Sidani, 2000). Concrete steps for obtaining the composite variables are discussed in detail (see Chapter 4 for results).

2. Univariate analysis was used to clean and check the quality of data. It was also used to examine the variability of data, describe the characteristics of each variable, and check statistics assumptions prior to analyses.

3. Bivariate relationship analysis was used to examine the linear relationships between each independent variable and dependent variables. If the data violated the assumptions of normality, Spearman Rank order was used to test bivariate relationships rather than Pearson Product moment. In this study, the independent variable is the composite of caregiving stressors, familism, and perceived social support. The dependent variables in this study are caregiving subjective burden, caregiving satisfaction, coping, and caregiver outcomes regarding their physical and psychological health. These analyses responded to the first research question. In addition, these correlations guided the path analysis. The variables that were significantly correlated to the dependent variables were used as predictors in the path analyses.

4. Bivariate correlations between independent variables were also examined to check multicollinearity of explanatory variables. The Variance Inflation Factor (VIF) and Tolerance were also checked for multicollinearity among the explanatory variables.

5. Structural equation modeling is a combination of two analytic strategies, Path Analysis and Confirmatory Factor Analysis. In this study, SEM software was used to obtain path coefficients and model fit indices for a hypothesized model. Path analysis is “a tool for evaluating the interrelationships among variables by analyzing their correlational structure” (Everitt & Dunn, 1991, p.247). It is used to answer questions regarding the relationship between a set of independent variables and a dependent variable (Norris, 2005). It was used to test the proposed Dementia Caregiving Model to explain caregiver outcomes in term of health. Path analysis was conducted to analyze paths or lines in the Dementia Caregiving Model that represent the influence of one

variable on another (see Figure 2). The hypothesized relationships are also depicted in Figure 2. All model estimations were conducted with AMOS 5.0 by using maximum-likelihood estimation. Path analysis was conducted to answer the second research question and test 8 hypotheses under the second research question. Model fit indices were examined to test the overall fit of the collected data to the model. The fit indices included Chi-Square, the Goodness-of-fit Index, the Comparative Fit Index, the Normed Fit Index, the Incremental Fit Index, and the root mean square error of approximation (RMSEA). These indices were used to evaluate whether the estimated covariance matrix from the model was an adequate representation of the sample covariance matrix.

#### Protection of Human Subjects

The institutional Review Board (IRB) Human Subjects Committee of the University of Arizona reviewed this study for approval to conduct the study. A disclosure form was provided to participants at the first meeting and oral consent was obtained before initially completing the questionnaires. At the same time, the purpose of this study, procedures for completing the questionnaires and potential risks and benefits of the study were explained by the researcher to each potential participant who was a current caregiver with the invitation to participate. In addition, all participants were informed that they could stop participating in the study at any time without any effect on their care-recipients' medical care. Moreover, it was explained that their confidentiality would be maintained, that is, that only the researcher would know their specific identity. They were also informed that only the researcher and her advisor had access to questionnaire data. In order to protect subject's confidentiality, all subjects were assured that no individual

names were collected, and all documents were coded with a number. Identifying information voluntarily given by some participants was kept separate from questionnaires and could be accessed only by the researcher herself. However, it was established that the researcher would provide information for a needed referral if concerns about mental or physical health arose. Potential participants were also assured that no identifying information would be used in publications that might result from the study findings.

## CHAPTER IV FINDINGS

The purpose of this study was to describe the impact of providing care for elders with dementia on caregiver physical and psychological health. Data collection occurred in China and describes Chinese family caregiving investigating the roles of caregiving appraisal, coping, familism, and perceived social support on the relationship between caregiving stressors and caregiver outcomes. All data were entered and analyzed with a computerized statistic program, the Statistical Package for Social Science, version 16 (SPSS-16). Analysis of Moment Structures software 5.0 version (AMOS 5.0) was used in this study for path analysis. The results of this study are presented as follows: (1) description of the study setting and sample; (2) characteristics of study variables; (3) reliability of the instruments; (4) descriptive data analysis of study variables; (5) findings addressing the research questions and hypotheses.

### Characteristics of the Settings and Sample

#### *Settings*

A total of 96 family caregivers of elders with dementia were recruited from three clinics associated with hospitals in China. Two clinics were in Beijing, and one was in Shenyang, China. The two cities of Beijing and Shenyang are located in northeast China and have similar population characteristics and economic-cultural background. Thirty-one percent of the participants (n=30) were recruited from the clinic in Shenyang, China, and 69% of the participants (n=66) were from two clinics in Beijing, China. All three clinics were similar in size and available medical procedures.

### *Sample*

The sample consisted of 96 family caregivers of elders with dementia who agreed to participate in this study. The demographic characteristics of the family caregivers are shown in Table 1. The mean age of the caregivers was 59 (SD=14.1) years with a range of 25 to 83 years, and 50% (n=48) of caregivers were equal to or older than 60 years of age. Seventy-two point nine percent (n=70) of the participants were female, and 27.1% (n=26) were male. Ninety-one point seven percent (n=88) of the sample were married. The highest education level attained varied including college (n=25, 26%), junior college or vocational school (n=19, 19.8%), high school (n=18, 18.8%), middle school (n=16, 16.7%), and elementary school or below (n=18, 18.7%). The number of months providing care at home after the care-recipient was diagnosed with dementia ranged from 7 to 180 months with a mean of 54 months (SD=42.5). Among the caregivers, forty-five (46.9%) were spouses of care-recipients, 29 (30.3%) were children of care-recipients, 12 (12.5%) were children-in-law, and 10 (10.4%) were cousins.

Demographic characteristics of the care-recipients are shown in Table 2. The mean age of the care-recipients was 78 (SD=9.4) years with a range of 60 to 102 years. Fifty-five (57.3%) of the care-recipients were male, and forty-one (42.7%) were female. Fifty-seven (59.4%) of the care-recipients were diagnosed as with Vascular Dementia (VD) by their physicians, twenty-seven (28.1) were diagnosed as with Alzheimer's disease (AD), and twelve (12.5%) were diagnosed with a mixed etiology for dementia (MD), that diagnosed with both VD and AD. The level of severity of dementia of the care-recipients varied including mild (n=18, 18.8%), moderate (n=48, 50.0%), and severe

(n=30, 31.3%) (the severity of dementia was diagnosed by physician and was reported to the researcher by caregivers). The duration of a family member's diagnosis of dementia at the time of the interview was 61 months (SD=48.0) with a range of 9 to 180 months. The type of medical insurance included care-recipients (n = 42, 43.8%) who do not need to pay by themselves for medical expense, 46 (47.9%) care-recipients who paid partially with self-pay rate that varied from 10% to 50%, and 8 (8.3%) who had to pay their medical expense totally by themselves.

**TABLE 1: Demographic Characteristics of the Family Caregivers (N=96)**

	Range	Mean	SD	n (%)
Family Caregivers				
Age	25-83	60	14.1	
Gender				
Female				70 (72.9)
Male				26 (27.1)
Marital Status				
Married				88 (91.7)
Divorced				3 ( 3.1)
Widowed				1 ( 1.0)
Single				4 ( 4.2)
Education				
Elementary school or below				18 (18.7)
High school				18 (18.8)
Middle school				16 (16.7)
Junior college or vocational education				19 (19.8)
College				25 (26.0)
Length of Providing Care in months	7-180	54	42.5	
7-24 months				30 (31.3)
25-60 months				32 (33.3)
61-120 months				30 (31.3)
> 120 months				4 ( 4.2)
Relationship to the Care-recipients				
Spouse				45 (46.9)
Son/daughter				29 (30.3)
Son-in-law/daughter-in-law				12 (12.5)
Cousins				10 (10.4)

**TABLE 2: Demographic Characteristics of the Care-recipients (N=96)**

	Range	Mean	SD	n (%)
Care-recipients				
Age	60-102	78	9.4	
Gender				
Female				41 (42.7)
Male				55 (57.3)
Type of Dementia				
VD				57 (59.4)
AD				27 (28.1)
MD				12 (12.5)
Level of Severity of Dementia				
Mild				18 (18.8)
Moderate				48 (50.0)
Severe				30 (31.3)
Duration of Diagnosis with Dementia in months	9-180	61	48.0	
Type of Medical Insurance				
Do not need to pay by care-recipient				42 (43.8)
Partly pay by care-recipient				46 (47.9)
Totally pay by care-recipient				8 ( 8.3)

### Characteristics of Study Variables

Before checking the characteristics of study variables, the composite variable of coping was developed. In order to obtain the composite score of coping, the z score of positive coping and separately the z score of negative coping were calculated. Then the z score of negative coping was subtracted from the z score of positive coping. The higher the positive score meant more positive coping strategies used by the family caregiver, and higher negative composite meant less positive and more negative coping strategies used by the caregiver. A variable named coping composite was added in the dataset to represent the composite variable of coping. The correlation between the coping composite and positive coping was highly positively correlated ( $r=.509, p=.000$ ). An almost high negative correlation was also found between the coping composite and negative coping ( $r_s=-.487, p=.000$ ). These significant correlations described that both positive and negative coping were significantly related to the coping composite score in the expected directions.

The data distributions for each study variable were first examined for normality by the Kolmogorov-Smirnov test (K-S). This test compares the scores in the sample to a normally distributed set of scores with the same mean and standard deviation (Field, 2005). If the K-S is not significant ( $p>.05$ ), the distribution of scores within the sample is normally distributed. However, if the K-S is significant ( $p\leq.05$ ), the normal distribution assumption is in question because the sample distribution differs significantly from a normal distribution.

Among the study variables, the following 4 variables were not normally distributed in this sample based on the K-S test ( $p<.05$ ; see Table 3): Activities of

Daily Living (ADL), Familism, Caregiving Satisfaction, and negative coping. Other variables (caregiving subjective burden, perceived social support, positive coping, and the coping composite, SF36\_physical health, and SF36\_psychological health) were not significantly different from a normal distribution ( $p > .05$ ), an indication they were probably normal. For the variables that were not normal distributions, non-parametric tests (i.e., Spearman's correlation) were used to examine the zero order correlations.

**TABLE 3: Tests of Normal Distribution among Variables in the Study (N=96)**

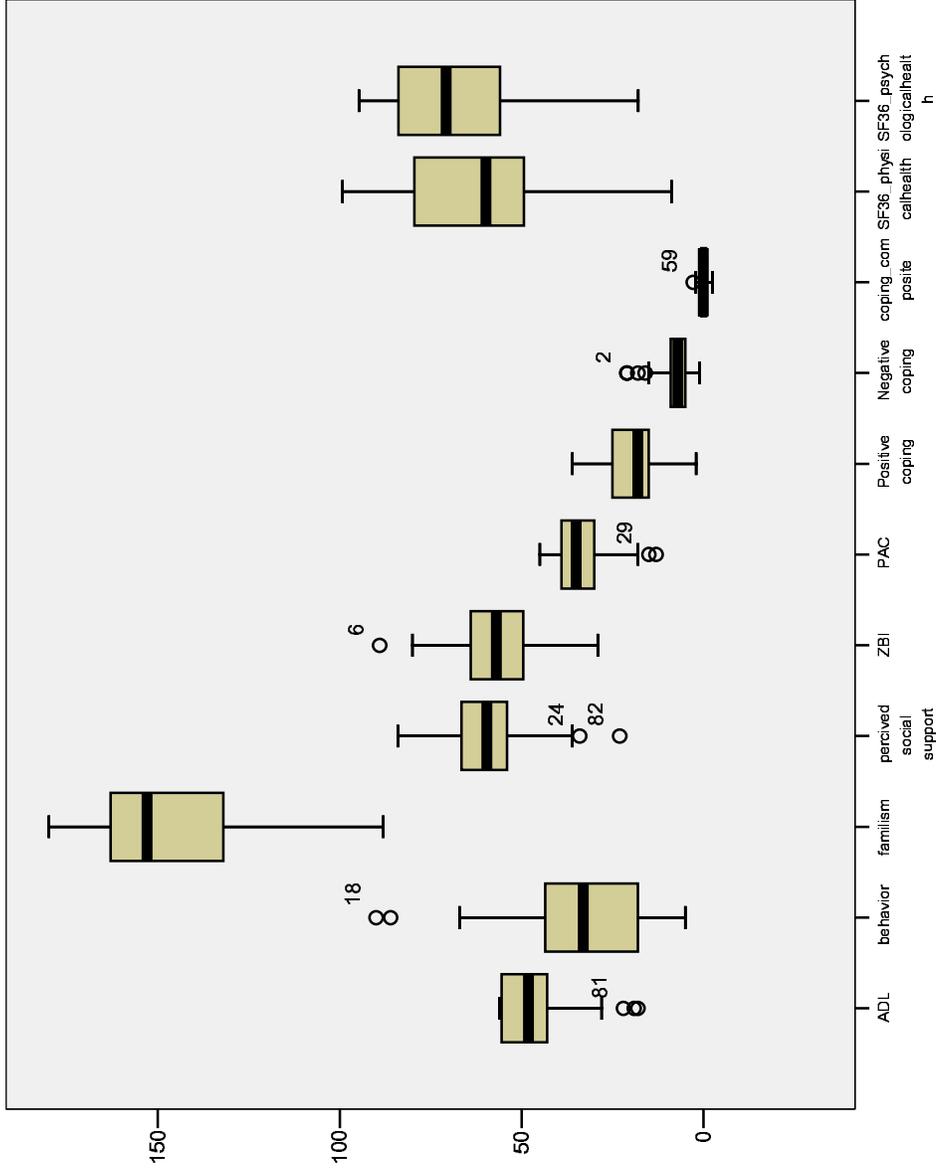
	Kolmogorov-Smimov Test		
	Statistic	df	P
ADL	.154	96	.000
Behavioral Problems	.071	96	.200
Familism	.149	96	.000
Perceived Social Support	.067	96	.200
Caregiving Subjective Burden	.059	96	.200
Caregiving Satisfaction	.106	96	.010
Positive Coping	.076	96	.200
Negative Coping	.163	96	.000
Coping Composite	.057	96	.200
SF36_physical health	.082	96	.118
SF36_psychological health	.078	96	.187

The distribution of study variables were also assessed for skewness and kurtosis by the Fisher's measure, which is calculated by dividing the measure of skewness (or kurtosis) by the standard error for skewness (or kurtosis). Values above +1.96 or below -1.96 are interpreted as having statistically significant skewness and kurtosis at the .05 significant level (Munro, 2001). The variables used to indicate caregiving satisfaction (-2.51), familism (-3.98), and ADL (-4.76) were significantly negatively skewed. The negatively skewed distribution on ADL indicated that more care-recipients in this study were impaired on daily activities. Negatively skewed distributions on the variables of caregiving satisfaction and familism indicate that the caregivers in this study appraised the caregiving experience positively and the

distribution reflects a high value of familism. The variable used to indicate negative coping was significantly positively skewed (4.71) indicating that more care-recipients in this study implemented less negative coping strategies. In terms of kurtosis, there were three variables, ADL, perceived social support, and negative coping that demonstrated significant kurtosis by Fisher's measure as the number of 2.67, 2.03, and 3.96, indicating that the distributions are too peaked to be normal (leptokurtic) and also predict the presence of some extreme values.

Outliers were then examined by inspecting descriptive statistics and boxplots. Cases are traditionally labeled outliers if the value is located more than three standard deviations from the mean (Munro, 2001). Based on this standard, two values were identified as outliers. One was identified in the variable of perceived social support; the value of the case 82 was located -3.43 standard deviations from the mean. The other one was identified in the variable of negative coping; the value of the case 2 was located 3.17 standard deviations from the mean. The boxplots of data distributions of the study variables are shown in Figure 3. The examination of the boxplots indicates no extreme outlier more than three interquartiles from the upper or lower edges of the box. But there were some smaller deviations for particular cases in which values were between 1.5 and 3 interquartiles from upper and lower edges of the box, in the variable of ADL, behavioral problems, perceived social support, caregiving subjective burden, caregiving satisfaction, negative coping, and the coping composite. These smaller deviations were checked by going back to the raw data. No coding errors were found. The outliers were also examined to see if including the outliers produced different results in the bivariate correlational analysis, which would be used to answer the first research question. Since the results with or without the outliers were similar

in the bivariate correlational analysis, they were retained in the data as suggested by Munro (2001).



○ Indicates cases with smaller deviations

**FIGURE 3. Boxplots of Scores in Study Variables**

### Reliability of the Instruments

Conceptually, 3 independent variables (the composite of caregiving stressors, familism, and perceived social support) and 3 mediating variables (caregiving subjective burden, caregiving satisfaction, and the coping composite) were hypothesized to influence family caregiver outcomes regarding their health. The level of stressors family caregivers faced was represented by the degree of disability of the elders with dementia and evaluated by their functional capabilities and dementia related behavior problems. The Chinese version of Activities of Daily Living Scale (ADL-C) and the Revised Memory and Behavior Problems Checklist (RMBPC) were used to assess the care-recipients' functional capabilities and behavioral problems correspondingly. Overall, the measurements in this study included: (1) Activities of Daily Living Scale (ADL); (2) Revised Memory and Behavior Problems Checklist (RMBPC); (3) Attitudinal Familism Scale (AFC); (4) Multidimensional Scale of Perceived Social Support (MSPSS); (5) Zarit Burden Interview (ZBI); (6) Positive Aspect of Caregiving instrument (PAC); (7) Simplified Coping Style Questionnaire (SCSQ); (8) Medical Outcomes Study 36 Item Short Form Health Survey (SF-36); Except AFC, all other measurements (ADL, RMBPC, MSPSS, ZBI, PAC, SCSQ, and SF-36) have corresponding Chinese versions and have been used among Chinese populations with acceptable reliability and validity. Thus, in this section, except for the AFC, other instruments were only tested for reliability.

*Chinese Version of Activities of Daily Living Scale (ADL-C)*

ADL-C contains 14 items to assess how much assistance the care-recipient required with activities of daily living. In this study, internal consistency as measured by Cronbach's alpha for ADL-C was .95, which is more than the accepted criterion for a scale (Field, 2005). Thus, ADL-C demonstrated good internal consistency in this sample.

*Chinese Version of the Revised Memory and Behavior Problems Checklist (RMBPC-C)*

RMBPC assessed the presence of 24 problem behaviors that people with dementia may have exhibited in the past week (e.g., trouble remembering recent events, asking the same question over and over). Caregivers rated the frequency of problem behaviors on a 4-point scale from 0 = never occurred to 4 = daily or more often, with a total score range from 0 to 96. A sum "frequency of problem behaviors" score was totaled and used as a measure of the presence of behavioral problems likely related to the dementia diagnosis. In this study, internal consistency of RMBPC-C was .89, which indicates good reliability of the instrument.

*Chinese Version of Zarit Burden Interview (ZBI-C)*

ZBI-C was used to measure appraised caregiving subjective burden. There were 22 items in the scale, and the item response ranged from 0=never to 4=nearly always, with a total score range from 0 to 88. Internal consistency of ZBI-C was measured by Cronbach's alpha and found at .82. Hence, the 22-item ZBI-C showed acceptable psychometric properties.

*Chinese Version of Positive Aspect of Caregiving Instrument (PAC-C)*

PAC-C included 9 items, each measured on a 5-point Likert scale ranging from ‘disagree a lot’ to ‘agree a lot’. Possible scores for the entire scale ranged from 9 to 45. Higher scores mean high levels of appraised caregiving satisfaction. In this study, Cronbach’s alpha of PAC-C was 0.89, which identified excellent reliability.

*Simplified Coping Style Questionnaire (SCSQ)*

SCSQ was originally a Chinese scale used to assess the ways of coping that were used by caregivers in their daily lives. It consisted of 20 items referring to different ways of coping with four choices (0 = not use, 1 = use occasionally, 2 = use sometimes, 3 = use frequently), with a total score range from 0 to 60. There were two subscales under SCSQ to assess positive and negative styles of coping that consisted of 12 and 8 items correspondingly. In this study, Cronbach’s alpha for the whole scale was 0.85, and 0.85 and 0.70 for the subscales of positive and negative styles of coping. Thus, the reliability for the entire SCSQ and two subscales were acceptable.

*Chinese Version of Attitudinal Familism Scale (AFS-C)*

Attitudinal Familism Scale (AFS) was used in this study to assess familism among Chinese family caregivers of elders with dementia. Attitudinal Familism Scale consists of 18 items, which could be divided into four subscales: familial support (6 items), familial interconnectedness (5 items), familial honor (4 items) and subjugation of self to family (3 items). The items were rated on a 10-point Likert scale ranging from 1 (strongly disagree) to 10 (strongly agree). Responses on all the items were summed to create an overall familism score. The total scores ranged from 18 to 180, with a higher

score indicating a stronger value of familism. In this study, only the total score for the entire scale was used to describe the level of familism that family caregivers held.

Since the Chinese translated version of AFS was used for the first time in the Chinese population, it was considered a new scale. The internal consistency of AFS was evaluated using the Cronbach's alpha coefficient. The alpha coefficients for the Chinese version of the AFS were .91 for the overall scale and .67 to .85 (.76, .85, .68, and .67) for the four subscales. The Cronbach's alpha for the entire AFS-C is acceptable criterion for a new scale (Cronbach's alpha recommended to be at least .70) (Nunnally & Bernstein, 1994). Interitem correlations ranged from -.008 (between item 2 and item 13) to .709, and 55% of item to item correlations fell within the range of 0.30 to 0.70 (61% were higher than .30). Item to total scale correlations were between .32 and .75, and 100% of the item to total scale correlations were higher than .30. Nunnally and Bernstein (1994) indicate that 40 to 50% of interitem as well as item-to-total scale correlations are expected to be between .30 and .70 for a new scale. Therefore, reliability of the Chinese version of AFS was satisfactory. The Chinese version of the AFS demonstrated satisfactory internal consistency among items may be regarded as homogeneous to the extent that most of its items measure the same characteristic or critical attribute. However, item 2 ('aging parents should live with their relatives') still needs more attention because it showed a lower correlation with other items (e.g.,  $r = -.008$  with item 13, and  $r = .014$  with item 15) in the AFS-C. One possible reason for the discrepancy might be the different interpretation the word 'relatives' may take in the Chinese culture. An understanding of the word relatives, may have led to a different interpretation of the item. However, it is

not advisable to change an existing scale on the basis of a single study. Paying specific attention to this item in further cross-cultural research is suggested. On the other hand, the word “relatives” indicates a broader family context and in the Chinese culture the son or daughter is the expected relative for the elder to live with, but not cousins or nephews. It is expected that the adult children of the elder will be responsible for the ongoing care of the elder.

To examine validity of AFS-C, predictive validity was used. The value of familism for Chinese people, especially people who are born after 1949 may differ from those born before 1949. The reasons for this difference are the following: a) people who are born before 1949 are all older than 60 years old. This group has experienced aging parents and their increasing needs, which may call forth a sense of familial obligation and family support, which were not previously appreciated. The increased recognition of familial obligation and family support would strengthen their value of familism compared to people who were born after 1949 and have had fewer chances to experience aging parents; China was established in 1949. After the establishment, China has opened her door and accepting different values and beliefs because of interaction with other countries. The traditional value of familism may be affected by the changes. Therefore, taken together, it is hypothesized that people who were born before 1949 may more highly value familism than people who were born after 1949.

To examine this hypothesis, the 96 family caregivers were divided into two groups. People in group 1 (n=48) were all born after 1949 and people in group 2 (n=48) were born before 1949. The point-biserial correlation coefficient was used to explore if

there was a relationship between the strength of value on familism and date of birth. The result showed that there was a significant positive correlation between familism and group ( $r=.219, p=.032$ ) meaning that people who were born before 1949 (group 2) had a relatively higher value on familism than people who were born after 1949 (group 1).

Given the hypothesis, predictive validity of AFS-C was provided.

*Chinese Version of Multidimensional Scale of Perceived Social Support (MSPSS-C)*

MSPSS-C was a 12-item self-report questionnaire designed to measure the perception of individuals' social support sufficiency. The response format was based on a 7-point Likert scale ranging from 1 (very strongly disagree) to 7 (very strongly agree). Internal consistency as measured by Cronbach's alpha for MSPSS-C was .91, which was excellent for a scale with only 12 items. Thus, the reliability of MSPSS-C in this study was demonstrated.

*Chinese Version of Medical Outcomes Study 36 Item Short Form Health Survey (SF-36-C)*

The SF-36-C included multi-item scales that assessed eight health concepts: physical functioning (PF), bodily pain (BP), role limitations due to physical problems (RP), role limitations due to emotional problems (RE), mental health (MH), social functioning (SF), vitality (VT), and general health (GH). The internal consistency assessed by Cronbach's alpha for each subscale is shown in Table 4 as well as the item-total coefficients. The findings indicate subscales of SF-36 were acceptable concerning reliability (Cronbach's alpha  $> .70$ ) except VT (alpha = .527) and SF (alpha = .494). Considering the relatively small number of items in VT (4 items) and SF (2 items), it was not surprising that the Cronbach's alpha were relatively low. However, the item-total

coefficients for SF were all above .30, and 66.7% item-total coefficients for VT were above .3, SF and VT were considered as having acceptable internal-consistency.

**TABLE 4: Number of Items, Cronbach's Alpha and Item-total Coefficient for Eight Subscales of SF-36**

Subscales	Number of Items	Cronbach's Alpha	Item-total Coefficient
GH	5	.898	.715~.810
PF	10	.894	.369-.794
RP	4	.863	.681~.744
BP	2	.784	.660 and .660
RE	3	.770	.549~.672
MH	5	.737	.299~.658
VT	4	.527	.144~.433
SF	2	.494	.337 and .337

*Notes: GH-general health; PF-physical functioning; RP-role limitations; BP-bodily pain; RE-role limitations; MH-mental health; VT-vitality; SF-social functioning*

In conclusion, all instruments used in this study demonstrated excellent to good reliability with few exceptions. The reliability of the measures lessened the chance of measurement error in the study. Noticeably, even though it is the first time the Attitudinal Familism Scale was first translated into Chinese and utilized in the Chinese population, findings support it has acceptable reliability and good predictive validity.

#### Descriptive Data Analysis of Study Variables

The results of descriptive analysis of the study variables on respondents are presented in Table 5. No missing data existed among these variables.

For the caregiver stressors, the score of ADL function ranged from 18 to 56, with a mean score of 46.9 ( $SD = 8.9$ ). The score of behavioral problems ranged between 5 and 90, with a mean score of 32.9 ( $SD=17.3$ ).

Caregiving subjective burden was measured by Zarit Burden Interview which consisted of 22 items with a possible range of scores between 0 and 88. The Level of

caregiving subjective burden in this study ranged from 7 to 67 and the mean score was 35.0 ( $SD = 8.9$ ). The Positive Aspect of Caregiving Instrument was used in this study to assess appraised caregiving satisfaction among family caregivers. The possible score was between 1 and 45. In this study, the level of caregiving satisfaction was between 13 and 45, with a mean score of 34.1 ( $SD = 6.8$ ).

The coping strategies that caregivers implemented were assessed by a Simplified Coping Style Questionnaire, which included 20 items where positive coping strategies were evaluated by 12 items and negative coping strategies were assessed by the other 8 items, with a possible range from 0 to 60. Higher scores implied strategies were utilized more frequently. In this study, the score of positive coping strategies ranged from 2 to 36, with a mean score of 19.1 ( $SD = 7.9$ ). The level of negative coping strategies were between 1-21, and the mean score was 7.9 ( $SD = 4.1$ ). The composite variable of coping ranged from -2.49 to 2.81, and the median was .019.

The value of familism in this study was assessed by utilizing the Attitudinal Familism Scale (AFS). AFS has 18 items with a possible score ranging from 1 to 180. Higher score indicate a higher value on familism. In this study, the level of familism ranged from 88 to 180, and a mean score was 146.4 ( $SD=22.9$ ).

Perceived social support was evaluated by the Multidimensional Scale of Perceived Social Support (MSPSS), which consisted of 12 items with a possible score from 12 to 84. A higher score indicates more perceived social support. The mean of perceived social support in this study was 59.3 ( $SD = 10.6$ ) with a range of 23 to 84.

The variable of caregiver outcomes in this study was determined by the medical Outcomes Study 36 Item Short Form Health Survey (SF-36). There were two sub-scores, which were related to physical health and psychological health. The standardized score for each of them ranged from 0 to 100. Higher scores indicate better health. In this study, the score ranged from 8.8 to 99.3 (*Mean* = 62.8, *SD* = 20.5) for physical health, and from 17.9 to 94.8 (*Mean* = 67.5, *SD* = 18.3) for caregiver psychological health.

**TABLE 5. Range, Mean, Standard Deviation (SD) of Variables of Caregiving Stressors, Caregiving Appraisal, Coping, Familism, Perceived Social Support, and Caregiver Outcomes (N=96)**

	Possible Range	Actual Range	Mean	SD
<b>Caregiving Stressors</b>				
ADL Function	16-56	18-56	46.9	8.9
Behavioral Problem	1-96	5-90	32.9	17.3
<b>Caregiving Appraisal</b>				
Caregiving Subjective Burden	0-88	7-67	35.0	10.7
Caregiving Satisfaction	1-45	13-45	34.1	6.8
<b>Coping</b>				
Positive Coping Strategies	0-36	2-36	19.1	7.9
Negative Coping Strategies	0-24	1-21	7.9	4.1
The Coping Composite	N/A	-2.49-2.81	.0	1.0
Familism	1-180	88-180	146.4	22.9
Perceived Social Support	1- 84	23-84	59.3	10.6
<b>Caregiver Outcomes</b>				
Physical Health	0-100	8.8-99.3	62.8	20.5
Psychological Health	0-100	17.9-94.8	67.5	18.3

*Note: N/A= non applicable*

### Research Question One

The first research question “What are the associations among caregiving stressors (functional impairments and behavioral problems), caregiving appraisal (caregiving subjective burden and caregiving satisfaction), coping, familism, perceived social support, and caregiver outcomes (physical and psychological health) among family caregivers of elders with dementia in China?” was addressed using correlational procedures. For the variables that were not normally distributed, non-parametric correlational analysis (e.g., Spearman’s correlation) was used to test the correlations among them and  $r_s$  was used to represent the correlational coefficient.

#### *The Relationship between Caregiving Stressors and Caregiving Appraisal*

The construct of caregiving stressors consisted of two main concepts, which were ADL function and behavioral problems. Through correlational test it was determined there were no relationship between these two variables ( $r_s = -.150, p = .144 > .05$ ).

For the construct of caregiving appraisal, the two concepts (caregiving subjective burden and caregiving satisfaction) were significantly inversely correlated ( $r_s = -.230, p = .024 < .05$ ). Green and Salkind (2005) indicated that correlation coefficients of .10, .30, .50, are interpreted as small, medium, and large coefficients, respectively, regardless of sign. Thus, based on this standard, the correlation between caregiving subjective burden and caregiving satisfaction was small to moderate because the correlation coefficient was less than .30.

The results of the correlational analysis between concepts included in caregiving stressors and caregiving appraisal are presented in Table 6. It was demonstrated that ADL

did not have any significant relationship with either caregiving subjective burden or caregiving satisfaction ( $p > .05$ ). The results also indicated that behavioral problems had a moderate to large positive relationship with caregiving subjective burden ( $r = .435$ ,  $p < .01$ ) and had a small negative relationship with caregiving satisfaction ( $r_s = -.209$ ,  $p < .05$ ). That is, more behavior problems among care-recipients were related to more subjective burden and less caregiving satisfaction as appraised by family caregivers.

**TABLE 6. Correlations between Each Variable of Caregiving Stressors and Caregiving appraisal**

	Caregiving Appraisal	
	Caregiving Subjective Burden	Caregiving Satisfaction
Caregiving Stressors		
ADL Function	-.059 ( $p=0.566$ )	.053 ( $p=0.611$ )
Behavioral Problems	.435** ( $p=0.000$ )	-.209* ( $p=0.041$ )

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

#### *The Relationship between Caregiving Stressors and Coping*

Table 7 shows the results of the correlational analysis between concepts of caregiving stressors and the coping composite. Significant correlations were found between behavioral problems and the coping composite ( $r = -.427$ ,  $p < .001$ ), and no significant relationship between ADL and the coping composite, which indicates that behavioral problems were significantly associated with the coping composite. Specifically, it identified that more behavioral problems were significantly correlated with less implementation of positive coping strategies.

**TABLE 7. Correlations between Caregiving Stressors and the Coping Composite**

	The Coping Composite
Caregiving Stressors	
ADL Function	-.028 ( $p=0.789$ )
Behavioral Problems	-.427*** ( $p=0.000$ )

\*  $p<.05$ , \*\* $P<.01$ , \*\*\* $p<.001$

*The Relationship between Caregiving Stressors and Caregiver Outcomes*

The findings of the correlation between concepts of caregiving stressors and caregiver outcomes are presented in Table 8. There was no significant correlation between ADL function and caregiver outcomes. However, the variable of behavioral problems was found to have significantly negative correlations with all indicators of caregiver outcomes. That is, more behavioral problems among care-recipients were correlated with worse physical ( $r=-.274$ ,  $p<.01$ ) and psychological health ( $r=-.318$ ,  $p<.01$ ).

**TABLE 8. Correlations between Each Variable of Caregiving Stressors and Caregiver Outcomes**

	Caregiver Outcomes	
	SF36_physical health	SF36_psychological health
Caregiving Stressors		
ADL Function	-.048 ( $p=0.640$ )	-.002 ( $p=0.982$ )
Behavioral Problems	-.274** ( $p=0.007$ )	-.318** ( $p=0.002$ )

\*\*  $p<.01$

*The Relationship between Caregiving Appraisal and Coping*

Table 9 shows the results of the correlational analysis between concepts of caregiving appraisal and coping. The correlation between caregiving appraisal and the coping composite indicate that caregiving subjective burden was negatively related to the

coping composite ( $r=-.304, p<.01$ ), while caregiving satisfaction was positively associated with the coping composite ( $r_s=.360, p<.001$ ). The results indicate that more appraised caregiving burden was correlated with less positive coping, while more appraised caregiving satisfaction was associated with more positive coping.

**TABLE 9. Correlations between Each Variable of Caregiving Appraisal and the Coping Composite**

	The Coping Composite
Caregiving Appraisal	
Caregiving Subjective Burden	-.304** ( $p=0.003$ )
Caregiving Satisfaction	.360*** ( $p=0.000$ )

\*  $p<.05$ , \*\*  $p<.01$ , \*\*\*  $p<.001$

*The Relationship between Caregiving Appraisal and Caregiver Outcomes*

The correlations between each variable of caregiving appraisal and caregiver outcomes are presented in Table 10. Noticeably, caregiving subjective burden was significantly and negatively correlated with caregiver outcomes in terms of physical health and psychological health ( $r=-.345, -.417; p<.01$ ), and the associations were moderate. In addition, caregiving satisfaction was found to have a significant positive correlations with psychological health ( $r_s=.210, p<.05$ ). However, no significant relationship was found between caregiving satisfaction and caregiver physical health. The results indicate that more burden as appraised by the caregiver was associated with worse caregiver health including the physical and psychological health. Conversely, more caregiving satisfaction was associated with better caregiver psychological health.

**TABLE 10. Correlations between Each Variable of Caregiving Appraisal and Caregiver Outcomes**

	Caregiver Outcomes	
	SF36_physical health	SF36_psychological health
Caregiving Appraisal		
Caregiving Subjective Burden	-.345** ( $p=0.001$ )	-.417** ( $p=0.000$ )
Caregiving Satisfaction	.161 ( $p=0.118$ )	.243* ( $p=0.017$ )

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

*The Relationship among Caregiving Appraisal, Familism, and Perceived Social Support*

Table 11 shows the result of correlational analysis among caregiving appraisal, familism, and perceived social support. The only non-significant finding was found between caregiver subjective burden and familism, other relationships were found to be significantly correlated. There was a small negative correlation between caregiving subjective burden and perceived social support ( $r=-.294$ ,  $p<.01$ ), which indicated that caregivers who appraised their caregiving situation as less burdened were associated with more perceived social support. In addition, caregiving satisfaction was found to have positive moderate correlations with familism ( $r_s=.322$ ,  $p<.01$ ) and perceived social support ( $r_s=.299$ ,  $p<.01$ ). The results describe that caregiving satisfaction was correlated with higher level of the value of familism and more perceived social support.

**TABLE 11. Correlations among Caregiving Appraisal, Familism, and Perceived Social Support**

	Contextual Factors	
	Familism	Perceived Social Support
Caregiving Appraisal		
Caregiving Subjective Burden	-.200 ( $p=0.051$ )	-.294** ( $p=0.004$ )
Caregiving Satisfaction	.332** ( $p=0.001$ )	.299** ( $p=0.003$ )

\*\* $p<.01$

#### *The Relationship between Coping and Caregiver Outcomes*

The findings of the correlations between coping and caregiver outcomes are presented in Table 12. There were significant positive correlations between the coping composite and caregiver health including physical ( $r=.249, p<.05$ ) and psychological health ( $r=.412, p<.001$ ). The correlation between the coping composite and psychological health was moderate. However, the association between the coping composite and physical health was relatively small. The results indicate that caregivers who use more positive coping strategies also had better physical and psychological health.

**TABLE 12. Correlations between Coping and Caregiver Outcomes**

	Caregiver Outcomes	
	SF36_physical health	SF36_psychological health
The Coping Composite	.249* ( $p=0.015$ )	.412*** ( $p=0.000$ )

\*  $p<.05$ , \*\*  $p<.01$ , \*\*\*  $p<.001$

#### *The Relationship among Coping, Familism, and Perceived Social Support*

Table 13 shows the results of correlational analysis among coping, familism, and perceived social support. The results describe that the coping composite had a significant relationship with familism ( $r_s=.225, p<.05$ ) as well as perceived social support ( $r=.318,$

$p < .01$ ). The positive correlation between the coping composite and familism indicates that caregivers who utilized more positive coping strategies also had higher values on familism, while the moderate association between the coping composite and perceived social support suggests that caregivers who utilized more positive coping strategies also perceive more social support.

**TABLE 13. Correlations among Coping, Familism, and Perceived Social Support**

	Contextual Factors	
	Familism	Perceived Social Support
The Coping Composite	.225* ( $p=0.027$ )	.318** ( $p=0.002$ )

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

*The Relationship among Familism, Perceived Social Support, and Caregiver Outcomes*

The findings of the correlations among familism, perceived social support, and caregiver outcomes are presented in Table 14. There were no significant correlations among familism, physical health and psychological health ( $p > .05$ ). However, perceived social support had a significantly moderate relationship with caregiver outcomes in terms of physical and psychological health ( $r = .337, .452; p < .01$ ). The results indicate that caregivers who perceived more social support also had better physical and psychological health.

**TABLE 14. Correlations among Familism, Perceived Social Support, and Caregiver Outcomes**

	Caregiver Outcomes	
	SF36_physical health	SF36_psychological health
Contextual Factors		
Familism	-.011 ( <i>p</i> =0.914)	.096 ( <i>p</i> =0.350)
Perceived Social Support	.337** ( <i>p</i> =0.001)	.452*** ( <i>p</i> =0.000)

\*\* *p*<.01, \*\*\**p*<.001

In summary, the associations between variables of caregiving stressors (functional impairments and behavioral problems), caregiving appraisal (caregiving subjective burden and caregiving satisfaction), coping (the composite variable), familism, perceived social support, and caregiver outcomes (overall health, physical and psychological health) among family caregivers of elders with dementia in China were analyzed using bivariate correlational analysis and summarized in Table 15. It was noticed that ADL function, which describes the functional impairments of care-recipients, did not have a significant relationship with other variables, but the variable of behavioral problems had significant correlations with every variable in the study except perceived social support. This suggests that ADL impairments might not have a role in defining caregiving stressors, which could induce the coping process for caregivers in this study. Conversely, behavioral problem of care-recipients appears to be a primary stressor for caregivers as they care for elders with dementia and results in different coping processes. Therefore, the model testing that follows included behavioral problem, which was considered as the only identified caregiving stressor in this study.

TABLE 15. Correlations among Each Variable in the Study

	1	2	3	4	5	6	7	8	9
1. ADL	1.00								
2. Behavioral Problems	-.150 (.144)	1.00							
3. Familism	.143 (.164)	-.294** (.004)	1.00						
4. Perceived Social Support	.176 (.087)	.031 (.766)	.302** (.003)	1.00					
5. Caregiving Subjective Burden	-.059 (.566)	.435*** (.000)	-.200 (.051)	-.294** (.004)	1.00				
6. Caregiving Satisfaction	.053 (.611)	-.209* (.041)	.332** (.001)	.299** (.003)	-.230* (.024)	1.00			
7. The Coping Composite	-.028 (.789)	-.427*** (.000)	.225* (.027)	.318** (.002)	-.304** (.003)	.360*** (.000)	1.00		
8. Caregiver physical Health	-.048 (.640)	-.274** (.007)	-.011 (.914)	.337** (.001)	-.345** (.001)	.161 (.118)	.249* (.015)	1.00	
9. Caregiver Psychological Health	-.002 (.982)	-.318** (.002)	.096 (.350)	.452*** (.000)	.417*** (.000)	.243* (.017)	.412*** (.000)	.590*** (.000)	1.00

Notes: a. 1=ADL, 2=Behavioral Problems, 3=Familism, 4=Perceived Social Support, 5=Caregiving Subjective Burden,

6=Caregiving Satisfaction, 7=the Coping Composite, 8= Caregiver physical Health, 9=Caregiver Psychological Health;

b. \* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$ ;

c. *Italic* means Spearman coefficient

### Research Question Two

For research question 2, a path analysis was performed to test the effects of caregiving stressors, caregiving subjective burden, caregiving satisfaction, coping, familism, and perceived social support on the caregiver outcomes of health among family caregivers of elders with dementia in China. The path analysis was conducted using AMOS 5 (Arbuckle, 2003), which uses a covariance matrix to estimate the parameters of the proposed Dementia Caregiving Model (see Figure 1 in Chapter 1). Based on the relatively small sample size for path analysis in this study, Maximum Likelihood (ML) was utilized as the estimation method because many studies indicate that it performs reasonably well under a variety of less-than-optimal analytic conditions (e.g., small sample size, excessive kurtosis) (Hoyler, 1995).

The outputs of path analysis by AMOS yield a measure of explained variability of the model ( $R^2$ ) and a coefficient ( $\beta$ ) for each path within the model. Global model fit tests were used to determine how well the model fit the data. First, the chi-square and its associated  $p$ -value were used to describe model fit. A chi-square probability value greater than .05 indicates acceptable model fit (Byrne, 2001). In addition to chi-square, other indices of fit to determine how well the model fit the data were also examined suggest by Hu and Bentler (1995). In general, goodness-of-fit statistics with higher values (e.g., goodness-of-fit index [GFI], comparative fit index [CFI], normed fit index (NFI), and incremental fit index [IFI]) indicate better fitting models. Values of such indices exceeding .9 are desired to indicate a good fit between the model and data (Bentler, 1990). However, for root mean square error of approximation (RMSEA), which has been considered as one of the most informative criteria in covariance structure modeling because it takes into account the error of

approximation in the population, lower values mean better fit. Ideally, it is desirable for the RMSEA to be less than .05, which indicates a good fit, and values as high as .08 represent reasonable errors of approximation in the population (Browne & Cudeck, 1993). In addition, MacCallum and colleagues (1996) noted that RMSEA values ranging from .08 to .10 indicate mediocre fit, and those greater than .10 indicate poor fit.

#### *Data Preparation for Path Analysis*

One assumption of path analysis requires that variables are normally distributed. Based on the results of exploratory data analysis done previously in this chapter, there were two variables, caregiving satisfaction and familism, which were negatively skewed rather than normally distributed. Thus, transformations of these two variables were performed based on the following steps (Tabachnik & Fidell, 2001):

1. “Reflect” the variable by finding the largest score in the distribution, and add one to it to form a constant that is larger than any other score in the distribution.
2. Form a new variable by subtracting each person’s score from the constant. Thus, the negative skewness is converted to a positive skewness before transformation.
3. Then apply the appropriate transformation to the newly formed variable to transform the variable as normally distributed.

A square root transformation was used to transform the variable of caregiving satisfaction into a normally distributed variable, while a log transformation was utilized to transform the variable of familism as normally distributed. Since each resulting variable was derived from a “reflected” variable, each means just the opposite of what it meant before the reflection. Thus, a negative one was multiplied to

the transformed variables in order to have a same meaning for a higher score and lower score to be consistent with its original meaning. In the study, the transformed variables of familism and caregiving satisfaction were named as “familism\_transformed” and “caregiving satisfaction\_transformed”. The Kolmogorov-Smirnov test was performed again on familism\_transformed and caregiving satisfaction\_transformed and found non-significant  $p$  values ( $p=.057$  and  $.196$  respectively). The results indicate that transformed variables for familism and caregiving satisfaction were normally distributed. Thus, all variables in the proposed model were normally distributed and met the assumption of normality for path analysis.

Another assumption for path analysis is no multicollinearity among predictors in the model (Norris, 2005). That is, the predictor variables should not correlate too highly ( $r>.80$ ) (Field, 2005). The correlation matrix in this study (see Table 15) shows that the highest correlation coefficient among predictor variables was  $.435$  (between behavioral problems and caregiving subjective burden), which is less than  $.80$ , thus multicollinearity does not seem to exist among the predictor variables in this study. In addition, variance inflation factor (VIF) and tolerance statistics (with tolerance being  $1$  divided by the VIF) were also calculated by SPSS to assess the assumption of multicollinearity (see Table 16). If the largest VIF is greater than  $10$  then there is cause for concern; tolerance below  $.1$  indicates a serious problem and tolerance below  $.2$  indicates a potential problem (Field, 2005). The largest VIF for the predictor variables in this study was  $1.430$  which was lower than  $10$ , and the tolerance statistics were all higher than  $.2$ . These results indicate that there was no multicollinearity among predictor variables in the study and the assumption of no multicollinearity for

path analysis was met.

**TABLE 16. Variance Inflation Factor and Tolerance Statistics for Predictor Variables in the Study**

Predictor Variables	Collinearity Statistics	
	VIF	Tolerance
Behavioral Problems	1.319	.758
Familism_transformed	1.199	.834
Perceived Social Support	1.316	.760
Caregiving Subjective Burden	1.365	.733
Caregiving Satisfaction_transformed	1.199	.834
The Coping Composite	1.430	.699

#### *The Proposed Model*

The proposed Dementia Caregiving Model presented in Chapter 1 was tested to verify if the model fits the data well. The testing model (see Figure 2 in Chapter 1) based on the proposed model was entered into AMOS 5. Since caregiver health in the model was considered as physical and psychological health, path analysis was performed separately for these two types of health.

When considering caregiver health as physical health, the overall fit information for the proposed model was:  $\chi^2(9, N=96)=25.43, p=.003$ ; GFI= .93, CFI= .81, NFI= .76, IFI=.83, and RMSEA=.14. Moreover, the model fit information for psychological health were:  $\chi^2(9, N=96)=39.20, p=.000$ ; GFI= .91, CFI= .73, NFI= .71, IFI=.76, and RMSEA=.19.

Since the  $p$  values of chi-square for the two models were not higher than .05, the values of CFI, NFI, and IFI were all lower than .90, and RMSEA was higher than .08, the proposed model of the Dementia Caregiving Model (regarding caregiver physical health and psychological health) did not prove to adequately fit the data based on the standards of model fitting. However, the values of GFI, which were all

higher than .90 and RMSEA were all slightly higher than .10 providing some support for model modification to explore the relationships among variables in the Dementia Caregiving Model further.

#### *Model Modification*

Byrne (2001) stated that one advantage of using modeling techniques is that hypothesized models can be modified according to theory and fit information provided by statistical output to re-specify models that improve the fit of the data. Therefore, modifications were made to improve the overall fit.

Model modification involves adjusting a specified and estimated model by either freeing parameters that formerly were fixed or fixing parameters that formerly were free. Model modification typically follows estimation of a model that resulted in unfavorable indicators of fit. After the proposed model testing, the AMOS output provides the modification indexes suggesting that the fit would be improved if paths in Table 17 were estimated rather than constrained to zero. The modification index is the estimated decrease in chi-square from releasing the path (described as M.I. in the table) and estimating an effect (described as Par. Change in the table). New paths were released only if there was theoretical justification and if the modification index provided by AMOS showed that the model fit would be significantly improved by including the path (Byrne, 2001; Hoyle, 1995). In addition, based on the suggestion by Arbuckle (2003), each modification should be made one at a time.

Modification indices on the regression weights among observed variables for the proposed model are listed in the Table 17. Since caregiver health was considered as physical and psychological health, there were two sets of modification indices for the two proposed models correspondingly. In Table 17, the same three paths were

suggested for the model modification in the two proposed models. The paths were: from perceived social support to caregiver health; from caregiving subjective burden to caregiver health; from behavioral problems to the coping composite. Hoyle (1995) and Byrne (2001) emphasized that modification indices should be only adopted when they have theoretical support, thus all modification paths indicated by the modification indices were first examined based on theoretical relevance by the investigator. Since prior literature has shown that caregiving subjective burden and social support had a moderate or high relationship with caregiver health (see reviews by Dunkin & Anderson-Hanley, 1998; Knight & Sayegh, 2010; Torti et al., 2004) and the theoretical evidence for the path from caregiving subjective burden to caregiver health was strong (Zarit & Zarit, 2007), the path from burden to caregiver health was first freed in the modified model, followed by the path from perceived social support to caregiver health (physical health and psychological health), and then from behavioral problems to the coping composite. After the three modifications were performed one by one, there were no other modifications suggested by the AMOS software.

After these modifications were done, the modified model showed perfect fit with the data. For the modified model regarding caregiver physical health, the overall model fit indices were:  $\chi^2(6, N=96)=4.34, p=.63>.05$ ; GFI= .98, CFI= 1.00, NFI= .96, IFI=1.01, and RMSEA=.00; for the modified model regarding caregiver psychological health, the model fit indices were:  $\chi^2(6, N=96)=4.99, p=.54>.05$ ; GFI= .98, CFI= 1.00, NFI= .96, IFI=1.01, and RMSEA=.00.

**Table 17. Modification Indices on Regression Weights among Observed Variables in the Proposed Models**

	Regression Weights	M.I.	Par Change
<i>Model 1-1</i>			
	Perceived social support to Caregiver physical health	8.294	.543
	Caregiving subjective burden to Caregiver physical health	4.820	-.410
	Behavioral problems to the Coping composite	6.545	-.014
<i>Model 1-2</i>			
	Perceived social support to Caregiver psychological health	17.269	.654
	Caregiving subjective burden to Caregiver psychological health	7.156	-.418
	Behavioral problems to the Coping composite	6.545	-.014

*Note:* Model 1-1---The proposed Dementia Caregiving Model regarding caregiver physical health  
 Model 1-2---The proposed Dementia Caregiving Model regarding caregiver psychological health

Byrne (2001) also emphasizes that adding parameters to the model is only one part of fitting a model and another part of the model fitting process is the extent to which certain initial hypothesized paths may be irrelevant to the model. In order to do this, the statistical significance of all structural parameter estimates for the modified models were examined. Since this study was the first one to test the Dementia Caregiving Model,  $p \leq .10$  were set as the significant level in order to explore possible variables that might be related to caregiver health. The concrete information about parameter estimates and their  $p$  values is listed in Table 18 and non-significant parameters are described in *Italic*. Based on the significant level of .10, it was found that five parameters were non-significant in the modified model 1 regarding caregiver physical health. These parameters represented the paths from behavioral problems to caregiving satisfaction\_transformed; familism\_transformed to caregiving subjective burden; caregiving subjective burden to the coping composite; familism\_transformed to the coping composite; and the coping composite to caregiver physical health. In the modified model 2 regarding caregiver psychological health, the parameter

representing the path from the coping composite to caregiver psychological health became significant, but another four paths were non-significant and were the same as the modified model 1. Byrne (2001) suggested that the path with the non-significant parameter should be deleted from the model for model parsimony. Therefore, these paths with non-significant parameters were deleted from the corresponding model.

The overall goodness-of-fit indices are shown as follows. For the final model 1 (regarding caregiver physical health), model fit information was:  $\chi^2(11, N=96)=7.69$ ,  $p=.74>.05$ ; GFI= .98, CFI= 1.00, NFI= .93, IFI=1.03, and RMSEA=.00; The model fit information for the final model 2 (regarding caregiver psychological health) were  $\chi^2(10, N=96)=8.14$ ,  $p=.62>.05$ ; GFI= .98, CFI= 1.00, NFI= .94, IFI=1.02, and RMSEA=.00. From the model fit information above, the final models modified from the proposed model were judged to perfectly fit the data in this study based on the model fitting standards.

A schematic representation of this final model of Dementia Caregiving for family caregivers of elders with dementia in China were displayed in Figure 4 and 5 regarding caregiver physical and psychological health. In these figures, solid lines with standardized regression weights were utilized to indicate paths that were statistically significant and dashed lines were presented for paths that were not statistically significant. The final model explained 21.1% of the variance in caregiver physical health, and 39.7% of the variance in caregiver psychological health.

**Table 18. Unstandardized and Standardized Regression Weights for Modified Dementia Caregiving Models after Adding Paths**

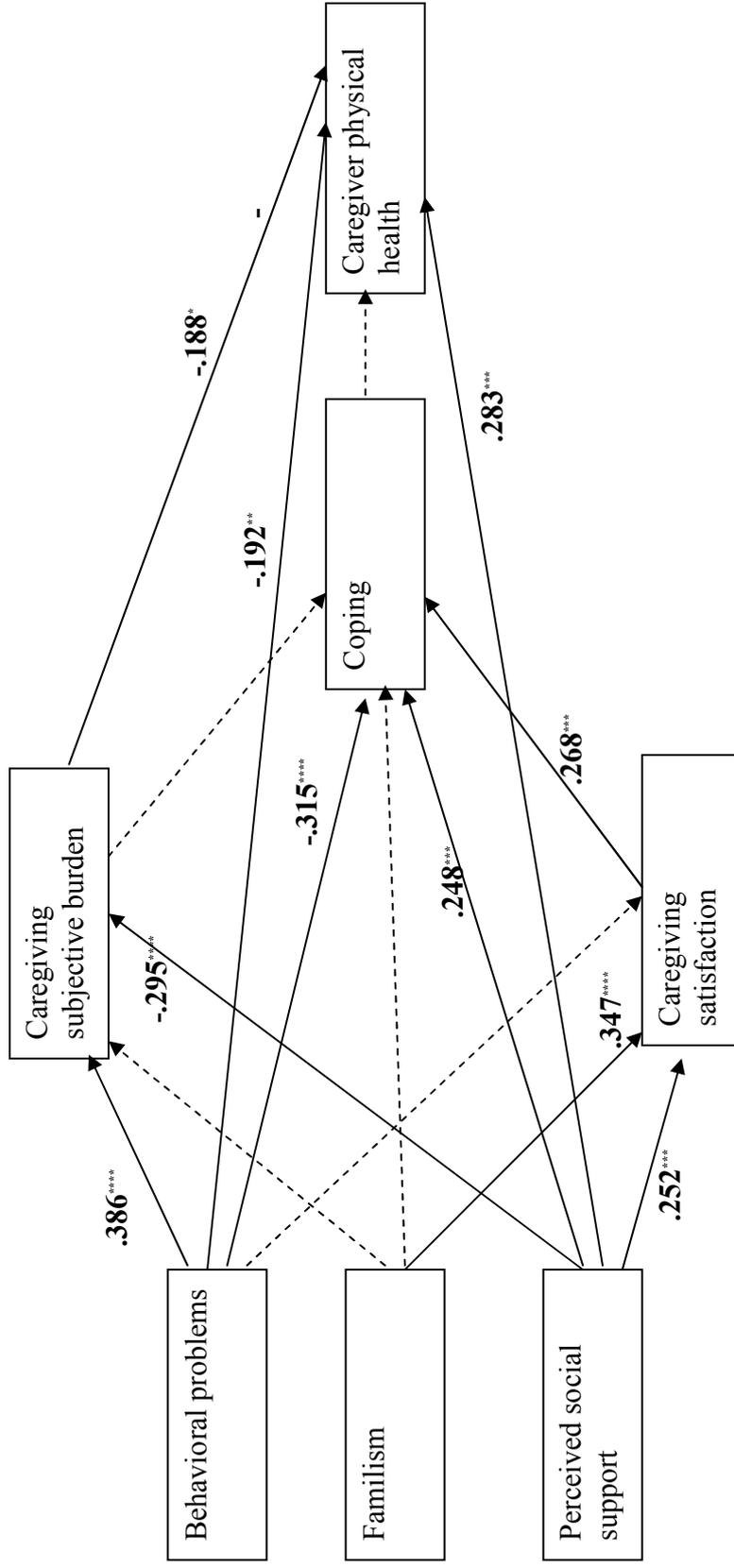
Path between Variables	Modified Model 1				Modified Model 2			
	Un-standard	Standard	C.R.	P	Un-standard	Standard	C.R.	P
ZBI <-- Behavior	.231	.375	4.189	***	.231	.375	4.189	***
PAC <-- Familism	.443	.341	3.678	***	.443	.341	3.678	***
ZBI <-- PSS	-.291	-.289	-3.230	.001	-.291	-.289	-3.230	.001
PAC <-- PSS	.025	.254	2.735	.006	.025	.254	2.735	.006
PAC <-- Behavior	<b>-.003</b>	<b>-.057</b>	<b>-.620</b>	<b>.536</b>	<b>-.003</b>	<b>-.057</b>	<b>-.620</b>	<b>.536</b>
ZBI <-- Familism	<b>-1.585</b>	<b>-.120</b>	<b>-1.336</b>	<b>.182</b>	<b>-1.585</b>	<b>-.120</b>	<b>-1.336</b>	<b>.182</b>
COPING <-- ZBI	<b>-.008</b>	<b>-.080</b>	<b>-.799</b>	<b>.424</b>	<b>-.008</b>	<b>-.080</b>	<b>-.799</b>	<b>.424</b>
COPING <-- PAC	.236	.244	2.531	.011	.236	.244	2.531	.011
COPING <-- PSS	.022	.227	2.385	.017	.022	.227	2.385	.017
COPING <-- Familism	<b>.063</b>	<b>.050</b>	<b>.531</b>	<b>.596</b>	<b>.063</b>	<b>.050</b>	<b>.531</b>	<b>.596</b>
COPING <-- Behavior	-.016	-.280	-2.944	.003	-.016	-.280	-2.944	.003
SF36 <-- Coping	<b>.961</b>	<b>.047</b>	<b>.462</b>	<b>.644</b>	2.941	.162	1.814	.070
SF36 <-- Behavior	-.210	-.178	-1.722	.085	-.223	-.211	-2.343	.019
SF36 <-- PSS	.520	.269	2.686	.007	.654	.379	4.329	***
SF36 <-- ZBI	-.349	-.182	-1.752	.080	-.321	-.187	-2.062	.039

Notes: a) ZBI=Caregiving subjective burden; Behavior=Behavioral problems; PAC=Caregiving Satisfaction\_transformed; PSS=Perceived Social Support; Coping=the Coping Composite; SF36=Caregiver health;

b) Model 1: Modified Dementia Caregiving Model regarding Caregiver Physical Health

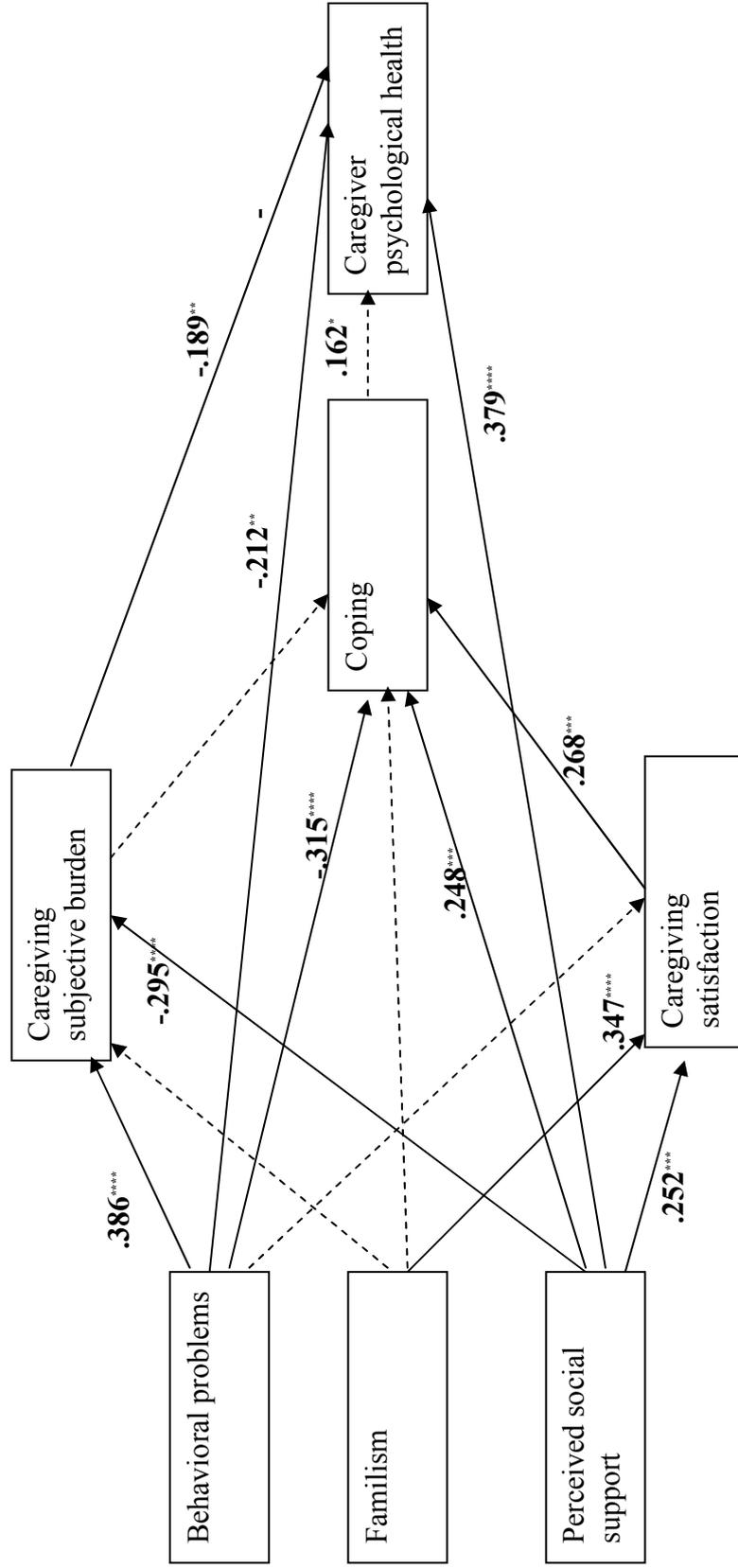
Model 2: Modified Dementia Caregiving Model regarding Caregiver Psychological Health

c) \*\*\* $p < .001$



**FIGURE 4. The Final Dementia Caregiving Model regarding Caregiver Physical Health**

Note: \* $p < .10$ , \*\* $p < .05$ , \*\*\* $p < .01$ , \*\*\*\* $p < .001$



**FIGURE 5. The Final Dementia Caregiving Model regarding Caregiver Psychological Health**

*Note:* \* $p < .10$ , \*\* $p < .05$ , \*\*\* $p < .01$ , \*\*\*\* $p < .001$

### *Hypothesis Tests*

For the original ten hypotheses under research question 2, the final model fully supported one hypothesis and partially supported six hypotheses. Only three hypotheses were rejected from the eight original hypotheses.

#### *Hypothesis (1).*

The first hypothesis predicted that the associations in the causal model fit the collected data on these relationships.

This hypothesis was rejected by the results of path analysis for the original proposed Dementia Caregiving Model with evidence of a less than adequate fit of the model.

#### *Hypothesis (2).*

The second hypothesis predicted that the caregiving stressors would have a direct negative effect on caregiver health.

Since the variable of ADL function was not included in the path model due to its non-significant relationships to other variables in the proposed model, only the variable of behavioral problems was considered a caregiving stressor and used in the model for testing. Thus, this hypothesis specifically predicted that there was a direct negative effect of behavioral problems of elders with dementia on the caregiver health regarding physical and psychological health.

This hypothesis was supported by a significantly negative path coefficient between behavioral problems and caregiver overall health (see Fig. 4 and 5). Consistently, behavioral problems had a significant direct negative effect on caregiver physical health ( $\beta=-.192$ , see Table 19) as well as psychological health ( $\beta=-.212$ , see

Table 19), suggesting that more frequent behavior problems of care-recipients predicted worse caregiver physical and psychological health.

Hypothesis (3).

The third hypothesis maintained that there would be an indirect effect of the caregiving stressors on the caregiver health through its relationships with caregiving satisfaction and coping.

This hypothesis was partially rejected because there was a non-significant direct effect of behavioral problems (as caregiving stressors) on caregiving satisfaction ( $\beta = -.057$ ,  $p = .54$ ; see Table 18). That meant the path that started from behavioral problems to caregiver health through caregiving satisfaction and coping was broken (see Fig. 4 and 5). However, behavioral problems did have an indirect effect on caregiver physical health ( $\beta = -.073$ , see Table 19) and psychological health through its relationship with coping ( $\beta = -.124$ , see Table 19) instead of going through both caregiving satisfaction and coping. That is, behavior problems among care recipients were associated with less positive coping strategies and thus, worse physical and psychological health.

Hypothesis (4).

The fourth hypothesis predicted that there was an indirect effect of caregiving stressors on caregiver health through its relationships with caregiving subjective burden and coping.

This hypothesis was partially rejected because there was no significantly direct effect of caregiving subjective burden on coping ( $\beta = -.080$ ,  $p = .42$ ; see Table 18) even though the direct effect of behavioral problems (as caregiving stressors) on caregiving subjective burden was supported by the path analysis ( $\beta = .375$ ,  $p < .001$ ; see Table 18).

However, since there was a significant path from caregiving subjective burden to caregiver health (physical and psychological health), behavioral problems did have an indirect effect on caregiver health through its relationship with burden rather than going through both burden and coping (see Fig. 4 and 5).

Hypothesis (5).

The fifth hypothesis held that there was an indirect effect of familism on the caregiver health through its relationships with caregiving satisfaction and coping.

This hypothesis was not supported when considering caregiver physical health because there was no significant path from coping to caregiver physical health ( $\beta=.047$ ,  $p=.64$ ; see Table 18). However, this hypothesis was supported when considering caregiver health as psychological health. There was an indirect effect of familism on caregiver psychological health ( $\beta=.015$ , see Table 19) through its relationships with caregiving satisfaction and coping (see Fig. 5). That is, caregivers who had a higher value of familism may experience better psychological health than caregivers who had lower value on familism because they had lower appraised caregiving satisfaction and used fewer positive coping strategies.

Hypothesis (6).

The sixth hypothesis predicted that familism had an indirect effect on the caregiver health through its relationships with caregiving subjective burden and coping.

This hypothesis was rejected because there was no significant path from familism to caregiving subjective burden ( $\beta=-.120$ ,  $p=.18$ ; see Table 18).

Hypothesis (7).

The seventh hypothesis held that familism had an indirect effect on the caregiver health through its relationship with the coping composite.

This hypothesis was rejected because there was no significant path from familism to the coping composite ( $\beta=-.05$ ,  $p=.596$ ; see Table 18).

Hypothesis (8).

The eighth hypothesis maintained that there was an indirect effect of perceived social support on the caregiver health through its relationships with caregiving satisfaction and coping.

The hypothesis was supported when considering caregiver health as psychological health because the path analysis showed that there was an indirect effect of perceived social support on the caregiver psychological health ( $\beta=.107$ , see Table 19) through its relationships with caregiving satisfaction and coping (see Fig. 5). This result suggested that caregivers who perceived more social support were likely to appraise the caregiving situation as more satisfied and utilize more positive coping strategies, and in turn, predicted their better psychological health.

However, when considering caregiver physical health, perceived social support did not have an indirect effect on caregiver health through its relationships with caregiving subjective burden and coping (see Fig. 4), because the paths were broken due to the non-significant path from coping to caregiver physical health ( $\beta=.099$ ,  $p=.321$ ; see Table 18).

Hypothesis (9).

The ninth hypothesis held that perceived social support had an indirect effect on caregiver health through its relationships with caregiving subjective burden and coping.

Even though there was no significant path from caregiving subjective burden to coping ( $r=-.080$ ,  $p=.42$ ; see Table 18), this hypothesis was still partially supported because there was an indirect effect of perceived social support on caregiver health only through its relationship with caregiving subjective burden instead of its relationships with both burden and coping (see Fig. 4 and 5). This suggested that caregivers who perceived more social support likely experienced better physical and psychological health than their counterparts, because they perceived less burden in their caregiving situation.

Hypothesis (10).

The tenth hypothesis predicted that perceived social support had an indirect effect on caregiver health through its relationship with coping.

When considering caregiver physical health, perceived social support did not have an indirect effect on caregiver health through its relationship with coping (see Fig. 4), because the paths were broken due to the non-significant path from coping to caregiver physical health ( $\beta=.099$ ,  $p=.321$ ; see Table 18). However, when considering caregiver psychological health, this hypothesis was supported. That is, perceived social support did have an indirect effect on caregiver psychological health through its relationship with coping (see Fig. 5). This suggested that caregivers who perceived more social support likely utilized more positive coping strategies, and in turn, had better psychological health than their counterparts.

*New Findings from the Data of this Study*

Three new findings from the data of this study were explored through model modification. They were:

- a. There was a negative direct effect of caregiving subjective burden on caregiver health for both physical and psychological health ( $\beta = -.182, -.187$ ;  $p = .08, .04$  respectively).
- b. There was a positive direct effect of perceived social support on caregiver health regarding physical and psychological health ( $\beta = .269, .379$ ;  $p = .007, .000$  respectively).
- c. There was a negatively direct effect of behavioral problems on the coping composite ( $\beta = -.280, p = .003$ ).

All of the standardized indirect, direct, and total effects of behavioral problems, familism\_transformed, perceived social support, caregiving subjective burden, caregiving satisfaction\_transformed, and the coping composite on caregiver health regarding physical and psychological health are summarized in Table 19. Overall, perceived social support had the highest total effect on caregiver physical and psychological health compared with other variables in the model, followed by behavioral problems and caregiving subjective burden. However, the directions of these effects differ. Perceived social support had a positive effect on caregiver physical and psychological health, which meant more perceived social support predicted better physical and psychological health for caregivers. Behavioral problems and caregiving subjective burden had negative effects on caregiver health indicating that more behavioral problems and more appraised subjective burden was associated with worse caregiver physical and psychological health. The variables of

the coping composite, caregiving satisfaction, and familism, had positive effects on caregiver psychological health, but not on physical health.

#### *Summary of Path Analysis*

The proposed Dementia Caregiving Model did not show a good fit to the data in this study, but the modified final model fit the data perfectly. Of 12 casual paths specified in the proposed model, seven were found to be statistically significant for caregiver physical health, and 8 of 12 paths were shown to be statistically significant for caregiver psychological health. These paths reflect the impact of (a) behavioral problems, perceived social support, and caregiving subjective burden on caregiver physical and psychological health, (b) coping, caregiving satisfaction, and familism on caregiver psychological health, (c) caregiving satisfaction, behavioral problems, familism, and perceived social support on coping, (d) behavioral problems and perceived social support on caregiving subjective burden, and (e) familism and perceived social support on caregiving satisfaction. In addition, three paths, not specified a priori (from behavioral problems to coping, caregiving subjective burden to caregiver physical and psychological health, and perceived social support to caregiver physical and psychological health), proved to be essential components of the structure, and they were therefore added to the model. Finally, four paths (from familism to caregiving subjective burden, familism to coping, behavioral problems to caregiving satisfaction, caregiving subjective burden to coping) were not significant and were subsequently deleted from the models on caregiver physical and psychological health. Furthermore, the path from coping to caregiver physical health was deleted from the final model because of its non-significant parameter.

**Table 19: Standardized Indirect, Direct, and Total Effects of Variables on Caregiver Health in the Final Modified Models for Dementia Caregiving**

Variables	Caregiver Physical Health			Caregiver Psychological Health		
	Indirect	Direct	Total	Indirect	Direct	Total
Behavioral problems	-.073	-.192	-.265	-.124	-.212	-.336
Familism_transformed	.000	.000	.000	.015	.000	.015
Perceived social support	.056	.283	.338	.107	.379	.486
Caregiving subjective burden	.000	-.188	-.188	.000	-.189	-.189
Caregiving satisfaction_transformed	.000	.000	.000	.044	.000	.044
The coping composite	-	-	-	.000	.162	.162

Note: “-” means no path between two variables

**Table 20. Standardized Indirect, Direct, and Total Effects of Variables on the Coping Composite, Caregiving Subjective Burden, and Caregiving Satisfaction\_transformed in the Final Modified Models for Dementia Caregiving**

Variables	The Coping Composite			Caregiving Subjective Burden			Caregiving Satisfaction_transformed		
	Indirect	Direct	Total	Indirect	Direct	Total	Indirect	Direct	Total
Behavioral problems	.000	-.315	-.315	.000	.386	.386	.000	.000	.000
Familism_transformed	.093	.000	.093	.000	.000	.000	.000	.347	.347
Perceived social support	.068	.248	.316	.000	-.295	-.295	.000	.252	.252
Caregiving subjective burden	.000	.000	.000	N/A	N/A	N/A	N/A	N/A	N/A
Caregiving satisfaction_transformed	.000	.268	.268	N/A	N/A	N/A	N/A	N/A	N/A

*Note:* "N/A" means non applicable

### Additional Findings

There were many comments from participants about feelings and perceptions on providing care for their elders. The comments were provided after they filled out the questionnaires. The comments were noted by the researcher using the participants' descriptions. After finishing the data collection, all comments were compared with each other and similar comments were grouped together and counted by frequencies. The grouped comments and the frequencies that the research participants mentioned are listed in Table 21.

**TABLE 21. *Participants' Comments Related to the Feelings and Perceptions about Providing Care to Elders***

Comments	<i>N</i> (%)
1. Family members should work together to take good care of elders because that is what family does.	51(53.13)
2. Providing good care of elders at home is Chinese culture and desired by society, and everyone should obey it.	48 (50.00)
3. Providing good care to elders is a way to love them.	35 (36.46)
4. Providing good care to elders at home is a way to repay elders.	25 (26.04)
5. Providing good care to elders is an unavoidable responsibility for being their children.	20 (20.83)
6. Providing good care to older parents is a way to be a model for my kids, and then they will take good care of me when I am old.	18 (18.75)

These comments demonstrate that Chinese family caregivers believe that family is the first source to provide care when family members are sick, and they also reflect the traditional values of familism and filial piety in the Chinese population.

## CHAPTER V DISCUSSION

The current study explored the relationships among caregiving stressors, familism, perceived social support, caregiving appraisal (caregiving subjective burden, caregiving satisfaction), coping, and caregiver physical and psychological health. A proposed model of Dementia Caregiving was tested in a sample of family caregivers who were taking care of their elders with dementia at home in China. Data were collected from 96 primary family caregivers. The model was used to explain the effects of familism, perceived social support, caregiving appraisal, and coping on the relationship between caregiving stressors and caregiver outcomes regarding their physical and psychological health. The following discussion is presented in 6 sections: (a) major demographic findings, (b) interpretation of the findings for research question 1, (c) interpretation of the findings for researching question 2 including the discussion of the underlying hypotheses, (d) implications of the research findings from the study, (e) limitations of the present study and recommendations, and (f) conclusion.

### Major Demographic Findings

The characteristics of the sample of this study were similar to characteristics of caregivers and care-recipients in other research in which similar variables were studied in China.

### *Characteristics of Caregivers*

In China, care of elders with dementia is generally provided by family members at home, either by spouses or adult children (Tian, 2003). The findings of this study converged with other studies that indicate 77.2% of caregivers were either the spouse or

children of the elder. This consistent finding demonstrates that family is the first source to provide care when family members are sick, and it also reflects the traditional values of familism and filial piety in Chinese population. Comments from research participants in this study also reflect these cultural influences in detail (see Table 21). Fifty-three point thirteen percent of caregivers believed that “family members should work together to take good care of elders because that is what family is”, and 50% confirmed that “providing good care to elders at home is Chinese culture and desired by the society, and everyone should obey it”. Beliefs in taking care of elders at home are deeply implanted in the minds of Chinese people.

In this study, the majority of caregivers were female ( $n=70$ , 72.9%) and showed an uneven split between male and female caregivers. This characteristic was similar to other related studies done in China (Meng et al., 2006; Wang et al., 2004; Zhang et al., 2003). Traditionally, Chinese culture emphasizes the dependence of the family on each other for support especially when one gets sick and wife or daughters are the first group to take this responsibility, followed by daughters-in-laws. This traditional trend was exactly reflected in this study. Among 70 female caregivers in the current study, 33, 18 and 10 were spouse, daughter, or daughter-in-law, respectively.

The mean age of the caregivers was 59 ( $SD=14.1$ ) years with a range of 25 to 83 years and 50% ( $n=48$ ) of caregivers were equal to or older than 60 years of age. Several studies from China also found that more than half of the family caregivers were older than 60 years (Li, Chen, & Luo, 1990; Meng et al., 2006; Wang et al., 2004; Zhang et al., 2003). This age distribution may reflect that spouses were the majority (46.9%) to

provide care to the elders in this study. This phenomenon may reflect more recent cultural factors where many younger people have moved to larger cities in order to get better jobs with benefits that accompany the economic reform in China. Chinese society has been based on stable family units living together at the same location throughout their lifetime and these stable units no longer exist to the same extent as in the past. Family resources are decreasing and are particularly noticeable when family members get sick. Spouses of elders with dementia need to take care of their husbands or wives at the same time that they may face their own declining health and the increased needs aging brings. Thus, addressing community resources that can be utilized by spouses and their dependent demented elders is a priority for the future.

The duration of caring for the care-recipients in the current study ranged from 7 to 180 months with a mean of 54 months and a median of 42.5 months. This finding of duration of caring for care-recipients is similar to the mean duration of caring provided by caregivers in other studies from China (Meng et al., 2006; Wang et al., 2004; Zhang et al., 2003). In this study, thirty caregivers (31.25%) cared for their relatives less than 2 years (from 7 to 24 months), approximately 33.33% of caregivers cared for their elders from 2 to 5 years (25 months to 60 months), and about 35.42% caregivers took care of demented elders from 5 to 10 years and over (61 months to 120 months and over). These results suggest that the duration of caring for elders after they were diagnosed with dementia seemed well distributed in this sample, and it also reflects that taking care of elders with dementia could be a long journey for family caregivers.

### *Characteristics of Care-recipients*

Characteristics of care-recipients in this study were similar to characteristics of care-recipients in other studies done in China. The proportion of male and female care-recipients, the average age of the care-recipients, and the type of dementia were similar with other studies (Li, Chen, & Luo, 1990; Meng et al., 2006; Wang et al., 2004; Zhang et al., 2003) and support the relative representativeness of the sample in this study.

The findings also showed that only 18.8% of care-recipients in this study were diagnosed with a mild dementia, most of the care-recipients in the study were diagnosed with moderate or severe dementia. These numbers may indicate that early-diagnosis of dementia is not well spread in China perhaps because of the Chinese culture and traditional values on aging. That is, in Chinese culture, it is expected that memory declines with age (Tang et al., 1994; Yu, 2005; Zhan, 2004), and loss of function in old age is also a given (Tang et al., 1994; Yu, 2005; Zhan, 2004). Many family members considered some dementia symptoms (forgetfulness, repeatedly asking the same question, wandering and getting lost) as a natural part of old age (Braun & Colette, 1998; Tang et al., 1994; Yu, 2005; Zhan, 2004; Zhang et al., 2003). Therefore, patients themselves and their family members often ignore impairment of memory and other symptoms of cognitive decline, resulting in the delay of seeking medical help and loss of the opportunity for an earlier diagnosis. In addition, some Chinese people interpret dementia symptoms as an imbalance of Yin and Yang and seek help from Traditional Chinese Medicine (TCM), which involves foods or herbs with strong Yin and Yang qualities to

restore the balance (Braun & Colette, 1998; Tang et al., 1994; Tian, 2003) instead of making a dementia diagnosis.

In this study, there were 59.4% care-recipients with a diagnosis of Vascular Dementia (VD), and only 28.1% were diagnosed with Alzheimer Disease (AD) and 12.5% were with mixed dementia (VD and AD co-existed). One possible reason for the higher proportion of VD in the sample might related to high prevalence of vascular disease among the Chinese population (Chou & Shi, 2005), and another possible explanation may indicate low rates of seeking medical diagnosis by possible AD patients and their families in China (Yu, 2005).

The study revealed that more than half of the care-recipients (n=54, 56.2%) needed to pay their medical expense partially by themselves (n=46, 47.9%) or totally pay (n=8, 8.3%) by themselves. Since the journey of dementia is long-term, and not much funding is allocated for community care in China, most costs for home care are not reimbursed by the Chinese government but paid directly by elders' families and their caregivers. The possible financial difficulty of caring for an elder with dementia in China is an unavoidable reality, which calls for more affordable health care services or community services for family caregivers and their demented elders.

#### Interpretation of the Findings for the Research Question 1

The first research question concerned associations among caregiving stressors (ADL impairments and behavioral problems of care-recipients), caregiving appraisal (caregiving subjective burden and caregiving satisfaction), coping (represented by the coping composite where higher levels mean more positive coping strategies were used),

familism, perceived social support, and caregiver outcomes (physical and psychological health) among family caregivers of elders with dementia in China. Zero-order correlations among these variables were examined by using bivariate analysis and significant relationships were reported at the .05 level.

Most correlations among variables were significantly associated in the predicted directions and consistent with previous studies, but some were not. In addition, some new findings especially for Chinese family caregivers were revealed in the current study. The findings are summarized in the following.

Consistent with previous reports, caregivers who took care of care-recipients with more frequent behavior problems, perceived less social support, appraised their caregiving situations as more burdensome and less satisfied, and utilized fewer positive coping, and were more likely to have worse psychological health. For caregiver physical health, these significant correlations also existed except the association between caregiving satisfaction and caregiver physical health.

As expected, behavioral problems were significantly and positively correlated with caregiving subjective burden, which has been a consistent finding reported by many other studies (Arai et al., 2007; Coen et al., 1999; Dunkin & Anderson-Hanley, 1998; George & Gwyther, 1986; Rymer et al., 2002). They all showed that caregivers who took care of demented patients with more frequent behavior problems also had higher level of appraised burden than caregivers whose care-recipients had less frequent behavior problems. Therefore, more attention should be given to caregivers whose care-recipients have more frequent behavioral problems.

In addition, the correlations between perceived social support and other variables in this study were as expected and also consistent with previous studies (Atienze et al., 2002; Thoits, 1995). The results indicate that caregivers who perceived more social support were more likely to appraise their caregiving situation as less burdensome with more satisfaction and they were more likely to use positive coping strategies in their caregiving situations.

Since this study is the first study in China to incorporate the concept of familism into family caregiving of elders with dementia, some new findings about familism and other variables among Chinese family caregivers were revealed.

Familism was found to have a significant positive relationship with caregiving satisfaction and coping. That is, caregivers who held a higher value of familism were more likely to appraise their caregiving situation as satisfying and utilize more positive coping strategies. The positive correlation between familism and caregiving satisfaction is consistent with prior studies (McCallum, Longmire, & Knight, 2007; Pyke & Bengtson, 1996), and also provides support to Lazarus and Folkman's (1984) stress and coping model that stress appraisal is strongly influenced by a person's belief, values, and attitudes about the stressor.

The correlation between familism and coping has not been confirmed since there are not many cross-cultural studies to explore the relationship between these two variables. Segall and colleagues (1998) proposed that caregivers with higher familism were more likely to implement more effective coping styles (i.e., active coping) and use less avoidant coping. The finding from the current study seemed to support the

assumption and suggests that caregivers who had higher levels on the value of familism also used more positive coping strategies in their caregiving situation. The finding was also consistent with a study done by Chun (2007) who found that filial piety (one construct associated the concept of familism) had a significant positive relation to active-cognitive coping (similar to positive coping) among caregivers of patients with dementia in Korea. However, the finding was inconsistent with the reports by Kim and colleagues (2007). They found that higher levels of familism resulted in increased levels of avoidant coping styles rather than active coping styles among their sample of African American and White family caregivers of patients with dementia. The possible reasons for the inconsistency may relate to different measurements used to measure familism and coping, and the different cultural background between the samples (Western population and Asia population) that could shape the meaning of coping differently (for a review, see Knight & Sayegh, 2010).

In addition to the concept of familism, caregiving satisfaction is another concept that has not been well studied in China. In the current study, it was found that caregivers whose care-recipients had more frequent behavior problems were more likely to feel less satisfied with their caregiving situation. Some previous studies have not found a significant inverse relationship between these two variables (Lawton et al., 1991; Lopez, Lopez-Arrieta, & Crespo, 2005), and some also suggest that the predictors of caregiving satisfaction differed from predictors (e.g., behavioral problems of care-recipients) of caregiving burden (Rapp & Chao, 2000). Since the correlation between these two variables was modest ( $r_s = -.209$ ,  $p = .041$ ) and the significance level was not very high as

well as there being no evidence from previous studies, this finding needs to be viewed with caution since these two variables may have an inverse correlation with further study.

In addition to the consistent and new findings described above, two unexpected results were also revealed in the current study.

First, care-recipients' ADL impairment was not found to have a significant relationship with caregivers' physical and psychological health as hypothesized. It also did not have significant relationships with other variables in the current study. The results are not supported by some previous studies (Aguglia et al., 2004; Chappell & Reid, 2002; Gonzalez-Salvador et al., 1999; Meng et al., 2006; Schulz et al., 1995; Zhang et al., 2003).

The non-significant linear correlation between ADL impairment and behavioral problems may indicate that the relationship between these two variables might be curvilinear rather than linear. Behavioral problems often manifest in the early and middle stages of dementia, and do not increase when the severity of dementia becomes severe (Davis, 1996). Usually, patients with dementia of moderate levels have more behavioral problems than patients with mild or severe dementia (Hart et al., 2003). It seems like behavioral problems do not increase linearly along with the severity of dementia, thus it is understandable that there was no significant linear correlation between ADL impairment and behavioral problems among elders with dementia in the current study.

The care-recipients in this study had high levels of ADL impairments because their ADL scores were all higher than 16, which is the cut-off point for functional impairment (He, 1990). However, these different levels of functional impairment were not significantly correlated with caregivers' appraisal of caregiving, caregivers' coping

strategies, and caregivers' physical and psychological health. Yates and colleagues (1999) suggested that the relationship between caregiving experiences and caregiver health may have more to do with the appraisal of the tasks of caregiving and the attached meaning of the task than the actual caregiving stressors (task or amount of care that results from ADL impairment). Thus, one possible explanation for the findings is different levels of functional impairments among care-recipients may not be the key factor influencing Chinese caregivers' appraisal and coping of their caregiving situation. In addition, Chinese culture emphasizes that family members should take good care of elders at home when they need help and it has been taken for granted that family caregivers will be around and provide care for elders to meet their basic needs, such as help bathing, eating, doing laundry, or dealing with financial issues. Thus, Chinese family caregivers may have a view that caring for older family members is a natural part of family life. Another possible reason for these findings might be that the associations between ADL impairments and caregiving appraisal, coping, or caregiver health were curvilinear instead of linear. For instance, some studies found that caregivers who took care of patients with a moderate severity of dementia reported a significantly higher level of burden compared with those who took care of patients with mild or severe dementia (Arai et al., 2007). However, these findings and possible explanations still need to be confirmed in future studies. For instance, when the sample size is larger, researchers could explore the relationships between ADL impairment and caregiving appraisal, coping, and caregiver health based on the different levels of severity of dementia among care-recipients and conduct the multi-level comparisons.

The other unexpected finding from the correlational analysis was a significant moderate negative relationship between behavioral problems and the coping composite (higher level of coping composite means more utilization of positive coping strategies in the study). The finding suggests that caregivers who cared for demented elders with more frequent behavior problems were more likely to implement less positive coping strategies than the caregivers whose care-recipients had less frequent behavior problems. In contrast to the proposition of Lazarus and Folkman's (1984) theory, the findings did not reveal that caregivers who were caring of persons with more disturbed behavioral problems would also require more implementation of problem-solving strategies to manage the behavior problems. The possible reason for this finding will be discussed shortly.

In summary, the results of bivariate correlational analysis conducted in the study indicate some significant and non-significant correlations among caregiving stressors (ADL impairment, and behavioral problems), caregiving appraisal (caregiving subjective burden, and caregiving satisfaction), the coping composite, and caregiver physical and psychological health. Most of them were consistent with expectations except the non-significant correlation between ADL impairment and other variables and the significant negative association between behavioral problems and the coping composite. In addition, some new findings for Chinese family caregivers of elders with dementia related to familism and caregiving satisfaction, which are two concepts that have not been well studied in China. The results from this study are also compared with results from other related studies and possible explanations were addressed. These correlations provide an indication of the variables and pathways that may support the proposed model. However,

while some suggestions regarding the reasons for the associations were presented, bivariate correlations can not explain the causal relationships among variables.

#### Interpretation of the Findings for the Research Question 2

The second question of the study asked what the effects of caregiving stressors, familism, perceived social support, caregiving subjective burden, caregiving satisfaction, and coping on the caregiver health are. Path analysis using AMOS 5.0 software was utilized to answer this question and the results are discussed in this section. The 10 hypotheses under this research question guide the discussion and new findings from the analysis are interpreted.

#### *The Overall Model: Hypothesis 1*

The first hypothesis predicted that the associations in the proposed Dementia Caregiving Model would fit the collected data.

This hypothesis was rejected through the results of path analysis using the original proposed Dementia Caregiving Model because the overall fit information of the original model was relatively poor and did not support the evidence that the proposed model fit the observed data well.

Consequently, based on Byrne's (2001) suggestions, a modified model was produced using modification indices from AMOS software and based on theoretical support to accept or reject the modification indices. These decisions were based on previous literature and theories. The modified final model was found to be a perfect fit with the data in this study. Compared to the original model, the modified final model was similar. The modified model retained most of the originally supposed paths between the

variables of the different constructs, but added three new direct paths between some variables in the model. The new paths were established as follows: the direct path from caregiving subjective burden to caregiver physical and psychological health, the direct path from perceived social support to caregiver physical and psychological health, and the direct path from behavioral problems to the coping composite.

Moreover, in the final model, there were four paths, which were supposed to be significant in the original model and yet they were not significant. These paths were: the path from familism to caregiving subjective burden, the path from familism to the coping composite, the path from behavioral problems to caregiving satisfaction, and the path from caregiving subjective burden to the coping composite. In addition, for the final model regarding caregiver physical health, the path from the coping composite to caregiver physical health was not significant. The path diagram of the final model regarding caregiver physical health and psychological health are shown in Figure 4 and Figure 5 which all show a perfect fit to the data in this study. All paths in the final models are significant at the .10 level. Since the final model was modified from the original proposed model and had been changed modestly, it indicates that the proposed Dementia Caregiving Model was theoretically acceptable within the context of caregiving for elders with dementia in China. The model findings lend support that caregiver cognitive appraisal and coping strategies explain some observed individual differences in stress response and outcomes.

The final path model explained 21.1% of the variance in caregiver physical health, and 39.7% of the variance in caregiver psychological health. In the final models, the

effects of caregiving stressors, perceived social support, familism, caregiving appraisal, and the coping composite on caregiver physical and psychological health are complex (see Table 19). Behavioral problems of care-recipients and perceived social support of caregivers, both had direct and indirect effects on caregiver physical health and psychological health (see Table 19 and Figure 4 and 5). Familism and caregiving satisfaction only had indirect effects on caregiver psychological health and no effects on caregiver physical health. Conversely, caregiving subjective burden and coping had direct effects on caregiver health; burden had direct effects on both physical and psychological health of caregivers, whereas coping had a direct effect on caregiver psychological health. Taken together, all variables in the final model explain the variance of caregiver health and all play roles in the caregiving stress process, even though some of them affected both physical and psychological health and some only affected one of the outcomes.

Specifically, behavioral problems of care-recipients and caregiving subjective burden are the only two variables that negatively affect caregiver physical and psychological health (see Table 19). For the variable of behavioral problems, it had higher total negative effects on caregiver health than caregiving subjective burden (see Table 19). Opposite to behavioral problems and burden, perceived social support had the highest positive total effect on caregiver physical and psychological health. Therefore, future intervention programs for helping family caregivers of elders with dementia in China should put more emphasis on these three issues and consider how to decrease the

frequency of behavioral problems of dementia patients, reduce appraised burden among caregivers, and enhance social support through interventions.

In addition, the variables of familism, caregiving satisfaction, and the coping composite all had important positive influences on caregiver psychological health. Thus, when designing some intervention programs to improve caregivers' psychological health, nurses and other health care personnel also need to incorporate these 3 variables in the design and utilize some strategies to increase the level of value of familism, strengthen caregiver satisfaction on caregiving experience, and facilitate caregivers to utilize more positive coping strategies.

The final modified models showed that the relationships among these variables are interrelated, and changes on some variables will predict changes on other variables. From the final modified models in Figures 4 and 5, it can be seen that behavioral problems of care-recipients and perceived social support by caregivers are the two very important independent variables, which have more paths to influence other variables in the model. Thus, future intervention programs should include interventions for caregivers (e.g., establish some accessible and affordable social support resources for caregivers in communities) as well as some interventions for care-recipients especially to decrease the frequency of their behavioral problems.

In addition, since the final path model explained 21.1% of the variance in caregiver physical health and 39.7% of the variance in caregiver psychological health, it indicates that there may be other conceptual constructs or variables that can explain the remaining variance of caregiver physical and psychological health. Further explorations

are needed. As it was described in the proposed Dementia Caregiving Model, other contextual factors, which are characteristics of caregivers (e.g., age, gender, education, kinship, duration of providing the care, hours of providing care every day) and quality of pre-morbid relationship history between care-recipient and caregiver can also influence caregiver health outcomes during the caregiving process. In addition, perceived support from community health care or hospital health care by caregivers may also influence the stress process of caregiving and have effects on caregiver health. The testing of the effects of these variables on caregiver physical and psychological health is beyond the scope of the current study, but do need to be addressed in future research.

*Effect of Behavioral Problems on Caregiver Outcomes: Hypothesis 2 to 4*

The hypotheses of 2, 3 and 4 were related to the effects of behavioral problems as the caregiving stressor on the caregiver physical and psychological health. Hypothesis 2 predicted a direct effect of behavioral problems as the caregiving stressor on caregiver health, was supported by the findings of path analysis. Hypothesis 3 and hypothesis 4 predicted that behavioral problems had an indirect effect on caregiver health through its relationship with caregiving satisfaction (or caregiving subjective burden) and coping. These two hypotheses were partially supported. Taken together, behavioral problems had both direct and indirect effects on caregiver physical and psychological health. The indirect effects on caregiver health were through its relationship with burden, or through its relationship with coping.

Both direct and indirect effects reflect the strong negative influence of behavioral problems on caregiver health. It has been reported by many studies that behavioral

problems are the most detrimental stressor to caregiver health (see reviews by Dunkin & Anderson-Hanley, 1998; Knight & Sayegh, 2010; Pinquart & Sørensen, 2007; Schulz et al., 1995; Tori et al., 2004).

The direct effect of behavioral problems on caregiver health indicates that caregivers' health would be affected whenever behavioral problems existed in care-recipients. And this direct effect of behavioral problems even though not mediated, can influence caregiver's health even if caregivers do not appraise it as burdensome or regardless of what coping strategies they utilized. When behavioral problems exist, it will influence caregiver physical and psychological health. The underlying reason for this direct negative effect of behavioral problems on caregiver health may relate to the special characteristics of behaviors (e.g., hitting, kicking, wandering, disrobing, awaken in the midnight, or some problem behaviors may happen suddenly), which consequently induce caregivers to spend more hours to deal with these behavioral problems than handling other symptoms of dementia (Rabinowitz et al., 2009). This long-term exposure to behavioral problems may induce physiological responses among caregivers that are manifested by some changes in the activity of the hypothalamic-pituitary-adrenal (HPA) axis, and in turn influence caregivers health (De Vugt et al., 2005; Vitaliano et al, 2003).

It is acknowledged that behavioral problems represent a more specific type of stressor than the general stressors involved with caregiving and were the greatest stressor in the dementia caregiving experience appearing to have a major impact on caregiver physical and psychological health outcomes (Gerdner, Buckwalter, & Reed, 2002;

Pinquant & Sörense, 2007; Robinson, Adkisson, & Weinrich, 2001; Wang et al., 2004).

The negative effect of behavioral problems on caregiver health might relate to time consuming monitoring of the care-recipient's behaviors, which can result in long-term lack of rest for caregivers (Pinquant & Sörense, 2004), and isolation of caregivers from their usual social activities due to the shame of demented elders' behavioral problems (Lou, 2007; Wang et al., 2004). Behavioral problems usually manifest in the early or middle stages of dementia in demented patients (Hart et al., 2003). Thus, in such stages, caregivers should be highly supported both physically and mentally.

The indirect effect of behavioral problems on caregiver health through its relationship with caregiving subjective burden was consistently found by many studies even across different ethnic groups (e.g., Hispanic Americans, African Americans, non-Hispanic Whites Americans, caregivers in Korea, Spain, and Canada) studied to date (see the review by Knight and Sayegh, 2010). The consistent relationships between behavioral problems of care-recipients and caregiving subjective burden and then in turn affecting caregiver health are considered as a core model for dementia caregiving research. The findings from this study provide converging evidence of support for the core model and are unique by involving Chinese family caregivers.

Another indirect effect of behavioral problems on caregiver health was through its relationship with the coping composite. However, this indirect effect only worked for caregiver psychological health. Surprisingly, the result indicated that caregivers who took care of elders with more frequent behavioral problems, utilized less positive coping

strategies than the caregivers whose care-recipients had less frequent behavioral problems. To the researcher's knowledge, there are currently no studies converging on this finding in the research area of dementia caregiving. Presumably, based on the stress and coping model of Lazarus and Folkman (1984), caregivers who were caring for persons with more disturbed behavior problems would also be subjected on a more frequent basis to situations requiring more implementation of problem-solving strategies to manage the behavioral problems. However, in the current study, the finding indicates the opposite was actually occurring.

One possible reason for this may relate to the incorrect perception of the meaning of dementia and related behavioral symptoms in the Chinese population. In China, even though public education on dementia has improved, some people still look at dementia as the retribution for individual or family sins (Elliot et al., 1996; Lou, 2007; Tian, 2003), and some behavioral problems (e.g., abnormal sexual behavior, aggressive behaviors) that occur in elderly with dementia still can not be correctly understood by some neighbors or caregivers (Elliot et al., 1996; Lou, 2007; Tian, 2003; Wang et al., 2004). For instance, Wang and colleagues (2004) found that 59.7% family caregivers stopped patients' aggressive behavior by using scolding or physical restraints, and family caregivers did not seek help from the community or society because they looked at these kinds of behavior as a family stigma. Therefore, continuous public education on dementia and its special manifestations (e.g., behavioral problems) is needed and effective ways to educate are required to be explored.

Another possible reason for this finding may relate to the lack of corresponding strategies among caregivers to manage the behavioral problems, which are not usually seen in elders with other chronic illnesses. Lacking the understanding and management strategies to handle behavioral problems may make caregivers feel these behavioral problems are unchangeable, and this in turn induces them to choose less positive coping strategies and more negative coping strategies. As Lazarus and Folkman (1984) mentioned, people use more problem-focused coping strategies (similar to the positive coping in this study) when they appraise stressors as changeable and utilize more emotion-focused coping strategies (similar to the negative coping strategies in this study) when the stressors are appraised as unchangeable.

It was predicted that behavioral problems would have an indirect relationship with caregiver health through its relationship to caregiving satisfaction and coping. This hypothesis was rejected because there was no significant path from behavioral problems to caregiving satisfaction. That is, behavioral problems as a caregiving stressor did not correlate with caregiving satisfaction. The results of correlation analysis also showed that there was no significant correlation between care-recipient's ADL and caregiving satisfaction. Taken together, these results indicate that caregiving stressors (ADL impairment and behavioral problems) did not influence caregiving satisfaction. These findings were also found by Lopez and colleagues (2005) who described that ADL impairment and behavioral problems were not significant predictors of caregiving satisfaction. The findings might reflect that family caregivers would express satisfied caregiving appraisal when they take the role of caregiver even when they are in the midst

of caregiving difficulties (e.g., the routine lifestyle interruption, long hours engaged in caring tasks and watching a loved elder regress). This positive appraisal on caregiving existed without being influenced by functional impairment and related behavioral problems of elders with dementia. Caregiving satisfaction could co-exist among caregivers who may experience burden at the same time.

To summarize, behavioral problems can negatively affect caregiver physical and psychological health through its relationship with burden or directly way; behavioral problems also indirectly affect caregiver psychological health through its inverse relationship with coping, and in turn harm caregiver psychological health.

*Effect of Familism on Caregiver Outcomes: Hypothesis 5 to 7*

Hypothesis 5, 6, and 7 predicted the effects of familism on the relationship between caregiving stressors and caregiver health. Based on the results, only hypothesis 5 was partially supported suggesting that familism had an indirect effect on caregiver psychological health through its relationship with caregiving satisfaction and the coping composite. Specifically, increased value of familism was linked to more caregiving satisfaction, more positive coping strategies, and better psychological health. Notably, the results emphasized that familism was not associated with caregiving subjective burden.

These results were consistent with the findings from a series of cross-cultural studies done by Knight and colleagues (for a review, please see Knight & Sayegh, 2010). They have been exploring the influence of cultural values on caregiver appraised burden and their associated health outcomes. From their studies, they found that familism as a cultural value operates through coping style to influence caregivers' physical and

emotional health outcomes, rather than through caregivers' appraisal of burden. These results were consistently found among caregivers of White Americans, African Americans (Kim et al., 2007), and Korean Americans, as well as caregivers in Korea (Chun et al., 2007) and Spain (Losada et al., 2006). Findings from both previous research and the current study all indicated that the protective effect of familism on caregiver health was not through decreasing caregiving subjective burden, which was suggested earlier.

However, in those cross-cultural studies, Knight and his research team only emphasized negative caregiving appraisal (i.e., caregiving burden) and did not include positive caregiving appraisal (i.e., caregiving satisfaction) in their theoretical model. Therefore, the findings from the current study enrich the findings from previous research and broaden understanding of the effects of familism on caregiver psychological health, especially for Chinese family caregivers of elders with dementia. That is, familism had an indirect beneficial effect on caregiver psychological health through its relationships with caregiving satisfaction and coping.

In the final model, the path coefficient from familism to caregiving satisfaction was positive, which indicates that higher values of familism would predict more appraised caregiving satisfaction. Based on Lazarus and Folkman's (1984) model, stressor appraisal is strongly influenced by a person's belief, values, and attitudes on the stressor. Caregivers holding a strong value of familism perceived the caregiving process as a natural extension of family life or even a positive aspect of family life (McCallum, 2002; Pyke & Bengtson, 1996). Familism, a core of Chinese culture, which is derived

from Confucian doctrine, always emphasizes the responsibilities and commitment of family members to take good care of their elders at home especially when the elders get sick. Thus, family caregivers, who were part of this culture and held a higher value on familism, might feel more self-affirmation when they were taking care of elders with dementia at home. Since self-affirmation was one of two components in the measurement of caregiving satisfaction in this study, it is understandable that caregivers who had higher values on familism were more likely to have more appraised caregiving satisfaction.

This study is the first study to explore the effect of familism, a core concept of Chinese culture, on caregiver health, therefore, more studies in this area are still required. Since familism is a complex multidimensional construct that is usually composed of familial obligation, family interconnectedness and support, familial honor, and family as referents. Knight and Sayegh (2010) argued that these subcomponents of familism could have competing effects on the variables studied (i.e., burden, health). For instance, familial obligations might have a negative effect on emotional health, while perceived support from family has a distress-inducing influence. These converse effects combined together result in the non significant relationship between familism and psychological health (Knight & Sayegh, 2010). This question is beyond the scope of the current study, but does need more attention in future research.

*Effect of Perceived Social Support on Caregiver Outcomes: Hypothesis 8 to 10*

Hypothesis 8, 9, and 10 predicted the effects of perceived social support on the relationship between caregiving stressors and caregiver health. These 3 hypotheses were

all partially supported, and the results showed the central role that perceived social support played in the model. It directly and indirectly predicts caregiver physical and psychological health. Specifically on the indirect effect, for caregiver psychological health, increased social support was linked to lower burden, higher satisfaction, more positive coping strategies, and better psychological health; for caregiver physical health, increased social support was linked to lower burden, and better physical health.

The significant path from perceived social support to burden suggests that a caregiver's perception of available resources for help when they need (e.g., I can count on my friends when things go wrong; my family really tries to help me), as well as a caregiver's perception of available emotional support (e.g., I get the emotional help and support I need from my family; I have friends with whom I can share my joys and sorrows), may reduce burden and promote better health. These findings are consistent with the general social support literature that has suggested that social support acts as a buffer against stress. High levels of perceived social support may increase the perception that resources are available to handle stress, and this perception bolsters or sustains a sense of control during the time of stress (Thoits, 1995), and the control belief may influence the caregiving appraisal as less burdensome (Atienza et al., 2002).

The significant path from perceived social support to the coping composite suggests that caregivers who perceived more social support also utilized more positive coping strategies, and in turn had better psychological health than caregivers who perceived less social support. Consistently, perceived social support has been considered a coping resource that includes the supportive provisions potentially available within the

individual's social network (Lazarus & Folkman, 1984; Pierce, Sarason, & Sarason, 1996). When caregivers perceived a higher level of social support, they may have more resources to seek help either for problem-solving (e.g., getting advice from relatives or friends, trying to come up with several strategies to solve problems) or emotional support (e.g., saying things to let the unpleasant feelings escape), which were the manifestations of positive coping strategies. Utilizing more positive coping strategies likely promotes caregiver psychological health.

The indirect effect of perceived social support on caregiver psychological health through its relationship with caregiving satisfaction and coping is a relatively new finding for the extant literature since there are not many studies that explore the underlying mechanism. The findings from the current study suggest that caregivers who perceived more social support were more likely to appraise their caregiving situation as satisfying, use more positive coping strategies, and then in turn have better psychological health. Harwood and colleagues (2000) also found that high levels of perceived social support predicted more caregiving satisfaction. They explained that caregivers who perceived more availability of others they could turn to for warmth, compassion and support appeared to appraise the caregiving situation as more satisfying. In addition, from a social-cognitive position, Mankowski and Wyer (1997) pointed out that one's appraisal and consequent perception of support are rooted in internal cognitive representations of his or her relationship with others. More perceived social support may indicate better relationships between the caregiver and others (i.e., other family members, friends, or significant others). The social relationships appear to make family caregivers have a

sense of contributing to caring for elders with dementia. The care they were providing may strengthened their relationships with others. All of these feelings (more self-affirmation, strengthened relationships with others) are positive aspects of caregiving and are associated with more satisfied appraisal of their caring experiences.

However, the reason that caregivers who appraised their caregiving situation as more satisfied would utilize more positive coping is not clear. To the researcher's knowledge, there is no prior study that explores this aspect. From the researcher's understanding, caregivers who were more satisfied with their caregiving situation may feel more confident and more useful, and they may have a more positive attitude toward life. All of these positive feelings facilitate more positive coping strategies.

In summary, perceived social support had both direct and indirect effects on caregiver health. Caregiving appraisal and coping did mediate the indirect effects of perceived social support on caregiver health. Specifically, caregiving subjective burden, caregiving satisfaction, and coping all played a mediating role in the indirect effects of perceived social support on caregiver psychological health. Moreover, caregiving subjective burden still kept the mediator role in the indirect effect of perceived social support on caregiver physical health.

#### *Effect of Caregiving Appraisal on Caregiver Outcomes*

In the current study, caregiving appraisal was also found to have an important role on the relationship between caregiving stressors and caregiver outcomes in terms of physical and psychological health. Caregiving appraisal not only had direct and indirect effect on caregiver health, but it also mediated the effect of caregiving stressors, familism,

and perceived social support on caregiver health. The results re-identify the mediator role of caregiving appraisal, which has been reported in prior research studies (Haley et al., 1987; Lawton et al., 1989; Knight et al., 2000; Knight & Sayegh, 2010). Since the discussion on mediation was provided earlier in this chapter, this section only addresses the direct and indirect effects of caregiving appraisal and related explanations.

### *Caregiving Subjective Burden*

The finding that burden negatively influenced caregiver physical and psychological health was expected and consistent with prior studies. Increased burden was found to predict the declining physical health (Vitaliano et al., 1997; Winslow, 1997; Schulz et al., 1995; Ducharme et al., 2007; Knight & Seygh, 2010) and psychological health (Brodaty & Hadzi-Pavlovic, 1990; Schulz et al., 1995; Ducharme et al., 2007; Knight & Sayegh, 2010). These results are also supported by some caregiving studies in China (Fu et al., 2007; Meng et al., 2006; Yue et al., 2007; Zhang et al., 2003).

Notably, in the proposed model, burden was supposed to have an indirect effect on caregiver health through its relationship with coping, but this hypothesis was rejected by the findings from this study, which only showed evidence of direct effects of burden on caregiver physical and psychological health rather than indirect effects. Some studies did report that burden had its indirect effect on caregiver health through coping as well as the direct effect of burden on caregiver health (see a review by Knight & Sayegh, 2010). The reason why burden did not show a significant link with coping in this study and in turn broke its indirect effect on caregiver health could be explained as follows. First, it might relate to different coping measurements. In this study, Xie's coping questionnaire,

developed by a Chinese psychologist, was considered as more culturally appropriated for the Chinese population. However, in the studies mentioned by Knight and Sayegh, Coping Orientations to Problems Experienced Inventory, developed by western scholars was applied. Even though Xie's coping questionnaire was developed based on Lazarus and Folkman's transactional model of stress and coping, which is a general stress coping model, some differences existed between these two coping instruments (e.g., number of items, different subscales). Second, from a statistical perspective and due to a relatively small sample size for path analysis, the non-significant path from burden to coping might relate to the interrelationship among behavioral problems, burden, and coping, and also the covariance of behavioral problems and burden to explain the variance in coping. From the correlational coefficient, behavioral problems seemed to explain more variance in the coping composite ( $r=-.427$ ) than burden did ( $r=-.304$ ). When they were put in the model together and run in the path analysis, behavioral problems might hide the effect of burden, which can also explain the variance in the coping composite. Therefore, the relationship between burden and coping among Chinese caregivers still needs to be explored in future research.

### *Caregiving Satisfaction*

In the current study, through its relationship with coping, caregiving satisfaction was found to have indirect effects on caregiver psychological health rather than physical health. Specifically, appraisal with more satisfaction of the caregiving situation linked to more implementation of positive coping strategies, and then predicted better

psychological health. Therefore, caregiving satisfaction seems to be more beneficial for caregiver psychological health.

The beneficial effect of caregiving satisfaction was also reported by Pinquart and Sørensen (2004) in their meta-analysis article on 60 previous research studies. It was suggested that caregiving uplifts (similar to caregiving satisfaction) were positively related to caregiver subjective well-being and more caregiving uplifts were related to lower levels of depression. They also revealed that the positive appraisal of the caregiving experience is an important coping resource and it contributes to subjective well being, whereas caregiving stressors were associated with depression (Pinquart & Sørensen, 2003). To date, not many studies have been conducted that explore the relationship between the positive appraisals of caregiving and coping, so the results from this study did enrich the limited findings in this research area. Based on the current and previous findings, future interventions, which are aimed to increase the implementation of positive coping strategies by caregivers, should also put forth effort to increase caregiving satisfaction, which could facilitate family caregivers to utilize more positive coping strategies.

In sum, caregiving subjective burden had direct effects on both physical and psychological health, while caregiving satisfaction only had an indirect effect on psychological health through its relationship with the coping composite. These two caregiving appraisals should be paid more attention by health care personnel because they reflect individual differences on the perception of the caregiving situation, which may

result in different outcomes for different caregivers. Helping family caregivers perceive the caregiving situation as less burdensome and more satisfying would be beneficial for caregivers' physical and psychological health.

#### *Effect of Coping on Caregiver Outcomes*

From the result of this study, coping was also found to have an important role in the model, specifically for caregiver psychological health. Coping directly affects caregiver psychological health. That is, caregivers who utilized more positive coping strategies would experience better psychological health than their counterparts.

This result was expected and is consistent with some prior studies from western countries (Haley et al., 1987; Vitaliano et al., 1985; Papastavrou et al., 2007; Powers et al., 2002) and China (Meng et al., 2006; Zhang et al., 2008). A literature review by Kneebone and Martin (2003) also concluded that problem-solving (similar to positive coping in this study) is likely to be advantageous for caregivers of family with dementia for their psychological health. With problem-focused coping, the individual has tried to solve caregiver problems and in turn get some control over the outcome of the situation, and therefore, taking an active role in changing the circumstance is likely to result in positive benefits. On the other hand, emotion-focused coping strategies (similar to negative coping strategies in this study, which are represented by a lower level of the coping composite), such as escape or avoidance, wishful thinking, have been reported to be correlated with high levels of distress and psychopathology because these coping strategies are maladaptive (Sander-Dewey, Mullins, & Chaney, 2001; Knussen et al., 2008).

However, this study reported that coping did not have any significant direct effect on caregiver physical health. To date, there are few studies that investigate the relationship between coping and caregiver physical health in the research area of dementia caregiving, and the findings are inconsistent. Goode and colleagues (1998) reported that the use of more problem-focused coping was significantly associated with better physical health of caregivers of AD individuals, but they did not give more explanation on the reasons. Based on Lazarus and Folkman (1984), problem-focused coping (similar to the positive coping strategies in this study) may favorably influence one's physical health because problem-focused coping can eliminate the potential adverse effects of stressful situations. The opposite of this finding was reported in Kim and Knight's (2008) study that showed coping did not work as a mediator between caregiving stressors and caregiver physical health among Korean American caregivers of demented patients. They explained that self-report of physical health may not accurately reflect the actual physical health of the caregiver and biomarkers might be more accurate to reflect the changes of physical health before the caregiver perceives the health changes. In the current study, self-reported health questionnaire was used to assess caregiver's physical health. Future studies may need to consider biomarkers to evaluate caregiver physical health. In addition, the cross-sectional design is not optimal for detecting physical health effects of caregiving, which may take time to develop (Vitaliano et al., 2002). Future longitudinal studies would be beneficial. Finally, since the Chinese culture and Chinese society does not encourage people to complain about their hardness or the negative influences from taking care of elders at home, some negative impact of caregiving on

caregiver physical health might not be answered. Taken together, the effects of coping on caregiver physical health among Chinese family caregivers of elders with dementia need further exploration.

Since this study is a cross-sectional study, the conclusions of the protective effect of positive coping strategies on caregiver health need to be made carefully. Lazarus (2000) emphasized the use of strategies aimed at maintaining a balance in life. Thus, the most effective overall strategy may lie in obtaining a balance between problem-focused (similar as positive coping in this study) and emotion-focused (similar as negative coping in this study) coping for the changing caregiving situation, which result from the progression of dementia. Future studies do need to explore the specific coping strategies that are effective to specific caregiving situations or even specific behavioral problems of demented patients, and patients with different severity of dementia could result in different caregiving situation should be studied in groups.

In summary, the final model showed that the effects of caregiving stressors (represented by behavioral problems), caregiving appraisal (caregiving satisfaction and caregiving subjective burden), coping (represented by the coping composite), perceived social support, and familism on caregiver physical and psychological health were complex, and variables in the model were interrelated. This model reflects a complicated stress coping process for family caregivers of elders with dementia in China and provides evidence to support that behavioral problems and burden negatively affect caregiver health, even in Chinese culture. As found in prior studies, perceived social support had the strongest beneficial effects on caregiver health compared with familism, caregiving

satisfaction, and coping. Familism, a core concept in the Chinese culture, had its indirectly beneficial effect on caregiver psychological health through its relationship with caregiving satisfaction and coping. This result is first found and enriches our understanding about the influences of cultural factors on caregiving stress-coping processes. In addition, unique in the Chinese culture, more behavioral problems predicted less utilization of positive coping among caregivers, which may reflect a culture-related perception on dementia and its related behavioral problems. All of these findings and reflections will benefit future nursing practice, theory, and nursing research in family caregiving of patients with dementia.

#### Implications of the Study

The current study examined the correlations among caregiving stressors, familism, perceived social support, caregiving appraisal, coping, and caregiver physical and psychological health. It also tested a Dementia Caregiving Model and identified the effects of familism, perceived social support, caregiving subjective burden, caregiving satisfaction, and coping on the relationship between caregiving stressors and caregiver outcomes in terms of physical and psychological health. The implications of the research findings in this study are discussed as follows from the perspective of intervention, theory, and research.

#### *Implications for Interventions*

The findings from this study enhance understanding of the complex process of dementia caregiving and provide evidence concerning how caregiver health is affected by providing care to a family member with dementia. In addition, the findings of this study

can provide directions to create and test interventions for helping family caregivers cope with the challenging situations. All these interventions in turn can delay institutionalization of elderly with dementia, decrease the cost to the family, and help maintain elderly cared for at home, which is congruent with Chinese culture on elders' caring.

From the study, behavioral problems of care-recipients with dementia and caregiving subjective burden perceived by caregivers were consistently found to be detrimental predictors for caregivers physical and psychological health across multiply ethnic groups, which have different cultural backgrounds. Since family caregiving research on dementia in China is not currently well developed and related interventional programs to help family caregivers are lacking, it may be possible to develop and test successful intervention programs to China that focus on reducing behavioral problems of care-recipients and decreasing the burden of family caregivers possibly benefitting Chinese family caregivers of elders with dementia.

In addition, increasing affordable social support resources (e.g., adult day care, caregiver support groups, community in-home services, respite care, night care services) for family caregivers of elders with dementia and consequently increasing their level of perceived social support will also strength the beneficial effects of perceived social support on caregiver physical and psychological health.

Moreover, public education about dementia and its symptoms (especially its unique behavioral problems) is needed not only for family caregivers but also for community residents and may help gain improved understanding of the disease of

dementia and reduce caregiver's feelings of stigma when the care-recipient has more behavioral problems. Nurses also need to help family caregivers utilize positive coping strategies in the caregiving situation. Caregiver Support Groups could be developed not only in hospitals but also in communities where caregivers can share their feelings, experiences, and effective coping strategies with each other.

Nurses also need to evoke the Chinese government to strengthen the value of familism and reward family caregivers who are taking good care of their demented elders at home. Doing this can strength caregiving satisfaction of family caregivers and reinforce positive coping strategies, which in turn could improve psychological health of caregivers and maintain elders with dementia receiving better care at home. Multiple public media (e.g., Radio, TV advertisements, and newspapers) could be utilized to attain these aims.

#### *Implications for Theory*

The findings of this study enrich the knowledge of family caregiving of elders with dementia in the context of China and Chinese culture. The findings also add some important points to existing theories and models of stress and coping on family caregiving cross culturally. First, the findings support the common core to stress and coping in family caregivers of persons with dementia that moves from the stressor of the care recipients' behavioral problems to caregivers' appraisals of caregiving as burdensome to poor physical and psychological health outcomes for caregivers. Moreover, the findings suggest the importance of incorporating the caregivers' appraisal of caregiving satisfaction resulting from providing care to elders with dementia in the

core model and found that positive appraisal of caregiving affects coping style and consequently influences caregivers' psychological health.

Given that a concern about dementia caregiving is growing globally, it is vitally important to understand the role of culture in the caregiving situation and how it influences caregiving outcomes. Previous studies have found that familism might have an indirect effect on caregiver health through its relationship with coping. The findings of this study support this point and also enrich knowledge in this area. This study first found that familism could increase caregivers' appraisal of caregiving as satisfying. It is the positive appraisal that is associated with more positive coping strategies to cope with caregiving situations. Therefore, the beneficial effect of familism on caregiver psychological health is indirect rather than direct. That is, familism has the indirect positive effect on caregiver psychological health through its relationship with caregiving satisfaction and coping. The findings from the current study support that familism, a cultural value, could affect caregiver outcomes at the points of caregiving appraisal and coping within the process.

#### *Implications for Research*

This study is the first study to propose a Dementia Caregiving Model for Chinese caregivers of elders with dementia based on stress and coping theories. Even though the final model still needs to be tested and verified in future studies, it still provides a framework for understanding the effects of caregiving stressors on caregiver physical health outcome as well as on psychological health outcomes. It can be utilized as a

conceptual model for other researchers who have similar research interests especially who are exploring the cultural effects on the complex caregiving process.

The final model not only includes key concepts (caregiving stressors, caregiving subjective burden, coping, and caregiver physical and psychological health) in the caregiving research, which have been studied for almost 5 decades, but also adds some new concepts (familism, caregiving satisfaction, perceived social support), which have not been explored well in the caregiving research area. Model testing brought forth new research questions that could be addressed in the future. For instance, how and in which intensity will the other contextual factors (e.g., caregiver characteristics, pre-morbid relationship history, and perceived support from formal healthcare personnel) affect the relationship between caregiving stressors and caregiver physical and psychological health? How will different coping strategies operate their effects on the caregiving process and caregiver health under different cultural background and what kind of coping strategies will work for specific stressors? Will perceived social support improve the utilization of social support resources? In addition, since the results indicate inconsistent findings from other studies, for example, that caregivers whose care-recipients showed more frequent behavioral problems were more likely to utilize less positive coping strategies, a qualitative approach to explore this phenomenon should be considered in order to get more in-depth understanding.

The final modified model from this study can also provide a framework for future intervention research, which should incorporate the various individual (e.g., coping strategies) and situational variables (social support resources, or community resources) in

context. It is helpful to develop some actual intervention strategies for family caregivers in China or Chinese American caregivers who have strong Chinese culture background.

#### Limitations and Recommendations

Limitations of this study are discussed in terms of sampling and sample size, study instruments, data collecting methods, and research design. Related recommendations for future studies are also proposed.

#### *Sampling*

Sampling bias may exist in this study because the sampling method was a convenience sampling, and the participants were Chinese recruited from three clinics of general hospitals in only two cities of China. This could limit the generalizability of the findings to all primary caregivers of elders with dementia in China and other Chinese caregivers in other cities, as well as other populations of caregivers of dementia with different cultural backgrounds. Therefore, in order to add validity to the findings, this model should be tested in various samples across different areas of China and also be tested under different cultural contexts. Further, the group of family caregivers who agreed to participate in this study might not be representative of the entire group of family caregivers of demented elders resulting in self-selection bias. Thus, caution must be taken in regards to generalization of results in this study to the larger Chinese population of family caregivers of elders with dementia.

In addition, the minimum sample size required to test the model in this study was 90. Even though there were 96 subjects recruited in this study, it is better to recruit more participants to obtain a larger sample size in order to be able to get relatively stable

model-fit-indices. In addition, a bigger sample size will allow for including other contextual factors (e.g., caregiver demographic characteristics, pre-morbid relationship, caregiving involvement, and perceived support from formal healthcare personnel) in the model for further testing and model revisions.

#### *Study Instrument*

Even though the construct validity in this study was enhanced by assigning all variables with appropriate measures for assessment that were characterized by acceptable psychometric properties, a potential limitation still exists, which results from the fact that the Attitudinal Familism Scale (AFS) might not be worded adequately for Chinese subjects (previously discussed on p.113 of this dissertation). Thus, further content validity related to this issue needs to be examined. In addition, even though the predictive validity of AFS was satisfied, construct validity, which examines the underlining theoretical factors of AFS and test-retest reliability for testing the stability of the instrument, are required. Qualitative study may be also needed to revise some items in AFS for better cultural equivalence.

#### *Data Collection Method*

Questionnaires were utilized in this study to collect data and some questions were about the feelings of taking care of elders of dementia at home. In the Chinese culture, taking good care of elders at home without complaint is socially desired. Thus, some participants may hide their true feelings when filling out the questionnaires and may answer the questions in the way expected by the Chinese society. This phenomenon whereby participants respond to questions in a socially desirable manner is described as

social desirability response bias and it is a limitation of self-report, which may threaten the external validity of the current study. In order to overcome this possible limitation in future studies, the researcher should try to establish a trust relationship with family caregivers before asking them to fill out questionnaires (e.g., making several family visiting before asking them to fill out the questionnaires). Trained data collectors (e.g., nurses or community workers) who have been working with these families will be also helpful.

### *Research Design*

This study used a cross-sectional design, which limits the ability to make strong causal conclusions about the variables studied in the model. It is also difficult to verify the sequence of variables studied because the data collection was a one-time collection. Longitudinal and experimental research is required in order to fully address the issues of causality and improve the validity of the study.

### *Conclusion*

This research described the impact of family caregiving upon caregivers of elders with dementia in China, and identified the effects of familism, perceived social support, caregiving subjective burden, caregiving satisfaction, and coping on the relationship between caregiving stressors and caregiver outcomes in terms of physical and psychological health by testing a proposed Dementia Caregiving Model. The findings of the study enrich understanding of the effects of stress and coping among Chinese family caregivers of elders with dementia, and add new knowledge of the effects of the positive aspects of caregiving and a culture value, familism, on the caregivers physical and

psychological health. The final modified model can be used as a conceptual framework for researchers in China to conduct family caregiving research. Moreover, the study could be the first step in developing effective nursing intervention programs for helping family caregivers of demented elders cope with the caregiving situation smoothly and successfully.

APPENDIX A:  
DISCLOSURE FORM

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APPROVED BY UNIVERSITY OF AZ IRB  
THIS STAMP MUST APPEAR ON ALL  
DOCUMENTS USED TO CONSENT SUBJECTS.  
DATE: 08/06/09 EXPIRATION: 08/05/10

**SUBJECT'S DISCLOSURE FORM**  
(Interview)

Title of Project: **Impact of Family Caregiving upon Caregivers of Elders with Dementia**

You are being invited to voluntarily participate in the above-titled research study. The research study is being conducted by Yu Liu who is a Doctoral Candidate in the College of Nursing at the University of Arizona in the United States. The purposes of the study are to describe the impact of family caregiving on caregiver health when caring for an elder with dementia, and investigate the role of caregiving appraisal, coping, familism, and perceived social support on the relationship between caregiving stressors and caregiver health. You are eligible to participate because you are over the age of 18 and you are the primary family caregiver of your relative ( $\geq$  60 years) with dementia; functioning as a caregiver for at least 6 months; caring for the elder at least 4 hours/day; able to read Chinese and speak Mandarin; co-residing with elders with dementia; willing to participate in the study; and not currently providing care to another family member with a chronic physical or mental illness.

If you agree to participate, your participation will involve a questionnaire interview about the experience of taking care of your relative with dementia. The questions you will be asked include questions about memory and behavior problems of the elder, activities of daily living of the elder, how you have been feeling over the past week and, your health status. There are also questions about the positive and negative aspects of caring for a dependent elder and how you cope with the caregiving situation, your attitude about the familism and perceived social support. The interview will take place in a location convenient for you and will last approximately 40 minutes. You may choose not to answer some or all of the questions. During the interview, some written notes will be made in order to help the investigator better understand what you have said. Your name will not appear on these notes.

Any questions you have will be answered and you may withdraw from the study at any time. There are no known risks from your participation and no direct benefit from your participation is expected. There is no cost to you except for your time and you will not be compensated for your participation.

Only the principal investigator will have access to your name and the information that you provide. In order to maintain your confidentiality, your name will not be revealed in any reports that result from this project. Interview information will be locked in a cabinet in a secure place. You may decide to not begin or to stop the study at any time. Your refusing to participate or your decision to discontinue your participation will have no effect on your health care and health care of your relative. Also any new information discovered about the research will be provided to you. This information could affect your

Version Date: 08/06/09

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willingness to continue your participation.

You can call the Principal Investigator to tell her about a concern or complaint about this research study. The Principal Investigator Yu Liu (MSN, RN, Ph.D. Candidate) can be called at 86-24-86265588. If you have questions about your rights as a research subject you may call the University of Arizona Human Subjects Protection Program office at (520) 626-6721. If you have questions, complaints, or concerns about the research and cannot reach the Principal Investigator; or want to talk to someone other than the Investigator, you may call the University of Arizona Human Subjects Protection Program office. (If out of state use the toll-free number 1-866-278-1455.) If you would like to contact the Human Subjects Protection Program via the web (this can be anonymous), please visit <http://www.irb.arizona.edu/contact/>.

By participating in the interview, you are giving permission for the investigator to use your information for research purposes.

Thank you.

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DOCUMENTS USED TO CONSENT SUBJECTS.  
DATE: 08/06/09 EXPIRATION: 08/05/10

### 被研究对象信息公布表

研究题目：照顾居家痴呆老人对家庭照顾者的影响

您被邀请自愿参加有关上述题目的研究。它是由美国亚利桑那大学护理学院的在读博士生刘宇女士所进行的研究。该研究的目的是了解居家照顾患有痴呆的老年人对于家庭照顾者的影响，并探讨照顾者由于照顾家人而导致的健康的改变，以及照顾者对于照顾经历的评价、照顾者的应对方式、中国传统的家庭观、感受到的社会支持等因素是否对照顾者的健康有影响。您符合此项研究中对于参与者规定的条件，因为您是患有痴呆老人的主要家庭照顾者，照顾老人已经至少6个月，和老人住在一起，每天照顾老人至少4小时，并且能阅读中文材料和用普通话交流，自愿参与本项研究。除了照顾痴呆的老人之外，您目前没有照顾其他任何一位患有慢性病或者精神疾病的家人。

如果您同意参与，您将被请求填写一些有关您照顾感受和经历的问卷。这些问卷的内容包括您与您所照顾的老人的基本情况，老人的记忆以及行为方面的异常表现，老人的日常生活自理能力，您自身的健康状况，情绪状况，您在照顾老人时所感受到的正面的和负面的影响，在这种照顾状况下您怎么应对，您所感受到的社会支持，以及您对“中国家庭观”的态度。这个过程大约需要40分钟，将在您认为方便的地方进行（家里或者门诊）。您可以选择不回答问卷中的一些问题或者全部问题。在这个过程中，研究者可能会做一些笔记以便更好地理解您所提供的一些信息。您的名字绝对不会出现在这些笔记上。

您的任何问题都将会被回答，而且您可以在任何一刻退出研究。您的参与对您没有任何可知的危险，同时也不会给您带来直接的益处。除了您的时间，您不需要花费什么，同时您的参与也没有任何补偿。

只有研究者一人知道您的名字和接触到您所提供的信息。为了保护您的相关资料的保密性，您的名字不会出现在任何与此研究有关的报告中。从您这里所获取的信息会被锁在一个安全的文件柜中。你可以决定不参与研究或者在任何一刻停止参与研究。拒绝参与和决定不继续参与本项研究都不会对您的医疗服务和您所照顾的老人的医疗服务有任何影响。并且，您会被提供与此研究有关的新信息。这些信息有可能会影响您继续参与研究的意愿。

您可以打电话给研究者告诉她您对于此研究的意见或者不满意之处。研究者刘宇（护理硕

士，注册护士，在读博士生)的电话是86 - 24 - 86265588。

如果您有关于研究参与者权利的问题，您可以给美国亚利桑那大学人权保护办公室打电话，520 - 626 - 6721。如果您有疑问，抱怨，或者一些关于本研究的想法，但没有办法找到研究者，或者您想和其他人谈这些问题而不是研究者，您同样可以拨打美国亚利桑那大学人权保护办公室电话(美国境外可拨打免费服务电话，1 - 866 - 278 - 1455)。如果您想通过网络联系人权保护办公室(此为匿名)，请浏览网址<http://www.irb.arizona.edu/contact/>

参与这个问卷访谈过程，意味着您授权给研究者，研究者出于科研的目的使用您所提供的信息。

谢谢您！

刘宇

护理硕士，注册护士，在读博士生

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APPENDIX B:  
DATA COLLECTION INSTRUMENTS

### Demographic Questions for Caregivers and Care-recipients

Please circle the number that best describes you and your care-recipient's condition, or write the number or word on the line.

1. You are: ① Male ② Female

2. What is your age? \_\_\_\_\_ years

3. You are:

① Married ② Divorced ③ Widowed ④ Single

4. What is the highest level of formal education you have completed?

① None ② Elementary ③ Middle School ④ High School ⑤ Associates degree

⑥ Bachelor degree ⑦ Masters degree ⑧ Doctoral degree

5. You are the care-recipient's:

① Spouse ② Daughter ③ Son ④ Daughter-in-law ⑤ Son-in-law

⑥ Brother ⑦ Sister ⑧ Other relatives \_\_\_\_\_

6. How long have you taken care of the care-recipient? \_\_\_\_\_ years

\_\_\_\_\_ months

**7. Please help us fill out some information about the care-recipient as following:**

a. His/her sex: ① Male ② Female

b. His/her age: \_\_\_\_\_ years

c. Type of dementia:

① Alzheimer's Disease ② Vascular Dementia ③ Mixed Dementia

d. Level of severity of dementia:

- ① Mild   ② Moderate   ③ Severe

e. Duration of his/her illness (dementia). \_\_\_\_\_ years \_\_\_\_\_ months

f. Type of medical issuance:

- ① Don't need to pay by his/herself
- ② Pay partially by his/herself, the proportion is \_\_% of total medical expense
- ③ Totally pay by his/herself

### Chinese Version of Activity of Daily Living Scale (ADL-C)

Please circle the number that best describes your care-recipient's condition.

1= Performs without Difficulty or Help

2= Performs with Difficulty

3= Perform with Assistance

4= Unable to Perform

Items	Performs without Difficulty or Help	Performs with Difficulty	Perform with Assistance	Unable to Perform
1. Taking public transportation	1	2	3	4
2. Walking	1	2	3	4
3. Meal preparation	1	2	3	4
4. Housekeeping	1	2	3	4
5. Self-medication	1	2	3	4
6. Eating	1	2	3	4
7. Dressing	1	2	3	4
8. Grooming	1	2	3	4
9. Laundry	1	2	3	4
10. Bathing	1	2	3	4
11. Shopping	1	2	3	4
12. Toileting	1	2	3	4
13. Using of telephone	1	2	3	4
14. Money management	1	2	3	4

### Revised Memory and Behavior Problems Checklist

The following is a list of problems your care-recipient might have sometimes. Please indicate if any of these problems have occurred during the past week. Use the following scales for the frequency of the problem and your reaction to it. Please read the description of the ratings carefully.

#### FREQUENCY RATINGS

- 0=never occurred  
 1=not in the past week  
 2=1 to 2 times in the past week  
 3=3 to 6 times in the past week  
 4=daily or more often

Please answer all the questions below. Please circle a number from 0-4 for both *frequency* and *reaction*.

	Frequency				
1. Asking the same question over and over.	0	1	2	3	4
2. Trouble remembering recent events (e.g., items in the newspaper or on TV)	0	1	2	3	4
3. Trouble remembering significant past events.	0	1	2	3	4
4. Losing or misplacing things.	0	1	2	3	4
5. Forgetting what day it is.	0	1	2	3	4
6. Starting, but not finishing, things.	0	1	2	3	4
7. Difficulty concentrating on a task.	0	1	2	3	4
8. Destroying property.	0	1	2	3	4

9. Doing things that embarrass you. 0 1 2 3 4
10. Waking you or other family members up at night. 0 1 2 3 4
11. Talking loudly and rapidly. 0 1 2 3 4
12. Appears anxious or worried. 0 1 2 3 4
13. Engaging in behavior that is potentially dangerous to self or others. 0 1 2 3 4
14. Threats to hurt oneself. 0 1 2 3 4
15. Threats to hurt others. 0 1 2 3 4
16. Aggressive to others verbally. 0 1 2 3 4
17. Appears sad or depressed. 0 1 2 3 4
18. Expressing feelings of hopelessness or sadness about the future (e.g., “Nothing worthwhile ever happens”, “I never do anything right”) 0 1 2 3 4
19. Crying and tearfulness. 0 1 2 3 4
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
21. Talking about feeling lonely. 0 1 2 3 4
22. Comments about feeling worthless or being a burden to others. 0 1 2 3 4
23. Comments about feeling like a failure or about not having any worthwhile accomplishments in life. 0 1 2 3 4
24. Arguing, irritability, and/or complaining. 0 1 2 3 4

### Zarit Burden Interview (ZBI)

The following is a list of statements, which reflect how people sometimes feel when taking care of another person. After each statement, indicate how often you feel that way, never, rarely, sometimes, quite frequently, or nearly always. There are no right or wrong answers.

1. Do you feel the help that your close ones require is more than what they really need?  
 ① never    ② rarely    ③ sometimes    quite frequently    nearly always
2. Do you feel that you do not have enough time for yourself because you need spend time with your close ones?  
 ① never    ② rarely    ③ sometimes    quite frequently    nearly always
3. Do you think your pressure is from taking care of your close ones and trying to satisfy your family or your work?  
 ① never    ② rarely    ③ sometimes    quite frequently    nearly always
4. Do you feel embarrassing of your close one's behavior?  
 ① never    ② rarely    ③ sometimes    quite frequently    nearly always
5. Do you feel angry when you are around your close ones?  
 ① never    ② rarely    ③ sometimes    quite frequently    nearly always
6. Do you feel your close one drive the relationship between you and your other family members /friends.  
 ① never    ② rarely    ③ sometimes    quite frequently    nearly always
7. Do you worry about your close ones' future?  
 ① never    ② rarely    ③ sometimes    quite frequently    nearly always

8. Do you feel your close ones depend on you?  
① never ② rarely ③ sometimes  quite frequently  nearly always
9. Do you feel anxious when your close ones are nearby?  
① never ② rarely ③ sometimes  quite frequently  nearly always
10. Do you feel your healthy is affected by take care of your close ones?  
① never ② rarely ③ sometimes  quite frequently  nearly always
11. Do you feel that you do not have enough your privacy because of your close ones?  
① never ② rarely ③ sometimes  quite frequently  nearly always
12. Do you feel your social life is affected by taking care of your close ones?  
① never ② rarely ③ sometimes  quite frequently  nearly always
13. When your friends visit you, do you feel uncomfortable because of your close ones?  
① never ② rarely ③ sometimes  quite frequently  nearly always
14. Do you feel your close ones are looking for your help as if you are the one she/he can rely on?  
① never ② rarely ③ sometimes  quite frequently  nearly always
15. Do you feel that you don't have enough money to care for your relative in addition to the rest of your expense?  
① never ② rarely ③ sometimes  quite frequently  nearly always

16. Do you feel that you cannot take care of your close ones any longer?  
① never ② rarely ③ sometimes  quite frequently  nearly always
17. Do you feel that you lost control of yourself since your close ones become sick?  
 never  rarely  sometimes  quite frequently  nearly always
18. Do you wish that you can leave to someone else to take care your close ones?  
 never  rarely  sometimes  quite frequently  nearly always
19. You are not sure about what you can do for your close ones?  
 never  rarely  sometimes  quite frequently  nearly always
20. Do you feel you should do more for your close ones?  
 never  rarely  sometimes  quite frequently  nearly always
21. Do you feel that you can do better when you take care of your close ones?  
 never  rarely  sometimes  quite frequently  nearly always
22. Overall, how burdened do you feel in caring for your relative?  
 not at all  a little  moderately  quite a bit  extremely

### Positive Aspects of Caregiving (PAC)

Some caregivers say that, despite all the difficulties involved in giving care to a family member with memory or health problems, good things have come out of their caregiving experience too. Please circle the number that best describes your opinion.

1. Providing help to care-recipient has made me feel more useful.  
 disagree a lot    disagree a little    neither agree nor disagree    agree a little    agree a lot
2. Providing help to care-recipient has made me feel good about myself.  
 disagree a lot    disagree a little    neither agree nor disagree    agree a little    agree a lot
3. Providing help to care-recipient has made me feel needed.  
 disagree a lot    disagree a little    neither agree nor disagree    agree a little    agree a lot
4. Providing help to care-recipient has made me feel appreciated.  
 disagree a lot    disagree a little    neither agree nor disagree    agree a little    agree a lot
5. Providing help to care-recipient has made me feel important.  
 disagree a lot    disagree a little    neither agree nor disagree    agree a little    agree a lot
6. Providing help to care-recipient has made me feel strong and confident.  
 disagree a lot    disagree a little    neither agree nor disagree    agree a little    agree a lot
7. Providing help to care-recipient has enabled me to appreciate life more.  
 disagree a lot    disagree a little    neither agree nor disagree    agree a little    agree a lot
8. Providing help to care-recipient has enabled me to develop a more positive attitude toward life.  
 disagree a lot    disagree a little    neither agree nor disagree    agree a little    agree a lot

9. Providing help to care-recipient has strengthened my relationships with others.
- disagree a lot    disagree a little    neither agree nor disagree    agree a little    agree a lot

### Simplified Coping Style Questionnaire (SCTQ)

The following is a list of strategies, which reflect how people deal with the difficulties they meet in their daily lives. Please circle the number that best describes your opinion when you meet any difficulties as you provide care to your relatives.

Items	Not Use 0	Use Occasionally 1	Use Sometimes 2	Use Frequently 3
1. Turning to work or other activities to take my mind off things, or doing something to think about it less	0	1	2	3
2. Saying things to let my unpleasant feelings escape	0	1	2	3
3. Looking for something good in it	0	1	2	3
4. Changing my idea, and find out what is the important thing in the life	0	1	2	3
5. Don't take it too seriously	0	1	2	3
6. Concentrating my efforts on doing something about the situation I am in.	0	1	2	3
7. Trying to come up with several strategies to solve problems	0	1	2	3
8. Getting advice from relatives, or friends.	0	1	2	3
9. Changing ways to deal with problems	0	1	2	3
10. Learn from others who have to face similar problems	0	1	2	3
11 . Participating in some activities, and seek some hobbies.	0	1	2	3
12. Trying to control disappointment, regret, sad, and angry.	0	1	2	3

13. Trying away from the problem temporarily by taking a vocation or a rest	0	1	2	3
14. Using alcohol or other drugs to make myself feel better and help me get through it	0	1	2	3
15. Trying to wait until the time can fix the problems.	0	1	2	3
16. Trying to forget the whole situation	0	1	2	3
17. Be dependent on others to solve the problems	0	1	2	3
18 . Accepting the reality because there is nothing else I can do.	0	1	2	3
19 . Dreaming something happened to change the reality)	0	1	2	3
20. Self comfort self	0	1	2	3

### Attitudinal Familism Scale (AFC, Steidel & Contreras, 2003)

The following is a list of statements, which reflect how people think about their families. I would like you to tell me how much you agree or disagree with these statements. Please circle the number that best describes your opinion.

(1=strongly disagree, 10=strongly agree)

1. A person should live near his or her parents and spend time with them on a regular basis.

Strongly disagree=1    2    3    4    5    6    7    8    9    10=strongly agree

2. Aging parents should live with their relatives.

Strongly disagree=1    2    3    4    5    6    7    8    9    10=strongly agree

3. A person should help his or her elderly parents in times of need, for example, help financially or share a house.

Strongly disagree=1    2    3    4    5    6    7    8    9    10=strongly agree

4. Children should always help their parents with the support of younger brothers and sisters. For example, help them with homework, help the parents take care of the children, and do forth.

Strongly disagree=1    2    3    4    5    6    7    8    9    10=strongly agree

5. A person should rely on his or her family if the need arises.

Strongly disagree=1    2    3    4    5    6    7    8    9    10=strongly agree

6. A person should always support members of the extended family, for example, aunts, uncles, and in-laws, if they are in need even if it is a big sacrifice.

Strongly disagree=1    2    3    4    5    6    7    8    9    10=strongly agree

7. Parents and grandparents should be treated with great respect regardless of their differences in views.

Strongly disagree=1    2    3    4    5    6    7    8    9    10=strongly agree

8. A person should often do activities with his or her immediate and extended families, for example, eat meals, play games, go somewhere together, or work on things together.

Strongly disagree=1    2    3    4    5    6    7    8    9    10=strongly agree



### Multidimensional Scale of Perceived Social Support (MSPSS)

The following is a list of statements. Please circle the number that best describes your opinion.

Items	Strongly disagree	Disagree	Slightly disagree	Neither agree nor disagree	Slightly agree	Agree	Strongly agree
	①	②	③	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
1. There is a special person who is around when I am in need.	①	②	③	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. There is a special person with whom I can share my joys and sorrows.	①	②	③	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. My family really tries to help me.	①	②	③	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. I get the emotional help and support I need from my family.	①	②	③	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. I have a special person who is a real source of comfort to me.	①	②	③	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. My friends really try to help me.	①	②	③	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. I can count on my friends when things go wrong.	①	②	③	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. I can talk about my problems with my family.	①	②	③	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. I have friends with whom I can share my joys and sorrows.	①	②	③	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. There is a special person in my life who cares about my feelings.				<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	①	②	③					
11. My family is willing to help me make decisions.	①	②	③	<input type="checkbox"/>				
12. I can talk about my problems with my friends.	①	②	③	<input type="checkbox"/>				

### The Short-Form-36 Health Survey (SF-36)

The following questions ask for your views about your health and how you feel about *life in general*. If you are unsure about how to answer any questions, try and think about your *overall health* and give the best answer you can. Please *circle* the answer that seems to be most accurate.

1. In general, would you say your health is: (circle one)
- |                |   |
|----------------|---|
| Excellent..... | 1 |
| Very Good..... | 2 |
| Good.....      | 3 |
| Fair.....      | 4 |
| Poor.....      | 5 |

2. Compared to the time before you provided care to your relatives, how would you rate your health in general now? (circle one)
- |  |   |
|--|---|
| Much better now, than the time before providing care .....     | 1 |
| Somewhat better now, than the time before providing care ..... | 2 |
| About the same, as the time before providing care .....        | 3 |
| Somewhat worse, than the time before providing care .....      | 4 |
| Much worse, than the time before providing care .....          | 5 |

3. The following items are about activities you might do during a typical day. How much does your health right now limit you in these activities? (circle one number on each line)

<u>ACTIVITIES</u>	I Am Limited A Lot	I Am Limited A Little	Not Limited At All
a. Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports	1	2	3
b. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	1	2	3
c. Lifting or carrying groceries	1	2	3
d. Climbing several flights of stairs	1	2	3
e. Climbing one flight of stairs	1	2	3
f. Bending, kneeling or stooping	1	2	3
g. Walking more than a mile	1	2	3
h. Walking several blocks	1	2	3
i. Walking one block	1	2	3
j. Bathing or dressing yourself	1	2	3

4. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?  
(circle one number on each line)
- |  | YES | NO |
|--|-----|----|
| a. Cut down on the amount of time you spent on work or other activities?                       | 1   | 2  |
| b. Accomplished less than you would like?  | 1   | 2  |
| c. Didn't do work or other activities as carefully as usual?                                   | 1   | 2  |
| d. Had difficulty performing the work or other activities (for example, it took extra effort)? | 1   | 2  |
5. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)? (circle one number on each line)
- |  | YES | NO |
|--|-----|----|
| a. Cut down on the amount of time you spent on work or other activities? | 1   | 2  |
| b. Accomplished less than you would like?                                | 1   | 2  |
| c. Didn't do work or other activities as carefully as usual?             | 1   | 2  |
6. During the past 4 weeks, to what extent have your physical health and/or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups? (circle one)
- |                  |   |
|------------------|---|
| Not at all.....  | 1 |
| Slightly.....    | 2 |
| Moderately.....  | 3 |
| Quite a bit..... | 4 |
| Extremely.....   | 5 |
7. How much bodily pain have you had during the past 4 weeks?  
(circle one)
- |                  |   |
|------------------|---|
| None.....        | 1 |
| Very mild.....   | 2 |
| Mild.....        | 3 |
| Moderate.....    | 4 |
| Severe.....      | 5 |
| Very severe..... | 6 |

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

(circle one)

- Not at all..... 1  
Slightly..... 2  
Moderately..... 3  
Quite a bit..... 4  
Extremely..... 5

9. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling.

(circle one number on each line)

How much of the time during the <u>past 4 weeks</u> ,...	All of the Time	Most of the Time	A Good Bit of the Time	Some of the Time	A Little of the Time	None of the Time
a. Did you feel full of pep?	1	2	3	4	5	6
b. Have you been a very nervous person?	1	2	3	4	5	6
c. Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6
d. Have you felt calm and peaceful?	1	2	3	4	5	6
e. Did you have a lot of energy?	1	2	3	4	5	6
f. Have you felt downhearted and blue?	1	2	3	4	5	6
g. Did you feel worn out?	1	2	3	4	5	6
h. Have you been a happy person?	1	2	3	4	5	6
i. Did you feel tired?	1	2	3	4	5	6

10. During the past 4 weeks, how much of the time have your physical health and/or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

(circle one)

- All of the time..... 1  
Most of the time..... 2  
Some of the time..... 3  
A little of the time..... 4  
None of the time..... 5

11. How TRUE or FALSE is each of the following statements for you?

	Definitel y True	Mostly True	Don't Know	Mostly False	Definitel y False
a. I seem to get sick a little easier than other people.	1	2	3	4	5
b. I am as healthy as anybody I know.	1	2	3	4	5
c. I expect my health to get worse.	1	2	3	4	5
d. My health is excellent.	1	2	3	4	5

### 照顾者和被照顾者一般情况调查表

请圈出最符合您和被照顾者情况的选项，或者在横线上填入相应的数字或者文字。

1. 您的性别: ① 男 ② 女

2. 您的年龄? \_\_\_\_\_ 周岁

3. 您是否:

① 已婚 ② 离异 ③ 丧偶 ④ 单身

4. 您完成的最高学历?

① 文盲 ② 小学 ③ 中学 ④ 高中 ⑤ 大专

⑥ 本科 ⑦ 硕士 ⑧ 博士

5. 您是被照顾者的:

① 配偶 ② 女儿 ③ 儿子 ④ 儿媳 ⑤ 女婿

⑥ 哥哥/弟弟 ⑦ 姐姐/妹妹 ⑧ 其他亲属 \_\_\_\_\_

6. 您照顾被照顾者多长时间了? \_\_\_\_\_ 年 \_\_\_\_\_ 月

7. 请帮助我们填写您的被照顾者的相关问题

a. 他/她的性别: ① 男性 ② 女性

b. 他/她的年龄: \_\_\_\_\_ 周岁

c. 他/她患有痴呆的类型:

① 阿尔茨海默氏症 ② 血管性痴呆 ③ 混合性痴呆

d. 他/她患有痴呆的严重度:

① 轻度 ② 中度 ③ 重度

e. 他/她患有痴呆的时间 \_\_\_\_\_ 年 \_\_\_\_\_ 月

f. 医疗保险类型:

- ① 他/她自己不需要付任何费用
- ② 他/她自己需要付部分费用, 需要付的比例是 \_\_\_\_\_% 的全部医疗费用
- ③ 医疗费用全部由他/她自己付

### 中文版日常生活能力量表

请圈出最符合您的被照顾者的情况:

1= 自己完全可以做,无困难不需要帮助

2= 有些困难

3= 需要帮助

4= 根本无法做

条目	自己完全可以 做,无困难不需 要帮助	有些困难	需要帮 助	根本无 法做
1.使用公共车辆	1	2	3	4
2.行走	1	2	3	4
3.做饭菜	1	2	3	4
4.做家务	1	2	3	4
5.吃药	1	2	3	4
6.吃饭	1	2	3	4
7.穿衣	1	2	3	4
8.梳头刷牙等	1	2	3	4
9. 洗衣	1	2	3	4
10. 洗澡	1	2	3	4
11. 购物	1	2	3	4
12. 定时上厕所	1	2	3	4
13.打电话	1	2	3	4
14.处理自己钱财	1	2	3	4

### 记忆与行为问题修订评价表

以下这些问题是您的被照顾者可能会有的一些问题。请描述您的被照顾者最近一周是否有这些问题发生。请根据下面对于这些问题的频率，圈出您的被照顾者的症状的发生频率。

发生频率  
 0=从未发生  
 1=一周内没有发生  
 2=一周内发生 1 - 2 次  
 3=一周内发生 3 - 6 次  
 4=每天都有

请回答下列全部问题。在问题发生的频率和您的反应的评定中分别从 0 - 4 中圈出一个最符合您和您的被照顾者的情况情况的数字。

1. 重复问相同的问题	发生频率	0	1	2	3	4
2. 最近发生的事记不清楚 ( 报纸或电视 )	发生频率	0	1	2	3	4
3. 过去重要的事记不清楚	发生频率	0	1	2	3	4

4. 丢了东西或东西乱放  
0 1 2 3 4
5. 忘了今天的日子  
0 1 2 3 4
6. 事情做一做就忘了，无法完成  
0 1 2 3 4
7. 做工作时注意力不集中  
0 1 2 3 4
8. 破坏物品  
0 1 2 3 4
9. 做些让您觉得难堪的事情  
0 1 2 3 4
10. 三更半夜叫醒家人  
0 1 2 3 4
11. 大声而快速地说话  
0 1 2 3 4
12. 表现焦虑或担心  
0 1 2 3 4
13. 做一些可能危及自己或别人的行为  
0 1 2 3 4
14. 威胁要伤害自己  
0 1 2 3 4
15. 威胁要伤害他人  
0 1 2 3 4
16. 骂别人或用言语刺伤别人  
0 1 2 3 4

17. 表现忧郁、苦闷  
0 1 2 3 4
18. 无望感或表示对未来悲观(如没有什么事情值得去做的, 我没有一样事情做对)  
0 1 2 3 4
19. 哭泣流泪  
0 1 2 3 4
20. 谈论自己或他人的死亡(如, “活着没意思”, “死了可能比较好”).  
0 1 2 3 4
21. 谈到觉得孤单  
0 1 2 3 4
22. 觉得没有价值或觉得自己成为他人的负担  
0 1 2 3 4
23. 觉得人生是失败的.  
0 1 2 3 4
24. 好辩、易怒、及/或抱怨  
0 1 2 3 4

## Zarit's 照顾者负担问卷

下面的陈述反应了人们在照顾痴呆患者的一些感受。在每个陈述的后面，描述了该感觉出现的频率，如从不，很少如此，有时候，经常如此，及总是如此。回答没有错误与正确之分，请圈出最符合您的情况的数字。

1. 您是否觉得痴呆患者的要求超出了他/她所需要的帮助？

① 从不 ② 很少如此 ③ 有时候  经常如此  总是如此

2. 您是否觉得照顾痴呆患者花费了太多时间，以致没有足够的时间留给自己？

① 从不 ② 很少如此 ③ 有时候  经常如此  总是如此

3. 您是否觉得在照顾痴呆患者和您的家庭、工作上的其他责任间有冲突？

① 从不 ② 很少如此 ③ 有时候  经常如此  总是如此

4. 您是否为痴呆患者的行为感到难堪（不好意思）？

① 从不 ② 很少如此 ③ 有时候  经常如此  总是如此

5. 当您在痴呆患者周围时您是否觉得生气？

① 从不 ② 很少如此 ③ 有时候  经常如此  总是如此

6. 您是否觉得痴呆者对您和其他家人、朋友的关系有负面影响？

① 从不 ② 很少如此 ③ 有时候  经常如此  总是如此

7. 您是否担心痴呆者的未来状况？

① 从不 ② 很少如此 ③ 有时候  经常如此  总是如此

8. 您是否觉得痴呆患者依赖您？

① 从不 ② 很少如此 ③ 有时候  经常如此  总是如此

9. 当痴呆者在您周围时，您是否觉得紧张（有压力）？

① 从不 ② 很少如此 ③ 有时候  经常如此  总是如此

10. 您是否觉得因为投入照顾痴呆患者而影响了自己的健康？

① 从不 ② 很少如此 ③ 有时候  经常如此  总是如此

11. 您是否觉得因为痴呆患者而没有自己的隐私？

① 从不 ② 很少如此 ③ 有时候  经常如此  总是如此

12. 您是否觉得因为要照顾痴呆患者而影响了自己的社交活动？  
① 从不 ② 很少如此 ③ 有时候 □ 经常如此 □ 总是如此
13. 当有朋友到家里时，您是否会因为痴呆患者而觉得不自在？  
① 从不 ② 很少如此 ③ 有时候 □ 经常如此 □ 总是如此
14. 您是否觉得痴呆患者似乎期待您照顾他，好象您是他唯一可以依靠的人？  
① 从不 ② 很少如此 ③ 有时候 □ 经常如此 □ 总是如此
15. 您是否觉得没有足够的钱来照顾痴呆患者？  
① 从不 ② 很少如此 ③ 有时候 □ 经常如此 □ 总是如此
16. 您是否觉得将无法更长久地照顾痴呆患者？  
① 从不 ② 很少如此 ③ 有时候 □ 经常如此 □ 总是如此
17. 您是否觉得自从痴呆患者生病后，您的生活失去控制？  
① 从不 ② 很少如此 ③ 有时候 □ 经常如此 □ 总是如此
18. 您是否希望能把照顾工作放手给别人？

① 从不 ② 很少如此 ③ 有时候  经常如此  总是如此

19. 您是否不确定如何照顾痴呆患者?

① 从不 ② 很少如此 ③ 有时候  经常如此  总是如此

20. 您是否觉得应该为痴呆患者再多做一些?

① 从不 ② 很少如此 ③ 有时候  经常如此  总是如此

21. 您是否觉得在照顾痴呆患者方面您还可以做的更好?

① 从不 ② 很少如此 ③ 有时候  经常如此  总是如此

22. 总体而言, 您觉得照顾痴呆患者是多大的负担?

一点也不不是负担  一点点  有些负担  很重的负担  十分沉重的负担

### 照顾积极感受量表

一些照顾者谈到尽管照顾有记忆障碍和健康问题的家人会面临很多的困难，但是也有从照顾过程中所体会到的积极的方面。我在下面列出一些照顾者所提到的好的方面。我希望您能告诉我对这些陈述您同意或者反对的程度。请圈出最符合您想法的选项。

1. 提供照顾使我感到自己更加有用。  
 很反对    有点反对    不确定    有点同意    非常同意
2. 提供照顾使我对自己的感觉良好。  
 很反对    有点反对    不确定    有点同意    非常同意
3. 提供照顾使我觉得被人需要。  
 很反对    有点反对    不确定    有点同意    非常同意
4. 提供照顾使我觉得自己被人感激。  
 很反对    有点反对    不确定    有点同意    非常同意
5. 提供照顾使我觉得自己很重要。  
 很反对    有点反对    不确定    有点同意    非常同意
6. 提供照顾使我觉得自己很坚强自信。  
 很反对    有点反对    不确定    有点同意    非常同意
7. 提供照顾使我更加感激生活。  
 很反对    有点反对    不确定    有点同意    非常同意
8. 提供照顾使我对生活的态度更加积极。

很反对    ② 有点反对    ③ 不确定    有点同意    非常同意

9. 提供照顾使我与他人的关系更加牢固.

很反对    ② 有点反对    ③ 不确定    有点同意    非常同意

### 简易应对方式问卷

下面陈列的是人们在应对日常生活中的困难时所使用的一些方法。针对您在每日的照顾过程中所遇到的困难和使用的应对方法，请圈出最符合您自己的情况的选项。

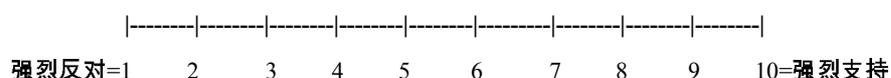
条目	没用过 0	偶尔 使用 1	有时 使用 2	经常 使用 3
1. 通过工作学习或一些其它活动解脱	0	1	2	3
2. 与人交谈，倾诉内心烦恼	0	1	2	3
3. 尽量看到事物好的一面	0	1	2	3
4. 改变自己的想法，重新发现生活中什么重要	0	1	2	3
5. 不把问题看得太严重	0	1	2	3
6. 坚持自己的立场，为自己想得到的斗争	0	1	2	3
7. 找出几种不同的解决问题的方法	0	1	2	3
8. 向亲戚朋友或同学寻求建议	0	1	2	3
9. 改变原来的一些做法或自己的一些问题	0	1	2	3
10. 借鉴他人处理类似困难情景的办法	0	1	2	3
11. 寻求业余爱好，积极参加文体活动	0	1	2	3
12. 尽量克制自己的失望、悔恨、悲伤和愤怒	0	1	2	3
13. 试图休息或休假，暂时把问题（烦恼）抛开	0	1	2	3
14. 通过吸烟、喝酒、服药、和吃东西来	0	1	2	3

解除烦恼				
15. 认为时间会改变现状，唯一要做的便是等待	0	1	2	3
16. 试图忘记整个事情	0	1	2	3
17. 依靠别人解决问题	0	1	2	3
18. 接受现实，因为没有其它办法	0	1	2	3
19. 幻想可能会发生某种奇迹改变现状	0	1	2	3
20. 自己安慰自己	0	1	2	3

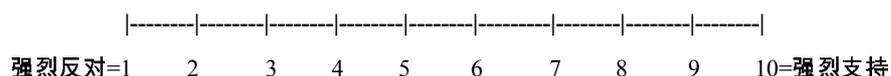
### 家庭观量表

以下的陈述是关于人们如何看待自己的家庭的。请告诉我您对这些陈述同意或者不同意的程度。1 代表强烈反对，10 代表强烈支持。请从 1 到 10 中选择一个数字代表您的意见。数字越靠近 10 表示越支持，数字越靠近 1 则代表越不支持。

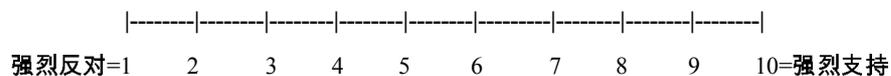
1. 人们应该住在离父母近的地方并且经常与父母在一起。



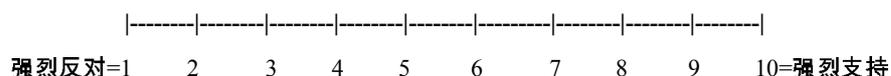
2. 老人应该和他们的亲属一起住。



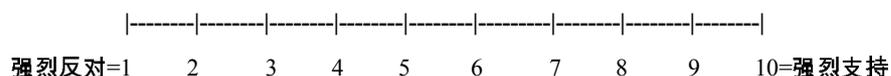
3. 人们应该在年迈父母需要帮助时给以帮助，如在经济上帮助他们或者让老年父母与自己同住。



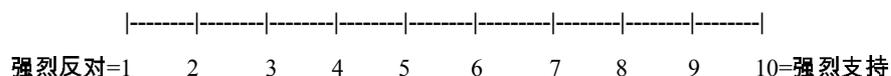
4. 年长的孩子应该帮助他们的父母照顾年幼的弟弟妹妹，如辅导他们做家庭作业，帮助父母照顾他们，等等。



5. 当需要帮助时，人们应该依靠他们的家人。



6. 人们总是应该帮助自己的亲戚，如姨、舅舅、姑姑、叔叔、以及爱人的家人，即使要做出很大的牺牲。



7. 对待父母和祖父母应给予极大的尊重，即使他们有不同的观点。



强烈反对=1    2    3    4    5    6    7    8    9    10=强烈支持

8. 人们应该经常和他们的直系亲属或者亲戚们在一起活动，如一起吃饭，玩游戏，一起去旅游或者一起做某件事情。

-----|-----|-----|-----|-----|-----|-----|-----|-----|  
 强烈反对=1    2    3    4    5    6    7    8    9    10=强烈支持

9. 家庭应该掌控 18 岁以下孩子们的行为。

-----|-----|-----|-----|-----|-----|-----|-----|-----|  
 强烈反对=1    2    3    4    5    6    7    8    9    10=强烈支持

10. 人们应该珍惜与亲属共度的时光。

-----|-----|-----|-----|-----|-----|-----|-----|-----|  
 强烈反对=1    2    3    4    5    6    7    8    9    10=强烈支持

11. 子女们应该帮助干家务活，不能期待有任何的报酬。

-----|-----|-----|-----|-----|-----|-----|-----|-----|  
 强烈反对=1    2    3    4    5    6    7    8    9    10=强烈支持

12. 低于 18 岁的子女们应该把他们挣的几乎所有的收入给父母。

-----|-----|-----|-----|-----|-----|-----|-----|-----|  
 强烈反对=1    2    3    4    5    6    7    8    9    10=强烈支持

13. 如果一个人做了使家庭蒙羞的事情，他应该感到惭愧。

-----|-----|-----|-----|-----|-----|-----|-----|-----|  
 强烈反对=1    2    3    4    5    6    7    8    9    10=强烈支持

14. 子女应该和父母同住直到结婚。

-----|-----|-----|-----|-----|-----|-----|-----|-----|  
 强烈反对=1    2    3    4    5    6    7    8    9    10=强烈支持

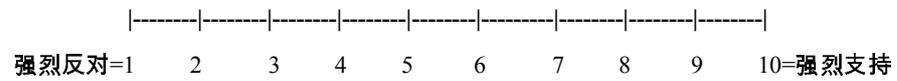
15. 无论需要多大的代价，一个人应该总是被期待为他的家庭荣誉而战。

-----|-----|-----|-----|-----|-----|-----|-----|-----|  
 强烈反对=1    2    3    4    5    6    7    8    9    10=强烈支持

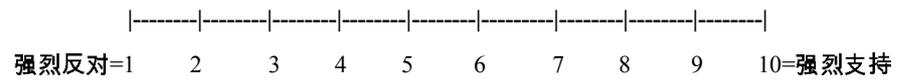
16. 人们应该尊重他们的哥哥或者姐姐不管他们的观点（与自己）有多么不同。

-----|-----|-----|-----|-----|-----|-----|-----|-----|  
 强烈反对=1    2    3    4    5    6    7    8    9    10=强烈支持

17. 人们为了他们的家庭应该做一个好人.



18. 子女应该毫无疑问地服从父母 ( 的意愿 ) , 既使他们相信父母是错的.



### 社会支持感知量表

下面是有关的一些陈述。请圈出最符合您的想法的数字。

条目	极不符 合 ①	很不 符合 ②	不符 合 ③	不确 定  □	符合  □	很符 合 □	极其 符合 □
1. 总有人在我需要时提供帮助	①	②	③	□	□	□	□
2. 我有一个可以与我分享欢乐和痛苦的人	①	②	③	□	□	□	□
3. 我的家人总是在竭力帮我	①	②	③	□	□	□	□
4. 我从家庭中能得到感情上的帮助和支持	①	②	③	□	□	□	□
5. 我身边有一个能真正使我感到舒适的人	①	②	③	□	□	□	□
6. 我的朋友们真正尽力帮我	①	②	③	□	□	□	□
7. 我事情不顺时可以指望朋友们	①	②	③	□	□	□	□
8. 我可以与家人商量自己的问题	①	②	③	□	□	□	□
9. 我有一些朋友可以分享自己的快乐和忧愁	①	②	③	□	□	□	□
10. 我的生活中有一个特定的人关心我的感情	①	②	③	□	□	□	□
11. 家人愿意帮我拿主意	①	②	③	□	□	□	□
12. 我可以和朋友们讨论自己的问题	①	②	③	□	□	□	□



### 健康调查简表 (SF-36)

下面的问题询问的是您对自己的健康的看法和您生活的总体感受。如果您不确定如何回答某项问题，请尽可能从您整体的健康角度考虑并尽可能给出您最真实的答案。请圈出那些最符合您情况的选项。

1. 总体而言，您的健康状况是：

(选择一个)

- |          |   |
|----------|---|
| 非常好..... | 1 |
| 很好 ..... | 2 |
| 好 .....  | 3 |
| 一般.....  | 4 |
| 差 .....  | 5 |

2. 与您没有照顾被照顾者之前比，您觉得您目前的健康状况是？

(选择一个)

- |                  |   |
|------------------|---|
| 比提供照顾之前好多了 ..... | 1 |
| 比提供照顾之前好一些 ..... | 2 |
| 跟提供照顾之前差不多 ..... | 3 |
| 比提供照顾之前差一些 ..... | 4 |
| 比提供照顾之前差多了 ..... | 5 |

3. 以下这些问题都和日常活动有关。请您想一想，您的健康状况是否限制了这些活动？如果有限制，程度如何？(每一条目只选择一个答案)

<u>活动</u>	限制	有些	毫无
	很大	限制	限制
a. 重体力活动。如跑步举重、参加剧烈运动等	1	2	3
b. 适度的活动。如移动一张桌子、扫地、打太极拳、做简单体操等	1	2	3
c. 手提日用品。如买菜、购物等	1	2	3
d. 上几层楼梯	1	2	3
e. 上一层楼梯	1	2	3
f. 弯腰、屈膝、下蹲	1	2	3
g. 步行 1500 米以上的路程	1	2	3
h. 步行 1000 米的路程	1	2	3
i. 步行 100 米的路程	1	2	3
j. 自己洗澡、穿衣	1	2	3

4. 在过去 4 个星期里，您的工作和日常活动有无因为身体健康的原因而出现以下这些问题?? (每一条目只选择一个答案)

	是	否
a. 减少了工作或其他活动时间?	1	2
b. 本来想要做的事情只能完成一部分?	1	2
c. 想要干的工作或活动种类受到限制?	1	2
d. 完成工作或其他活动困难增多 (比如需要额外的努力)?	1	2

5. 在过去 4 个星期里，您的工作和日常活动有无因为情绪的原因（如压抑或忧虑）而出现以下这些问题？（每一条目只选择一个答案）

	是	否
a. 减少了工作或活动时间？	1	2
b. 本来想要做的事情只能完成一部分？	1	2
c. 干事情不如平时仔细？	1	2

6. 在过去 4 个星期里，您的健康或情绪不好在多大程度上影响了您与家人、朋友、邻居或集体的正常社会交往？（选择一个）

完全没有影响.....	1
有一点影响.....	2
中等影响 .....	3
影响很大 .....	4
影响非常大 .....	5

7. 在过去 4 个星期里，您有身体疼痛吗？

（选择一个）

完全没有疼痛.....	1
有一点疼痛 .....	2
轻度疼痛 .....	3
中等疼痛 .....	4
严重疼痛 .....	5
很严重疼痛 .....	6

8. 在过去 4 个星期里，您的身体疼痛影响了您的工作和家务吗？

(选择一个)

- 完全没有影响..... 1
- 有一点影响..... 2
- 中等影响 ..... 3
- 影响很大 ..... 4
- 影响非常大 ..... 5

9. 以下这些问题是关于过去 4 周里您自己的感觉，对每一条问题所说的事情，您的情况是什么样的？

(每一条目选择一个答案)

在 <u>过去 4 周</u> 里有多少时间...	所有 的时 间	大部分 时间	比较多 时间	一部 分时 间	小部 分时 间	没有这 种感觉
a. 您觉得生活充实？	1	2	3	4	5	6
b. 您是一个敏感的人？	1	2	3	4	5	6
c. 您的情绪非常不好，什么事都不能使您高兴起来？	1	2	3	4	5	6
d. 您的心理很平静？	1	2	3	4	5	6
e. 您做事精力充沛？	1	2	3	4	5	6
f. 您的情绪低落？	1	2	3	4	5	6
g. 您觉得筋疲力尽？	1	2	3	4	5	6
h. 您是个快乐的人？	1	2	3	4	5	6



11. 请看下列每一条问题，哪一种答案最符合您的情况？

	绝对正确	大部分正确	不能肯定	大部分错误	绝对错误
a. 我好象比别人容易生病	1	2	3	4	5
b. 我跟周围人一样健康	1	2	3	4	5
c. 我认为我的健康状况在变坏.	1	2	3	4	5
d. 我的健康状况非常好.	1	2	3	4	5

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