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# Perceived stigma in caregivers of persons with dementia and its impact on depressive symptoms

Megan Fong Liu  
*University of Iowa*

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PERCEIVED STIGMA IN CAREGIVERS OF PERSONS WITH DEMENTIA AND  
ITS IMPACT ON DEPRESSIVE SYMPTOMS

by

Megan Fong Liu

An Abstract

Of a thesis submitted in partial fulfillment  
of the requirements for the Doctor of  
Philosophy degree in Nursing  
in the Graduate College of  
The University of Iowa

December 2011

Thesis Supervisor: Professor Emeritus Kathleen Buckwalter

## ABSTRACT

Although findings from a pilot study indicate that caregivers of persons with dementia (PwD) report feeling stigmatized (Burgener, 2007; Burgener & Buckwalter, 2010), little research has been conducted on the effects of perceived stigma on fostering depressive symptoms among caregivers of PwD. The purpose of this study was to examine the relationship between perceived stigma and depressive symptoms among caregivers of PwD. The Modified Labeling Theory (MLT) developed by Link et. al. (1987; 1989) served as the organizing framework. The design of this study was a mixed methods approach including a descriptive longitudinal design with a qualitative interview. Caregivers of PwD (n=51) were interviewed regarding ethnic background, geographic location (rural and urban), knowledge of dementia, perceived stigma, depressive symptoms, and were asked to rate the extent of PwD's behavioral symptoms, while PwD (n=47) were assessed on their mental ability and disease stage. Caregivers were also asked to share their perceptions of stigma and mood change once their family members were diagnosed. Pearson product-moment correlations and a linear mixed model analysis determined the relationship between variables; for qualitative analysis, a directed approach to content analysis was applied.

Findings indicated that caregivers' perceptions of stigma were significantly associated with depressive symptoms, both at baseline ( $r = 0.357$ ,  $p = 0.0175$ ) and over 18 months ( $p = 0.0045$ ). Results also indicated that caregivers of PwD felt more depressed when they perceived additional stigma ( $p = 0.0019$ ), regardless of caregiver ethnicity/race and caregivers' reactions in response to PwD memory and behavior problems. Moreover, perceived stigma minimally mediated the effect between caregivers' reactions toward the PwD's memory and behavior problems and depressive

symptoms (14.4% decrease in the coefficient). Analysis of the qualitative data provided preliminary validation of the MLT and an in-depth understanding of caregivers' mood change since the diagnosis of their family member. Together our findings suggest that depressive symptoms among caregivers of PwD in response to the stresses of perceived stigma underscore the seriousness of this social problem. There is a need for effective interventions to combat caregivers' perceived stigma in order to enhance their psychological well-being.

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Graduate College  
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CERTIFICATE OF APPROVAL

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PH. D. THESIS

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This is to certify that the Ph. D. thesis of

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To My Family



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## **CHAPTER 1**

### **INTRODUCTION**

The population over age 65 is projected to reach 86 million by the year 2050, and the prevalence of persons affected with Alzheimer's disease (AD) by that same year will grow to 13.2 million (Hebert, Scherr, Bienias, Bennett, & Evans, 2003). Dementia is a degenerative, irreversible, and progressive brain disorder. It is widely assumed that persons with dementia (PwD) are stigmatized and that its magnitude is comparable to or greater than other populations of persons with chronic illness (Burgener & Berger, 2008). PwD are stigmatized due to their progressive impairments such as decline in cognitive function, personality change, disruptive behaviors, poor self-care and incontinence (Benbow & Reynolds, 2000; Burgener & Berger, 2008; Graham et al., 2003; Jolley & Benbow, 2000).

The stress of caring for a PwD can be multi-dimensional, including financial, physical and psychological stress. Direct and indirect care of PwD costs the U.S. an estimated \$148 billion a year and these costs do not include the \$89 billion associated with an estimated 10 million AD caregivers who provide unpaid services (Alzheimer's Association, 2008a; Koppel, 2002; Lewin Group, 2004). Studies indicate that caregivers of PwD are more stressed both physically and psychologically than caregivers of persons with other chronic conditions (Alzheimer's Association and National Alliance for Caregiving, 2004; Schulz, O'Brien, Bookwala, & Fleissner, 1995; Vitaliano, Zhang, & Scanlan, 2003). The physical and psychological demands of caring for PwD often result in psychiatric morbidity in the form of increased depression (Baumgarten et al., 1992; Mahoney, Regan, Katona, & Livingston, 2005; Schulz et al., 1995). The incidence and severity of caregiver depression has been reported based on the different characteristics



of PwD and their caregivers as well as environmental conditions. Higher frequency of problem behaviors, greater functional impairments and less social support are associated with elevated depression (Buhr, Kuchibhatla, & Clipp, 2006; Clyburn, Stones, Hadjistavropoulos, & Tuokko, 2000; Cook, Pearson, & Ahrens, 1997; Levesque, Cossette, & Laurin, 1995; Molyneux, McCarthy, McEniff, Cryan, & Conroy, 2008). Female caregivers and caregivers who reside with PwD are known to have higher levels of depression (Chumbler, Grimm, Cody, & Beck, 2003; Gallicchio, Siddiqi, Langenberg, & Baumgarten, 2002; Papastavrou, Kalokerinou, Papacostas, Tsangari, & Sourtzi, 2007). A clustering of factors predicts caregiver depression; however, many of these variables are not changeable. On the other hand, perceived stigma is a potentially changeable and understudied condition that may be associated with caregiver depression.

### **Statement of the Problem**

Defined as the labeling behaviors of others which brings about an internalization process and results in negative consequences (Link, Cullen, Frank, & Wozniak, 1987; Link, Cullen, Struening, Shroud, & Dohrenwend, 1989), perceived stigma affects not only people with mental illnesses but their families as well (Greenberg, 1997). Research demonstrates that 43% of caregivers of people with mental illness report feeling stigmatized, and that perceived stigma is associated with depressive symptoms (Perlick et al., 2007; Phelan, Bromet, & Link, 1998; Struening et al., 2001). Although findings from a pilot study indicate that caregivers of persons with dementia also report feeling stigmatized (Burgener, 2007; Burgener & Buckwalter, 2010), little research has been conducted on the effects of perceived stigma on fostering depressive symptoms among caregivers of PwD.

### **The Parent Study**

This study is part of a NIH-funded grant entitled, Understanding Perceived Stigma in Persons with Dementia. The larger multi-site (e.g., Illinois, Iowa, and North Carolina) study's purpose is to explore the impact of perceived stigma on persons with Alzheimer's disease (PwD) and their family caregivers. The overall principle investigator is Sandy Burgener, Ph.D., APRN-BC, FAAN at the University of Illinois at Chicago College of Nursing and the primary investigator of the Iowa site is Kathleen Buckwalter, Ph.D., FAAN at the University of Iowa College of Nursing.

The aims of the larger study are to examine PwD in the early stages of the disease (e.g. no more than one year since diagnosis) and to: 1) describe the natural history of perceived stigma over an 18 month period; 2) describe the relationships between perceived stigma in PwD and Quality of Life (QOL) outcomes; and 3) describe the relationship between family caregiver's perceived stigma and QOL outcomes in PwD (Burgener & Buckwalter, 2008).

### **Purpose of the Study**

This study examined the relationships between perceived stigma and depressive symptoms among caregivers of PwD as well as caregivers' perceptions of stigma. The following paragraph explains the purpose of the study and describes its difference from the larger study.

The research questions and hypotheses guiding the study include (question #4 is exploratory in nature; therefore, no hypothesis is identified):

Research question #1: What is the relationship between perceived stigma and depressive symptoms among caregivers of PwD in the early stages of the disease?

The hypothesis associated with research question #1: Higher levels of perceived stigma will be related to higher levels of depressive symptoms.

Research question #2: Does the relationship between perceived stigma and depressive symptoms among caregivers of PwD in the early stages of the disease change over 18 months? Also, are depressive symptoms affected by perceived stigma as well as personal (disease stage, cognitive impairment, caregivers' knowledge of dementia, behavior symptoms, demographic information), environmental (different geographic location: rural and urban) and ethnic background variables?

The hypothesis associated with research question #2: Higher levels of perceived stigma will be related to higher levels of depressive symptoms and this relationship will persist over 18 months.

Research question #3: Does perceived stigma among caregivers of PwD mediate the effect of dementia caregiving (including personal, environmental and ethnic background variables) on caregiver depressive symptoms?

The hypothesis associated with research question #3: As dementia progresses, the severity of symptoms will advance and the labeling behaviors of others will be intensified, resulting in higher levels of perceived stigma among caregivers of PwD. This higher level of perceived stigma may contribute to the onset or severity of depressive symptoms.

Research question #4: What are caregivers' perceptions of stigma and how did their mood change since the diagnoses of their family members?

## **Summary**

This study examined the relationships between perceived stigma and depressive symptoms among caregivers of PwD as well as caregivers' perceptions of stigma.

Chapter two discusses the literature related to the main definitions included in this study; stigma and dementia labels; dementia caregiving; courtesy stigma and dementia; and describes the theoretical framework guiding the study.

## **CHAPTER 2**

### **LITERATURE REVIEW**

#### **Definitions**

The following definitions and descriptions encompass the main concepts included in this study.

#### **Dementia**

Dementia is a non-specific illness syndrome characterized by cognitive and behavioral disturbances. Memory loss is the main symptom of dementia although other areas of functioning are also affected. These include attention, orientation, language, mood, personality, judgment, and visual spatial performance. In order to meet the criteria for dementia of the Diagnostic and Statistical Manual of Mental Disorders – IV – Text Revision criteria (DSM-IV, American Psychiatric Association, 2000), memory impairment and one of the following cognitive impairments must be present:

Aphasia: loss of expressive and/or receptive language,  
Apraxia: Impairment in performing voluntary movements,  
Agnosia: Inability to interpret sensory stimuli, or  
Disturbance in executive functioning (higher order intellectual functioning such as planning and inhibition).

Sufficient impairments in social or occupational function are also required in order to have a diagnosis of dementia. There are many different types of dementia; however, the end result is often the same. Consequently, the medical community often classifies these diseases together in a group called Alzheimer's disease and related dementias (ADRD) (Heston & White, 1983). For this study, dementias of the following types are included: Alzheimer's disease (AD), vascular dementia, mixed types of dementias (AD and vascular), and frontotemporal dementia.

There are different stages of disease progress in ADRD including early, middle, later, and terminal. In the early stages, short-term memory is impaired and PwD may lose or forget things. PwD may blame their memory loss on aging, stress, or fatigue and effectively utilize lists or memory aids to compensate for their deficiencies. In addition, depression is common in early stage dementia and is often a comorbid diagnosis. Individuals in the middle stages of ADRD exhibit symptoms of confusion. There may be loss of memory and increasing disorientation regarding time, place, person, and things. Later stage dementia impacts ambulation. The progressive loss of ability to complete activities of daily living (e.g. willingness and ability to bathe; grooming; choosing clothing; dressing; gait and mobility; toileting; communication; reading and writing skills) interferes with functional abilities. As a result, PwD may become increasingly withdrawn and self-absorbed. In addition, in the later stages, PwD exhibit more behavioral symptoms such as irritability, agitation, anxiety, and pacing. There is often a reduced tolerance for stress and resistance to care. The terminal stage is when most abilities are lost and individuals typically become mute, unable to walk, do not participate in meaningful activities, and forget to eat, chew, or even swallow. Although these stages provide a guideline for the progression of ADRD, they are not necessarily distinct and vary from person to person (Buckwalter, 2009). The variations depend upon the extent of brain cell loss, location of brain cell death, and the rate at which the losses occur. This review focuses only on early stage dementia, as participants in this study were in the early stages.

## **Early Stage Dementia**

Dementia progresses at an individual rate but the first sign is often a gradual decline in memory. Despite memory decline, early stage dementia includes mild impairment in verbal expression, executive functioning, judgment, and physical abilities (Boyd, Garand, Gerdner, Wakefield, & Buckwalter, 2005; Brechling & Schneider, 1993).

In the early stages of dementia, PwD have the best response to therapeutic interventions and as a result, many people are living longer with milder symptoms. PwD in the early stages are often able to remain active but their personal identity may change due to the changes in their memory, perceptions, and ability (American Psychiatric Association, 2000). In this stage, short-term memory loss impacts the ability to complete daily tasks such as balancing the checkbook and completing activities that have several steps (e.g. cooking a complicated meal) (American Psychiatric Association, 1997). Most memory loss issues are manageable through reminders (e.g. calendars, daily medication dispensers, or writing things down) and allow PwD to remain active in social and community activities (Snyder, 2007). In addition, PwD in the early stages are often capable of understanding their diagnosis and making decisions about their lives (Brechling & Schneider, 1993; Smith & Buckwalter, 2005). As a result of this understanding and awareness of their cognitive deficits, PwD may experience stigma.

## **Stigma**

Goffman (1963), in his seminal work, defined stigma as “an attribute that is deeply discrediting” and proposed that the stigmatized person is reduced “from a whole and usual person to a tainted, discounted one” (p. 3). According to Goffman, there are three types of stigmatizing attributes: blemishes of individual character, abominations of

the body and tribal stigma. In other words, stigmatizing marks are linked to behavior (e.g., child abuser), appearance (e.g., loss of limbs), or group membership (e.g., African American). However, these stigmatizing marks differ in their level of visibility. The “discreditable” conditions refer to people with invisible characteristics, while the “discredited” conditions refer to those with visible socially judged stigmatizing characteristics that are marginalized by the surrounding world (Goffman, 1963). Later, Link and Phelan (2001) conceptualized stigma as a collective term that includes recognition and behavior of societal members that lead to labeling, negative stereotyping, separation, status loss, and discrimination.

Labeling and stereotyping involves recognition and assignment of the differences according to the dominant cultural belief and labels those differences with negative stereotypes. Separation occurs when stereotypes accumulate to a certain level and lead to a sense of “self” and “others” (Link & Phelan, 2001). Later, the labeled person experiences status loss and discrimination that prohibit him or her from participating fully in society. However, stigmatization is contingent on the person’s social, economic, and political power. Consequently, the term stigma evolves when elements of labeling, stereotyping, separation, status loss, and discrimination co-occur in a power situation (Link & Phelan, 2001).

When internalizing the labeling behaviors of others in the society results in negative consequences, it is defined as perceived stigma (Link et al., 1987; Link et al., 1989). There are various definitions of stigma; however, in this study the definitions of Goffman and Link and Phelan are used because they developed their conceptualizations from observations of persons with mental illnesses. Also, Link and Phelan responded to



the criticisms of Sayce (1998) by including the labeling behaviors of others in the external environment in addition to locating the “problem” in the individual. Dementia is a neurological disorder; however, in the stigma literature dementia is often categorized as a kind of mental disorder. This is because dementia frequently often co-occurs with depression, and often behavioral, psychological, and psychiatric symptoms (e.g., hallucinations and delusions) may arise as the disease progresses. Therefore, for purposes of this study, dementia will be considered as a kind of mental disorder, and the literature relevant to stigma associated with mental illness is assumed to be relevant.

### **Courtesy Stigma**

Stigma may not only affect the individual but also tends to “spread from the stigmatized individual to his/her close connections” (Goffman, 1963, p.30). Goffman called this courtesy stigma, namely the stigma experienced by parents, siblings, spouses, and children of people with mental illness. For purposes of this study this includes caregivers of PwD. In other words, family members may experience stigma through their association with the person with mental illness or dementia, and the wider society may “treat both individuals in some respects as one” (Goffman, 1963, p.30). Goffman argues that these individuals “are obliged to share some of the discredit of the stigmatized person to whom they are related” (Goffman, 1963, p.30).

### **Summary**

As mentioned above, the severity of symptoms advance and become more visible as dementia progresses. Short-term memory impairment often appears in the early stages, while behavioral and psychological symptoms tend to worsen as the dementia progresses toward the middle and late stages of the disease. Thus, PwD may experience higher levels

of stigma with disease progression. Moreover, according to Link and Phelan's (2001) definition, the experience of stigma may vary based on the cultural and socioeconomic status of the PwD. Through their association with PwD, caregivers may also experience various levels of stigma, depending on different characteristics of the PwD, including disease stage, cognitive impairment, culture and socioeconomic status.

### **Stigma and Dementia Labels**

This section notes that people with a diagnostic label of schizophrenia, major depression, and dementia are often viewed as homogeneous with certain manifestations by health care professionals and the general public. Homogeneity of a diagnostic group can exacerbate stigmatization (Ben-Zeev, Young, & Corrigan, 2010; Corrigan, 2007). Stigmatization of dementia may affect the PwD's daily living and impact their quality of life. Also, diagnostic labels not only affect individuals but also their family, friends, colleagues and co-workers.

Persons with mental illnesses receive diagnoses from health care professionals to describe their conditions. One benefit of using diagnostic classification is that it assumes all members of a group are homogeneous with definable boundaries, and thus helps health care professionals understand a large amount of information (American Psychiatric Association, 2000; Frances, First, Pincus, Widiger, & Davis, 1990; Rosch & Mueller, 1978), including signs and symptoms of the disease, the course and prognosis, and suggested causes as well as effective interventions (Corrigan, 2007).

On the other hand, diagnostic labels may act as cues that signal stereotypes. Moreover, the criteria that define a diagnosis may augment stereotypes, prejudice, and discrimination through groupness, homogeneity, and stability. The perception of

groupness exists when associated with descriptive attributes. When these attributes are considered negative, stereotypes arise (Link & Phelan, 2001). Homogeneity of group membership exacerbates stigmatization (including stereotypes, prejudice, and discrimination) through an overgeneralization that all members within a group are expected to manifest the characteristics attributed to that certain group. Concerns for overgeneralization of homogeneity have been raised in the text revision of the DSM-IV and by the Institute of Medicine (2001). Health care professionals have been advised to use clinical judgment and flexibility to ensure that the description of individual mental illness is not solely depicted in terms of the diagnostic criteria (American Psychiatric Association, 2000). Also, the Institute of Medicine (2001) emphasized the heterogeneity of individuals within the same diagnostic category. Despite recent efforts to promote heterogeneity, stereotypic descriptions of the members of a certain mental illness group often include the stability of the illness which is considered relatively static and unchanging (Corrigan, 2007).

The impact of labeling on public attitudes toward people with various mental illnesses is different; also, labeling effects on different mental illnesses vary by culture. A German study by Angermeyer and Matschinger (2003) examined the impact of labeling on public attitudes toward people with schizophrenia and major depression. They found that schizophrenia labeling has an impact on public attitudes, with negative effects outweighing positive effects, while labeling has no effect on public attitudes toward people with major depression. Later, a research team led by Angermeyer (Angermeyer, Buyantugs, Kenzine, & Matschinger, 2004) conducted a study to further investigate whether the effects of labeling differ by culture. Surveys were conducted in Novosibirks

(Russia) and in Ulaanbaatar (Mongolia). Some results were similar to those found in the German study, in that labeling of mental illness was positively correlated with public beliefs that the individual illustrated in the vignette was in need of help. However, in contrast to the German study, labeling had no significant effect on endorsing the stereotype of dangerousness toward people with schizophrenia.

In addition to the negative consequences of the diagnostic label of mental illness, the diagnostic label of dementia is even more complex. This is because dementia is often seen as a natural part of aging (Ayalon & Arean, 2004; Graham et al., 2003), and is considered untreatable (Devlin, MacAskill, & Stead, 2007). More than a decade ago, Hinton and Levkoff (1999), for example, noted that many laypersons attribute the causes of AD to folk models rather than to the biomedical model. Later Hinton, Levkoff et. al. (2005) used the same typology and examined caregivers' conceptions of AD. They found that 54% of caregivers attributed the causes of dementia to the mixed model, which combined folk and biomedical elements by using biomedical terms but drawing on folk models to explain the illness. For example, caregivers attributed AD to psychosocial stress or normal aging.

PwD and their caregivers may delay seeking evaluation of the PwD's cognitive symptoms due to false beliefs about AD (Devlin et al., 2007; Garand, Lingler, Conner, & Dew, 2009; Rimmer, Wojciechowska, Stave, Sganga, & O'Connell, 2005). A study by Werner (2003) assessed the symptoms of AD among the lay public in Israel and found that over 60% of the participants correctly recognized warning signs related to disorientation, problems with language, difficulty performing familiar tasks, decreased judgment, problems with abstract thinking, loss of initiative, and changes in mood or

behavior. However, only 47% considered continuous difficulty remembering the location of glasses or keys as symptoms of AD and memory deficit, yet these symptoms have been described as one of the criteria for mild cognitive impairment (Burns & Zaudig, 2002). These beliefs suggest that PwD and their caregivers may delay seeking evaluation of their cognitive symptoms (Devlin et al., 2007; Garand et al., 2009; Rimmer et al., 2005). Further, patients, their families, and the general public may incorrectly attribute the causes of AD and believe that treatment is not useful.

Another important factor affecting timely recognition and diagnosis of dementia is stigma (Iliffe et al., 2005; Vernooij-Dassen et al., 2005; Werner & Giveon, 2008). A qualitative study examined the meaning of dementia from the perspective of persons with dementia and found that the general public had a negative attitude toward them and saw PwD as helpless victims (MacRae, 1999). In certain instances, the diagnosis of dementia is used to exclude individuals from some forms of health care, such as inpatient treatment or nursing home care (Graham et al., 2003).

Stigma may lead people to avoid socializing with, employing, working with, renting to, or living near PwD. Also, PwD are often stigmatized as having little to no quality of life or capacity for pleasure, resulting in ignorance of personal preferences and cultural or religious beliefs (Graham et al., 2003; Wang, 1998). A public poll conducted among 1000 randomly selected adult Canadians found that 81% of the participants felt that they would be looked upon or treated differently if others knew they were diagnosed with AD (Alzheimer's Society of Canada, 2003). Moreover, when interviewing caregivers of PwD, almost two-thirds of the caregivers reported perceptions of stigma

regarding PwD including reduced social contacts and inability to function in basic social roles (Werner & Heinik, 2008).

What are the PwD's own experiences with the diagnostic label of dementia? More than 300 people with early stage dementia shared their experiences and perspectives on how they wished to be viewed, respected, engaged, and treated by health professionals, researchers, and the general public. The study was conducted by the Alzheimer's Association at nationwide town hall meetings and online virtual town meetings. The overriding theme was that people with early stage dementia are misunderstood due to myths and misconceptions about the disease, thus leading to negative conceptualization toward those who have the condition. Also, people with early stage dementia described negative interactions with their family and friends, colleagues and co-workers, as well as with the medical community. They believed these changes were due to a negative association with Alzheimer's disease (Alzheimer's Association, 2008b). Table 1 is a summary of themes from the town hall meetings.

**Table 1. A Summary of Themes from the Voices of Alzheimer's Town Hall Meetings**

<b>Themes</b>
1. The stigma of Alzheimer's and its impact on relationships
2. Dissatisfying interactions with the medical community
3. Uncertainty about availability of support services
4. Sources of major concern in daily life
5. Desire to stay involved and make a difference

Even though the diagnostic label of dementia may elicit negative reactions toward PwD and PwD may be negatively influenced by their diagnosis, research also indicates positive emotions toward PwD. A study conducted by Werner and Davidson (2004) asked Israeli laypersons about their emotional reactions when reading vignettes describing individuals with dementia. They found the vignettes elicited more positive emotions (compassion and concern) than negative reactions (rejection, disgust, anger, irritation, and dismay) because the disease was associated with biological causes and uncontrollable onset. Another study conducted in the United States found similar results when participants were asked to respond to vignettes describing "your mother" or "your father" who displayed behaviors consistent with a diagnosis of dementia, major depression, or no label at all. Results showed that the Alzheimer's disease label produced more sympathy toward the parent, less blame, and a greater willingness to help (Wadley & Haley, 2001). These two studies suggest that dementia diagnostic labels may also foster positive attitudes and enhanced caregiving toward older adults with the condition.

Another study addressed the consequences of these positive and negative reactions and found prosocial feelings (including sympathy, the desire to help, concern, and compassion) to decrease the behavioral discrimination against PwD, while antisocial feelings (including rejection, ridicule and impatience) increased the discrimination (Werner, 2005).

### **Dementia Caregiving: Physical, Psychological and Fiscal Costs**

Dementia caregiving can be a physically and psychologically stressful life experience. The effects of caregiving are not limited to health status, but may also influence occupational, economic, and social activity status. A study conducted by the Alzheimer's Association and the National Alliance for Caregiving (2004) discussed the needs and experiences of caregivers of PwD, age 50 and older. The report revealed that 65% of dementia caregivers helped with one or more Activities of Daily Living (ADLs), and 23% of dementia caregivers provided 40 or more hours of care per week. Caregivers of PwD not only carried heavy burdens and spent a great amount of time in a given week; they provided care for a long period of time. Seventy one percent (71%) had cared for a PwD for more than a year, and 32% reported a caregiving commitment of five years or more. Due to this caregiving commitment, 66% of employed caregivers had missed work, while 57% of dementia caregivers worked full or part time. Not counting those who cared for a spouse, 49% of dementia caregivers provided financial assistance as well as unpaid care. These caregivers expended an average of \$218 per month on the care recipient.

### **Impact on the Caregiver's Physiological Function**

Two meta-analyses have found that family caregivers have poorer physical health than noncaregivers, measured both by perceived health (Pinquart & Sorensen, 2003) and



by objective health measures, such as stress hormones, antibodies, and medication use (Vitaliano et al., 2003).

Studies have demonstrated various health risks due to dementia caregiving. Caregivers of PwD are more likely to develop hypertension and hyperlipidemia (Grant et al., 2002; Shaw et al., 1999; Vitaliano, Russo, & Niaura, 1995), and are at a higher risk for developing cardiovascular disorders and diabetes compared to noncaregiving controls (Kiecolt-Glaser, Dura, Speicher, Trask, & Glaser, 1991; Kolanowski, Fick, Waller, & Shea, 2004; Lee, Coldtz, Berkman, & Kawachi, 2003; Schulz et al., 1995; Shaw et al., 2003; Vitaliano et al., 2002). Furthermore, in a four-year longitudinal study, caregivers had a 63% higher risk of mortality than their noncaregiving counterparts (Schulz & Beach, 1999).

Aging is associated with increased production of the circulating proinflammatory cytokine Interleukin-6 (IL-6), which often exacerbates in individuals under chronic stress, such as those who care for PwD. A cross sectional study has shown that family caregivers of PwD have higher IL-6 levels than elderly women undergoing housing relocation, and healthy age-matched controls (Lutgendorf et al., 1999). A subsequent study with 116 spousal caregivers also found that chronically stressed elders have higher serum IL-6 levels than less stressed individuals (von Kanel et al., 2006). Moreover, a 6-year longitudinal study observed that compared to individuals in the non-caregiving control group, the rate of increase in IL-6 production is, on average, four-fold higher in the family caregivers of PwD (Kiecolt-Glaser et al., 2003).

Research also suggests that caregivers of PwD have poorer responses to vaccines than their noncaregiving counterparts (Kiecolt-Glaser, Glaser, Gravenstein, Malarkey, &

Sheridan, 1996; Vedhara et al., 1999); indeed, caregivers' self-reported psychological distress has been associated with impaired responses to vaccines (Li et al., 2007). The chronic stress of dementia caregiving appears to influence both initial responses to vaccines and the long term maintenance of immune response among caregivers (Glaser, Sheridan, Malarkey, MacCallum, & Kiecolt-Glaser, 2000). Together these findings help explain why caregivers of PwD are more vulnerable to influenza and other infectious agents than their non-caregiving counterparts.

### **Depression as a Result of Dementia Caregiving**

In the past several decades, many studies on the psychological effects of dementia caregiving have been published with depression being viewed as one of the most common consequences. A meta-analysis found that the association between the physical health of caregivers and depression is stronger than associations with sociodemographic characteristics, stressors, and resources (Pinquart & Sorensen, 2007). A meta-analysis by these same researchers (2003) comprised of 84 studies found greater instances of depression occurred among caregivers compared to noncaregivers. Using different depression screening instruments, and with different sample sizes, the prevalence of depressive symptoms among caregivers ranged from 21% to 65 % (Molyneux et al., 2008; Papastavrou et al., 2007). Also, caregivers make more physician visits, take more prescribed pharmaceuticals (Donaldson & Burns, 1999); moreover, psychotropic drug use is higher among caregivers than noncaregivers (Schulz et al., 1995).

The physical and psychological demands of caring for PwD often result in psychiatric morbidity in the form of increased depression (Baumgarten et al., 1992; Mahoney et al., 2005; Schulz et al., 1995). A review conducted by Kiecolt-Glaser and

Glaser (2002) suggested that depression contributes to disease and death through immune dysregulation. The review showed that depression can directly and indirectly alter immune function. Depression can directly stimulate the production of proinflammatory cytokines that influence a spectrum of conditions associated with aging such as cardiovascular disease, osteoporosis, arthritis, type 2 diabetes, certain cancers, periodontal disease, frailty, and functional decline. Depression can also cause prolonged infection or delayed wound healing, processes which can promote sustained proinflammatory cytokine production.

In addition to the significant relationship between depression and morbidity and mortality, depressive symptoms among caregivers may continue following the PwD's admission to a nursing home, as revealed by longitudinal studies (Gaugler, Pot, & Zarit, 2007; Schulz et al., 2004). A review of 80 studies found that caregivers with greater emotional stress and experiences of feeling trapped in care responsibilities, along with other care recipient characteristics, were more likely to admit PwD to a nursing home (Gaugler, Yu, Krichbaum, & Wyman, 2009). Early detection and intervention with caregiver depression is essential due to its profound and prolonged effects on caregiver health and wellbeing.

### **Predictors of Caregiver Depression**

Caregiver depression is a complex process involving the interplay of medical, social and economic factors. A cluster of factors predicts the incidence and severity of caregiver depression, based on different characteristics of PwD and their caregivers as well as environmental conditions. Higher frequency of problem behaviors, greater functional impairment and less social support are associated with elevated depression

(Buhr et al., 2006; Clyburn et al., 2000; Cook et al., 1997; Hooker et al., 2002; Levesque et al., 1995; Molyneux et al., 2008). Female caregivers and caregivers who reside with the PwD are known to have higher levels of depression (Chumbler et al., 2003; Gallicchio et al., 2002).

A large cross sectional study analyzed various PwD and caregiver characteristics in relation to predicting depression in caregivers of patients with moderate to severe dementia (Covinsky et al., 2003). Independent patient predictors of caregiver depression included younger patient age and dementia severity in multiple dimensions of ADL function and behavioral symptoms. Caregiver predictors of depression included low levels of financial resources (income), relationship to the patient (daughter or wife), more hours spent caregiving, and poor caregiver functional status. As noted, numerous factors predict caregiver depression; however, many of these variables are not changeable. Perceived stigma, however, is amenable to change and is an understudied phenomenon.

### **Summary**

The literature reviewed indicates that depression is a well-documented consequence of caregiving for PwD and is associated with morbidity and mortality. The prevalence of depression is higher among caregivers of PwD compared to those who care for persons with other non-dementing diseases. The next section discusses perceived stigma experienced by caregivers of PwD and further describes the purpose of the study: to examine the relationship between stigma and depression experienced by caregivers of PwD, as many of the identified predictors of caregiver depression are not amenable to change.

### **Courtesy Stigma and Dementia**

In an attempt to understand the stigma related to mental illness, studies began by examining public attitudes and beliefs (Angermeyer & Matschinger, 2003; Wolff, Pathare, Craig, & Leff, 1996). Later studies explored subjective perspectives and experiences related to stigma among patients, relatives, or mental health practitioners, especially focusing on schizophrenia (Angermeyer, Schulze, & Dietrich, 2003; Dinos, Stevens, Serfaty, Weich, & King, 2004; Gonzalez-Torres, Oraa, Aristegui, Fernandez-Rivas, & Guimon, 2007; Schulze & Angermeyer, 2003; Wahl & Harman, 1989).

As mentioned above, there is ample research evidence revealing that families experience a great deal of stress as they struggle to cope with the unique challenges of caring for PwD. However, there has been little research on stigma as one aspect of the impact of this disease on families. Defined by Goffman (1963) as courtesy stigma, it is assumed that stigma and discrimination extend from PwD to their family caregivers (Benbow & Reynolds, 2000; Bond, Corner, Lilley, & Ellwood, 2002; Jolley & Benbow, 2000). This is because dementia is a degenerative brain disorder and currently there is no treatment to reverse the disease. Dementia often leads to problematic behaviors as the disease progresses such as forgetfulness, loss of words, emotional outbursts, including anger and aggression, and violation of social norms regarding appropriate conduct. Symptoms such as poor self-care or incontinence may be regarded as evidence of neglect (Graham et al., 2003). Furthermore, when individuals avoid social interactions with the PwD, their family caregivers may be inadvertently excluded from social events as well.

Little research has been conducted on courtesy stigma among family members of PwD. MacRae (1999) investigated the phenomena and found that both primary caregivers

and other family members caring for PwD experience stigma including shame, fear, and embarrassment. However, findings also reveal that a substantial number of family members do not appear to have experienced stigma and/or claimed not to have ever been embarrassed or ashamed. In addition, very few respondents noted a need to avoid going places or participate in situations where they feared they might be embarrassed (MacRae, 1999). Another study explored family caregivers' management of courtesy stigma in the course of their relationship with a PwD. Responses from in-depth interviews and from support group meetings of caregivers of PwD suggest that stigma management by the caregiver moves through two distinct phases: the first marked by collusion with the PwD, while, the second by realignment and collusion with an expanding circle of others. As caregivers move through these phases, there is a gradual shift of management priorities from control of information to control of problematic situations with concealment used to a great extent as a management technique (Blum, 1991).

In a more recent study, Liu and colleagues (2008) examined the relationship between stigma and dementia qualitatively among 32 Chinese and Vietnamese family caregivers. They found two sources of stigma experienced by caregivers of PwD: the stigma associated with the chronic and severe characteristics of mental illness such as schizophrenia, and the stigma reflecting negative stereotypes of aging or the aged in the Chinese and Vietnamese cultures. However, these findings are unique to the examined cultures. Courtesy stigma was also studied in Israel. Werner and Heinik (2008) interviewed 61 caregivers of PwD and examined courtesy stigma, using the conceptual definition by Angermeyer and colleagues (2003) developed for schizophrenia. Caregivers perceived a minimal amount of stigma but reported high levels of stigma regarding PwD.

They found high levels of structural discrimination, especially regarding the delivery of services, toward PwD and their caregivers. Later Werner and colleagues (2010) explored courtesy stigma reported by 10 children of PwD. Findings showed that courtesy stigma associated with dementia was experienced in three dimensions: caregiver's stigma (intrapersonal aspects of stigma), lay public's stigma (interpersonal aspects of stigma), and structural stigma (social aspects of stigma).

Given the above mentioned results from previous studies and the growing population of PwD and their caregivers, the Stigma Impact Scale (SIS) was developed and tested in order to assess perceived stigma from the perspectives of PwD and their caregivers (Burgener & Berger, 2008). This quantitative measure of perceived stigma, allows researchers to effectively assess levels of perceived stigma and to examine the effects of courtesy stigma on health and well-being outcomes. Together with qualitative studies of courtesy stigma from the perspectives of caregivers of PwD, we can identify the circumstances under which courtesy stigma is most likely to occur, avoid situations that might elicit courtesy stigma, and further develop appropriate interventions.

Both theory and empirical studies suggest depressive symptoms are a response to stigma (Link et al., 1987; Link, Struening, Rahav, Phelan, & Nuttbrock, 1997). Moreover, as reported earlier, research demonstrates that 43% of caregivers of people with mental illness report feeling stigmatized and that perceived stigma is associated with depressive symptoms (Perlick et al., 2007; Phelan et al., 1998; Struening et al., 2001). However, none of these studies focused on caregivers of PwD. Thus, this study makes a unique contribution by examining the effects of perceived stigma on fostering depressive

symptoms among caregivers of PwD. The next section describes the theoretical framework that grounded the study.

### **Theoretical Framework**

Several models of stigma describe the internalization of stereotypes as a key mechanism for how stigma may affect caregivers of PwD. One model emphasizes maintenance of the integrity of self-esteem via the cognitive construction of social identities in response to direct discrimination (Crocker, Major, & Steele, 1998). A second model indicates that stigmatized individuals appraise direct discrimination by considering collective representations of cultural stereotypes relevant to the self and situational cues that signal the risk of being devalued; this appraisal is further modified by personal traits of the individual. In order to decrease threat to the self, individuals may then respond to the direct discrimination via involuntary responses or through cognitive coping responses that decrease threat to the self (Major & O'Brien, 2005).

According to the Modified Labeling Theory (MLT) developed by Link and colleagues (Link et al., 1987; Link et al., 1989), stigma is not only an internal process but a process that inherently involves the negative responses of persons in the environment, defined as the “labeling” behaviors of others. In addition to cognitive coping strategies described in the first two models, Link and colleagues proposed that labeled individuals will respond behaviorally to anticipate social rejection. Harmful effects may arise from internalized conceptions of anticipated stigma or from the stigma coping response enacted. Labeling thus may negatively affect one’s psychological state.

Variables relevant to PwD include personal and environmental factors such as: demographic information (gender, living situation), disease stage, mental ability, setting



(e.g. urban or rural), ethnic background, and caregiver knowledge of Alzheimer's disease. These factors may lead to stigmatizing responses of others and perceived stigma in caregivers of PwD (Burgener & Buckwalter, 2008). These factors were examined in this study in order to determine if they impacted the relationship between perceived stigma and depressive symptoms among caregivers of PwD (Figure 1).

The MLT served as the organizing framework for this study. Based on this theory, the mechanisms of perceived stigma were conceptualized by Fife and Wright (2000) to include four dimensions: social rejection (e.g., friends, family, colleagues abandoning PwD), financial insecurity (e.g., feeling stressed financially), internalized shame (e.g., feelings of embarrassment about PwD's diagnosis), and social isolation (e.g., limiting social contact due to abandonment, fear of PwD's cognitive deficits being obvious) (Figure 1). Support for these four dimensions of perceived stigma was found through testing of the relationships of stigma and a variety of demographic variables on persons with HIV/AIDS, cancer, Alzheimer's dementia, and Parkinson's disease (Burgener & Berger, 2008; Fife & Wright, 2000). Thus, this study examined how these dimensions might mediate the effects of dementia caregiving.

Studies on the relationship between social rejection, internalized shame, social isolation and depressive symptoms provided evidence of the association between perceived stigma and depressive symptoms among caregivers of PwD. Based on the definition of Link and colleagues (1989), social rejection was significantly associated with depressive symptoms among persons with mental illnesses (Link et al., 1997).

Shame consists of both internal and external experiences, even though the distinction is not always made by researchers (Gilbert, 1998). Internal shame refers to

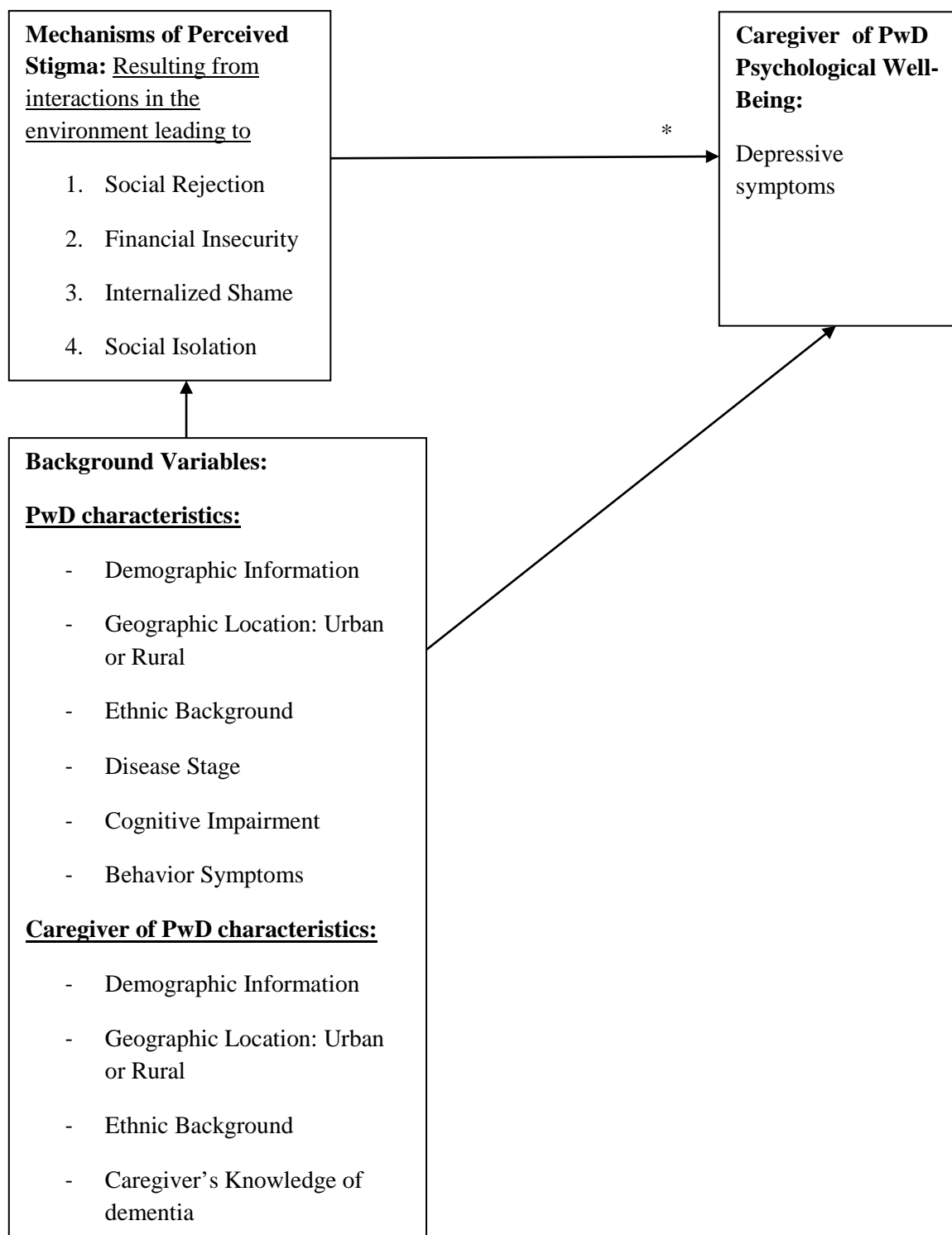
one's negative views and feelings of one's personal attributes, characteristics, or behaviors (Cook, 1996; Kaufman, 1989). External shame, which has also been called stigma consciousness and awareness (Pinel, 1999), refers to how one thinks others think of oneself. Consequently, a combination of internal and external shame results in feeling inadequate, flawed, and inferior (Gilbert, 1998). Similar to internalized shame conceptualized in the MLT, shame was linked to depression in caregivers of PwD (Gilbert, 2000; Martin, Gilbert, Mcewan, & Irons, 2006).

Caregivers often lack social contact and support due to the great amount of time they spend caring for the PwD. Thus they often experience feelings of social isolation (Brodaty & Hadzi-Pavlovic, 1990; Logiudice et al., 1999). Waite and colleagues (2004) found a significant relationship between lack of social support and depression among caregivers of PwD. Additionally, social support was found to mediate the effect of stress on caregivers' psychological health such as depression (Drentea, Clay, Roth, & Mittelman, 2006; Goode, Haley, Roth, & Ford, 1998; Haley et al., 1996; Musil & Ahmad, 2002; Navaie-Waliser et al., 2002; Pinquart & Sorensen, 2006). Collectively, financial insecurity, social rejection, internalized shame, and social isolation are conceptualized as perceived stigma in this study. It is logical to assume a relationship between perceived stigma and depressive symptoms among caregivers of PwD and that perceived stigma might mediate the effects of dementia caregiving on caregiver depressive symptoms.

## **Summary**

A review of the literature revealed that stigmatization associated with dementia may affect not only the daily living and quality of life of PwD, but also their caregivers. Depression is a well-documented consequence of caregiving for PwD; however, many of the identified predictors of caregiver depression are not amenable to change. The relationship between stigma and depressive symptoms among caregivers of PwD has not yet been explored, and there is a need to replicate studies of courtesy stigma from the perspective of caregivers of PwD. Thus, this study examined the effects of perceived stigma on fostering depressive symptoms among caregivers of PwD as well as caregivers' perceptions of stigma. Chapter three describes the proposed research methodology used to provide answers to the specific aims research questions and hypotheses.

**Figure 1. Conceptual Model of the Relationship between Perceived Stigma and Depressive Symptoms of Caregivers of PwD**




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\*Primary interest of study

## **CHAPTER 3**

### **METHODOLOGY**

This chapter sets forth the methodology of the study, including the study design; participant inclusion criteria and recruitment strategies; measures utilized within the study and study procedures; and finally the statistical analysis.

#### **Study Design**

To more fully understand the stigmatizing effects of being caregivers of PwD on psychological well-being and caregivers' perceptions of stigma and their mood change, as well as to answer the research questions and hypotheses posed, a mixed methods approach was selected. This included a descriptive longitudinal design along with a qualitative interview. The study was carried out as part of a major multi-site study, Understanding Perceived Stigma in Persons with Dementia. The parent study used the same mixed method descriptive and longitudinal study design. Data collection was carried out at baseline (within one year of diagnosis), 6, 12, and 18 months.

More specifically, the mixed method approach used an embedded correlational design based on the research questions. Quantitative and qualitative data were collected concurrently with the two sets of data of unequal weight. Concurrent timing refers to the temporal relationship between the quantitative and qualitative components within the study and technically the two sets of data were collected, analyzed, and interpreted at the same time. The study mixed the two sets of data at the design level, with the qualitative data embedded within the quantitative data. Therefore, qualitative data played a supplemental role within the overall quantitative design. This weighting was mainly determined by the research questions and the use of data collection methods. For the

study, the qualitative data played a secondary and supportive role by exploring caregivers' perceptions of stigma and their mood change since the diagnoses of their family members.

### **Participants**

The study capitalized on data collection from the parent study but was not a secondary analysis. The principle investigator was Sandy Burgener, Ph.D., APRN-BC, FAAN and the primary investigator at the Iowa site was Kathleen Buckwalter, Ph.D., FAAN. This researcher collected all data on caregivers of PwD at the Iowa site together with Rebecca Riley, a doctoral student from College of Education, who collected all data on PwD at the Iowa site. Participant inclusion criteria and recruitment procedures were the same as in the parent study and were adapted to increase participant numbers.

Inclusion criteria for PwD were as follows:

1. A confirmed Alzheimer's disease and related disorders (ADRD) diagnosis within the last 12 months using standard diagnostic criteria. Persons with diagnoses of Alzheimer's disease (AD), vascular dementia, mixed types of dementias (AD and vascular), and frontotemporal dementia were included, while those with Lewy body dementia were excluded from this study.
2. PwD must have a Mini Mental Status Exam (MMSE) score of greater than 15 in order to participate.
3. PwD must live in the community or in an assisted living facility. PwD living in nursing homes were excluded from this study.

Inclusion criteria for primary family caregivers of PwD included:

1. Caregivers must be a non-paid family caregiver
2. Caregivers must have at least 3 contacts weekly with the PwD

### 3. Caregivers must be at least 21 years old

This study, like the parent study, was anticipated to enroll 80 persons with dementia and 80 of their family caregivers. Three sites were used to enhance ethnic and geographic diversity (rural/urban) of the sample: Illinois, Iowa, and North Carolina. The sample size of 80 was calculated with an estimated standardized effect size 0.33 ( $R^2=0.25$ ) with the consideration of 30% attrition rate over 18 months. Subjects at all three sites were selected from Institutional Review Board (IRB) approved diagnostic centers, community centers, the Veterans Affairs system, and assisted living facilities. At the Iowa site, participants were recruited through the Memory Disorders Clinic in the Department of Neurology and the Geriatric Assessment Clinic at the University of Iowa Hospitals and Clinics (UIHC). Potential participants self referred to the study based on information provided by the staff from the UIHC clinics, and study brochures placed in the clinics. In addition to the UIHC clinics, participants were also recruited through the Seniors Together in Aging Research (STAR) Registry developed by the University of Iowa Center on Aging. The STAR registry is a database of people age 50 and over who wish to volunteer for research studies and live within a two-hour driving radius of Iowa City. Brochures were sent to eligible participants listed in the registry. Additionally, brochures were placed in diagnostic centers, community settings, doctor's offices, and agencies (e.g. Alzheimer's Associations, assisted living communities, visiting nurses, parish nurses, senior centers, Veteran's Affairs hospitals) in south east and central Iowa where potential participants might visit. Lastly, the primary investigator in Iowa, Dr. Buckwalter, made several presentations on dementia and other related illnesses and discussed the study at assisted living facilities, senior centers, and area Alzheimer's

Associations throughout Iowa. Despite strenuous efforts to recruit participants, a total of 47 PwD and 51 family caregivers of PwD were recruited. The unmatched numbers of PwD and their family caregivers were due to recruitment difficulties, time constraints, and length of funding period. Consequently, in seven of the cases, instead of enrolling a dyad of PwD and their family caregivers, either the PwD or the family caregiver of a PwD was recruited alone, if one of them was willing to participate.

### **Measures**

Study variables and operational measures in order to answer the research questions and hypotheses are summarized in Table 2 (see Appendix A for all study measures). Instruments included the Mini-Mental State Examination (MMSE) (Folstein, Folstein, & McHugh, 1975), Clinical Dementia Rating Scale (CDR) (Hughes, Berg, Danziger, Coben, & Martin, 1982), The Knowledge of Alzheimer's Test Family Version (FKAT) (Maas, 1990), Revised Memory and Behavior Problems Checklist (RMBPC) (Teri et al., 1992), Stigma Impact Scale (SIS) (Burgener & Berger, 2008), and the Center for Epidemiologic Studies Depression Scale (CES-D) (Radloff, 1977).



**Table 2. Study Variables with Operational Measures**

<b>Variables</b>	<b>Measure</b>	<b>Completed by/ Time</b>
Demographic information	Demographic data sheet	Trained researcher/ baseline and as needed
Cognitive ability	The Mini-Mental State Examination (MMSE)	Trained researcher/ baseline, 6 months, 12 months, 18 months
Stage of disease	Clinical Dementia Rating Scale (CDR)	Trained researcher/ baseline, 6 months, 12 months, 18 months
Caregivers' knowledge of dementia	The Knowledge of Alzheimer's Test Family Version (FKAT)	Trained researcher/ baseline, 12 months
Behavior symptoms	Revised Memory and Behavior Problems Checklist (RMBPC)	Trained researcher/ baseline, 6 months, 12 months, 18 months
Perceived stigma	Stigma Impact Scale (SIS)	Trained researcher/ baseline, 6 months, 12 months, 18 months
Depression	Center for Epidemiologic Studies Depression Scale (CES-D)	Trained researcher/ baseline, 6 months, 12 months, 18 months
Personal response to stigma	Qualitative interview	Trained researcher/ 12months

Participant characteristics were assessed using a demographic data sheet that included: age, gender, education, occupation, relationship to the person with dementia, living arrangement, medical diagnoses for both the caregiver and the PwD, medications the person with dementia was receiving, socio-economic status, and ethnic origin.

Participants recruited from Iowa were solely Caucasian/White, while participants recruited from Illinois and North Carolina were mainly African American/Black and Caucasian/White, respectively. The definition of rural and urban varies across agencies in federal government and an appropriate taxonomy selection is critical for health policy and research (Hart, Larson, & Lishner, 2005). For the purpose of this study, the definition from the Census Bureau was applied. According to American FactFinder, a source of population, housing, economic and geographic data provided by the Census Bureau, the percentage of urban and rural settings (in parentheses) for Iowa, Illinois, and North Carolina are as follows: 61.1% (38.9%); 87.8% (12.2%); and 60.2% (39.8%). Due to a similar demographic distribution between Iowa and North Carolina, these states were considered to have a significant percentage of the sample as rural, while Illinois was considered predominantly urban.

The Mini-Mental State Examination (MMSE) was used to assess cognitive ability. It includes items on orientation, registration, memory, attention, and concentration. The score is the sum of correct responses and ranges from 0 to 30. Scores below 24 indicate global cognitive impairment and below this, scores can indicate severe ( $\leq 9$  points), moderate (10-20 points) or mild cognitive impairment (21-24 points). As noted earlier, subjects must score  $\geq 15$  to be included in this study and the mean score of MMSE for study participants was 20.3. Thus on average, study participants were mildly cognitively impaired and were able to respond to study instruments. The MMSE has a test-retest reliability of .83 and convergent validity demonstrated by positive correlations on the verbal ( $r = .78$ ) and performance ( $r = .66$ ) sections of the Wechsler Adult Intelligence Scale (Folstein et al., 1975).

The Clinical Dementia Rating Scale (CDR) measures participants' stage of disease and assesses six categories including memory, orientation, judgment and problem solving, community affairs, home and hobbies, and personal care (Hughes et al., 1982). The CDR has good inter-rater reliability and accurately measures the six categories noted above (Hughes et al., 1982). The CDR has a 0 through 3 scoring system and each of the six categories is scored based on the following scale: 0 = Healthy; 0.5 = Questionable Dementia; 1 = Mild Dementia; 2 = Moderate Dementia; and 3 = Severe Dementia. The rater scores participants in each of the six categories and an overall score is determined.

The Knowledge of Alzheimer's Test Family Version (FKAT) was used to assess caregivers' knowledge of Alzheimer's disease, including caregivers' understanding of dementia and its management, and has been widely used in previous research (Mass, 1990). The scale consists of 22 items that are rated as either true or false. The score is the sum of correct responses and ranges from 0 to 22 with higher scores indicating better caregiver knowledge of dementia. Content validity was established from a review of the literature and by a panel of gerontological nurses expert in the care of AD patients (Maas, 1990). Internal consistency (Cronbach's alpha) is .49 for the scale.

The Revised Memory and Behavior Problems Checklist (RMBPC) was used to measure behavioral symptoms found more commonly in the early disease stages such as anxious or sad mood, feelings of failure, repeated questions, losing objects, and reduced concentration (Teri et al., 1992). There are three subscales in the RMBPC that are memory-related, depression, and disruptive behaviors. In addition to the frequency of the behavior problem (RMBPCF), the caregivers' reaction to the behavior is recorded on a separate scale (RMBPCR). The scale consists of 24 items that are rated on a 0-4-point

Likert-type scale. There are two sets of scores ranging from 0 to 96 with higher scores representing more frequent or more types of behavior problems and how bothered or upset the caregivers' were when the behavioral problems occurred. Internal consistency (Cronbach's alpha) is .83 for the scale for behaviors of PwD and .88 for the scale assessing caregivers' reaction to the behaviors. Subscale alphas range from .75 to .86. Validity is supported through comparing scores on the RMBPC with MMSE and a memory-related problems subscale ( $r = -.48$ ) and diagnosis of major depression and depression subscale ( $r = .36$ ) (Teri et al., 1992).

The Stigma Impact Scale (SIS) was used to measure perceived stigma. It comprises four subscales: social rejection (9 items), financial insecurity (3 items), internalized shame (5 items), and social isolation (7 items). The instrument consists of 24 items in total with scores that are rated on a 0-4-point Likert-type scale. Scores range from 0 to 96 with higher scores indicating higher perceived stigma (Burgener & Berger, 2008). Internal consistency (Cronbach's alpha) is .92 for the scale and subscale alphas range from .69 to .85.

The Center for Epidemiologic Studies Depression Scale (CES-D) was used to measure caregiver depression. The CES-D consists of 20 items with scores that are rated on a 0-3-point Likert-type scale (Radloff, 1977). Scores were summed, with higher scores indicating greater depression and a score of 16 or higher indicative of depressive symptoms. Internal consistency (Cronbach's alpha) is .84 for the scale

In order to capture the caregivers' perceptions of stigma and their mood change since the diagnoses of their family members, a qualitative approach with a set of semi-structured interview questions, developed from the Modified Labeling Theory, was used.

Interview questions related to financial situations were not included in the study due to consideration of the sensitivities of financial issues and study length. We didn't want to burden the caregivers of PwD or elicit fatigue. Questions included the following: (1) Please describe how you feel about talking about your family member's diagnosis with friends or acquaintances. (2) Have you disclosed your family member's diagnosis to friends or acquaintances? (3) What about your family member's diagnosis are you uncomfortable discussing or disclosing? (4) Which groups or acquaintances are you most comfortable interacting with at present? (5) What changes have you made in your social networks? (6) If you are not participating socially, what are the major reasons for not taking part in activities? (7) What are you actively doing to manage or deal with any restrictions in your social participation? (8) Do family members treat you differently since the diagnosis of your family member? If yes, in what ways? (9) Have friends or acquaintances treated you differently since your family member's diagnosis? If yes, in what ways? (10) Have you experienced any negative interactions or responses from others due to your family member's diagnosis? (11) Please describe how your mood has been affected since your family member has been diagnosed with a memory loss.

### **Procedures**

This study, like the parent study, was longitudinal in nature and data were collected over a period of 18 months at six month intervals: baseline (Time 1: T1), 6 months (Time 2: T2), 1 year (Time 3: T3), 18 months (Time 4: T4). As noted, it was a multi-site study with data collected in Illinois, Iowa, and North Carolina. The different sites assisted in gathering data from participants from both rural and urban and various ethnic backgrounds making the sample more diverse and the results more generalizable.

As for the qualitative interview, data were collected at T3 and only at the Iowa site, due to the location of the researcher.

### **Recruitment**

Participants recruited from the IRB approved diagnostic centers, community centers, the Veterans Affairs system, and assisted living facilities were given a description of the study and asked about their willingness to participate in the study when they contacted the research team. A phone log of recruitments was utilized to ensure that study criteria were met. When concern about an ADRD diagnosis arose, participants were asked to obtain further diagnostic information from their provider. Participants' statuses were reexamined at each six month visit. If any changes in diagnosis or cognitive ability had occurred, such as an altered MMSE score, further information was obtained to determine if study criteria were still met.

### **Informed Consent**

Once confirmed that participants met study criteria and were willing to participate, a data collection interview was scheduled. Data collection meetings took approximately 100 to 120 minutes to complete including the consent process. The consent process took about 30 minutes to complete and the process allowed the PwD (see Appendix B for informed consent document: Person with dementia) and their caregivers (see Appendix C for informed consent document: Family caregiver) to read through the consent form and to ask questions regarding the research study. When they agreed to participate, the PwD and family caregivers signed the informed consent document in the presence of the research staff. For usable data, both PwD and their caregivers were ideally needed to consent because it took the dyad to complete the study. In some cases

(n=7), only the PwD (n=3) or the family caregiver (n=4) was recruited due to recruitment difficulties, time constraints, and length of funding period. In this situation, consent was completed by the person who was recruited.

Since capacity to consent could be an issue with PwD, an additional form, Evaluation to Sign an Informed Consent (see Appendix D), was administered which included a set of questions that examined PwD's understanding of the consent document. This document requires the researcher to verbally ask PwD to explain the risks of the study, what they would do if they no longer wanted to participate, and what they would do if they felt distress or discomfort during the study. If PwD appeared unable to provide adequate responses to the questions, it was the researcher's responsibility to inform the PwD that they would be unable to participate in the study. Due to the typically slow progression of ADRD in the early stages and early stage dementia symptomatology (e.g. mild impairment in memory and verbal expression) (Brechling & Schneider, 1993), participants were able to understand the study and consent form and remained able to provide informed consent throughout the study period.

All research team members across sites were trained by the PI and co-investigator, with the following special emphasis in regard to the consent process: (1) assuring that prospective subjects understand the research purpose, procedures, and requirements; and (2) understand the risks and benefits of the study. The only anticipated risks were tiring and the risk of discomfort; however, if fatigue and discomfort did occur, the researcher stopped the interview and re-scheduled at another time; (3) participants' autonomy; (4) avoidance of any undue pressure for enrollment; and (5) the subject's right to withdraw from the study at any time (Burns & Grove, 2005).

## **Data Collection**

After the consent form was completed, the PwD completed the Mini-Mental State Exam (MMSE), and Clinical Dementia Rating Scale (CDR), while their caregivers completed the Demographic Data Form, The Knowledge of Alzheimer's Test Family Version (FKAT), Revised Memory and Behavior Problems Checklist (RMBPC), Stigma Impact Scale (SIS), Center for Epidemiologic Studies Depression Scale (CES-D) and the qualitative interview. For purposes of this study, an interview using the above mentioned instruments and interview questions with the caregiver followed in order to address all areas of the theoretical model. Additional instruments were used to collect other information for the parent study that was not addressed in this study. The interview was conducted by researchers trained by the PI and co-investigator in order to ensure the objectivity, reliability and validity of the information.

For the qualitative interview, in addition to the nine questions posed, the researcher kept field notes and tape recorded the entire interview. Field notes were to describe the environment and any other incidents during the interview, while the tape recording was to ensure the integrity of the interview process.

During data collection, each participant was assigned a number in order to ensure confidentiality. A master code list with participant names and corresponding numbers was stored separately from data so the researcher was able to contact participants every six months to schedule the next visit. Client files were kept at the College of Nursing in a locked file cabinet inside a locked office and were accessible only to research staff. Data files were stored on the College of Nursing server, which was password protected and met the guidelines of the Iowa Human Subjects office.



## **Biases**

In order to maintain rigor in the mixed methods study, which included a descriptive longitudinal design and a qualitative interview, we attempted to minimize bias from both the quantitative and qualitative approaches.

Types of bias that can occur in the quantitative aspect include selection bias and measurement bias. Selection bias can reduce the external validity of the study; however, it was hard to avoid selection bias in the study, because participants were self-selected into the study. Detailed sampling procedures and adherence to inclusion and exclusion criteria were followed closely, so that the characteristics of the study sample would be described precisely and the generalizability of the results can be more accurately determined (Peat, Mellis, Williams, & Xuan, 2002). All of the measurements employed within the study were psychometrically sound, which is a critical aspect of avoiding measurement bias. In addition to the soundness of all instruments used, all researchers were trained by the PI or co-investigator to ensure consistent and appropriate data collection across data collection sites. Training included PI or co-investigator observation of all researchers in an assessment with a volunteer PwD and their caregivers, and booster training sessions when necessary. Percentage of agreement was calculated for all instruments in order to obtain inter-rater reliability. Inter-rater reliability scores were obtained in the middle of the study based on three different visits with different combinations of Iowa research team members: one visit for PwD only, one for family caregiver only, and another one for both PwD and family caregiver interview. Inter-rater reliability scores ranged from 97% to 100%. The percentages were calculated based on items of agreement and then between two different visits. For the most part, the

disagreements were only one point off because sometimes the tone of voice of the PwD was used to subjectively judge the scores.

Sandelowski's (1986) evaluation criteria were applied to assure rigor within the qualitative aspect of the study. In order to achieve auditability, a scrutinizing trail of decision making, data collection, data management, and analysis processes were comprehensively reported. This consisted of how evidence was included and approached, the methods used to collect data, depiction of the environment including the location and the length of the interview, and justification for data analysis. Sandelowski (1986) also suggests triangulation across data sources and data collection procedures to determine congruence of findings. In this study, interview data were triangulated with the scores from the four subscales of the Stigma Impact Scale. Lastly, the researcher kept a personal document about her thoughts and biases on perceived stigma of caregivers of PwD to ensure truth value and applicability as the last criteria suggested by Sandelowski (1986). Initial coding of the qualitative data was completed by this researcher, even though the codes were reviewed and agreement was obtained with one of the committee members, no inter-rater reliability was established in the qualitative codes.

### **Data Analysis**

This section provides a description of how the quantitative and qualitative data were managed separately. Table 3 summarizes the basic methodology of the research study by research questions.

Research question #1: What is the relationship between perceived stigma and depressive symptoms among caregivers of PwD in the early stages of the disease?

A Pearson product-moment correlation was conducted to determine if there is a significant relationship between perceived stigma and depressive scores at baseline.

Research question #2: Does the relationship between perceived stigma and depressive symptoms among caregivers of PwD in the early stages of the disease change over 18 months? Also, are depressive symptoms affected by perceived stigma as well as personal (disease stage, cognitive impairment, caregivers' knowledge of dementia, behavior symptoms, demographic information), environmental (different geographic location: rural and urban) and ethnic background variables?

A linear mixed model (LMM) was used to develop an appropriate model to examine the relationship between perceived stigma and depressive symptoms among caregivers of PwD over an 18-month period after adjusting for personal, environmental, and ethnic background covariates. The linear mixed model framework allows for: (1) all collected participant data to be included, even if participants have incomplete data across time points; (2) both time-varying and time-invariant covariates to be included in the model; and (3) trajectories of sample average and individual variability change over time to be captured (Hedeker & Gibbons, 2006). In this study, time-invariant covariates included demographic information, environmental and ethnic background variables which did not change over the 18 month study period. On the other hand, all other variables were time-varying covariates. The analysis has more statistical power than analysis of variance methods for longitudinal data analysis and is more representative of the participant population when all collected data are used. Initially, after first considering possible covariance structures to model the variances at each measurement, a first-order autoregressive (AR (1)) structure was chosen based on the Akaike (AIC)

measure. Covariates were included in the model based on significance. The final model included the following covariates: RMBPCR scores, and caregiver ethnicity/race.

Research question #3: Does perceived stigma among caregivers of PwD mediate the effect of dementia caregiving (including personal, environmental and ethnic background variables) on caregiver depressive symptoms?

A LMM was used to test whether perceived stigma among caregivers of PwD mediated the effect of dementia caregiving on caregiver depressive symptoms. To test for mediation, there needs to be a direct effect between the background variables of interest and the depressive symptoms (outcome variable). Then, perceived stigma, the indirect effect, was added to the model to examine its mediation effect on the relationship between the potential background variable(s) and depressive symptoms. Last, a percentage of change in the coefficient was calculated to determine the degree of mediation effect.

Research question #4: What are caregivers' perceptions of stigma and how did their mood change since the diagnoses of their family members?

For the qualitative data, interviews collected at 12 months (T3) from Iowa were transcribed verbatim. A latent content analysis using a directed approach was performed to capture the manifestation of caregiver perceived stigma. The goal of this approach was to validate and/or extend a theoretical framework or theory (Hsieh & Shannon, 2005). In this study, the dimensions of perceived stigma conceptualized by Fife and Wright (2000), based on the Modified Labeling Theory (MLT), were used to guide the researcher's initial coding and to determine the operational definitions. Initial coding was completed

by this researcher. The codes were reviewed and agreement was obtained with one of the committee members, who is an expert in qualitative research.

Analytic strategies for a directed approach to content analysis suggested by (Hsieh & Shannon, 2005) included the following: (1) Reading the transcript and highlighting all text to represent caregivers' perceptions of stigma. (2) Coding all highlighted text using the predetermined codes. (3) Creating new codes for those texts that could not be categorized with the initial coding process. Percentage and frequency were calculated to determine the percentage of agreement among all caregivers. For the purpose of the study, percentage was defined as the number of caregivers among all nine caregivers who mentioned the specific code, while frequency was defined as the number of times mentioned within the specific code.

**Table 3. Analysis Methodology by Research Questions**

<b>Research Questions</b>	<b>How Measured</b>	<b>Analysis Methodology</b>
<p><u>Research question #1:</u></p> <p>What is the relationship between perceived stigma and depressive symptoms among caregivers of PwD in the early stages of the disease?</p>	<p>Perceived Stigma (Stigma Impact Scale)</p> <p>Depressive Symptoms (Center for Epidemiologic Studies Depression Scale)</p>	<p>Pearson product-moment correlation</p>
<p><u>Research question #2:</u></p> <p>Does the relationship between perceived stigma and depressive symptoms among caregivers of PwD in the early stages of the disease change over 18 months? Also, are depressive symptoms affected by perceived stigma as well as personal (disease stage, cognitive impairment, caregivers' knowledge of dementia, behavior symptoms, demographic information), environmental (different geographic location: Illinois, Iowa, North Carolina) and ethnic background variables?</p>	<p>Perceived Stigma (Stigma Impact Scale)</p> <p>Depressive Symptoms (Center for Epidemiologic Studies Depression Scale)</p> <p>Demographic Information (Demographic Data Sheet)</p> <p>Cognitive Ability (Mini-Mental State Examination)</p> <p>Behavior Symptoms (Revised Memory and Behavior Problems Checklist)</p>	<p>Linear mixed model analysis</p>

**Table 3 continued**

<u>Research question #3:</u>	Perceived Stigma (Stigma Impact Scale)	Linear mixed model analysis
Does perceived stigma among caregivers of PwD mediate the effect of dementia caregiving (including personal, environmental and ethnic background variables) on caregiver depressive symptoms?	Depressive Symptoms (Center for Epidemiologic Studies Depression Scale)  Demographic Information (Demographic Data Sheet)  Cognitive Ability (Mini-Mental State Examination)  Behavior Symptoms (Revised Memory and Behavior Problems Checklist)	
<u>Research question #4:</u>	Qualitative Interview	Directed approach to content analysis
What are caregivers' perceptions of stigma and how did their mood change since the diagnoses of their family members?		

## CHAPTER IV

### RESULTS

This chapter presents the characteristics of the study participants and results of the study by research questions and hypotheses. All data were collected and analyzed with the computerized statistical program, SAS version 9.2.

#### **Characteristics of the Study Participants**

Data are presented for the sample collected as of April 8, 2011 on PwD and their family caregivers. Frequencies/percentages for categorical demographic variables and means/standard deviations for continuous variables are given in Table 4. A total of 47 PwD and 51 family caregivers were included in the analysis. As seen in Table 4, the study sample had an almost equal distribution between geographic location and PwD gender; however, most caregivers of PwD were female (74%). Just over half of PwD and their caregivers were married (53.19%). Despite similar recruitment efforts across geographic locations, the study sample had more Caucasians/White individuals than African American/Black individuals. Most of the participant dyads were of the same ethnicity/race, but one dyad was of different ethnicity/race. Mean years of education ( $p = 0.01$ ) and age ( $p < 0.000$ ) were both significantly different between PwD and caregivers. Lastly, the mean length of time with a diagnosis of dementia was 12.6 months for PwD (SD = 11.67).



**Table 4. Characteristics of the Study Participants**

<b>Variables</b>	<b>Person with Dementia (PwD) n=47 Frequency (%) or Mean (SD)</b>	<b>Caregiver of PwD n=51 Frequency (%) or Mean (SD)</b>
<b>Geographic Location</b>		
Rural	26 (50.98%)	
Urban	25 (49.02%)	
<b>Gender</b>		
Female	26 (55.32%)	37 (74.00%)
Male	21 (44.68%)	13 (26.00%)
<b>Marital Status*</b>		
Married	25 (53.19%)	
Other	1 (2.13%)	
Single (divorced)	3 (6.38%)	
Single (never married)	3 (6.38%)	
Widowed	15 (31.91%)	
<b>Ethnicity/Race</b>		
African American/Black	19 (40.43%)	18 (35.29%)
Caucasian/White	28 (59.57%)	33 (64.71%)
<b>Age (year)</b>	78.04 (SD = 8.45)	64.31 (SD = 12.55)
<b>Education (year)</b>	13.16 (SD = 4.01)	14.92 (SD = 2.55)

**Table 4 continued**

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<b>Length of AD (month)</b>	12.6 (SD = 11.67)
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\* Marital status between PwD and their caregivers

## Results Presented by Research Questions

Research question #1: What is the relationship between perceived stigma and depressive symptoms among caregivers of PwD in the early stages of the disease?

A Pearson product-moment correlation was conducted to determine the relationship between perceived stigma and depressive scores at baseline. As hypothesized, caregivers' perceptions of stigma were, at baseline, moderately positively associated with depressive symptoms ( $r = 0.357, p = 0.0175$ ).

Research question #2: Does the relationship between perceived stigma and depressive symptoms among caregivers of PwD in the early stages of the disease change over 18 months? Also, are depressive symptoms affected by perceived stigma as well as personal (disease stage, cognitive impairment, caregivers' knowledge of dementia, behavior symptoms, demographic information), environmental (different geographic location: rural and urban) and ethnic background variables?

A linear mixed model (LMM) was used to develop an appropriate model to examine the relationship between perceived stigma and depressive symptoms among caregivers of PwD over an 18-month period after adjusting for personal, environmental, and ethnic background covariates. The bivariate relationship between perceived stigma and depressive symptoms over time was significant ( $p = 0.0045$ ). Other background variables were added when significantly related to depression at baseline, in an attempt to determine the final model. The final model included the following covariates as seen in Table 5: Revised Memory and Behavior Problems Checklist scores (RMBPCR) and caregiver ethnicity/race. Caregivers' perceptions of stigma were significantly associated with depressive symptoms after adjusting for the other covariates in the model ( $p =$

0.0019); caregivers became increasingly depressed when they perceived more stigma. However, contradictory to the hypothesis, caregivers' depressive symptoms did not change significantly over time ( $p = 0.1379$ ). Among the covariates included in the model and consistent with the hypothesis, scores on the RMBPCR were positively associated with depressive symptoms ( $p = 0.0116$ ). As caregivers' reaction in response to PwD's memory and behavior problems increased, caregivers' level of depression also increased, given that all other covariates remained the same.

Research question #3: Does perceived stigma among caregivers of PwD mediate the effect of dementia caregiving (including personal, environmental and ethnic background variables) on caregiver depressive symptoms?

A LMM was used to assess whether perceived stigma among caregivers of PwD would mediate the effect of dementia caregiving on caregiver depressive symptoms. Each of the personal (disease stage, cognitive impairment, caregivers' knowledge of dementia, behavior symptoms, demographic information), environmental (different geographic location: rural and urban) and ethnic background variables were examined univariately and multivariately for their effect on depressive symptoms. Scores on the RMBPCR was the only variable (predictor variable) in this study to be significantly ( $p = 0.0039$ ) associated with depressive symptoms (outcome variable) of caregivers of PwD. Scores on the RMBPCR (predictor variable) was also significantly associated with caregivers' perceived stigma (mediator variable) ( $p = 0.002$ ). Together with the significant relationship between caregivers' perceived stigma (predictor variable) and their depressive symptoms (outcome variable) ( $p = 0.0045$ ), caregivers' perceived stigma was verified to mediate the relationship between scores on the RMBPCR and depressive

symptoms among caregivers of PwD. Therefore, perceived stigma was added to the LMM model to examine the degree of its mediation effect. As hypothesized, perceived stigma minimally mediated the effect between RMBPCR and depressive symptoms (14.4% decrease in the coefficient) (see Table 6). Such a reduction in coefficient indicated the positive effect of caregivers' reaction in response to PwD's memory and behavior problems on depressive symptoms may have been slightly mediated through perceived stigma. Those caregivers feeling more bothered or upset by the PwD's memory and behavioral problems had more perceived stigma, which in turn was associated with more depressive symptoms.

**Table 5. Result of Linear Mixed Model on the Relationship between Perceived Stigma and Depressive Symptoms as well as Included Covariates**

<b>Variable</b>	<b>Estimate</b>	<b>Standard Error</b>	<b>Confidence Interval</b>	<b><i>p</i>-value</b>
<b>Time*</b>				0.1379
1	-0.85	1.48	(-3.78, 2.08)	0.5659
2	-0.30	1.34	(-2.95, 2.35)	0.8249
3	-1.98	1.09	(-4.15, 0.18)	0.0724
<b>SIS</b>	0.15	0.05	(0.06, 0.24)	0.0019**
<b>RMBPCR</b>	0.11	0.04	(0.03, 0.20)	0.0116**
<b>Caregiver Ethnicity/Race*</b>				
African American/Black	-2.28	1.87	(-6.06, 1.50)	0.2302

Notes: SIS: Stigma Impact Scale; RMBPCR: Revised Memory and Behavior Problems Checklist Ratings.

\* Reference categories are 4 for Time, Caucasian/White for Ethnicity

\*\*  $p < 0.05$

**Table 6. Result of Linear Mixed Model of Caregiver Depressive Symptoms and Evaluation of Potential Mediating Effect of Perceived Stigma**

Variables	Depression Without Mediation Effect	Depression With Mediation Effect	
	Estimate	Estimate	Percent Change
RMBPCR	0.1323*	0.1132*	14.4%

Notes: RMBPCR: Revised Memory and Behavior Problems Checklist Ratings.

\*  $p < 0.05$

Research question #4: What are caregivers' perceptions of stigma and how did their mood change since the diagnoses of their family members?

A total of nine interviews from caregivers of PwD in the early stages of dementia from Iowa were included in the direct approach to content analysis. These nine caregivers of PwD were the ones able to finish the entire interview, while the other eight interviews conducted in Iowa were incomplete. Incompleteness of the interviews was either due to the condition of the PwD, which resulted in a distracted caregiver, or the status of the recorder which led to an inaudible tape.

An independent t-test was used to determine the differences between the nine caregivers and the other caregivers of the same ethnicity/race, Caucasian/White (n=32). In this study, time-invariant variables included: PwD's age, caregiver's age, PwD's total education years, caregiver's total education years, and length of time individual has been diagnosed with dementia (months). On the other hand, time-varying variables included MMSE, RMBPCF, RMBPCR, Stigma, and CES-D scores. There were a total of 33 Caucasian/White caregivers; however, only 32 were included in the comparison for time-invariant variables across time because one dyad was of different ethnicity/race making comparison difficult. For time-varying variables, Time 3 data were used in accordance with the time point for collected qualitative data. Due to withdrawal from the study and missing data, the total number of Caucasian/White caregivers was not the same between time-invariant and time-varying variables as well as across each variable. Mann-Whitney U was used to compare the selected with the non-selected caregivers for categorical data including gender and marital status.



There were no significant differences on PwD gender, caregiver gender, and marital status between PwD and their caregivers among the nine caregivers included in the qualitative analysis and the non-selected Caucasian/White caregivers. As seen in Tables 7 and 8, only PwD age ( $p = 0.015$ ), Revised Memory and Behavior Problem Checklist Frequency (RMBPCF) ( $p = 0.031$ ), Center for Epidemiologic Studies Depression Scale (CES-D) ( $p = 0.01$ ) were significantly different between the included and the non-selected caregivers. The nine caregivers included in the analysis reported fewer depressive symptoms and took care of younger PwD who had more memory and behavior problems.

Based on the interviews with the caregivers of PwD, three out of the four mechanisms of perceived stigma conceptualized by Fife and Wright (2000) were partially validated by the study. Social isolation, internalized shame, and social rejection were validated while financial insecurity was not. The percentages and frequencies of the themes and sub-themes indicated by the caregivers of PwD during the interviews are presented in Table 9 (see Appendix E for percentage, frequency, and quotes of themes). For the purpose of this study, percentage was defined as the number of caregivers among all nine caregivers who mentioned the specific theme, while frequency was defined as number of times mentioned within a specific theme.

### **Social Isolation**

According to Fife and Wright (2000), social isolation related to limited social contact due to abandonment “incorporating feelings of loneliness, inequality with others, and uselessness” (p. 56). Five out of nine caregivers (55.6%) described that it was difficult to leave the PwD alone and/or involve PwD in activities due to limitations of

their physical and mental abilities. Consequently, caregivers often felt more lonely because they had to cut back on their work and social activities and/or occupy their time with individual activities, so they could be with their loved ones, such as walking and puzzles. One caregiver expressed her experiences as such:

*I guess I've done more walking on my own. You know when I have to be close to home anyway I'll just go out for walks. I guess that would be part of the biggest thing. I do the yard work and the gardening. That passes a lot of time and I work Sudoku's every night.*

Caregivers also sometimes encountered embarrassing situations due to the PwD's disease progression and increasing needs and behavior problems. Hence they felt unequal in their relationships with others. According to two caregivers:

*I think the only time I've noticed a difference would be things that involved the two of us like we used to golf together a lot with other couples and that of course had to end; mainly activities that we would do together with couples. That's kind of become less.*

*Well, behavior problems are awkward, and I just don't talk about it.*

### **Internalized Shame**

Fife and Wright (2000) conceptualized internalized shame as feeling embarrassed about their loved ones' diagnoses as a result of rejection and financial insecurity and includes "feeling set apart from others who are well, blaming oneself for the illness, and feeling a need to maintain secrecy about the illness" (p. 56). Five out of nine caregivers (55.6%) reported that they cannot be open with others about their family members' illness and felt a need to keep it a secret. One caregiver expressed her feelings toward revealing the diagnosis of her family member to acquaintances, while another caregiver expressed how she dealt with acquaintances when asked to reveal the diagnosis of her family member's diagnosis.

*Friends yes and acquaintances I don't know them that well. I don't think I need to express families' problems. I really don't see acquaintances that often. I feel very awkward, other than the fact that she has the disease. I just don't talk about it...if they ask questions like how she is doing, I just say oh, pretty good. She's in a very good humor all of the time.*

Internalized shame also encompassed caregivers feeling less competent after their family members' diagnoses of memory loss. One caregiver described how she felt less competent as follows:

*Well, you know it's hand and glove with the physical disability and just really wish you could interact like you always did being able to do things with him. It's not so easy to get him out in a group of people because of his physical frailty also the confusion. It's just not worth upsetting him. So it confines him which is a frustration. We'd like to include him in more things that we do but we can't.*

### **Social Rejection**

According to Fife and Wright (2000), social rejection refers to being abandoned by friends, family, and colleagues “including the perception that others have less respect for them, do not act as though they are competent, avoid them, and appear to feel awkward in their presence” (p. 56). Two out of nine caregivers (22.2%) reported being set apart by their family members' illness. One caregiver reported that it was easier to talk to friends or acquaintances within the same age group about their loved one's diagnosis of memory loss, while it was more difficult to talk to friends or acquaintances in the younger age group. As a result, one caregiver was inclined to feel set apart from the younger age group whose family members were well. According to this caregiver:

*Most of my friends, many of my friends are in my age group and they're going through sort of the same thing so it becomes easier and easier the more people that I know. The younger the friend is, the more difficult it is because they're obviously not there yet. They don't quite understand. They try.*

Another caregiver described feeling embarrassed by the reactions of others related to his family member's diagnosis. This caregiver expressed:

*Um, not unless they were embarrassed by it, you know too embarrassed to talk about it. Um, but if I sense they are avoiding it, then I would just leave the subject alone.*

In addition to the validated mechanisms of perceived stigma conceptualized by Fife and Wright (2000), themes including support seeking, adaptation, and unstable mood of caregivers were mostly identified from the interview question: “Please describe how your mood has been affected since your family member has been diagnosed with a memory loss”.

### **Support Seeking**

Seven out of nine caregivers (77.8%) reported seeking out support and two types of support were recognized: peer support and family support. According to the caregivers’ descriptions, it was helpful to talk to friends and people who were often their peers and who also had experiences taking care of a family member. Coping skills frequently developed through sharing and listening to stories, and these story exchanges served as a kind of support group among caregivers. One caregiver stated:

*Probably I have several friends who have parents or a spouse in a nursing home and so we share our war stories and I think it’s kind of like a support group. You know we tell what happened and how we handled it and the outcome so I learn things from this.*

In addition to friends, caregivers also reported that family is the group they are most comfortable interacting with after their loved ones’ diagnoses of memory loss.

Family members were supportive as described by one of the caregivers:

*Our friends and our immediate family and they’re very supportive. My grandsons are 25 and 22 and I always get hugs from them no matter where we’re at, in a restaurant or what, we hug when they come in and they give me a hug when they leave. They’re very loving children, 25 year old children.*

## **Adaptation**

Eight out of nine caregivers (88.9%) described how they adapted to changes in their lives after their love ones' diagnoses of memory loss. Changes they indicated included reducing social activities, being responsible for a parent, and developing new skills working in the house. One caregiver described changes in her routine and how she learned to adapt:

*I've cut back on my social networking a little bit just so I can be around the house more, but I'm making up for that with picking up some of the slack of, you know, household maintenance that John used to do that he doesn't do so I do it now. I have more to do here at home so it's taken place of some of the social stuff but that's okay.*

Not only did caregivers adapt to changes, but they also sought to maintain a normal life. One caregiver stated:

*Let's see, to get out of the house because it gets a little boring in there. Just to go have coffee and visit with people and try to keep things as normal as possible.*

## **Unstable Mood of Caregivers**

Four out of nine caregivers (44.4%) reported having unstable mood since their family members have been diagnosed with memory loss. Depending on the progression of the disease, PwD may suffer one or more losses which interfere with their abilities to function and increase their reliance on their caregivers. It was this constant reminder of being a caregiver to their loved one that was affecting their everyday living and further influenced their mood. According to one caregiver:

*It's a lot of baggage. That's a good word for it; baggage. We all have baggage, but your parents getting old are one piece of baggage you just can't put aside. People say, "Oh you just have to focus and throw the excess baggage away, simplify." That's too much. Less is better. I have stopped working with less is better and you can't throw this baggage out. It's your family. I can't throw it out so I'm forced to have to deal with it.*

Not only did caregivers' mood fluctuate from time to time, but they also identified feeling irritable. Irritability resulted from being responsible for more tasks around the house and being responsible for a parent without anticipated support from siblings. One primary caregiver expressed her feelings toward her siblings:

*I guess I should say sometimes I do feel a little resentful of my brother and sister that they don't have part of this responsibility. Especially when...I think it's up to them to call and I also use e-mail a lot to tell them about dad's condition and if they don't reply it really irritates me. It just, I mean, at least they could say thanks for the information and so I think that, you know, that in reality I know they have busy lives but I think they could take a moment out to be a little bit more supportive of me perhaps and my husband. I mean my husband has taken on a big role in this, too. So I guess when you're talking about moods that does come into play not every day but just once in a while.*

**Table 7. Comparison between Caregivers Selected and Non-selected Time-invariant Variables**

Variables		N	Mean	Std. Deviation	<i>p</i> - value
PwD Education (year)	Non-selected	23	12.80	4.49	.783
	Selected	9	12.11	9.78	
	Total	32	12.61	6.25	
Caregiver Education (year)	Non-selected	23	15.26	2.55	.347
	Selected	9	16.22	2.59	
	Total	32	15.53	2.56	
PwD Age (year)	Non-selected	23	74.87	18.94	.015*
	Selected	9	49.44	37.18	
	Total	32	67.72	27.31	
Caregiver Age (year)	Non-selected	23	63.26	14.21	.122
	Selected	9	71.44	9.36	
	Total	32	65.56	13.41	
Length of AD (month)	Non-selected	22	13.23	12.13	.130
	Selected	6	22.67	16.57	
	Total	28	15.25	13.45	

Notes: Length of AD: length of time individual has been diagnosed with dementia.

\*  $p < 0.05$

**Table 8. Comparison between Caregivers Selected and Non-selected Time-varying Variables (Time 3)**

Variables		N	Mean	Std. Deviation	<i>p</i> -value
MMSE	Non-selected	15	19.20	5.63	.126
	Selected	6	23.17	3.31	
	Total	21	20.33	5.32	
FKAT Total	Non-selected	15	15.73	2.05	.158
	Selected	9	17.22	2.95	
	Total	24	16.29	2.48	
RMBPCF	Non-selected	15	30.60	7.48	.031*
	Selected	9	39.56	11.64	
	Total	24	33.96	10.04	
RMBPCR	Non-selected	15	16.93	12.29	.249
	Selected	9	23.78	15.86	
	Total	24	19.50	13.81	
SIS	Non-selected	15	28.20	10.99	.431
	Selected	9	31.89	10.76	
	Total	24	29.58	10.83	
CES-D	Non-selected	15	11.27	4.65	.010*
	Selected	9	5.67	4.85	
	Total	24	9.17	5.39	



**Table 8 continued**

Notes: MMSE: The Mini-Mental State Examination; FKAT: The Knowledge of Alzheimer's Test Family Version; RMBPCF: Revised Memory and Behavior Problems Checklist Frequency; RMBPCR: Revised Memory and Behavior Problems Checklist Ratings; SIS: Stigma Impact Scale; CES-D: Center for Epidemiologic Studies Depression Scale.

\*  $p < 0.05$

**Table 9. Percentage and Frequency of Themes**

<b>Themes (n=9)</b>	<b>Percentage</b>	<b>Frequency</b>
Adaptation	88.9%	10
Support Seeking	77.8%	11
Social Isolation	55.6%	11
Internalized Shame	55.6%	10
Unstable Mood of Caregivers	44.4%	8
Social Rejection	22.2%	2

Notes: Percentage: the number of caregivers among all nine caregivers who mentioned the specific theme; Frequency: number of times mentioned within a specific theme.

## **CHAPTER V**

### **DISCUSSION**

The previous chapter provided the results of the study research questions and hypotheses. This chapter explains and discusses the results, limitations of the study and possible recommendations for future nursing research and practice.

#### **Overview of Study and Findings**

The purpose of the current study was to examine the relationship between perceived stigma and depressive symptoms among caregivers of PwD in the early stages of the disease over an 18 month period. Personal (disease stage, cognitive impairment, caregivers' knowledge of dementia, behavior symptoms, demographic information), environmental (different geographic location: rural and urban) and ethnic/racial background variables were also considered in order to examine their effect on caregiver depressive symptoms in addition to perceived stigma. Based on significance and the Akaike (AIC) measure as presented in Chapter 3, the final linear mixed model (LMM) consisted of the following covariates: Revised Memory and Behavior Problems Checklist (RMBPCR) scores, and caregiver ethnicity/race.

This study confirms previous findings of a positive relationship between depressive symptoms and caregivers' reaction in response to PwD's memory and behavior problems ( $p = 0.0028$ ) (Clyburn et al., 2000; Covinsky et al., 2003; Hooker et al., 2002; Molyneux et al., 2008). As the symptoms and behavioral problems of ADRD change over time, so does the nature of caregiving required. In general, family caregivers provide a great amount of care, including ADL assistance for long periods of time, with the majority providing care for more than a year (Alzheimer's Association and National

Alliance for Caregiving, 2004; Alzheimer's Association, 2008a). Consequently, the physical and psychological demands of caring for PwD often result in psychiatric morbidity in the form of increased depression (Baumgarten et al., 1992; Mahoney et al., 2005; Schulz et al., 1995).

However, inconsistent with most studies, there was no association between caregivers' ethnicity/race and depressive symptoms, given all other variables in the model ( $p = 0.2302$ ). Most studies found African American/Black caregivers less depressed and with better well-being, suggesting that African American/Black caregivers respond differently to the caregiving burden in comparison to their Caucasian/White counterparts, especially when using depression as an outcome measure (Covinsky et al., 2003; Dilworth-Anderson, Williams, & Gibson, 2002; Janevic & Connell, 2001; Roth, Ackerman, Okonkwo, & Burgio, 2008; Skarupski, McCann, Bienias, & Evans, 2009). A recent study done by Siegler and colleagues (2010) found that when caregivers and PwD are living apart, African American/Black caregivers of PwD report fewer depressive symptoms in comparison to Caucasian/White caregivers. Another study by Clay et. al. (2009) found that African American/Black caregivers had fewer depressive symptoms and higher levels of life satisfaction, when compared to their Caucasian/White counterparts. This finding can be partially explained by higher levels of satisfaction with social support among African American/Black caregivers (Clay, Roth, Wadley, & Haley, 2008). Consequently, a measure of depression alone, such as the CES-D, without considering factors such as living arrangements and caregivers' satisfaction with social support, may not capture the whole picture of racial differences and caregivers' depressive symptoms. Another possible explanation may be that the current study had

more Caucasians/White caregivers than African American/Black caregivers, making it difficult to detect racial differences on depressive symptoms.

Insofar as contributing to the literature, the current study examined the effects of perceived stigma on fostering depressive symptoms among caregivers of PwD which had previously not been examined. Specifically, the results showed significant relationships between perceived stigma and depressive symptoms, both at baseline ( $r = 0.357$ ,  $p = 0.0175$ ) and at over 18 months ( $p = 0.0045$ ). Moreover, the study noted that caregivers of PwD felt more depressed when they perceived more stigma ( $p = 0.0019$ ) despite ethnicity/race and their reaction to the PwD's memory and behavior problems. Findings suggest that caregivers of PwD feel stigmatized, including elements of shame, fear, and embarrassment. As a result, stigma may erode caregivers' psychological health and further impede their ability to provide support and to help take care of the PwD. Additional analyses were conducted to examine the mediation effect of perceived stigma on the relationship between scores on the RMBPCR and depressive symptoms among caregivers of PwD. Findings indicated that perceived stigma minimally mediated the effect between RMBPCR and depressive symptoms (14.4% decrease in the coefficient). In other words, caregivers' reaction in response to PwD's memory and behavior problems had not only direct but also indirect effects on caregivers' depressive symptoms. For indirect effect, those caregivers feeling more bothered or upset by the PwD's memory and behavioral problems had more perceived stigma, which in turn was associated with more depressive symptoms (see Figure 2).

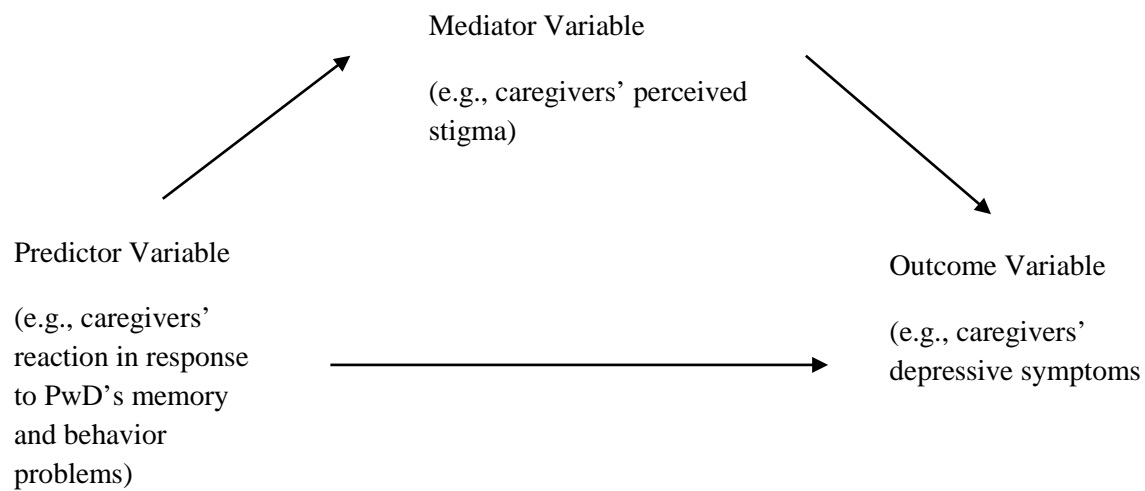
However with such a minimal mediation effect, direct effect was stronger than indirect effect. Thus, based on the results of this study, interventions should be directed

toward PwD's behavioral and psychological symptoms in order to reduce caregivers' depressive symptoms. Dementia often leads to problematic behaviors and psychological symptoms as the disease progresses. These include forgetfulness, loss of language, emotional outbursts, including anger and aggression, and violation of social norms regarding appropriate conduct. Additionally, PwD often act in different and unpredictable ways depending on their individual disease trajectory. Consequently, these problematic behaviors and psychological symptoms may directly increase caregivers' depressive symptoms or indirectly cause caregivers of PwD to feel stigmatized and then increase their depressive symptoms. With reference to this study, the importance of knowledge and management of behavioral and psychological symptoms cannot be emphasized enough. A recent article by O'Connor et. al. (2009) systematically reviewed studies on psychosocial interventions of behavioral disturbances in PwD. Psychosocial interventions were included only when they were developed based on one of the following theoretical models: The ABC model (Teri et al., 1998), the unmet needs model (Algase et al., 1996), and the stress threshold model (Hall & Buckwalter, 1987). Interventions including aromatherapy, ability-focused caregiver education, bed baths, preferred music and muscle relaxation training were identified with a moderate or large effect size. O'Connor et. al. (2009) explained that interventions with a small to moderate effect size often only work best in specific, time-limited situations. They also concluded that regardless of intervention type, treatment tailored to PwD's individualized preferences is usually more effective. These interventions can be used by clinicians in institutional settings and can also be adopted by caregivers in community settings. Many interventions are available to manage PwD's memory and behavioral problems. These may be applied to directly

increase caregivers' psychological well-being or indirectly decrease caregivers' level of perceived stigma and in turn enhance caregivers' psychological well-being. Rigorous intervention studies that examine these caregiver outcomes are warranted.

In sum, the results of these analyses were consistent with predications and in line with existing literature that suggests caregivers who felt more bothered or upset by the PwD's memory and behavioral problems exhibited more depressive symptoms (Clyburn et al., 2000; Covinsky et al., 2003; Hooker et al., 2002; Molyneux et al., 2008). Secondly, the current study not only found a relationship between caregiver perceived stigma and depressive symptoms, but also found perceived stigma served as a mediator between caregivers' reaction in response to PwD memory and behavior problems and depressive symptoms.

**Figure 2. Diagram of Paths in Mediation Model: Caregivers' Perceived Stigma as Potential Mediator**





As mentioned before, a directed approach to content analysis was specifically chosen for this embedded correlational design study. Through this approach, we were able to partially validate the conceptual framework, Modified Labeling Theory (MLT) (Fife & Wright, 2000), and to gather an in-depth understanding of caregivers' mood change since the diagnosis of their family member.

Based on interviews with the caregivers of PwD, social isolation (55.6%), internalized shame (55.6%), and social rejection (22.2%) were partially validated as mechanisms of perceived stigma. However, social rejection in comparison to social isolation and internalized shame was endorsed by a relatively lower percentage of the nine Caucasian/White caregivers interviewed. Stigma is both a process that inherently involves the negative responses of the person in that environment and an internal process (Link et al., 1987; Link et al., 1989). Social rejection and financial insecurity, which was not included in the study, represent the experience of stigma, while social isolation and internalized shame represent an internalized experience of stigma. Thus, based on a small sample size and similar sample characteristics, results of this study suggest that caregivers internalized the experience of stigma more than they actually experienced discrimination from others within their surrounding environment or from society as a whole. This may suggest that the small number of caregivers interviewed in this study is in a relatively safe and supportive environment, especially since most of them interact mainly with family, long-time friends, or people from the same religious group. However, our results also suggest that these caregivers still feel labeled by other members of society, even though they are highly educated (an average 16.2 years of education) and are well informed regarding the signs and symptoms of ADRD (an average score of 17.2 out of a

total of 22 as measured by Family Knowledge of Alzheimer's Test (FKAT)). The diagnosis of mental illness varies across cultures because it is often given based on deviations from sociocultural and behavioral norms. Studies have found that African American/Black individuals are less knowledgeable about AD than their Caucasian/White counterparts (Roberts et al., 2003). Hispanic and Chinese caregivers tend to consider changes related to dementia as part of the normal aging process and that AD can be easily diagnosed by a blood test in comparison to Caucasian/White caregivers (Gray, Jimenez, Cucciare, Tong, & Gallagher-Thompson, 2009; Hinton, Guo, Hillygus, & Levkoff, 2000; Zhan, 2004). Moreover, qualitative studies have shown that stigmatization associated with the diagnosis of ADRD exists in the Hispanic and Chinese culture (Hinton et al., 2000; Hinton et al., 2005). The phenomenon of caregivers expressing more internalized sense of stigma rather than the actual experience of stigma warrants replication with a larger, more diverse sample in order to validate and/or extend the MLT and to better understand the underlying mechanisms of caregiver perceived stigma within different cultures.

In addition to providing beginning support for the mechanisms of perceived stigma, other themes emerged. Unstable mood, following the diagnosis of memory loss, was mainly due to being a caregiver of a PwD. Depending on disease progression and loss of abilities in the PwD, caregivers were often alone in the caregiving situation with limited support from family and friends. Qualitative studies exploring the psychological experiences of caregivers of early-stage PwD indicate that caregivers often describe a gradual learning experience about the signs and symptoms of dementia and how to manage these symptoms in their loved ones (Kuhnt 1998; Perry, 2002; Robinson, Clare,

& Evans, 2005). One possible explanation of caregivers' unstable mood may be their gradually increasing knowledge of the nature and meaning of the diagnosis as well as changes in the relationship between caregiver and care-recipient; nevertheless, more studies are needed to be able to systematically evaluate the caregivers' "learning curve." These studies should be longitudinal in nature in order to document changes over time. A limitation of this study is that the qualitative data was collected at only one point in time and could not capture, therefore, such changes. More attention must be given to the subjective experiences of caregivers of early-stage PwD in order to develop appropriate interventions.

The nine caregivers included in the qualitative analysis, in comparison to the non-selected Caucasian/White caregivers, reported fewer depressive symptoms, although they took care of younger PwD who had more memory and behavior problems. This may be explained in part by the protective mechanisms of support seeking and adaptation addressed in the qualitative analysis. Caregivers often learned to adapt to the caregiving role and to maintain a normal life through developing new skills. Adaptation also occurred through developing coping skills from talking to friends, families, and people with the same experiences. New skill development identified in the current study was similar to the process of "interpretative caring" identified by Perry (2002), whereby wives took over their husbands' roles and formed new identities for both themselves and their husbands. The difference between the current study and Perry's study is that the latter focused on husbands taking over their wives' roles and developing new skills around the house.

### **Limitations**

The design of the study was a mixed methods approach including a descriptive 18-month longitudinal design and a qualitative interview. Therefore, we are not able to make causal inferences about the effects of perceived stigma among caregivers of PwD on depressive symptoms. In relation to the design of the study, 18 months may not be enough to capture ADRD progression in order to reflect the changes in caregiver perceived stigma. However, the study duration is reasonable given the unpredictable condition changes of PwD and limited research resources. In addition, qualitative data were collected at only one point in time; therefore, we were not able to capture caregiver's mood changes over time. More longitudinal studies are needed.

Another limitation is the sample used in the quantitative portion of the study. The small sample size and homogeneous sample characteristics, including ethnicity and gender, make it difficult to generalize study findings to all caregivers of PwD. Despite strenuous efforts to recruit participants, we were not able to meet the desired sample size. Hence, power of the analysis was impaired and the number of variables, for example living arrangement, included in the analysis at the same time was limited. Living arrangement was collected for the current study and, according to Siegler et. al. (2010), this variable moderates the effect of caregiving stress on depressive symptoms for both black and white caregivers. However, living arrangement was not included in our model and analysis due to the small sample size. Given sample size, we did find significant associations between caregiver perceived stigma and their depressive symptoms since the effect sizes were greater than the minimum detectable effect size set in the power calculations.

Recruitment difficulties may be explained by the stigma associated with dementia (Garand et al., 2009), which makes it challenging to meet the desired sample size in a study of this nature. On the other hand, participants may have had lower levels of perceived stigma in general, given their willingness to participate in this study. Also, the study had more Caucasians/White individuals than African American/Black participants regardless of similar recruitment efforts across geographic location. Older African American/Black individuals are harder to recruit than Caucasians/White individuals in research on Alzheimer's disease even though they suffer disproportionately from AD (Bachman et al., 2003; Stahl & Vasquez, 2004).

The small sample size and the similar sample characteristics make it difficult to explore other protective mechanisms among caregivers experiencing mood changes and to validate the MLT among African American/Black caregivers of PwD respectively. We were not able to validate the mechanism of financial insecurity in addition to social rejection, internalized shame, and social isolation based on the mechanisms of perceived stigma in the MLT as conceptualized by Fife and Wright (2000). This was because interview questions related to financial situations were not included in the study in consideration of the sensitivities of financial questions and study length.

Overall, the present study had limitations that reduced the ability to generalize both quantitative and qualitative findings. Through understanding these limitations, however, we can better direct future research and develop more appropriate interventions.

### **Implications and Future Research**

The present study confirms previous findings of a positive relationship between depressive symptoms and caregivers' reaction in response to PwD's memory and

behavior problems. Moreover, findings in this study are an extension of previous quantitative and qualitative studies conducted with caregivers of PwD. A positive relationship was not only found between caregiver-perceived stigma and depressive symptoms at baseline, but the relationship persisted over an 18-month period of time. More importantly, the current study also found perceived stigma served as a minimal mediator between caregivers' reaction in response to PwD memory and behavior problems and depressive symptoms. In addition to the importance of behavioral and psychological symptoms management in PwD, findings also suggest the importance of caregiver-perceived stigma on caregivers' depressive symptoms because it is amenable to change, unlike many of the identified predictors of caregiver depression. The need for further research focusing on perceived stigma among caregivers of PwD is evident. The following section includes implications for nursing research and nursing practice.

As mentioned in the limitations section, a larger and more diverse sample is needed to further examine the longitudinal relationship between caregivers' perceived stigma and depressive symptoms. Also, studies should replicate this study using caregivers' perceived stigma as a mediator. If a greater coefficient change is found, we can develop interventions specifically to lower caregivers' perceived stigma and to enhance caregivers of PwD's psychological well-being. Given the significant relationship between caregivers' perceived stigma and depressive symptoms, it is critical to start looking at methods to reduce stigma.

Efforts to reduce stigma should be multifaceted due to its embedded complex nature in social constructs (McAllister, 2008). Corrigan and Penn (1999) suggested that contact, education, and protest are all critical interventions. The best approach to reduce

stigma in mental illness is unclear; however, contact and education consistently appear to be effective across disciplines (Rusch, Angermeyer, & Corrigan, 2005). Furthermore, contact approaches seem to be more influential compared to educational approaches based on the work of Rusch et. al. (2005). Contact is the personal interaction between individuals with and without mental illness. Through this interaction, those without mental illness may develop attitude and behavior changes in response to individuals with mental illness, including dementia (Pinto-Foltz & Logsdon, 2009). Based on the current literature and the findings of this study, contact and education should be employed by family members and caregivers of PwD, as well as the public at large. For example, elementary and high schools should partner with local long-term care facilities to establish volunteer programs, so that young students would have exposure to older adults and more specifically, older adults with neurological disorders such as, dementia and associated memory and behavior problems.

It is critical for nurses in all specialties to understand the pervasive nature of stigma and its impact on PwD and their caregivers, but this is particularly true for psychiatric/mental health nurses who work with persons with mental illnesses and dementia and their caregivers. Positive attitudes toward people with mental illnesses and psychiatric/mental health nursing increased among nursing students who increased their hours in psychiatric/mental health theory and clinical experiences (Happell, Robins, & Gough, 2008a; Happell, Robins, & Gough, 2008b). Curricular and practicum changes are called for at both the undergraduate and graduate levels that could infuse more content about stigma and educate people with how to manage both signs and symptoms of dementia. Nurses are great interdisciplinary facilitators due to their ability to speak the

language of different healthcare professions and to collaborate among members of the healthcare team. Moreover, nurses, the largest health care occupation, can influence the public because they are respected for their integrity and honesty. Given nurses' potential influence, it is possible that education regarding the myths associated with mental illness and dementia can be debunked within the nursing profession and disseminated to the health care community and the public using principles from Rogers' Diffusion of Innovation Theory (Rogers, 1995).

Regardless of their level of practice or area of expertise, all nurses can initiate change by sharing knowledge about the signs and symptoms of dementia and dementia care, especially with community members in venues such as churches, schools, and workplaces. Moreover, nurses can be involved in anti-stigma organizations and direct other colleagues and clients to these resources (Pinto-Foltz & Logsdon, 2009). The National Alliance on Mental Illness (NAMI) is the nation's largest mental health organization and it has formed *StigmaBusters* as a protest venue. Through this venue, advocates protest against poorly and disrespectfully illustrated images of persons with mental illnesses. *In Our Own Voice* is a public contact and educational approach dedicated to fighting stigma by persons with mental illnesses sharing their stories about living with the disease (National Alliance on Mental Illness, 2011). NAMI does not address approaches to fighting stigma with regard to dementia, because dementia is a neurological disorder and is only categorized as a kind of mental illness in the stigma literature. However, NAMI approaches may be adopted and modified by the Alzheimer's Association, as an extension of their nationwide and online virtual town hall meetings, in order to reduce stigma perceived by PwD and their caregivers. In fact, similar to NAMI's



*In Our Own Voice* approach, Richard Taylor, a retired psychologist diagnosed with dementia, has a blog in which he shares his personal stories about fighting his disease on a daily basis. In addition to his blog, he holds online chat rooms and gives public talks at various professional conferences, long-term care facilities, and public programs. Through sharing his stories, the public becomes more aware of dementia, is in a better position to correctly identify its associated signs and symptoms, and should have more compassion, concern, and willingness to help when they encounter PwD and their caregivers.

Besides efforts to reduce stigma within society, primary care providers (PCPs) including advanced practice registered nurse, and visiting nurses who care for PwD and their caregivers should not only be aware of both stigma and depression, but also be able to provide referrals and /or early intervention. PCPs and visiting nurses should investigate stigma by asking questions related to changes in social lives of PwD and their caregivers and the reasons for these changes. Depending on the reasons for changes in their social lives, appropriate interventions could be implemented, such as education related to dementia or support groups offered by the Alzheimer's Association (AA). PCPs and visiting nurses should also routinely perform depression screening on caregivers, for example, by using the Patient Health Questionnaire (PHQ-9) (Kroenke, Spitzer, & Williams, 2001) or some other standardized, short, assessment tool. If depression is detected, they could offer appropriate treatments such as antidepressants, psychotherapies, and refer caregivers of PwD to community mental health centers for additional treatment and support. Psychotherapies such as behavioral management therapy for PwD and teaching caregivers coping strategies have been found to be effective in improving

caregivers' psychological health (Selwood, Johnston, Katona, Lyketsos, & Livingston, 2007).

This study provided unique insights into the relationship between perceived stigma and depressive symptoms among caregivers of PwD in the early stages of the disease and over an 18 month course. Despite the limitations mentioned earlier, the current study represents a valuable contribution to the literature. Given the dearth of research on perceived stigma among caregivers of PwD, this study offers researchers and healthcare providers information to adapt interventions that focus on caregiver-perceived stigma with an emphasis on PwD's memory and behavioral problems as a means to reduce depressive symptoms in caregivers. Additionally, this study contributes to the literature regarding validation of the MLT theoretical framework.

**APPENDIX A**  
**ALL STUDY MEASURES**

**Demographic Data**

Person with AD (Participant):

Date of Birth: \_\_\_\_\_

Gender: Male: \_\_\_\_\_

Female: \_\_\_\_\_

Caregiver:

Date of Birth: \_\_\_\_\_

Gender: Male: \_\_\_\_\_

Female: \_\_\_\_\_

Married: \_\_\_\_\_ Widowed: \_\_\_\_\_

Single (never married): \_\_\_\_\_ Single (divorced): \_\_\_\_\_

Living Arrangements:

Lives with spouse/family member: \_\_\_\_\_

Lives alone: \_\_\_\_\_

Lives with friends/significant other: \_\_\_\_\_

Lives in own home: \_\_\_\_\_ or Assisted Living: \_\_\_\_\_

Caregiver(C)/Participant(P) race: \_\_\_\_\_ White/Caucasian \_\_\_\_\_ Hispanic or Latino

\_\_\_\_\_ American Indian or Alaskan Native

\_\_\_\_\_ Asian \_\_\_\_\_ Native Hawaiian

\_\_\_\_\_ Black or African American

\_\_\_\_\_ Other (Specify)

Caregiver Education: Total years (including high school): \_\_\_\_\_

Participant Education: Total years (including high school): \_\_\_\_\_

Length of time participant has been diagnosed with AD: \_\_\_\_\_ months

CDR Score: \_\_\_\_\_

Participant medical diagnoses: (please list) \_\_\_\_\_

Medications participant is currently taking: \_\_\_\_\_

Is participant currently taking part in a clinical drug trial? \_\_\_\_\_ Yes \_\_\_\_\_ No

If yes, please specify the drug name and location of the trial:

\_\_\_\_\_

## **Mini-Mental State Examination (MMSE)**

### **ORIENTATION**

*(Ask the general question first, then the specific questions below)*

Name this place (building or hospital). What floor are you on now? What state are you in?

What county are you in? *(If not in a county; score correct if city is correct)*

What city are you in (or near) now?

What is the date today?

*(Ask the general question first, then the specific questions below)*

What year is it? What season is it?

What month is it?

What is the day of the week? What is the date today?

Score 1 for each correct. (Max = 10)

### **REGISTRATION**

Name three objects (ball, flag, and tree) and have patient repeat them. Score 1 for each object

*(Say objects at about 1 word per second. If patient misses object, ask correctly repeated him/her to repeat it after you until he/she learns it. Stop at 6 repeats.) (Max = 3)*

### **ATTENTION AND CALCULATION**

Subtract 7s from 100 in a serial fashion to 65. Score 1 for each correct answer up to 65 (Max. = 5)

*Alternatively*

Ask the subject to spell the word WORLD. Then have the subject spell it backward. Score 1 for each correctly placed letter

### **RECALL**

Do you recall the names of the three objects? Score 1 for each correctly recalled object (Max = 3).

### **LANGUAGE**

Ask subject to provide names of a watch and pen as you show them to them (Max = 2).

Repeat "no ifs, ands, or buts." (Only one trial) Score 1 if correct.

Give subject a piece of plain blank paper and say, "Take the paper in your right hand (1), fold it in half (2), and put it on the floor". Score 1 for each part done correctly (Max = 3).

Ask subject to read and perform task written on paper: "Close your eyes." Score 1 if subject closes eyes.

Ask subject to write a sentence on a piece of paper. Score total of 1 if sentence has a subject, object, and verb. (Max = 1)

### **CONSTRUCTION**

Ask subject to copy a design of the interlocking five-sided figures. Score 1 if all 10 angles are present and the two angles intersect. Ignore tremor and rotation. (Max = 1)

**TOTAL SCORE:** \_\_\_\_\_ (Maximum score = 30)

### Clinical Dementia Rating (CDR)

Participant ID	Date (mm-dd-yy)
----------------	-----------------

	Memory	Orientation	Judgment & Problem Solving	Community Affairs	Home & Hobbies	Personal Care
<b>None 0</b>	No memory loss or slight inconsistent forgetfulness	Fully oriented	Solves everyday problems and financial and business affairs well; judgment good in relation to past performance	Independent function at usual level in job, shopping, and volunteer and social groups	Life at home, hobbies, and intellectual interests well maintained	Fully capable of self-care
<b>Questionable 0.5</b>	Consistent slight forgetfulness; partial recollection of event; "benign" forgetfulness	Fully oriented except for slight difficulty with time relationships	Slight impairment in solving problems, similarities, and differences	Slight impairment in these activities	Life at home, hobbies, and intellectual interests slightly impaired	Fully capable of self-care
<b>Mild 1</b>	Moderate memory loss, more marked for recent events; defect interferes with everyday activities	Moderate difficulty with time relationships; oriented for place at exam; may have geographic disorientation elsewhere	Moderate difficulty in handling problems, similarities, and differences; social judgment usually maintained	Unable to function independently at these activities although may still be engaged in some; appears normal to casual inspection	Mild but definite impairment of function at home; more difficult chores and more complicated hobbies and interests abandoned	Needs Prompting
<b>Moderate 2</b>	Severe memory loss; only highly learned material retained; new material rapidly lost	Severe difficulty with time relationships; usually disoriented to time, often to place	Severely impaired in handling problems, similarities, and differences; social judgment usually impaired	No pretense of independent function outside home; appears well enough to be taken to functions outside home	Only simple chores preserved; very restricted interests, poor sustained	Requires assistance in dressing, hygiene, keeping of personal effects
<b>Severe 3</b>	Severe memory loss; only fragments remain	Oriented to person only	Unable to make judgment or solve problems	No pretense of independent function outside home; appears too ill to be taken to	No significant function in home	Requires much help with personal care; frequent

				functions outside home		incontinence	
<b>Profound</b> 4	Even fragments generally are lost; often unable to test memory because of unintelligible or irrelevant speech	Occasionally responds to own name	Unable to follow even simple instructions or commands	Unable to participate meaningfully in any social setting	Unable to engage meaningfully in any hobby or home activity	May attempt to dress or feed self, non-ambulatory without assistance	
<b>Terminal</b> 5	No meaningful memory function; often uncomprehending or obtunded	No recognition of self	No awareness of problems or comprehension of surroundings	Completely unable to engage in any activity	Completely unable to engage in any activity	Needs to be fed; bed-ridden	
<b>Totals</b>	M=	O=	JPS=	CA=	HH=	PC=	SOB=

Global CDR score. (*Complete CDR Worksheet and then complete M, O, J, etc.*

*above for SOB score. For Global CDR score, refer to scoring instructions or leave blank for scoring at Stanford.)*

0 = No dementia, 0.5 = Questionable dementia or mild cognitive impairment, 1 = Mild dementia, 2 = Moderate dementia, 3 = Severe dementia, 4 = profound dementia, 5 = Terminal dementia

Baseline visit  6-month visit  12-month visit

CDR

### Family Knowledge of Alzheimer's Test (FKAT)

**Directions:** Circle T if the statement is true or F if the statement is false.

- |  | Circle One |   |
|--|------------|---|
| 1. Memory loss is part of the normal aging process.  | T          | F |
| 2. Alzheimer's is a disease which progresses at an individual rate.  | T          | F |
| 3. Avoiding over-stimulation is important to the individual with advanced Alzheimer's disease.   | T          | F |
| 4. The only loss produced by Alzheimer's disease is a progressive decline in memory.   | T          | F |
| 5. In the care setting, restraints are the best way to manage a demented person who wanders.   | T          | F |
| 6. When a person with Alzheimer's disease shows signs of increasing confusion or stress, isolation is sometimes an appropriate management technique. | T          | F |
| 7. Repeatedly asking questions is a symptom of the memory loss of Alzheimer's disease.   | T          | F |
| 8. When a person with Alzheimer's disease becomes accusatory, it is best to deny the accusation and remind the person of his disease.                | T          | F |
| 9. Maintaining a routine is important to the person with Alzheimer's disease.  | T          | F |
| 10. Making the care setting more meaningful with family pictures is helpful to the person with Alzheimer's disease.                                  | T          | F |
| 11. Physical exercise should be avoided by the person with Alzheimer's disease because it increases the person's stress level.                       | T          | F |
| 12. Rest periods should not be planned for the person with Alzheimer's disease in order to assure sleeping throughout the night.                     | T          | F |
| 13. Generally, the cause for disruptive behaviors in the person with   | T          | F |



Alzheimer's disease is the loss of ability to cope with stress.

- |  |   |   |
|--|---|---|
| 14. Alzheimer's disease is easily diagnosed with laboratory tests and X-rays.  | T | F |
| 15. Radios and TVs are usually good ways to keep persons with Alzheimer's disease in touch with the world.   | T | F |
| 16. Persons with Alzheimer's disease should be made to stay in bed all night so that they can get their sleep.   | T | F |
| 17. Persons with Alzheimer's disease are often not able to learn anymore because of their brain damage.  | T | F |
| 18. Nutritional requirements for persons with Alzheimer's disease are the same as they are for others of the same age and amount of activity.                | T | F |
| 19. Persons with Alzheimer's disease may step high over cracks of lines in the floor because they misinterpret what they see or hear.                        | T | F |
| 20. There is always a continual decrease in sex drive from the early to the last stage of Alzheimer's disease.   | T | F |
| 21. The loss of ability to recognize the urge to go to the bathroom may be a reason for persons with Alzheimer's disease to have bowel and bladder problems. | T | F |
| 22. How Alzheimer's disease affects the person depends on the size and location of lesions in the brain.   | T | F |

## Revised Memory and Behavior Problems Checklist

### Instructions:

The following is a list of problems patients sometimes have. Please indicate if any of these problems have occurred during the past week. If so, how much has this bothered or upset you when it happened? 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  
 9=don't know/not applicable

#### REACTION RATINGS:

0=not at all  
 1=a little  
 2=moderately  
 3=very much  
 4=extremely  
 9=don't know/not applicable

Please answer all the questions below. Please circle a number from 0-9 for both *frequency* and *reaction*.

	Frequency	Reaction
1. Asking the same question over and over.	0 1 2 3 4 9	0 1 2 3 4 9
2. Trouble remembering recent events (e.g. items in the Newspaper or on TV).	0 1 2 3 4 9	0 1 2 3 4 9
3. Trouble remembering significant past events.	0 1 2 3 4 9	0 1 2 3 4 9
4. Losing or misplacing things.	0 1 2 3 4 9	0 1 2 3 4 9
5. Forgetting what day it is.	0 1 2 3 4 9	0 1 2 3 4 9
6. Starting, but not finishing, things.	0 1 2 3 4 9	0 1 2 3 4 9
7. Difficulty concentrating on a task.	0 1 2 3 4 9	0 1 2 3 4 9
8. Destroying property.	0 1 2 3 4 9	0 1 2 3 4 9
9. Doing things that embarrass you.	0 1 2 3 4 9	0 1 2 3 4 9
10. Waking you or other family members up at night.	0 1 2 3 4 9	0 1 2 3 4 9
11. Talking loudly and rapidly.	0 1 2 3 4 9	0 1 2 3 4 9
12. Appears anxious or worried.	0 1 2 3 4 9	0 1 2 3 4 9
13. Engaging in behavior that is potentially dangerous to self or others.	0 1 2 3 4 9	0 1 2 3 4 9
14. Threatens to hurt oneself.	0 1 2 3 4 9	0 1 2 3 4 9

15. Threatens to hurt others.	0 1 2 3 4 9	0 1 2 3 4 9
16. Aggressive to others verbally.	0 1 2 3 4 9	0 1 2 3 4 9
17. Appears sad or depressed.	0 1 2 3 4 9	0 1 2 3 4 9
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 9	0 1 2 3 4 9
19. Crying and tearfulness.	0 1 2 3 4 9	0 1 2 3 4 9
20. Commenting about death of self or others (e.g., “Life isn’t worth living,” Or “I’d be better off dead”.)	0 1 2 3 4 9	0 1 2 3 4 9
21. Talking about feeling lonely.	0 1 2 3 4 9	0 1 2 3 4 9
22. Comments about feeling worthless or being a burden to others.	0 1 2 3 4 9	0 1 2 3 4 9
23. Comments about feeling like a failure or about not having any worthwhile accomplishments in life.	0 1 2 3 4 9	0 1 2 3 4 9
24. Arguing, irritability, and/or complaining.	0 1 2 3 4 9	0 1 2 3 4 9

### Stigma Impact Scale: Caregiver

**DIRECTIONS:** Illness or memory loss can affect many areas of a person's life. Please circle the number for each item that best describes your recent experiences (within the past 3 to 4 weeks) in relation to your family member with irreversible memory loss.

Not applicable=0	Strongly disagree=1	Disagree=2	Agree=3	Strongly Agree=4	
1. I have experienced financial hardship that has affected how I feel about myself.	0	1	2	3	4
2. My job security has been affected by the illness in my family member.	0	1	2	3	4
3. My employer/co-workers have discriminated against me.	0	1	2	3	4
4. I have experienced financial hardship that has affected my relationships with others.	0	1	2	3	4
5. I feel I have been treated with less respect than usual by others.	0	1	2	3	4
6. I feel set apart from others whose family members are well.	0	1	2	3	4
7. I feel others are concerned they could "catch" my family member's illness through contact like a handshake or eating food I prepare.	0	1	2	3	4
8. I feel others avoid me because of my family member's illness.	0	1	2	3	4
9. Some <u>family members</u> have rejected me because of my contact with my family member with memory loss.	0	1	2	3	4
10. I feel others think I am to blame for my family member's illness.	0	1	2	3	4
11. I do not feel I can be open with others about my family member's illnesses.	0	1	2	3	4
12. I fear someone telling others about my family	0	1	2	3	4

	member's illness without my permission.					
13.	I feel a need to keep my family member's illness a secret.	0	1	2	3	4
14.	I feel some friends have rejected me because of my family member's illness.	0	1	2	3	4
15.	I have a greater need than usual for reassurance that others care about me	0	1	2	3	4
16.	I feel lonely more often than usual.	0	1	2	3	4
17.	Due to my family member's illness, I have sense of being unequal in my relationship with others.	0	1	2	3	4
18.	I feel I am at least partially to blame for my family member's illness.	0	1	2	3	4
19.	I feel less competent than I did before my family member's illness	0	1	2	3	4
20.	I encounter embarrassing situations as a result of my family member's illness.	0	1	2	3	4
21.	Due to my family member's illness others seem to feel awkward and tense when they are around me.	0	1	2	3	4
22.	Some people act as though I am less competent than usual.	0	1	2	3	4
23.	Due to the illness of my family member, I sometimes feel useless.	0	1	2	3	4
24.	Changes in the appearance of my family member with memory loss have affected my social relationships.	0	1	2	3	4

### Center for Epidemiologic Studies Depression Scale (CES-D)

Below is a list of some of the ways you may have felt or behaved. Please indicate how often you have felt this way during the past week (mark one number on each line)

<b>During the past week....</b>	<b>Rarely or none of the time (less than 1 day)</b>	<b>Some or a little of the time (1-2 days)</b>	<b>Occasion ally or a moderate amount of time (3-4 days)</b>	<b>All of the time (5-7 days)</b>
1. I was bothered by things that usually don't bother me	0	1	2	3
2. I did not feel like eating; my appetite was poor	0	1	2	3
3. I felt that I could not shake off the blues even with help from my family	0	1	2	3
4. I felt that I was just as good as other people	0	1	2	3
5. I had trouble keeping my mind on what I was doing	0	1	2	3
6. I felt depressed	0	1	2	3
7. I felt that everything I did was an effort	0	1	2	3
8. I felt hopeful about the future	0	1	2	3
9. I thought my life had been a failure	0	1	2	3
10. I felt fearful	0	1	2	3
11. My sleep was restless	0	1	2	3
12. I was happy	0	1	2	3
13. I talked less than usual	0	1	2	3
14. I felt lonely	0	1	2	3
15. People were unfriendly	0	1	2	3
16. I enjoyed life	0	1	2	3
17. I had crying spells	0	1	2	3

18. I felt sad	0	1	2	3
19. I felt that people disliked me	0	1	2	3
20. I could not "get going"	0	1	2	3

### **Interview with Caregiver of Person with Dementia**

1. Please describe how you feel about talking about your family member's diagnosis with friends or acquaintances.
2. Have you disclosed your family member's diagnosis to friends or acquaintances?
3. What about your family member's diagnosis are you uncomfortable discussing or disclosing?
4. Which groups or acquaintances are you most comfortable interacting with at present?
5. What changes have you made in your social networks?
6. If you are not participating socially, what are the major reasons for not taking part in activities?
7. What are you actively doing to manage or deal with any restrictions in your social participation?
8. Do family members treat you differently since the diagnosis of your family member?  
If yes, in what ways?
9. Have friends or acquaintances treated you differently since your family member's diagnosis? If yes, in what ways?
10. Have you experienced any negative interactions or responses from others due to your family member's diagnosis?
11. Please describe how your mood has been affected since your family member has been diagnosed with a memory loss.



## **APPENDIX B**

### **INFORMED CONSENT DOCUMENT: PERSON WITH DEMENTIA**

Project Title: **Examining Perceived Stigma in Persons with Dementia**

Research Team: Kathleen Buckwalter, PHD; Megan Liu, BSN; Rebecca Riley, BS, MA

This consent form describes the research study to help you decide if you want to participate. This form provides important information about what you will be asked to do during the study, about the risks and benefits of the study, and about your rights as a research subject.

- If you have any questions about or do not understand something in this form, you should ask the research team for more information.
- You should discuss your participation with anyone you choose such as family or friends.
- Do not agree to participate in this study unless the research team has answered your questions and you decide that you want to be part of this study.

#### **WHAT IS THE PURPOSE OF THIS STUDY?**

This is a research study. We are inviting you to participate in this research study because you have been diagnosed with a disorder that results in progressive memory impairment and may be eligible to participate.

The purpose of this research study is to help understand the impact of stigma on quality of life in persons with progressive memory loss. We also hope to increase our knowledge about any stigma family members of persons with memory loss may experience. We would hope to discover any ways in which the stigma experienced by family members affects the person with memory loss. Ultimately, we are hopeful this study will help us create ways to assist persons with memory loss to manage the stigma they experience with the goal of increasing their quality of life.

#### **HOW MANY PEOPLE WILL PARTICIPATE?**

Approximately 80 people will take part in this study conducted by investigators at the University of Iowa, 40 persons with dementia and 40 family caregivers. Another 80 people (40 persons with dementia and 40 family caregivers) will participate in the study at the University of Illinois, Chicago, for a total of 160 participants at both study sites.

#### **HOW LONG WILL I BE IN THIS STUDY?**

If you agree to take part in this study, your involvement will last for 18 months. The interviews and questionnaires will be administered every 6 months over an 18-month

time frame, for a total of 4 assessments. Each assessment is expected to take about 2 hours of your time.

### **WHAT WILL HAPPEN DURING THIS STUDY?**

If you agree to be in this research, we would ask you to do the following things, at a time and place that is convenient for you:

- Complete an interview including questions about your experiences with stigma.
- Provide demographic data such as your age, educational level, marital status and so forth
- We will also ask you to respond to several questionnaires that reflect your quality of life, including depressive symptoms, anxiety symptoms, your perceived personal control, your physical health, your self-esteem, and the degree to which you participate in activities.
- We will also ask you to complete a measure of your mental ability.
- The interviews and questions will take place at your home or the assisted living facility where you reside. If you prefer, we can also collect the information in a private room at the University of Iowa Hospitals and Clinics in the Geriatric Assessment Clinic or Memory Disorders clinic.
- The information will be gathered with only you and a member of the research team present. Your caregiver will complete similar information separately from you.
- Your participation in this research is voluntary. Your decision whether or not to participate will not affect your current or future relations with the University or the Departments of Geriatric Medicine or Neurology. If you decide to participate, you are free to withdraw at any time without affecting that relationship. You are also free to skip any questions that you would prefer not to answer.
- We will not use any information from your existing or future medical records in this study.
- No family members or health care providers will be given access to the information we collect from you unless you specifically ask that some of the assessment data (for example your mental ability scores) be shared with them.
- If you make a request for the research team to share study data with a family member or care provider then you will have to give permission, in writing, for us to share the requested information with the designated care provider or family member only.
- During the course of the study, you will be informed of any significant new findings (either good or bad) such as changes in the risks or benefits resulting from participation in the research or new alternatives to participation that might cause you to change your mind about continuing in the study. If new information is provided to you, your consent to continue participating in this study will be obtained again.

### **Audio Recording/Video Recording/Photographs**

One aspect of this study involves the possibility of making an audio recording of you. This will be done only to monitor the quality of the interview or assessment. If you agree, the audiotape will be reviewed only by members of the research staff and will be used only for training purposes. You will have the right to review the audiotape, if desired, prior to providing the tape to the research team for review. The audiotape recording is optional and you can still be enrolled in the study even if you do not give permission to be audiotaped. If you are asked to allow the interview to be audiotaped, all tapes will be destroyed immediately after the study is over. No names will appear on the tapes. All tapes will be stored in a locked file cabinet in the research office at the College of Nursing.

Yes  No I give you permission to make audio recordings of me during this study.

### **WHAT ARE THE RISKS OF THIS STUDY?**

You may experience one or more of the risks indicated below from being in this study. In addition to these, there may be other unknown risks, or risks that we did not anticipate, associated with being in this study.

→ Risk of tiring: It is possible that you will become tired during the assessments. The risk of becoming tired is low, however, as many persons with memory loss find the interview interesting and helpful. We will ask you about tiring during the interviews and offer to complete the interview at another time, should tiring occur.

→ Discomfort with testing: At times you may be uncomfortable with some of the testing of your mental abilities that occurs as part of the assessment. This discomfort may be due to some difficulties you may have answering some of the questions. This discomfort is not unusual, but does not occur in all persons with memory loss. To decrease this discomfort, you will be interviewed separately from your family members, with only the researcher present.

→ Participating in other studies: Although you may be able to participate in more than one study at a time, we ask that you inform us of any other research in which you are participating.

Based on our prior research on persons with dementia, the risks of tiring or discomfort are rare (less than 10%), and mild in nature

### **WHAT ARE THE BENEFITS OF THIS STUDY?**

We don't know if you will benefit from being in this study, however, you may benefit by:

- 1) Improving your understanding of the effects of perceived and experienced stigma on a variety of outcomes, including health and depression
- 2) Improving your coping skills and adaptation to memory loss through increased understanding of the impact of stigma on your life, including your participation in social activities
- 3) Having a positive experience and contact with health professionals who are knowledgeable about memory loss and stigma associated with memory loss

### **WILL IT COST ME ANYTHING TO BE IN THIS STUDY?**

You will not have any costs for being in this research study. The assessment will be conducted by an experienced health professional with no costs or fee applied.

### **WILL I BE PAID FOR PARTICIPATING?**

You will be paid for being in this research study. You and your family member will be paid a total of \$10.00 per visit and will be paid at the time of each visit. We will be visiting you four times over an 18 month period, so you and your family member will be paid a total of \$40.00 for the study. You may need to provide your address if a check will be mailed to you. Should you prefer to have the assessment at the Memory Disorders Clinic or Geriatric Assessment Clinic, the costs of parking will be reimbursed to you.

### **WHO IS FUNDING THIS STUDY?**

The National Institute of Nursing Research at the National Institutes of Health is funding this research study. This means that the University of Iowa is receiving payments from the National Institute of Nursing Research to support the activities that are required to conduct the study. No one on the research team will receive a direct payment or increase in salary from the National Institute of Nursing Research for conducting this study.

### **WHAT IF I AM INJURED AS A RESULT OF THIS STUDY?**

- If you are injured or become ill from taking part in this study, medical treatment is available at the University of Iowa Hospitals and Clinics.
- No compensation for treatment of research-related illness or injury is available from the University of Iowa unless it is proven to be the direct result of negligence by a University employee.
- If you experience a research-related illness or injury, you and/or your medical or hospital insurance carrier will be responsible for the cost of treatment.

### **WHAT ABOUT CONFIDENTIALITY?**

We will keep your participation in this research study confidential to the extent permitted by law. However, it is possible that other people such as those indicated below may

become aware of your participation in this study and may inspect and copy records pertaining to this research. Some of these records could contain information that personally identifies you.

- federal government regulatory agencies,
- auditing departments of the University of Iowa, and
- the University of Iowa Institutional Review Board (a committee that reviews and approves research studies)

To help protect your confidentiality, the only people who will know that you are a research subject are members of the research team. No information about you, or provided by you during the research will be disclosed to others without your written permission, except:

- If necessary to protect your rights or welfare (for example, if you are injured and need emergency care or when the University of Iowa Institutional Review Board monitors the research or consent process); or
- If required by law.

When the results of the research are published or discussed in conferences, no information will be included that would reveal your identity. If photographs, videos, or audiotape recordings of you will be used for educational purposes, your identity will be protected or disguised. Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission or as required by law.

All instruments and responses to the interviews will be coded with a number, with no names being on any of the instruments. Your actual name will appear only on this informed consent document. This informed consent document will be the only written material that will link the number assigned to you to your name. All informed consent documents will be kept in a locked research office at the University of Iowa once the document is obtained. Only the members of the research team will have access to these documents. As it is expected that the information will be collected in your home, all of the information will be transported to the research office using a locked, portable file.

Computer files containing your responses to the interview and questionnaires will be developed and will include only the numbers assigned to you. The computerized data files will be password protected and available only to the immediate research staff. If for some reason you want some of the information to be shared with a family member or health care provider, you must give written permission to share this information. Unless you request the information be shared and provide this written permission, your responses will not be shared with anyone outside the immediate research team. Your responses will be stored with the numerical code for approximately 5 years after the completion of the research. This raw data will be stored in file cabinets that are housed in

locked research offices at the College of Nursing at the University of Iowa. Only the immediate research staff members will have access to these data files. After five years, the raw data will be stripped of the numbered codes and all identifying links will be destroyed.

### **WILL MY HEALTH INFORMATION BE USED DURING THIS STUDY?**

No health information from existing medical records will be used in this study

The Federal Health Insurance Portability and Accountability Act (HIPAA) requires the University of Iowa to obtain your permission for the research team to access or create "protected health information" about you for purposes of this research study. Protected health information is information that personally identifies you and relates to your past, present, or future physical or mental health condition or care. We will access or create health information about you, as described in this document, for purposes of this research study. Once the University of Iowa has disclosed your protected health information to us, it may no longer be protected by the Federal HIPAA privacy regulations, but we will continue to protect your confidentiality as described under "Confidentiality."

We may share your health information related to this study with other parties including federal government regulatory agencies, the University of Iowa Institutional Review Boards and support staff, study researchers at the University of Illinois at Chicago and the funding agency, the National Institute of Nursing Research.

You cannot participate in this study unless you permit us to use your protected health information. If you choose not to allow us to use your protected health information, we will discuss any non-research alternatives available to you. Your decision will not affect your right to medical care that is not research-related. Your signature on this Consent Document authorizes the University of Iowa to give us permission to use or create health information about you.

Although you may not be allowed to see study information until after this study is over, you may be given access to your health care records by contacting your health care provider. Your permission for us to access or create protected health information about you for purposes of this study has no expiration date. You may withdraw your permission for us to use your health information for this research study by sending a written notice to Dr. Kathleen Buckwalter, 494B, University of Iowa College of Nursing. However, we may still use your health information that was collected before withdrawing your permission. Also, if we have sent your health information to a third party, such as the study sponsor, or we have removed your identifying information, it

may not be possible to prevent its future use. You will receive a copy of this signed document.

### **IS BEING IN THIS STUDY VOLUNTARY?**

Taking part in this research study is completely voluntary. You may choose not to take part at all. If you decide to be in this study, you may stop participating at any time. If you decide not to be in this study, or if you stop participating at any time, you won't be penalized or lose any benefits for which you otherwise qualify.

### **What if I Decide to Drop Out of the Study?**

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you don't want to answer and still remain in the study. The investigator may withdraw you from this research if circumstances arise which warrant doing so.

Leaving the study early will cause you no harm or discomfort.

### **Will I Receive New Information About the Study while Participating?**

If we obtain any new information during this study that might affect your willingness to continue participating in the study, we'll promptly provide you with that information.

During the course of the study, you will be informed of any significant new findings (either good or bad) such as changes in the risks or benefits resulting from participation in the research or new alternatives to participation that might cause you to change your mind about continuing in the study. If new information is provided to you, your consent to continue participating in this study will be obtained again.

### **Can Someone Else End my Participation in this Study?**

Under certain circumstances, the researchers or the study sponsor might decide to end your participation in this research study earlier than planned. This might happen because in our judgment it is causing you too much discomfort to answer study questions or because the condition of your family member with dementia has become worse such that they are no longer able to answer the questions in the study.

### **WHAT IF I HAVE QUESTIONS?**

We encourage you to ask questions. If you have any questions about the research study itself, please contact: Kathleen Buckwalter, PhD, RN, at 319-353-3019. If you experience a research -related injury, please contact: Kathleen Buckwalter at 319-353-3019.

If you have questions, concerns, or complaints about your rights as a research subject or about research related injury, please contact the Human Subjects Office, 340 College of Medicine Administration Building, The University of Iowa, Iowa City, Iowa, 52242, (319) 335-6564, or e-mail [irb@uiowa.edu](mailto:irb@uiowa.edu). General information about being a research subject can be found by clicking "Info for Public" on the Human Subjects Office web site, <http://research.uiowa.edu/hso>. To offer input about your experiences as a research subject or to speak to someone other than the research staff, call the Human Subjects Office at the number above.

This Informed Consent Document is not a contract. It is a written explanation of what will happen during the study if you decide to participate. You are not waiving any legal rights by signing this Informed Consent Document. Your signature indicates that this research study has been explained to you, that your questions have been answered, and that you agree to take part in this study. You will receive a copy of this form.

Subject's Name (printed): \_\_\_\_\_

**Do not sign this form if today's date is on or after EXPIRATION DATE: 01/22/10.**

\_\_\_\_\_  
(Signature of Subject)

\_\_\_\_\_  
(Date)

### **Statement of Person Who Obtained Consent**

I have discussed the above points with the subject or, where appropriate, with the subject's legally authorized representative. It is my opinion that the subject understands the risks, benefits, and procedures involved with participation in this research study.

\_\_\_\_\_  
(Signature of Person who Obtained Consent)

\_\_\_\_\_  
(Date)



## APPENDIX C

### INFORMED CONSENT DOCUMENT: FAMILY CAREGIVER

Project Title: **Examining Perceived Stigma in Persons with Dementia**

Research Team: Kathleen Buckwalter, PHD; Megan Liu, BSN; Rebecca Riley, BS, MA

This consent form describes the research study to help you decide if you want to participate. This form provides important information about what you will be asked to do during the study, about the risks and benefits of the study, and about your rights as a research subject.

- If you have any questions about or do not understand something in this form, you should ask the research team for more information.
- You should discuss your participation with anyone you choose such as family or friends.
- Do not agree to participate in this study unless the research team has answered your questions and you decide that you want to be part of this study.

#### **WHAT IS THE PURPOSE OF THIS STUDY?**

This is a research study. We are inviting you to participate in this research study because your family member for whom you provide care has been diagnosed with a disorder that results in progressive memory impairment and may be eligible to participate.

The purpose of this research study is to help understand the impact of stigma on quality of life in persons with progressive memory loss. We also hope to increase our knowledge about any stigma family members of persons with memory loss may experience. We would hope to discover any ways in which the stigma experienced by family members affects the person with memory loss. Ultimately, we are hopeful this study will help us create ways to assist persons with memory loss to manage the stigma they experience with the goal of increasing their quality of life.

#### **HOW MANY PEOPLE WILL PARTICIPATE?**

Approximately 80 people will take part in this study conducted by investigators at the University of Iowa, 40 persons with dementia and 40 family caregivers. Another 80 people (40 persons with dementia and 40 family caregivers) will participate in the study at the University of Illinois, Chicago, for a total of 160 participants at both study sites.

#### **HOW LONG WILL I BE IN THIS STUDY?**

If you agree to take part in this study, your involvement will last for 18 months. The interviews and questionnaires will be administered every 6 months over an 18-month

time frame, for a total of 4 assessments. Each assessment is expected to take about 2 hours of your time.

### **WHAT WILL HAPPEN DURING THIS STUDY?**

If you agree to be in this research, we would ask you to do the following things, at a time and place that is convenient for you:

- Complete an interview including questions about your experiences with stigma. We will also ask you to respond to several questions that reflect your knowledge of dementia, your observation of any behavioral symptoms of the person with memory loss, and your depressive symptoms.
- Provide demographic data such as your age, educational level, marital status and so forth
- The interviews and questions will take place at your home or the assisted living facility where you reside. If you prefer, we can also collect the information in a private room at the University of Iowa Hospitals and Clinics in the Geriatric Assessment Clinic or Memory Disorders clinic.
- The information will be gathered with only you and a member of the research team present. Your family member with dementia will complete similar information separately from you
- Your participation in this research is voluntary. Your decision whether or not to participate will not affect your current or future relations with the University or the Departments of Geriatric Medicine or Neurology. If you decide to participate, you are free to withdraw at any time without affecting that relationship. You are also free to skip any questions that you would prefer not to answer.
- We will not use any information from your existing or future medical records in this study, nor those of your family member.

### **Audio Recording/Video Recording/Photographs**

One aspect of this study involves the possibility of making an audio recording of you. This will be done only to monitor the quality of the interview or assessment. If you agree, the audiotape will be reviewed only by members of the research staff and will be used only for training purposes. You will have the right to review the audiotape, if desired, prior to providing the tape to the research team for review. The audiotape recording is optional and you can still be enrolled in the study even if you do not give permission to be audiotaped. If you are asked to allow the interview to be audiotaped, all tapes will be destroyed immediately after the study is over. No names will appear on the tapes. All tapes will be stored in a locked file cabinet in the research office at the College of Nursing.

Yes  No I give you permission to make audio recordings of me during this study.

### **WHAT ARE THE RISKS OF THIS STUDY?**

You may experience one or more of the risks indicated below from being in this study. In addition to these, there may be other unknown risks, or risks that we did not anticipate, associated with being in this study.

→ Risk of tiring: It is possible that you will become tired during the assessments. The risk of becoming tired is low, and many family caregivers find the interview interesting and helpful. We will ask you about tiring during the interviews and offer to complete the interview at another time, should tiring occur.

→ Discomfort with testing: At times you may be uncomfortable with some of the testing of your knowledge of dementia as part of the assessment. This discomfort may be due to some difficulties you may have answering some of the questions. To decrease this discomfort, you will be interviewed separately from your family member, with only the researcher present.

Based on our prior research with family caregivers the risk of tiring or discomfort are rare (less than 10%), and mild in nature

### **WHAT ARE THE BENEFITS OF THIS STUDY?**

We don't know if you will benefit from being in this study. However, the potential benefits to you of participating in this study include:

- 1) The possibility of increasing your understanding of the effects of stigma to you and the overall functioning of your family member with memory loss;
- 2) Improved ability to cope with the effects of stigma;
- 3) Consistent contact with health professionals knowledgeable about the dynamics of family caregiving and progressive memory loss; and
- 4) Increased understanding of how stigma may keep you from being as active and socially engaged as you desire to be.

For future family caregivers and persons with memory loss, the findings of this study may lead to the development of positive activities and programs to decrease the negative effects of stigma.

### **WILL IT COST ME ANYTHING TO BE IN THIS STUDY?**

You will not have any costs for being in this research study. The assessment will be conducted by an experienced health professional with no costs or fee applied.

### **WILL I BE PAID FOR PARTICIPATING?**

You will be paid for being in this research study. You and your family member will be paid a total of \$10.00 per visit and will be paid at the time of each visit. We will be visiting you four times over an 18 month period, so you and your family member will be

paid a total of \$40.00 for the study. You may need to provide your address if a check will be mailed to you. Should you prefer to have the assessment at the Memory Disorders Clinic or Geriatric Assessment Clinic, the costs of parking will be reimbursed to you.

### **WHO IS FUNDING THIS STUDY?**

The National Institute of Nursing Research at the National Institutes of Health is funding this research study. This means that the University of Iowa is receiving payments from the National Institute of Nursing Research to support the activities that are required to conduct the study. No one on the research team will receive a direct payment or increase in salary from the National Institute of Nursing Research for conducting this study.

### **WHAT IF I AM INJURED AS A RESULT OF THIS STUDY?**

- If you are injured or become ill from taking part in this study, medical treatment is available at the University of Iowa Hospitals and Clinics.
- No compensation for treatment of research-related illness or injury is available from the University of Iowa unless it is proven to be the direct result of negligence by a University employee.
- If you experience a research-related illness or injury, you and/or your medical or hospital insurance carrier will be responsible for the cost of treatment.

### **WHAT ABOUT CONFIDENTIALITY?**

We will keep your participation in this research study confidential to the extent permitted by law. However, it is possible that other people such as those indicated below may become aware of your participation in this study and may inspect and copy records pertaining to this research. Some of these records could contain information that personally identifies you.

- federal government regulatory agencies,
- auditing departments of the University of Iowa, and
- the University of Iowa Institutional Review Board (a committee that reviews and approves research studies)

To help protect your confidentiality, the only people who will know that you are a research subject are members of the research team. No information about you, or provided by you during the research will be disclosed to others without your written permission, except:

- If necessary to protect your rights or welfare (for example, if you are injured and need emergency care or when the University of Iowa Institutional Review Board monitors the research or consent process); or
- If required by law.

When the results of the research are published or discussed in conferences, no information will be included that would reveal your identity. If photographs, videos, or audiotape recordings of you will be used for educational purposes, your identity will be protected or disguised. Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission or as required by law.

All instruments and responses to the interviews will be coded with a number, with no names being on any of the instruments. Your actual name will appear only on this informed consent document. This informed consent document will be the only written material that will link the number assigned to you to your name. All informed consent documents will be kept in a locked research office at the University of Iowa once the document is obtained. Only the members of the research team will have access to these documents. As it is expected that the information will be collected in your home, all of the information will be transported to the research office using a locked, portable file.

Computer files containing your responses to the interview and questionnaires will be developed and will include only the numbers assigned to you. The computerized data files will be password protected and available only to the immediate research staff. If for some reason you want some of the information to be shared with a family member or health care provider, you must give written permission to share this information. Unless you request the information be shared and provide this written permission, your responses will not be shared with anyone outside the immediate research team. Your responses will be stored with the numerical code for approximately 5 years after the completion of the research. This raw data will be stored in file cabinets that are housed in locked research offices at the College of Nursing at the University of Iowa. Only the immediate research staff members will have access to these data files. After five years, the raw data will be stripped of the numbered codes and all identifying links will be destroyed.

### **WILL MY HEALTH INFORMATION BE USED DURING THIS STUDY?**

No health information from existing medical records will be used in this study

The Federal Health Insurance Portability and Accountability Act (HIPAA) requires the University of Iowa to obtain your permission for the research team to access or create "protected health information" about you for purposes of this research study. Protected health information is information that personally identifies you and relates to your past, present, or future physical or mental health condition or care. We will access or create health information about you, as described in this document, for purposes of this research study. Once the University of Iowa has disclosed your protected health information to us,

it may no longer be protected by the Federal HIPAA privacy regulations, but we will continue to protect your confidentiality as described under "Confidentiality."

We may share your health information related to this study with other parties including federal government regulatory agencies, the University of Iowa Institutional Review Boards and support staff, study researchers at the University of Illinois at Chicago and the funding agency, the National Institute of Nursing Research.

You cannot participate in this study unless you permit us to use your protected health information. If you choose not to allow us to use your protected health information, we will discuss any non-research alternatives available to you. Your decision will not affect your right to medical care that is not research-related. Your signature on this Consent Document authorizes the University of Iowa to give us permission to use or create health information about you.

Although you may not be allowed to see study information until after this study is over, you may be given access to your health care records by contacting your health care provider. Your permission for us to access or create protected health information about you for purposes of this study has no expiration date. You may withdraw your permission for us to use your health information for this research study by sending a written notice to Dr. Kathleen Buckwalter, 494B, University of Iowa College of Nursing. However, we may still use your health information that was collected before withdrawing your permission. Also, if we have sent your health information to a third party, such as the study sponsor, or we have removed your identifying information, it may not be possible to prevent its future use. You will receive a copy of this signed document.

### **IS BEING IN THIS STUDY VOLUNTARY?**

Taking part in this research study is completely voluntary. You may choose not to take part at all. If you decide to be in this study, you may stop participating at any time. If you decide not to be in this study, or if you stop participating at any time, you won't be penalized or lose any benefits for which you otherwise qualify.

### **What if I Decide to Drop Out of the Study?**

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you don't want to answer and still remain in the study. The

investigator may withdraw you from this research if circumstances arise which warrant doing so.

Leaving the study early will cause you no harm or discomfort.

### **Will I Receive New Information About the Study while Participating?**

If we obtain any new information during this study that might affect your willingness to continue participating in the study, we'll promptly provide you with that information.

During the course of the study, you will be informed of any significant new findings (either good or bad) such as changes in the risks or benefits resulting from participation in the research or new alternatives to participation that might cause you to change your mind about continuing in the study. If new information is provided to you, your consent to continue participating in this study will be obtained again.

### **Can Someone Else End my Participation in this Study?**

Under certain circumstances, the researchers or the study sponsor might decide to end your participation in this research study earlier than planned. This might happen because in our judgment it is causing you too much discomfort to answer study questions or because the condition of your family member with dementia has become worse such that they are no longer able to answer the questions in the study.

### **WHAT IF I HAVE QUESTIONS?**

We encourage you to ask questions. If you have any questions about the research study itself, please contact: Kathleen Buckwalter, PhD, RN, at 319-353-3019. If you experience a research-related injury, please contact: Kathleen Buckwalter at 319-353-3019.

If you have questions, concerns, or complaints about your rights as a research subject or about research related injury, please contact the Human Subjects Office, 340 College of Medicine Administration Building, The University of Iowa, Iowa City, Iowa, 52242, (319) 335-6564, or e-mail [irb@uiowa.edu](mailto:irb@uiowa.edu). General information about being a research subject can be found by clicking "Info for Public" on the Human Subjects Office web site, <http://research.uiowa.edu/hso>. To offer input about your experiences as a research subject or to speak to someone other than the research staff, call the Human Subjects Office at the number above.

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This Informed Consent Document is not a contract. It is a written explanation of what will happen during the study if you decide to participate. You are not waiving any legal rights by signing this Informed Consent Document. Your signature indicates that this

research study has been explained to you, that your questions have been answered, and that you agree to take part in this study. You will receive a copy of this form.

Subject's Name (printed): \_\_\_\_\_

<b>Do not sign this form if today's date is on or after EXPIRATION DATE: 01/22/10.</b>	
_____	_____
(Signature of Subject)	(Date)

**Statement of Person Who Obtained Consent**

I have discussed the above points with the subject or, where appropriate, with the subject's legally authorized representative. It is my opinion that the subject understands the risks, benefits, and procedures involved with participation in this research study.

\_\_\_\_\_

(Signature of Person who Obtained Consent) (Date)



**APPENDIX D****EVALUATION TO SIGN AN INFORMED CONSENT**

Subject Identifier: \_\_\_\_\_ Date of Evaluation: \_\_\_\_\_

## Directions

Make a subjective judgment regarding item 1. Ask the subject questions 2-5 and record responses. The evaluator may use different wording in asking the questions in order to assist the subject's understanding.

1. Is the subject alert and able to communicate with the examiner? Yes \_\_\_ No \_\_\_

2. Ask the subject to name at least two potential risks of participating in the study.

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3. Ask the subject to name at least two things that he/she will be expected to do during the study.

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4. Ask the subject to explain what he/she would do if he/she no longer wanted to participate in the study.

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5. Ask the subject to explain what he/she would do if he/she experienced distress or discomfort during the study.

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Evaluator's Signature

It is my opinion that the subject is alert, able to communicate, and gave acceptable answers to the questions above.

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Evaluator's Signature

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Date

## APPENDIX E

## PERCENTAGE, FREQUENCY, AND QUOTES OF THEMES

Themes (n=9)	Percentage	Frequency	Quotes
Adaptation	88.9%	10	<ol style="list-style-type: none"> <li>1. Well, like I say, you always wish things were different but my feeling is that you have two choices in this sort of thing. You either deal with it and do the best you can or you sit in the corner and mope.</li> <li>2. I've cut back on my social networking a little bit just so I can be around the house more, but I'm making up for that with picking up some of the slack of, you know, household maintenance that John used to do that he doesn't do so I do it now. I have more to do here at home so it's taken place of some of the social stuff but that's okay.</li> <li>3. Something that you gradually get used to is being responsible for a parent and I think it's a gradual thing and it becomes more of, I don't want to say a burden, but it definitely increases and the disease progresses and I think I've adapted to that.</li> <li>4. I know that there are things I need to do that I didn't do before around the house. To know that there's thing you can't do that you used to do as far as traveling and sometimes social life, I've had to adjust. I can load and unload the dishwasher blindfolded now.</li> <li>5. I don't think about it much, and if I do, I just, I've adjusted to the fact that it's gonna continue, so I've adapted to it, I guess you could say. If I could change it to where she doesn't have what she has, that's what we would do, but I</li> </ol>

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			<p>can't change it... so there is no use to...uh... fixating on that. And so what I gotta do is continue to do things that occupy my mind, where that's not the concern. I'm not trying to avoid it I'm just trying to realize it for what it is...and deal with it.</p> <p>6. Let's see, to get out of the house because it gets a little boring in there. Just to go have coffee and visit with people and try to keep things as normal as possible.</p> <p>7. I think it's only social.</p> <p>8. Just enjoyment, something different, to get out. I love my dad. I don't just like to go to the nursing home.</p> <p>9. To eat, (Laughs) and you know to see some of our friends. We usually call up and see if they're doing anything a certain night and get together but I don't know how long we'll be able to do that. Not because of her, it's because of our friend's wife.</p> <p>10. Oh, because I'm aware that I'm already depressed and socially I need to get away from her and my work.</p>
<b>Support Seeking</b>	77.8%	11	<p>1. I feel that it is helpful to be able to talk to friends and family about it.</p> <p>2. Close friends or people who otherwise have the same experience perhaps with some of the same illnesses with their family.</p> <p>3. My friends...one of the advantages of being my age, 60, is most of my peers, that'd be people my age, have recently or are constantly going through the same issues. That's probably my best support system.</p> <p>4. My peers.</p>

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5. Most people I know are, have a family member with some type of illness. Maybe not dementia or Alzheimer's but other serious illness. So it's something at my age that we talk about.
  6. Probably I have several friends who have parents or a spouse in a nursing home and so we share our war stories and I think it's kind of like a support group. You know we tell what happened and how we handled it and the outcome so I learn things from this.
  7. Most of my friends, many of my friends are in my age group and they're going through sort of the same thing so it becomes easier and easier the more people that I know.
  8. Our age bracket because they're putting their parents in care facilities and dealing with a lot of the same things.
  9. Our friends and our immediate family and they're very supportive. My grandsons are 25 and 22 and I always get hugs from them no matter where we're at, in a restaurant or what, we hug when they come in and they give me a hug when they leave. They're very loving children, 25 year old children.
  10. Family.
  11. Well mostly groups of family, I'm the most comfortable with.

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**Social Isolation** 55.6% 11

1. I am a little uncomfortable if he is with me. Just because he requires certain needs and my mind is focusing on him and what he's doing and what he might need. That takes away from socializing much, you know, when we're in groups of people.
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2. I've cut back on my social networking a little bit just so I can be around the house more...
  3. I guess I've done more walking on my own. You know when I have to be close to home anyway I'll just go out for walks. I guess that would be part of the biggest thing. I do the yard work and the gardening. That passes a lot of time and I work Sudoku's every night.
  4. I think the only time I've noticed a difference would be things that involved the two of us like we used to golf together a lot with other couples and that of course had to end; mainly activities that we would do together with couples. That's kind of become less.
  5. It just means reducing of time that I have to socialize and do other things. You just don't get around to everybody that you'd like to.
  6. Well we have slowed it down tremendously from what we used to do, but we still go to restaurants. We haven't been to any plays or anything like we used to like Circa 21 and we had season tickets to the symphony and we don't do that anymore. I think we keep about as much social, you know if she wants to do it. A lot of times she doesn't want to leave the house. When we do it works out pretty well, but we've got to walk more.
  7. I'm quieter; it's hard for me to believe this, not when I'm out. Then I'm usually the same. I'll talk to this person as I always have.
  8. I haven't changed too much. Just quieter around the house because she doesn't feel good or would like
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			<p>to get some sleep and then when we watch the television we hardly ever talk. I have the clicker and she's very patient with me on that.</p> <p>9. Well, behavior problems are awkward, and I just don't talk about it.</p> <p>10. Well, I don't think I have as much time as I used to, because she takes a lot of time and I'm beginning to cut back on work too. I do have a good friend and we do have lunch together and another friend that we talk on the phone, and I don't change that. I try to keep up with all friends, but it gets a little hard on time.</p> <p>11. Um, we may not go to some things that other people are involved in because she's got to go to bed at 8 o'clock or if it's gonna go past that I, there's no use to get reckless (inaudible)...so, we are only going to do things where other people are aware of her limitations.</p>
<b>Internalized Shame</b>	55.6%	10	<p>1. I don't really talk about him with other people.</p> <p>2. Well I just only have one close friend that I would trust with information and she's real supportive too so.</p> <p>3. Yeah, well to other people but to family and the people I talk to I'm comfortable with.</p> <p>4. Yes, mom and my sister. Mostly my mother and my sister because they can't talk about it but that's not that uncommon. My nephew can't even make eye contact with me. I've been there since he was born and I can't even make...I haven't made eye contact with him.</p> <p>5. Well, you know it's hand and glove with the physical disability</p>

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			and just really wish you could interact like you always did being able to do things with him. It's not so easy to get him out in a group of people because of his physical frailty also the confusion. It's just not worth upsetting him. So it confines him which is a frustration. We'd like to include him in more things that we do but we can't.
			6. Friends yes but acquaintances I don't think I feel comfortable with.
			7. Friends yes and acquaintances I don't know them that well. I don't think I need to express families' problems. I really don't see acquaintances that often.
			8. No, No just friends if they're close.
			9. I feel very awkward, other than the fact that she has the disease. I just don't talk about it...if they ask questions like how she is doing, I just say oh, pretty good. She's in a very good humor all of the time.
			10. If appropriate.
<b>Unstable Mood of Caregivers</b>	44.4%	8	1. Negatively, major negatively. I find myself angry, frustrated, short, you know, impatient. That's the word, impatient.
			2. I am absolutely restless. Sometimes if I get too, when I meditate, sometimes my thoughts will go toward these issues. It interrupts my meditation and that's not good, but I am definitely more angry; frustrated and angry.
			3. Much less forgiving of other people's shortcomings.
			4. Moody, did I include moody?
			5. It's a lot of baggage. That's a good word for it; baggage. We all have baggage, but your parents getting old is one piece of baggage you just can't put aside. People say, "Oh you just have you focus and

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- throw the excess baggage away, simplify.” That’s too much. Less is better. I have stopped working with less is better and you can’t throw this baggage out. It’s your family. I can’t throw it out so I’m forced to have to deal with it.
6. Fluctuating mood, uh, and it’s, if I had to do it I could do it all over again, had to do it all over again, I would barely be able to anticipate, if the experience is exactly the same, however, if it were a totally different experience, that wouldn’t have been (inaudible) now you have to learn how to adapt to that..., so I just, I uh,...I’m comfortable where we are at right now, and learn that’s it’s gonna get, thing the (inaudible) less of the person that I’ve known all my life. Less, and less, and less. What’s worse is some days she won’t know who I am. There’s nothing that won’t stop that, even the medications won’t slow it down (inaudible)....
  7. I think I’m maybe a little more irritable then I used to be. I know that happens because I have many more things that I have to do now.
  8. I guess I should say sometimes I do feel a little resentful of my brother and sister that they don’t have part of this responsibility. Especially when...I think it’s up to them to call and I also use e-mail a lot to tell them about dad’s condition and if they don’t reply it really irritates me. It just, I mean, at least they could say thanks for the information and so I think that, you know, that in reality I know they have busy lives but I think they could take a moment out to be
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			a little bit more supportive of me perhaps and my husband. I mean my husband has taken on a big role in this, too. So I guess when you're talking about moods that does come into play not every day but just once in a while.
<b>Social Rejection</b>	22.2%	2	<ol style="list-style-type: none"><li>1. The younger the friend is, the more difficult it is because they're obviously not there yet. They don't quite understand. They try.</li><li>2. Um, not unless they were embarrassed by it, you know too embarrassed to talk about it. Um, but if I sense they are avoiding it, then I would just leave the subject alone.</li></ol>

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