Resilience among Older Adults with Cognitive Impairment and Informal Caregivers

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Abstract

The concept of resilience, which indicates people's capability of using resources in difficult circumstances in order to reduce or prevent negative effects and achieve positive outcomes, has given a new perspective to the scientific literature on the experience of late-life memory loss and the experience of caring for persons with memory loss. The current research was guided by incorporation of resilience into the stress process model for assessing personal and caregiver burden associated with mild and more severe memory loss. I conducted two studies to investigate the association of protective factors with the well-being of people with dementia or mild cognitive impairment and their caregivers. The first study focused on the well-being of older persons with dementia (PwDs). I employed data from a large national sample of older adults to examine how the perceived social cohesion of neighborhoods affects quality of life among people with and without cognitive impairment in conjunction with their engagement in valued leisure activities. Findings revealed that, regardless of cognitive health status, all participants who perceived high neighborhood social cohesion reported better quality of life along with more participation in valued activities. However, PwDs reported significantly lower perceived neighborhood social cohesion, less involvement in valued activities, and poorer quality of life than persons without cognitive impairment. The second study focused on the well-being of caregivers for older persons with mild cognitive impairment (PwMCIs). I used dyadic data from families dealing with mild cognitive impairment to examine how well-being of caregivers for PwMCIs differed according to whether PwMCI-caregiver dyads had similar or different perceptions of the PwMCIs' cognitive impairment severity. Caregivers reported lower caregiving burden when they and PwMCIs had a similar cognitive impairment representation, or when caregivers rated the

PwMCIs’ cognitive functioning more positively than the PwMCIs rated themselves. Also, PwMCIs’ and caregivers' perceptions, and their concordance or discrepancy in those perceptions, varied across the multiple domains related to MCI symptoms. These findings demonstrate that care dyads' perception of MCI-related deficits is not a unitary construct, and that the context of PwMCIs’ and caregivers’ dyadic illness appraisals is significantly associated with the caregivers' well-being. Taken together, the results of these two studies illustrate the value of considering resilience processes in people with cognitive impairment and their caregivers. Examining dimensions of resilience, in association with assessment of the intersecting effects of personal, interpersonal, and environmental factors, provides additional information about the effects of cognitive impairment on older adults’ well-being and the effects of assisting someone with cognitive impairment on caregiver well-being.

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General Audience Abstract

Resilience indicates people's ability to successfully adapt to or bounce back from life adversity by using personal, social, and environmental resources. Resilience helps explain what makes some people with dementia and their caregivers tolerant of changes in memory functioning and able to adapt to difficulties associated with dementia. I conducted two studies to investigate the role of protective resources in buffering negative effects of memory loss on people with dementia and their caregivers. The first study compared people with and without dementia to find out how their sense of belonging to the community and their participation in valued leisure activities influenced their quality of life. Regardless of whether they had memory loss or not, all the people with a stronger sense of belonging in the community participated in more leisure and valued activities and, in turn, had better quality of life. However, compared to cognitively healthy people, those with dementia had lower sense of belonging, less participation in leisure activities, and poorer quality of life. These findings indicate that people with dementia may feel excluded from their community and experience barriers to participation in valued activities. Nevertheless, feeling that one belongs in the neighborhood and participating in valued leisure activities is important for well-being of older adults both with and without cognitive impairment. The second study examined how the well-being of caregivers for persons with mild cognitive impairment (MCI) differed according to whether caregivers and their care recipients had similar or different views on the care recipients' memory problems. When they both had similar views or the caregivers had a more positive view than their care recipients did, the caregivers reported higher well-being. This finding suggests that some caregivers for people with MCI understand how the person with MCI views their own memory loss, and others either are not aware of all the memory

loss symptoms or choose to ignore some of them. In either case, these caregivers feel less burdened than those who think their loved one's symptoms are worse than the person with memory loss believes. Support for these caregivers is needed to help them cope better with the memory loss in their loved one. The results from these two studies provided valuable evidence about resilience in older adults facing memory loss and their caregivers. Being resilient can help people with dementia and their caregivers manage or overcome the difficulties associated with dementia.

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Resilience among Older Adults with Cognitive Impairment and Informal Caregivers

Introduction

Advanced medical technology and better living environments improve survival rates, while fertility rates decline. These transitions result in demographic changes such as an increased population of older adults with a longer life expectancy than in the past. Accompanying these trends is an increased likelihood of surviving older adults being at risk for chronic illnesses that interfere with their functioning and contribute to their need for support and help. Among the chronic illnesses interfering with older adults' independent lives is dementia, a condition especially likely to impose caregiving burdens on their families and friends.

The *Diagnostic and Statistical Manual of Mental Disorders (5th ed.; DSM–5;* American Psychiatric Association [APA], 2013) lists dementia as an umbrella term, indicating either a mild or major cognitive impairment interfering with one's independence in performing daily living activities (APA, 2013*).* Alzheimer's disease is the most common dementia, accounting for 60%-80% of all dementia cases in the United States (Alzheimer's Association [AA], 2016). Other types of dementia include vascular dementia, Lewy body disease, frontotemporal dementia, and dementia comorbid with Down syndrome (APA, 2013). When memory, language, thinking, and judgment problems seem more severe than typical age-related changes, they could indicate an intermediate pre-dementia phase referred to as mild cognitive impairment (MCI) (Burns & Morris, 2008). However, given that dementia is a slow, progressive disorder, it is difficult for older adults and their families to determine the point at which a non-normative decline in cognitive ability could be viewed as MCI or signal the onset of dementia. However, criteria for the clinical judgement of MCI have been established by the National Institute on Aging (NIA) and the AA in 2011.

A national report in 2016 from the Alzheimer's Association about the prevalence and mortality rate of dementia revealed the significance of memory loss in the United States. In 2016, an estimated 5.5 million American elderly persons, or 1 in 10 adults aged 65 or older, were living with dementia. Because the baby boom generation has begun to enter the age group at high risk for dementia, projections of older adults with dementia reach 13.8 million people by 2050 (AA, 2016). Further, death from dementia increased by 89% between 2000 and 2014, with dementia listed as the fifth-leading cause of death among older adults in a nationally representative sample (AA, 2016). Dementia-related expenditures in the United States are substantial, anticipated to total $259 billion in 2017, 67% of which is paid by Medicare (AA, 2016). The total per-person health care and long-term care payments in 2014 were three times higher for older adults with dementia than for those without dementia (AA, 2016).

As the population of people with dementia grows rapidly, more people are offering unpaid care to a family member and friend who are living with dementia. Informal caregivers helping people with dementia (PwDs) were close to 46% of all caregivers who provided unpaid care to older adults in 2016 (Wolff, Spillman, Freedman, & Kasper, 2016). According to the 2016 report of the Alzheimer’s Association, more than 15 million unpaid American caregivers spent 18.2 billion hours in dementia caregiving and these efforts could be valued at 230.1 billion dollars (AA, 2016). Responsibilities of dementia caregivers include assistance with activities of daily living (ADLs) (e.g., bathing, toileting, eating) and instrumental activities or daily living (IADLs) (e.g., banking, shopping, meal preparing). Particularly, dementia caregiving is more intensive and often spans a longer period of time, compared to caregiving for people with other conditions. According to a study by Kochanek, Murphy, Xu and Tejada-Vera (2016), while 70% of people with dementia were receiving help from their caregivers with ADLs or household activities, only 20% of older adults without dementia were receiving the same kind of help. When it comes to duration of dementia caregiving, 38% of family caregivers for community-living people with dementia reported six or more years of caregiving (World Health Organization, 2004). As such, dementia caregiving requires a higher level of labor intensity for a relatively longer time than other caregiving, implying it potentially has a significant impact on dementia caregivers' health and well-being (e.g., Schulz, O'Brien, Bookwala, & Fleissner, 1995).

Along with the difficulty and duration of assisting someone with dementia increasingly being recognized by scholars of dementia care, literature on PwDs and related care issues has flourished. However, scholars' perspective on this issue has mostly been limited because they often approached dementia with a medical or pathological point of view, or conceptualized dementia caregiving as a chronic stressor (Pruchno & Gitlin, 2012). Thus, studies of PwDs have been focused largely on the causes, symptoms, and treatment of the disease, whereas comparatively fewer studies have been performed on everyday life and well-being experienced by PwDs. Regarding studies of dementia caregivers, scholars have focused on how dementia caregiving interferes with the caregivers' daily lives and exacerbates their health problems and interferes with their well-being (e.g., Pinquart & Sorensen, 2003; Pruchno & Gitlin, 2012; Schulz & Sherwood, 2008). That is, the negative aspects of dementia experiences and caregiving have been the main emphasis in dementia care research.

However, scholarly attention to the positive aspects of dementia experiences and caregiving is beginning to emerge. Scholars interested in positive aspects have paid attention to the phenomena demonstrating that dementia care not only increases stress and burden, but also enhances certain positive dimensions of caregiving (e.g., Lawton, Moss, Kleban, Glicksman & Rovine, 1991). Understanding the orthogonality of positive and negative aspects of dementia care has led scholars to focus more on the positive aspects of dementia care. Not only that, scholars have also begun to acknowledge that dementia experiences perceived by PwDs themselves should be taken into account when assessing the effects of memory loss, and that such information should be reflected in recommendations for improving the well-being of those with dementia (e.g., Lawton, 1994; and Kitwood, 1992). Although scholarly effort to examine positive aspects of dementia experience and care is minor compared to the more typical focus on negative aspects, this new perspective has nevertheless extended the discussion of the impact of dementia on persons with the condition and their care providers.

In this context, the concept of resilience has received attention from gerontology scholars. The main idea of resilience is that people are capable of achieving positive adaptation in the face of risk or adversity (Kaplan, 2006; Rutter, 2007; Wright & Masten, 2006). Dementia researchers have begun to consider how to apply the construct of resilience for better understanding of caregiving experiences. Dementia may be an overwhelming risk for problems and difficulties in PwDs' and their caregivers' lives because of its unpredictable prognosis with eventual serious consequences for cognitive, social, and physical functioning, and significant impact on the lives of both PwDs and their caregivers. Yet an emphasis on resilience shifts the focus to use of protective resources and coping strategies that can contribute to positive adaptation while minimizing or avoiding negative aspects of the situation. As such, applying the concept of resilience to the context of dementia care makes it possible to focus on how PwDs and caregivers can manage the adversity of dementia. This conceptual approach offers another facet of dementia care research beyond the main focus on negative aspects that have been studied so far.

Therefore, utilizing the concept of resilience, the current studies examined the role of protective factors that enable PwDs and caregivers to be more tolerant of their given risk, thus potentially reducing the negative impact of dementia and sustaining well-being for as long as possible. The first study, focusing on those diagnosed with dementia, examined how neighborhood social cohesion perceived by community-living PwDs affected their participation in activities they value, thus contributing to their well-being. The second study, turning attention to caregivers of persons in the early stage of memory loss, used dyadic data to examine how caregivers' well-being was affected over time by having similar or different perceptions of the severity of the memory loss in relation to the views of loved ones diagnosed with mild cognitive impairment.

Literature Review

Well-being of People with Dementia and Caregivers

When dementia occurs in older adults, they experience a decline in their physical and cognitive abilities. Because of the characteristics of dementia, which may progress gradually and continuously, there are more people with dementia who live in the community and experience cognitive and physical changes in their daily life than there are those who enter care facilities and start treatment at the onset of the disease. According to the 2016 national report by the Alzheimer's Association, 58% of elderly persons with dementia live in the community rather than in a care facility. Of those, 75% live with someone and the remaining 25% live alone. Although it is difficult to stop or slow cognitive impairment, research continues to explore how PwDs sustain and improve their quality of life when living in the community (Grossberg et al., 2010; Hall et al. 2009, Heward, Innes, Cutler, & Hambidge, 2016; Hill, Kolanowski, & Kurum, 2010, Swan, 2012; Vickrey et al., 2006; Voisin & Vellas, 2009). These studies have emphasized the value of active disease management, including appropriate use of dementia care strategies; cooperation among healthcare professionals, persons with dementia, and caregivers; appropriate treatment of any comorbidities; continued participation in meaningful and valued activities; and maintenance of social connections. These findings point to the importance of addressing the overall well-being of PwDs, not only their cognitive or physical symptoms.

In 2016, the Alzheimer's Association reported that 15.9 million informal caregivers were providing care for PwDs without material compensation. Dementia caregivers attend to PwDs' needs in performing daily routines and physical activities. Compared with caregivers of people without dementia, caregivers for those with dementia provide help in a more extensive range of daily living functions as well as for a longer time (AA, 2016). These intense caregiving demands have implications for caregivers' physical and mental well-being. They have higher stress levels (Mausbach, Chattillion, Roepke, Patterson, & Grant, 2013), a higher prevalence of depressive symptoms (Sallim, Sayampanathan, Cuttilan, & Chun-Man, 2015; Schulz, O'Brien, Bookwala, & Fleissner, 1995), lower quality of life (Bremer et al., 2015), more cognitive problems (Vitaliano, Ustundag, & Borson, 2016), higher mortality rates (Christakis & Allison, 2006), and higher susceptibility to disease and health problems (Dassel, Carr, & Vitaliano, 2015; Goren, Montgomery, Kahle-Wrobleski, Nakamura, & Ueda, 2016; Välimäki et al., 2016; Vitaliano, Zhang, & Scanlan, 2003) compared to caregivers for people without dementia and non-caregivers. Despite these wide-ranging risks, informal caregiving, usually by family members, is vital due to individual and family preferences and societal needs. Informal caregiving has always been regarded as the first source of available care for people with chronic illnesses, including dementia (Pruchno & Gitlin, 2012). Informal caregivers are usually first to acknowledge elderly relatives' physical and cognitive deterioration and provide initial care for them. This occurs not only because formal care and institutionalization are regarded as last resorts for the care of older people (Brody, 1985), but also because people and societies assume that family takes primary responsibility for personal care needs, such as household tasks, transportation, shopping, and financial support for medical and other types of formal care. Given society's expectations of informal caregivers, research on their well-being is warranted so that caregivers can sustain both their caregiving roles and their own health and well-being.

Critique of Dementia Care and Well-being Research to Date

A large number of studies on dementia have been carried out for many years. However, from the early days of the research to the present, the main focus has been on negative aspects of caregiving that PwDs and caregivers experience (Pruchno & Gitlin, 2012). Moreover, in dementia care research, the unit of analysis has been mainly individuals rather than the broader contexts in which PwDs are embedded, including care dyads, their families, and their communities (Pruchno & Gitlin, 2012).

In fact, research on PwDs and well-being has only emerged in recent years. It has been complicated for researchers to define what it means to live well with dementia, and many scholars have doubts about the accuracy and reliability of well-being self-reports from PwDs (Clarke & Wolverson, 2016). Thus, in the study of PwDs, the medical point of view has been applied mainly to address questions about why dementia occurs, what diagnostic characteristics it has, and how it should be controlled. However, Clarke and Wolverson (2016), Lawton (1994), and Kitwood (1992) have put well-being issues of PwDs in the foreground by arguing that dementia experiences perceived by PwDs themselves should be taken into account and that such information should be reflected in the direction of care to improve their quality of life. These voices, accompanied by innovations in measures for PwDs, have led some scholars to begin studying the well-being or quality of life issues of PwDs. However, many studies still focus only on the development and use of well-being measures to argue or assure validity of the tools

(Clarke & Wolverson, 2016; Venturato, 2010), so more understanding of the positive and resilient aspects of PwDs' experiences is needed.

In contrast to a relatively small number of PwDs' well-being studies, research on dementia caregivers' well-being has flourished. However, these studies have focused mainly on the negative aspects of caregiving because many scholars conceptualized dementia caregiving as a chronic stress that is associated with negative outcomes (Pruchno & Gitlin, 2012). Thus, much effort has gone toward identifying what stressors are experienced by caregivers (e.g., patients' deficits and dependencies, role conflicts, financial problems, constrained social life) as well as how these stressors adversely affect the physical and psychological well-being of caregivers (e.g., physical deterioration, anxiety, depression) (Bertrand, Fredman, & Saczynski, 2006; Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999).

Some scholars, however, have paid attention both to how caregiving increases stress and burden and also to positive dimensions of caregiving (e.g., Lawton, Moss, Kleban, Glicksman & Rovine, 1991), including caregiving satisfaction, sense of togetherness, and feeling of accomplishment (cf. Carbonneau, Caron & Desrosiers, 2010). As this orthogonality of positive and negative aspects of caregiving has been confirmed via empirical studies, more researchers have begun to investigate positive outcomes that dementia caregivers could experience, as well as paying attention to buffering factors that increase positive outcomes and/or reduce negative outcomes by mediating or moderating the effect of caregiving stress (Carbonneau et al., 2010; Zarit, 2012). This extended view of caregiving has recently begun to gain attention, and the need for more research continues.

Another critique of overall dementia research is the lack of consideration of the broader contexts that correlate with dementia-related experiences of PwDs and caregivers. The study unit mainly used in previous dementia research has been the individual (Pruchno & Gitlin, 2012). However, all individuals are nested within a larger and layered context (e.g., family, community), and the interactions occurring among individuals or among individuals and the broader environment influence one's life and vice versa (Bronfenbrenner, 2009; Lawton & Nahemow, 1973). Even in the case of dementia, a person with dementia and his or her caregiver are nested in a care dyad, and their interdependence influences their individual lives and well-being. In turn, the dyads further affect multiple lives of the family members and friends around them. Also, even a larger context that includes communities and societies has an impact on the families, care dyads, and individuals in them.

Resilience: An Extended Perspective of Dementia Care and Well-being Research

Therefore, for a better understanding of the well-being of PwDs and dementia caregivers, it is necessary to consider positive aspects of their dementia experiences as well as broader contexts that may influence their well-being. With respect to these suggestions, the concept of resilience may be useful to guide further research on dementia and well-being. Resilience secures attention from gerontologists and chronic illness researchers in their efforts to improve understanding of patients with chronic illnesses and their caregivers. Since the main idea of resilience is that people are capable of achieving positive adaptation in the face of risk or adversity (Kaplan, 2005; Rutter, 2007; Wright & Masten, 2006), this concept can shed light on the experiences of PwDs and dementia caregivers who encounter the unfavorable situation of dementia. The following sections discuss the concept of resilience and its application to dementia and well-being research.

Resilience and Dementia. Resilience has received growing scholarly attention, regarded as a useful construct because it provides theoretical and methodological guidance for studying many research issues and identifying practical implications of the research (Kaplan, 2005). Although the debate to establish all the elements of resilience is ongoing, scholars agree that resilience can be defined as an adaptive process by which persons utilize protective resources in the context of risk or adversity that triggers a substantial threat (Kaplan, 2005; Rutter, 2007; Wright & Masten, 2006). The concept of resilience explains how people successfully endure threatening situations, so a fundamental question resilience scholars have raised is: What factors enable people who encounter risk or adversity to be more tolerant and eventually to show positive adaptation and outcomes (Rutter, 2006)? Applying this question to the context of dementia care makes it possible to explore what resources resilient dementia patients and caregivers have, what resilience processes they use in handling their risks, and the extent to which they achieve positive adaptation.

The resilience process is identified by three key elements including risk, protective factors, and positive outcomes (Smith & Hayslip, 2012). Risk indicates an event or a context that contains a likelihood of undesirable outcomes in a particular population (Wright & Masten, 2006). Protective factors refer to individual and environmental resources that mediate or moderate the negative effect of risk, as well as consequently help at-risk individuals achieve positive outcomes (Goldstein & Brooks, 2005; Smith & Hayslip, 2012). Positive outcomes in the resilience process indicate not only maintenance of psychological and physical functioning, but also recovery from a risk to achieve better functioning than before (Ong, Bergeman, & Boker, 2009; Szanton & Gill, 2010). Thus, positive outcome can be either increases in desirable or adaptive outcomes (e.g., focusing on helpful emotions instead of on destructive ones) or decreases in negative outcomes (e.g., avoiding stress-induced illness).

The context of experiencing dementia can also be mapped with the key elements of resilience; each resilience element assessed in research on dementia care points to different research questions study participants. First, having dementia is a risk to PwDs as well as to their caregivers. Since dementia is a non-normative decline in cognitive and behavioral abilities, this undesirable change often increases PwDs' dependency on others for help and support, which subsequently might bring constraints and burden to the caregivers. Common risk factors among caregivers for PwDs include the greater likelihood of having physical illness and slower recovery (Fagundes, Gillie, Derry, Bennett, & Kiecolt-Glaser, 2012), psychological vulnerability (Bertrand, Fredman, & Saczynski, 2006), and work-related difficulties and lack of personal time (Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999). Second, use of protective factors (e.g., memory aids to help PwDs navigate the environment as independently as possible) can mediate the effect of adversity (PwDs' cognitive and behavioral deficits and related caregiving workload). Third, PwDs and their caregivers might even achieve an optimal adaptation and positive outcome from their experiences (e.g., working together on tasks instead of separately) (Goldstein & Brooks, 2005). Although little dementia research has focused on resilience and its protective factors (Coon, 2012), a variety of studies have identified positive outcomes, including studies of caregivers' problem-focused coping style (Garity, 1997), caregivers' self-efficacy and locus of control (Contador, Fernández-Calvo, Palenzuela, Miguéis, & Ramos, 2012), care dyad's relationship closeness (Fauth et al., 2012), and social support from family and friends (Wilks & Croom, 2008).

The positive outcomes reported in resilience studies range from the optimization or maintenance of human capacities to recovery from negative consequences of risk and adversity (Ong et al.,2009; Szanton & Gill, 2010). For this reason, positive outcomes have been regarded as a decrease or absence of negative outcomes as well as an increase or presence of positive outcomes (Vanderbilt-Adriance & Shaw, 2008). However, the number of dementia care research studies looking into positive outcomes for caregivers is small. Tarlow and colleagues (2004) developed a measure to assess caregivers' positive outcomes (Positive Aspects of Caregiving scale: PAC, Tarlow et al., 2004) and tested it with family caregivers for people with Alzheimer's disease. Caregivers reported they often felt useful, appreciated, needed, positive toward life and self, confident, and strong. Also, they reported strengthened relationships with their relatives.

As such, resilience provides an extended perspective for viewing dementia care differently than in the past. Of course, dementia gradually reduces cognitive and behavioral abilities in PwDs and providing care to them can diminish physical and psychological well-being among dementia caregivers. However, as the resilience process explains, someone encountering adversity can generate positive outcomes as well as utilize protective factors to reinforce the positive outcomes or reduce negative outcomes. As dementia and well-being research has focused mainly on the negative aspects of dementia experiences with the research question, "How does dementia deteriorate PwDs' physical and cognitive conditions or caregivers' well-being?" the other facet of dementia care has been overlooked. One's experience in dealing with dementia or dementia care can be also examined by considering resilience.

Resilience and Dementia in Broader Context. Many resilience scholars agree that resilience is a process involving the complex person-environment interrelation. The biopsychosocial resilience model introduced by Smith and Hayslip (2012) also demonstrates contextual resources including interpersonal relationships and environmental support along with individual attributes. Interpersonal and environmental resources include, for example, social network, family and friend support, feelings of belonging and being connected, and community attachment (Smith & Hayslip, 2012). Also, Aldwin and Igarashi (2012) indicated in a review paper on the ecological perspective of resilience during late adulthood that contextual resources known to affect one's resilience include housing, transportation, public understanding of older people, and one's social network. The 2007 World Health Organization initiative, "Age-Friendly Cities," addressed the role of social and built environments in promoting aging well by facilitating positive adaptation or resilience across the life span. Resilience and dementia care research also can adopt this contextual view by paying more attention to PwDs' and dementia caregivers' interpersonal and environmental transactions.

Theoretical Framework of Resilience

Several theoretical frameworks and perspectives support the importance of the resilient aspects of caregiving for caregivers' physical and mental health. Particularly, this study uses an integrated model of two theoretical frameworks, namely Smith and Hayslip's (2012) biopsychosocial resilience model, and Pearlin and colleagues' stress process model (Pearlin, Mullan, Semple, & Skaff, 1990). Smith and Hayslip (2012) adjusted the biopsychosocial resilience model in their review paper on resilience in adulthood and later life using the literature on older adult resilience. In keeping with the elements of resilience described previously, their model incorporated risk (or adversity), protective factors, and positive outcomes (Smith & Hayslip, 2012).

Pearlin and colleagues' stress process model (1990) is added to the risk and adversity part of the resilience model. The stress process model was developed with a primary focus on the dementia care context. Even though it focuses on dementia caregivers' stress process, there are meaningful implications for PwDs' stress process as well. That is, this model provides a comprehensive understanding of possible stressors in the entire dementia context. An important feature of the model is the notion of spillover effects (i.e., secondary stressors), which are caused by the primary stressor of the care recipient's cognitive impairment. Well-elaborated series of stressors in Pearlin's model could be integrated into Smith and Hayslip's biopsychosocial resilience model to help explain the characteristics of risk and adversity that PwDs and their caregivers may have.

While Pearlin and colleagues raised coping and social support as mediators to intervene in the impact of caregiving stress, Smith and Hayslip emphasized the role of the protective factors that can lead to positive outcomes even in a risk situation, and provided a detailed description of them. The biopsychosocial resilience model demonstrates protective factors at three levels, individual, interpersonal, and environmental (Smith & Hayslip, 2012). Protective factors at the individual level involve personality traits, psychological qualities, and individual coping; those at interpersonal and environmental levels include social network, family and friend support, feelings of belonging and being connected, and community attachment (Smith & Hayslip, 2012). The positive role of protective factors was highlighted in the resilience model as an influence on outcomes. Protective factors moderate or mediate vulnerabilities and risks, and therefore, lead to a more positive adaptation than would be the case if the protective factors were unavailable (Cohler, Stott, & Musick, 1995; Goldstein & Brooks, 2005). Thus, the current study examined the protective factors that enable PwDs and caregivers to be more tolerant of their given risk, with the potential of showing positive adaptation and outcomes. The resilience model of PwDs and their caregivers that was used as a conceptual framework for the current study is presented in Figure 1.

Based on this model, the overview of the resilience process of PwDs and their caregivers could broaden the viewpoint that has been focused mainly on negative aspects of the dementia experience. Of course, PwDs suffer from physical and psychological distress due to the memory loss and other problems associated with dementia, and their caregivers experience the burden and cost of caregiving for their PwDs. However, by paying more attention to protective factors, the difficulties of PwDs and caregivers might be alleviated and positive dimensions of dementia experiences might emerge. Also, this model displays PwDs' and their caregivers' resilience process together, and considers a series of nested contexts related to the protective factors. These points suggest that an individual's experience of dementia not only can change the individual's life, but also can influence and be influenced by his or her caregiver's life and, moreover, many other people's lives and even the larger social environment.

Brief Overview of Following Studies

To address the research suggestions for dementia and well-being that were discussed previously, two studies were conducted. Both studies focused on the role of protective factors in improving the well-being of people with dementia or MCI (PwMCIs) and caregivers in their dementia experiences. The first study examined how neighborhood social cohesion perceived by community-living PwDs affected their participation in valued activity and their well-being. The second study looked at how caregiver well-being changed when care dyads had similar or different perceptions of the PwMCIs' illness severity.

Study 1. This study elucidated how neighborhood social cohesion (a shared connection, trust, and feelings of belonging in physical living places: Aldwin & Igarashi, 2012) influenced PwDs' engagement in valued activities (e.g., visiting family or friends, religious meetings, classes or clubs, and going out for enjoyment) which may lead to positive outcomes. This study showed an ecological aspect of resilience in which a larger system, the community, influences individual-level resilience processes, and emphasized the need for collective efforts to increase community-level resilience. To examine the study question with a representative sample for better generalizability of the findings, the National Health and Aging Trends Study, a data set with a nationally representative sample, was utilized.

Study 2. In the second study, MCI care dyads' agreement on cognitive and behavioral deficits of PwMCIs was proposed as a protective factor to be associated with the caregivers' well-being. This study showed the interpersonal aspect of dementia caregiving, focusing on how shared illness representations between PwMCIs and their care partners (CPs) are related with the CPs' perceived caregiving burden. The study findings provided evidence that PwMCIs and their CPs need to take a teamwork approach to MCI management and psychological adjustment. To examine the given study question, data from a purposive sample of 61 MCI care dyads who were part of the Virginia Tech MCI research program were utilized. This study will be submitted to an academic journal, *Dementia,* in the future.

Study 1. Neighborhood Social Cohesion, Valued Activities and Quality of Life among Elders with and without Cognitive Impairment

Introduction

Significance of Community in Later Adulthood

Communities have resources and characteristics that could explain variability in individuals' well-being, including psychological and physical health (Morenoff, Sampson, & Raudenbush, 2001). As Bronfenbrenner, a pioneer of ecological system theory, elaborated in his classic paper (1992), individuals are nested in larger systems of the environment (i.e., family, neighbors, and community), and the transactional processes in which they engage with their environments influence their life. Among the various environmental elements, neighborhood in particular is a proximal environment that may be more crucial to older populations living in a community, compared to those in other age groups (Garin et al., 2014; Yen, Michael, & Perdue, 2009; Lawton, 1982). The reason for this is that older adults are known to stay longer at a particular home and in a given community than younger persons, due not only to retirement but also to physical and cognitive impairment, which often restrict their activities (Clarke & Nieuwenhuijsen, 2009). Thus, the types and extent of activities and social interactions of older people in their daily living can be influenced strongly by the nature of the surrounding neighborhood (Shaw, Krause, Liang, & Bennett 2007), which may be a more influential proximal environment for them than for younger persons.

Neighborhood Social Cohesion and Well-being

One key aspect of a desirable neighborhood environment is neighborhood social cohesion. Neighborhood social cohesion indicates the extent of interdependence and solidarity within neighborhoods (Kawachi & Berkman, 2000). Such cohesion represents a sense of community, a shared connection, trust, and feelings of belonging in physical living places (Aldwin & Igarashi, 2012; Kawachi & Berkman, 2000).

Although the community environment for older adults has received increasing scholarly attention, researchers have narrowly focused on material or built environments (e.g., neighborhood socioeconomic status, housing, street disorder, transportation) rather than on the social environment including neighborhood social cohesion (Cagney et al., 2009; Choi, Kim, DiNitto, & Marti, 2015). Despite the small amount of research on the topic of social environment, the positive effect of socially cohesive neighborhoods on older adults has been reported. For example, older adults living in communities with higher neighborhood social cohesion showed better physical (Dong & Bergren, 2016; Kim & Kawachi, 2006) and mental health (e.g., Ahern & Galea, 2011; Brown et al., 2009; Choi et al., 2015; Gale, Dennison, Cooper, & Sayer, 2011; Mair, Roux, & Morenoff, 2010) as well as higher subjective well-being (e.g., feelings of usefulness and accomplishment, quality of life, life satisfaction) (Cramm, van Dijk, & Nieboer, 2013; Elliott, Gale, Parsons, & Kuh, 2014; Engel et al., 2016; Friedman, Parikh, Giunta, Fahs, & Gallo, 2012; Gale et al., 2011).

In the results of the studies using subjective well-being as an outcome variable, the positive effect of neighborhood social cohesion on older adults' subjective well-being (e.g., positive affect, psychological functioning, enjoyment, personal mastery, and quality of life) is consistently revealed regardless of individual-level risk factors (i.e., demographic factors, physical and mental health, disability, and individual-level social support). However, all but Friedman and colleagues' (2012) study used samples from Europe (i.e., Cramm et al., 2013; Elliott et al., 2014; Gale et al., 2011) or Canada (Engel et al., 2016); thus, more research is needed on U.S. samples. Also, and more importantly, although previous studies on neighborhood social cohesion and subjective well-being revealed a meaningful correlation between the two, the pathway between them among older people has not yet been elucidated. Some researchers and scholars have speculated on this pathway, in which communities with a high level of neighborhood social cohesion are characterized by connectedness, trust in others, and knowing each other well, and these characteristics help the older residents to become more engaged in the community (Cagney et al., 2009; Cramm et al., 2013; Thompson & Krause, 1998). Such engagement encourages the older residents to initiate and sustain active participation in social activities (Cagney et al., 2009) or to have more opportunities to get help and support from the neighborhood (Thompson & Krause, 1998).

Indirect Effect of Valued Activities between Neighborhood Social Cohesion and Well-being

One key hypothesized pathway from neighborhood social cohesion to well-being is through increasing older adults' leisure or valued activities (Trieber et al., 1991; Lindström, Hanson, Östergren, & Berglund, 2000; Lindström, Hanson, & Östergren, 2001; Poortinga, 2006; Putnam, 1995). This is because the characteristics of engagement that accompany the leisure activity correspond to the positive aspects that highly neighborhood-social-cohesive communities offer to older people.

Leisure activities are productive, meaningful, and social activities that require further physical or social engagement beyond routine and functional activities in everyday life (Adams, Leibbrandt, & Moon, 2011). Leisure activities are known to increase physical activity to stimulate the body system and help maintain physical and cognitive health (e.g., James, Boyle, Buchman, Barnes, & Bennett, 2011; Haslam, Cruwys, Milne, Kan, & Haslam, 2015; Kåreholt, Lennartsson, Gatz, & Parker, 2011). In addition, they create social support and interactions that help to relieve older adults' stress, encourage emotional bonding (e.g., Aquino, Russell, Cutrona, & Altmaier, 1996), and provide new roles and goals to help older adults maintain their identity and sense of mastery (e.g., Adams et al., 2011; Flatt & Hughes, 2013; Newman, Tay, & Diener, 2014). These benefits of leisure activity may be synergistically maximized by high levels of neighborhood social cohesion in communities. When older adults live in highly neighborhood-socially-cohesive communities, they may be motivated to explore broader environment and various resources and to take collective actions for mutual benefit by sharing and adopting health-related behaviors (Kawachi & Berkaman, 2001, Kim, 2008; Putnam, 1995). In doing so, they may be encouraged to participate in productive, generative, and civic activities (Cagney et al., 2009; Kawachi & Berkman, 2000, 2001), which may include leisure activities, thus improving their quality of life.

This pathway may also be partially supported by activity theory (Havighurst, 1961; Lemon, Bengtson, & Petersen, 1972). This theory asserts that older adults' quality of life can be maintained when they remain socially active by participating in meaningful activities and social interactions, despite the loss of their social roles due to retirement and physical and cognitive limitations. Thus, living in a socially-cohesive community featuring active and meaningful social interactions and cooperation for mutual benefit may help the residents to remain socially active and maintain a higher quality of life.

As such, while there has been some research and theoretical discussion of the partial relationship (though not of the overall mechanism) with regard to neighborhood social cohesion, leisure activity, and quality of life, empirical studies on these three factors (i.e., the pathway between neighborhood social cohesion and well-being through leisure or valued activity) are still limited. A longitudinal study using nationally representative data by Choi et al. (2015) found cross-sectional associations between higher perceived neighborhood social cohesion and lower depressive symptoms through a higher frequency of going outside for female older adults. Nevertheless, this study was insufficient for understanding the role of leisure activity in the relationship between neighborhood social cohesion and well-being among older adults.

To address this research gap, the current study examined how the neighborhood social cohesion perceived by older adults affects their quality of life through engagement in leisure activities. Moreover, this study also addressed another limitation of existing studies, most of which are based on the overall population without consideration of cognitive impairment among older adults. According to a review paper investigating studies on the association between neighborhood environment and cognitive functions (Wu, Prina & Brayne, 2015), only 15 studies published up to 2014 examined that association in particular. The authors attributed this scarcity to the fact that people with dementia are more likely to dwell in residential care facilities or institutions and have high mortality rates; however, a recent annual report by the Alzheimer Association (2016) noted that a large proportion (58%) of older adults with Alzheimer's disease and dementia were living in the community. Also, older people with dementia not only have a desire to continue meaningful engagement but also to engage in some leisure activities despite their cognitive limitations (Genoe & Dupuis, 2012; 2013; Menne, Johnson, Whitlatch, & Schwartz, 2012; Phinney & Moody, 2011; Parisi, Roberts, Szanton, Hodgson, & Gitlin, 2015; Roland & Chappell, 2015). Therefore, more research in this regard is needed to comprehend the experiences of the cognitively unhealthy older population living in the community. For this reason, before discussing the specific research aims of the current study, experiences of community, leisure activities, and well-being in older adults with dementia are reviewed.

Experiences of Older People with Cognitive Impairment: Neighborhood Social Cohesion, Valued Activities, and Well-being

The prevalence of dementia among the older population is continuously increasing, and many older people with cognitive impairments currently reside in communities (Alzheimer's Association, 2016), where they may experience social exclusion and isolation. For example, people with dementia may feel loneliness and fear of external activity (Innes, Page, & Cutler, 2015) and may sense that they are not meaningfully engaged with the community (Alzheimer's Society, 2014; Innes, 2009). Such social exclusion and isolation hinder people with dementia from being exposed to physical, social and mental stimulation (Adams et al., 2011) and from receiving necessary support and services (Blackstock, Innes, Cox, Smith, & Mason, 2006), ultimately resulting in further deterioration in their psychological and physical health (Yevchak, Loeb, & Fick, 2008) and reduced quality of life (Everard et al. 2000). To break this adverse cycle, it is very important to comprehend the characteristics of neighborhood of the communities in which people with cognitive impairment or dementia currently live. In particular, research on neighborhood social cohesion can reveal ways to help people with dementia feel a sense of belonging to the community and live a meaningful life in their local community as long as possible.

Since existing studies on community characteristics experienced by community-living people with dementia are focused on the built environment (e.g., housing quality, home modifications, and accessible community infrastructure; Wu et al., 2015), a thorough search of the relevant literature yielded no solid evidence on the relationship between neighborhood social cohesion (community cohesion or sense of community) and subjective well-being in older people with dementia. According to the available research on social exclusion experienced by community-dwelling older adults with dementia (e.g., Innes, 2009, Everard et al., 2000), one's experiences of social exclusion from the wider community can lead to social isolation and loneliness and can also generate low levels of self-esteem and poor quality of life. Such findings imply the importance of a socially cohesive community for people with dementia, who can easily experience social exclusion and isolation due to their physical and cognitive disabilities.

Regarding the experiences of leisure or valued activities, research has shown that older adults with dementia not only have a desire to continue meaningful engagement but also engage in some leisure activities despite cognitive limitations (Genoe & Dupuis, 2012; 2013; Menne, Johnson, Whitlatch, & Schwartz, 2012; Phinney & Moody, 2011; Parisi et al., 2015; Roland & Chappell, 2015). For instance, using a nationally representative sample (*N*=6675) from the National Health and Aging Trends Study (NAHTS), Parisi and colleagues (2015) compared the perceived importance of leisure activity and participation status between older adults with and without cognitive impairment. They found that both groups valued leisure activities (i.e., visiting family or friends; going to religious services; joining clubs, classes or organized activities; and going out for enjoyment) and that visiting family or friends was the most important activity to both groups; however, older adults with cognitive impairment rated the importance lower and had lower participation rates. Some studies have also reported that leisure activities have a positive effect on well-being for people with dementia, consistent with the findings among cognitively healthy elderly people (Dupuis et al., 2012; Genoe & Dupis, 2011, 2013; Roland & Chappell, 2015). According to these studies, people with dementia reported social connectivity, physical and mental well-being, pleasure, and feelings of freedom and of being oneself as benefits of leisure activities.

However, the studies mentioned above are limited in their ability to provide clues about the indirect effect of leisure activities between neighborhood social cohesion and well-being among older people with dementia, as they only provide descriptive information about the leisure activities of people with dementia by assessing the meaning or importance they ascribed to leisure or valued activities. Also, several studies (e.g., Dupuis et al 2012; Genoe & Dupis, 2011, 2013; Phinney & Moody, 2011) provided exploratory findings through qualitative research about the benefit of leisure activities experienced by people with dementia; thus, more evidence should be obtained using larger samples and standardized measures. Moreover, research has not yet clarified why their experience of leisure activities differs from that of normal older people (e.g., Parisi et al., 2015), nor what factors explain the variability of experience of leisure activities among people with dementia. In particular, in order to encourage older people with dementia to participate more actively in meaningful leisure activities to improve their quality of life, neighborhood characteristics, including neighborhood social cohesion, need to be examined in this regard.

Aims of the Current Study

To fill the above-discussed research gaps, this study examined whether neighborhood social cohesion, one of features of a desirable social environment, was associated with subjective well-being through participation in valued activities among older adults with and without cognitive impairment. The aims of the current study are as follows:

Aim 1. The current study examined similarities and differences between elders with and without cognitive impairment in the levels of perceived neighborhood social cohesion, the number of participated valued activities, and the levels of perceived quality of life.

Hypothesis 1. Compared to participants in the typical group, those in the cognitive impairment group report significantly lower levels of neighborhood social cohesion, participate less in valued activities, and report lower levels of quality of life.

Aim 2. The current study proposed a model to explain the relationships between neighborhood social cohesion, and quality of life through participation in valued activity, and tested the validity of the model.

Aim 3. The current study explored how the associations between the constructs of interest would differ across typical and cognitive impairment groups.

Hypothesis 3a. Structural model invariance is satisfied in both the typical and cognitive impairment groups.

Hypothesis 3b. Higher neighborhood social cohesion is associated with participation in more valued activities in both the typical and cognitive impairment groups.

Hypothesis 3c. Participation in more valued activities is associated with higher quality of life in both the typical and cognitive impairment groups.

Methods

Original Database

This study utilizes data from the National Health and Aging Trends Study (NHATS), a longitudinal and nationally representative study providing scientific resource data on American older adults' health and functioning. The NHATS sample was drawn from the list of Medicare enrollees aged 65 and older. The first annual interview was initiated in 2011, and the fourth interview was completed in 2015. NHATS has replenished participants to maintain its representativeness of older enrollees of Medicare. Round 1 began with a sample of 8,245 Medicare beneficiaries, while 4,737 elderly participated in the Round 4 study.

Study Sample

The current study focuses on elderly people, both with and without cognitive impairment, who had resided in their current community (at Round 1) for more than a year, and were self-respondents. The reason for selecting only self-respondents is that the outcome variables used in this study are not asked of proxy-respondents. The number of elderly people who met these criteria was 6,931; however, missing data on the main study variables limited the sample size. Therefore, the analytic sample for the current study was 5,974, including 4,763 elders without cognitive impairment and 1,211 elders with cognitive impairment. The cognitive impairment subsample is further divided into those with probable dementia *(n* = 443, 37% of cognitive impairment sample) and those with possible dementia (*n* = 768, 63% of cognitive impairment sample), according to the NHATS dementia classification scheme (Kasper, Freedman, & Spillman, 2013).

NHATS Dementia Classification

The NHATS uses two bases of information to classify self-reporting participants with cognitive impairment: physicians' diagnoses and cognitive tests. The diagnoses may show either dementia or Alzheimer's disease. The latter tests assess three domains of cognitive ability: memory, orientation, and executive function.

First, all self-reporting participants are asked whether they have been physician-diagnosed with dementia or Alzheimer's disease. Respondents who did have such physician diagnoses were included in the *probable dementia* category. Respondents without physicians' diagnoses were asked to respond to the NHATS cognitive tests of memory, orientation, and executive function.

To assess memory, participants are given a list of 10 words on a computer screen, then asked to recall in any order as many as possible; after orientation and executive function tests, they are again asked to recall the words in any order. The range of these two memory tests is 0 to 10. To assess orientation, participants are asked, without being given any information, to tell the date, month, year, and day of the week and to name the current President and Vice President; each component of their answers is scored as 1 for a correct answer or 0 for an incorrect answer. To assess executive function, participants are asked to draw within 2 minutes a clock showing 11:10; these drawings are scored by NHATS team members according to accuracy and depiction, using a score range of 0 to 5. All three domains of cognitive functioning indicate the extent of cognitive impairment. In each cognitive test, the scale differs; thus, final scores per domain are standardized for further analysis. If a resulting score in a domain was at or below 1.5 standard deviations from the mean, *cognitive impairment* was defined. Impairment in 1 domain resulted in *possible dementia* being defined. Some studies used the NHATS criteria for possible dementia (i.e., 1.5 *SD* below the mean in 1 domain) to classify persons with mild cognitive impairment or cognitive impairment but not dementia (Seshadri et al., 2011; Morris, 2012). Impairment in at least two domains out of three would result in *probable dementia* being defined.

The participants with cognitive impairment in the current study were those who had cognitive impairment *and* lived in the community. Further, using a broad definition that also covers mild cognitive impairment is required to capture the population of interest. Thus, data for the current study are from self-respondents displaying both *probable* and *possible* dementia.

Measures

This study used the self-reported data from participants with cognitive impairment. Cognitive impairment could impede the respondents' ability to provide reliable and valid responses in the study; however, many studies have revealed that the deficit is mainly related to awareness of cognitive-impairment-related memory, executive functioning, and language abilities (e.g., Agnew & Morris, 1998; Green, Goldstein, Sirockman, & Green, 1993; Zanetti, 1999). Brod and colleagues (1999) suggested that people with dementia may be aware of their feelings despite impairment to their awareness of their cognitive deficits. They also reported high correlations between the answers provided by dementia patients and those provided by their proxy respondents on measures of mood, energy, health, and sense of identity, despite low correlations for measures of cognitive abilities. Since assessments of neighborhood social cohesion and quality of life in the current study measure subjective perceptions and feelings, I assumed that participants with cognitive impairment or dementia were able to provide reliable self-reports.

Neighborhood Social Cohesion. Neighborhood social cohesion was rated by participants who currently lived in the community and had lived in the same place for at least one year prior to data collection. Three statements — "People in this community know each other well," "People in this community are willing to help each other," and "People in this community can be trusted" — were given with 3-point response scales (0 = "do not agree", 1 = "agree a little", and 2 = "agree a lot"). This measure was adapted from the social cohesion and trust measure originally developed by Sampson, Raudenbush, and Earls (1997). Cronbach's alpha for this measure was 0.74. Based on the suggested cutoffs for normality (Skewness > |2|, Kurtosis > |7|; from Cohen et al., 2003), this variable did not violate univariate normality assumption.

Valued Activities. Sample members' participation in valued activities was measured for generative and social activities related to well-being beyond the ability to carry out essential self-care and household activities (Freedman, 2009). Participants indicated whether they had taken part in the following four activities in the preceding month: visiting friends or family, attending religious services, joining club meetings or group activities, and going out for enjoyment (e.g., to dinner or a movie). The number of activities in which a participant engaged in the last month was computed (Range: 0-4). The reliability and validity of the list of activity items was confirmed using a purposive sample that included participants with cognitive decline (Freedman et al., 2011). This variable was treated as a continuous variable and did not violate normality assumption.

Quality of Life. Quality of life was used as a well-being outcome. Participants rated their agreement with the following four items: My life has meaning and purpose, I feel confident and good about myself, I gave up trying to improve my life a long time ago, and I like my living situation very much. Responses were provided on a 3-point Likert scale ranging from 0 (agree a lot) to 2 (do not agree at all). Based on a reliability check using Cronbach's alpha, this measure of all four items was 0.54, which is fairly low. To get a higher Cronbach's alpha, items were removed iteratively until the scales reached a satisfactory value. The third item was deleted, and Cronbach's alpha increased to 0.63. This variable was treated as a continuous variable. Based on the suggested cutoffs for normality (Skewness > |2|, Kurtosis > |7|; from Cohen et al., 2003), this variable violated the univariate normality assumption (Skewness range: -2.44 to -2.35). This non-normality was adjusted by using a statistical estimation technique — maximum likelihood estimation with robust standard errors (MLR).

Data Analysis

Analyses for Aim 1 were performed using STATA 14.0 (Stata Corp, College Station, TX), and analyses for Aims 2 and 3 were conducted via structural equation modeling (SEM) using Mplus 7.4 (Muthén & Muthén, 1998-2012). All estimates presented in the current study were adjusted by applying the NHATS specified sampling weight to take into account the sampling design and nonresponses.

Aim 1. To examine similarities and differences between elders with and without cognitive impairment on neighborhood social cohesion, participation in valued activities, and well-being

To determine the similarities and differences between the typical and cognitive impairment groups on the study variables, Multivariate Analysis of Variance (MANOVA) was conducted. The dependent variables were neighborhood social cohesion, participation in valued activities, and well-being outcomes. A significant MANOVA test indicates that the typical and cognitive impairment groups' ratings on the study variables are significantly different when the correlations between the variables are considered. Given a significant overall *F*-test, paired *t*-tests or chi-square tests were conducted on each variable to determine the magnitude of differences between the typical and cognitive impairment groups' ratings on neighborhood social cohesion, participation in valued activities, and well-being.

Aim 2. To construct a model based on the literature review and test the validity of the model

Structural equation modeling (SEM) was utilized to construct a model based on the literature review. After the model had been formulated, confirmatory factor analysis was used to test each group separately to determine whether the measurement of the latent variables was psychometrically sound. Given the appropriate measurement model, the structural portion of a full SEM involving relationships among the latent variables was tested for each group.

A maximum likelihood estimation with robust standard errors (MLR) approach was utilized to estimate parameters. To evaluate the adequacy of the model fit, Satorra-Bentler scaled chi-square statistics (S-B χ^2: Satorra & Bentler, 2001) produced by MLR estimator, the Root Mean Squared Error of Approximation (RMSEA; Bentler, 1995; Brown & Cudeck, 1993; Steiger & Lind, 1980) and the Comparative Fit Index (CFI; Bentler, 1990) were used. RMSEA values of 0.06 or less indicate good model fit, while values from 0.06 to 0.08 indicate acceptable model fit (Hu & Bentler, 1999). The CFI values over 0.90 indicate a well-fitting model (Bentler, 1992).

Aim 3. To test measurement and structural model invariance between elders with and without cognitive impairment

With the well-fitting full structural models (baseline models) generated from the preceding analyses, a multigroup comparison was performed to test the equivalence of the causal structures across typical and cognitive impairment samples. To do so, configural invariance is first tested using the baseline models in which no parameter constraints are made. If the configural invariance model yields a good overall model fit, the measurement invariance model in which factor loadings are constrained to be equal across groups is tested. The overall model fit of the measurement invariance model was compared to that of the configural model using S-B χ^2 difference test and changes in RMSEA and CFI to examine the equivalence of factor loadings between the groups. The S-B χ^2 difference test examines whether the addition of constraint parameters (here, factor loadings) to the unconstrained model generates a significant increase in the value of the χ^2 statistic, which indicates worsened model fit. That is, when an χ^2 difference test is significant, it demonstrates that the typical and cognitive impairment groups are not invariant on the parameters that have been equally constrained. Although the S-B χ^2 difference test was significant, changes in RMSEA and CFI were used to further test model invariance. Because chi-square tests are strongly influenced by sample size, those with very large samples could be statistically significant although no absolute difference exists between the baseline and nested models. For this reason, researchers (Cheung & Rensvold, 2002; Meade, Johnson, & Braddy, 2008; Chen, 2007) suggest that approximate model fit indexes (i.e., CFI, RMSEA) should be considered instead of the significance test for model invariance used with large samples. Thus, in the current study, following the most stringent criteria, when changes in CFI values less than or equal to .002 (or ΔCFA $\leq$ .002; Meade et al., 2008) *and* in RMSEA value less than or equal to .015 (or ΔRMSEA $\leq$ .015; Chen, 2007) both occurred, the constraint parameters were regarded as invariant in both groups. If the results from the S-B χ^2 difference test and changes in RMSEA and CFI yield measurement invariance, the analysis proceeds to test the structural model invariance for associations between the factors. Finally, indirect effects from neighborhood social cohesion through valued activities to quality of life were compared to examine whether this effects were significantly different between the two groups. For all steps of the invariance test, factor means were fixed to 0 in each group for identification.

Results

Demographic characteristics and descriptive responses of the total sample and the typical and cognitive impairment groups are presented in Table 1.1. Correlation coefficients among study variables are shown by group in Table 1.2. It is noteworthy that participants in the cognitive impairment group, compared to those in the typical group, have greater racial and ethnic diversity, lower education, more mobility help from caregivers when going out, and more ADL or IADL limitations. Elderly people in the cognitive impairment group reported mostly lower ratings on neighborhood social cohesion and quality of life. For participants in both typical and cognitive impairment groups, visiting in person with friends and family was the most frequently performed activity, followed by going out for fun, attending religious services, and participating in organized activities such as classes and clubs. However, the cognitive impairment group's participation rates were lower than those of the typical group in all activities. Regarding the number of activities in which elders participated, more than 60% of those in the typical group had 3 or 4 activities, but only about 40% of those in the cognitive impairment group had 3 or 4 activities.

Aim 1. To examine similarities and differences between elders with and without cognitive impairment on neighborhood social cohesion, participation in valued activities, and well-being outcomes

A MANOVA was used to examine whether differences between the typical and cognitive impairment groups existed on the key study variables, including neighborhood social cohesion, participation in valued activities, and well-being. According to the Wilks' statistic, the overall multivariate test was significant [$\Lambda = 0.94$, $F(10, 5966) = 49.76$, $p < .001$], which means that the participant's group has an effect on those variables. Independent sample *t*-tests or chi-square tests were used to compare the group means on the key study variables (Table 1.1). According to those tests, elderly people in the cognitive impairment group showed significantly lower ratings on most of the study variables than did elderly people in the typical group (Hypothesis 1).

Neighborhood social cohesion. The mean score of each neighborhood social cohesion item was compared between the typical and cognitive impairment groups. The groups did not differ in their perception that people in the community know each other well [$t\ (5973) = 0.62$, $p = 0.536$]. Regarding perceived willingness of community members to help each other and trustworthiness of community members, those in the typical group showed significantly higher agreement than did those in the cognitive impairment group [t (5973) = -5.10, p < .001 for help; t (5973) = -4.45, p < .001 for trust].

Valued activities. Chi-square tests were used to determine whether the typical and cognitive impairment groups differed in the number of valued activities that participants attended or engaged in during the previous month. Significant group differences were found in the number of valued activities in which they participated, with the typical group reporting more activities [χ^2 (1, 5973) = 63.02, p < .001].

Quality of life. The mean score of each quality of life item was compared between the typical and cognitive impairment groups. Elderly people in the cognitive impairment group rated their quality of life significantly lower than did those in the typical group on all three items assessing the meaning and purpose of life [t (5973) = -7.64, p < .001], feeling self-confident [t (5973) = -7.98, p < .001], and liking one’s living situation [t (5973) = -5.74, p < .001].

Aim 2. To construct a model based on the literature review and test the validity of the model

The second aim of this study was to construct a model drawn from the literature review to explain the relationships among neighborhood social cohesion, participation in valued activities, and quality of life among participants. Three latent variables were formulated — 1) neighborhood social cohesion (independent variable), 2) valued activities (indirect effect variable) and 3) quality of life (dependent variable) — and causal relationships among them were postulated.

The constructed model is shown in Figure 1.1. Neighborhood social cohesion was a latent exogenous variable including three indicators from the neighborhood social cohesion questionnaire, with each measuring a different aspect of neighborhood social cohesion: People in this community (a) know each other well, (b) are willing to help each other, and (c) can be trusted. An indirect effect latent variable, valued activities, was created to measure the number of valued activities that participants performed in the last month with an observed indicator. A dependent variable, quality of life, was composed of three indicators denoting participants' agreement on each item on the quality of life questionnaire: (a) My life has meaning and purpose, (b) I feel confident and good about myself, and (c) I like my living situation very much. Also, to control relevant variables that might confound the relationship between neighborhood social cohesion and quality of life though participation in valued activities, five control variables were included in the model: age, sex (female = 1, male = 0), race/ethnicity (white, non-Hispanic = 1, other = 0), education (college level or higher = 1, less than college = 0) and number of ADL and IADL disabilities. The potential confounding variable of receiving mobility help was not included as a control variable due to lack of variability in the variable.

To check if the measurement of the latent variables was psychometrically sound, confirmatory factor analyses were conducted separately for the typical and the cognitive impairment groups (Table 1.3). The measurement models for both the typical [S-B$\chi^2_{(32)}$ = 217.74, CFI = 0.96, RMSEA= 0.04] and cognitive impairment groups [S-B$\chi^2_{(32)}$ = 156.10, CFI = 0.92, RMSEA= 0.06] exhibited good fit. All the standardized factors loadings were large enough to retain and were statistically significant for both the typical (values ranged from 0.47 to 0.84) and cognitive impairment groups (values ranged from 0.58 to 0.90).

Given that the measurement models showed a good fit to the data, full structural models involving relations among latent variables were subsequently tested for both typical and cognitive impairment groups without further modification. The model fit indices for the typical group met the criteria for good fit [S-B$\chi^2_{(33)}$ = 237.84, CFI = 0.95, RMSEA= 0.04], and those for the cognitive impairment group provided a reasonable fit to the data [S-B$\chi^2_{(33)}$ = 183.90, CFI = 0.90, RMSEA= 0.06] (Aim 2). All path coefficients of the structural portion of the model involving key latent variables (i.e., neighborhood social cohesion, valued activities, and quality of life) were statistically significant in both groups. When participants with and without cognitive impairment perceived a high level of neighborhood social cohesion in their community, they were likely to have participated in significantly more types of valued activities in the preceding month. Those who had been more committed to valued activities showed a significantly higher quality of life. Thus, participants' perception of the neighborhood influenced their participation in valued activities, which in turn affected their quality of life. The control variables were significantly associated with the key latent variables. All parameter estimates of the paths are presented in Table 1.4.

Aim 3. To test invariance between elders with and without cognitive impairment

All invariance testing results are presented in Table 1.5. First, configural invariance was tested using the well-fitting full structural model obtained from the Aim 2 analyses (Model 1). All parameters were freely estimated, but the same observed variables loaded on the same factors and the same path structures were established across both groups. The results indicated that Model 1 fit the data well statistically [S-B$\chi^2_{(66)}$ = 455.460, CFI = 0.938, RMSEA= 0.045], indicating that the pattern of fixed and free parameters is equivalent across groups. Thus, subsequently, measurement invariance was tested by constraining all factor loadings as equal across the typical and cognitive impairment groups (Model 2). This analysis showed a good model fit [S-B$\chi^2_{(70)}$ = 461.646, CFI = 0.937, RMSEA= 0.043]. A S-B χ^2 difference test to compare the model fit between Model 1 (unconstrained) and Model 2 (factor-loading constrained) demonstrated a significant S-B χ^2 difference, or a loss of fit between the two models [S-B$\chi^2_{(4)}$ = 12.913, p = 0.012]. Although the S-B χ^2 difference test was significant, changes in RMSEA and CFI (ΔRMSEA = 0.002, ΔCFA = 0.001) met the cutoff criteria for model invariance (ΔRMSEA ≤ .015 and ΔCFA ≤ .002). For large samples, such as that of the current study, changes in approximate model fit indexes are more informative than the significance test results (Cheung & Rensvold, 2002; Meade et al., 2008; Chen, 2007). Thus, the invariance of factor loadings was satisfied when comparing the typical and cognitive impairment groups, indicating that the same constructs were being measured in both groups. Therefore, Model 2, the measurement invariance model, was retained for further structural invariance testing, in which each regression path was constrained as equal across groups. First, the path from neighborhood social cohesion to valued activities was constrained (Model 3), and then the overall model fit and the S-B χ^2 difference test were examined. Model 3 yielded a good fit [S-B$\chi^2_{(71)}$ = 469.20, CFI = 0.936, RMSEA= 0.043], but the S-B χ^2 difference test was significant [ΔS-B$\chi^2_{(1)}$ = 7.688, p = 0.006]. However, changes in approximated model fit indexes again demonstrated that the absolute difference in the parameter of the path coefficient was of trivial magnitude (ΔRMSEA = 0, ΔCFA = 0.001). Thus, the path coefficient from neighborhood social cohesion to valued activities is invariant across both typical and cognitive impairment groups (Hypothesis 3b). The invariance of the path from valued activities to quality of life was also examined (Model 4). Model 4 had good statistical fit [ΔS-B$\chi^2_{(72)}$ = 472.30, CFI = 0.936, RMSEA= 0.043], and the S-B χ^2 difference test was not significant [ΔS-B$\chi^2_{(1)}$ = 3.412, p = 0.065]. Changes in CFI and RMSEA were too small to be detected at three decimal places. These findings verified that the regression coefficients for the path from valued activities to quality of life were statistically invariant across the typical and cognitive impairment groups (Hypothesis 3c). A Wald chi-square difference test was conducted to compare the indirect effect from neighborhood social cohesion through valued activities to quality of life across groups. The unstandardized coefficients of the indirect effect for the typical and cognitive impairment groups were 0.024 (*SE* = 0.003, $p < 0.001$) and 0.018 (*SE* =0.007, $p = 0.010$), respectively, and the difference test revealed no significant group difference on the coefficients [Wald$\chi^2_{(1)}$= 0.70, $p = 0.402$].

Discussion

The current study's purpose is to elucidate how the neighborhood social cohesion of communities affects the quality of life among older adults with and without cognitive impairment through engagement in valued activities. The analyses revealed a significant difference in the levels of neighborhood social cohesion, participation in valued activities, and quality of life between members of typical and cognitive impairment groups. Also, the constructed model in the current study was found to be valid for explaining the association of the key study variables within both groups. In addition, the relationships among the three key variables were found to be equivalent across the typical and cognitive impairment groups.

The findings from the Aim 1 analyses supported Hypothesis 1, which predicted that participants with cognitive impairment would perceive significantly lower levels of neighborhood social cohesion in their self-defined community, participate less in valued activities, and report lower quality of life. This pattern is consistent with previous studies showing that community-living people with dementia often have a high risk of social exclusion (Innes 2009), which can result in reduced physical, cognitive, and social stimulation (Adams et al., 2011). Also, people who experienced social exclusion from their community have feelings of isolations, loneliness, and being an outsider, all of which are also associated with a lower quality of life (Everard et al., 2000).

A possible explanation of the cognitive impairment group’s lower ratings on neighborhood social cohesion items is that older adults with cognitive impairment may experience social exclusion or isolation. They may lack social interactions with residents living in the same local community due to their physical and cognitive limitations or, perhaps, due to deficits in social tools or resources. Additionally, general understanding and acceptance of older adults with cognitive impairment among community residents may be low and involve stigmatizing or negative stereotyping. This context would make it difficult for residents with cognitive impairment to seek and experience satisfying social interactions.

Although the typical and cognitive impairment groups differed significantly in the number of valued activities in which their members participated, participants with cognitive impairment still performed valued activities to some extent in spite of their cognitive limitations. This finding is consistent with previous research showing that those with dementia participate in some social activities that provide meaningful interaction and express a desire to maintain social activity patterns at the level they had experienced before the cognitive impairment became severe (Genoe & Dupuis, 2014; Johnson, Whitlatch, & Menne, 2014; Menne et al., 2012; Parisi et al., 2015). Parisi and colleagues’ study using the same NHATS data also found that, regardless of cognition level (normal, possible, probable), older adults valued all four of the activities examined in the current study. The same research demonstrated that the magnitude of value indicated by the participants and the actual participation status on the four activities differed by level of cognitive functioning. In line with those findings, the current study also demonstrated significantly fewer valued activities reported by older adults with cognitive impairment compared to those of the cognitively healthy group. Although only 2% of older adults who were living in the community without cognitive impairment did not perform any valued activities in the preceding month, 9% of those who were living in the community with cognitive impairment reported no valued activities during that period. A closer examination of the types of valued activities in which older adults participated shows that the percentages of those who attended organized activities such as a class or club meeting or who went out for enjoyment were far lower in the cognitive impairment group than in the cognitively heathy group. Interestingly, group differences were less striking in the rest of the activities (visiting family and friends, attending religious services), which are more routine and ordinary examples of valued activities. These findings point to a high possibility that older adults with cognitive impairment experience exclusion from valued social activities or difficulties in accessing them, as compared to cognitively healthy ones.

The Aim 1 analyses compared group mean differences in the ratings of each observed variable (i.e., questionnaire items for the factors of neighborhood social cohesion and quality of life, and valued activities), but the Aim 2 and 3 analyses examined overall associations among the factors, neighborhood social cohesion, valued activities, and quality of life. First, a structural model was established to explain these associations based on the literature review, with the hypothesis that older adults with high perceived neighborhood social cohesion will have a higher quality of life through more participation in valued activities. The model reflecting Aim 1 was valid, and Aim 2 was also supported in both the typical and cognitive impairment groups. These findings are in accord with previous studies on the associations between community environment, activities, and well-being among older adults. Those in more positive social environments are more likely to leave their homes (Choi et al., 2015), participate in activities, and engage in physical exercise (Carney et al., 2009).

These findings confirmed previous research while also yielding new information. The structural model depicting the associations of three constructs as a whole suggested an indirect effect of activity participation in the relationship between environmental factors and quality of life. Previous studies examined relationships involving only two of these factors, whereas the present analyses included an assessment of mechanisms involving additional factors that can affect the relationship between environmental characteristics and older adults' well-being. In addition, although previous studies investigated the older population without differentiating across levels of cognitive functioning, or examined only cognitively healthy participants to the exclusion of those with cognitive impairment, the current study distinguished a cognitive impairment group from a cognitively healthy one and examined group similarities and differences. To do so, Aim 3 analyses compared the groups in terms of the associations of neighborhood social cohesion, participation in valued activities, and quality of life. The results indicated no statistical differences in the magnitude of the associations (i.e., regression coefficients) between the factors (Hypothesis 3a) for these groups. That is, regardless of cognitive health status, older adults who perceived higher neighborhood social cohesion in their self-defined community were more likely to experience a higher quality of life as a result of participating in more valued activities at a similar rate of change (Hypotheses 3b & 3c).

Despite the similarities across older adults with and without cognitive impairment (Aim 3), it is important to recall the findings from Aim 1 analyses at this point. As demonstrated in the Aim 1 analyses, older adults in the cognitive impairment group reported significantly lower ratings on almost all neighborhood social cohesion items, valued activity participation, and quality of life. To synthesize the findings of the present study, even though the *effect* of neighborhood social cohesion on quality of life through valued activities is *not* attenuated among participants with cognitive impairment (because they perceived neighborhood social cohesion as lower initially and reported fewer valued activities), the effect suggested in the model might be harder for them to initiate than for cognitively intact elders. Again, this finding shows a high likelihood that older adults with cognitive impairment may feel excluded from the community and experience barriers to participation in valued leisure activities.

Limitations and Suggestions for Future Research

Although the current study provided valuable findings, there are limitations and suggestions that need to be addressed by future research. First, the current study did not include measurements of neighborhood social cohesion based on geographical units; rather, it used individuals' perceptions of neighborhood social cohesion based on their own determination of the range of their neighborhood. Given the focus on an individual-level outcome — quality of life — it is reasonable to allow for personal definition of the range of neighborhood and personal evaluation of social cohesion. Future studies should use functional objective measurements of neighborhood or community if the associations between individuals' perception of social cohesion and community-level structural indicators are of research interest.

As pointed out in Wu and colleagues' (2015) review, perceived measurement of community characteristics can yield "same-source bias." That is, there might be a strong correlation between perception of neighborhood social cohesion and individual physical or cognitive abilities. Older adults with physical and social limitations tend to have negative attitudes toward neighborhood environments (Roux, 2007). Future research on this topic should employ study designs and statistical methods to differentiate the effect of the neighborhood environment net of individual perceptions and situations.

Another limitation is that multiple group analyses in this study were conducted with disproportionate sample sizes for the typical and cognitive impairment groups. Highly unequal sample sizes may increase type II errors. To solve this issue, random sampling from the typical group to generate the same sample size as cognitive impairment group is recommended in further research.

The findings of the current study were based on cross-sectional data. For this reason, although the tested model was established based on existing literature that informed hypotheses about associations among neighborhood social cohesion, valued activities, and quality of life, more empirical evidence based on longitudinal data is needed to examine the stability or change in the relationships among these factors, especially with regard to severity of cognitive impairment.

Implications

The findings of the current study suggest a need to establish neighborhood communities in which healthy older adults with cognitive impairment can feel supported and included. Efforts to reduce stigma and negative stereotypes toward older adults with dementia or other cognitive impairment would be beneficial, as well as increasing the public understanding of cognitive impairment through educational campaigns and activities that promote interaction with persons experiencing dementia or cognitive impairment.

Furthermore, findings from this study suggest that older adults with cognitive impairment could benefit from more options for participating in valued activities of interest to them. Intrinsic factors such as health limitations, as well as extrinsic difficulties including transportation and lack of opportunities, hinder participation in valued social or leisure activities among these older adults (Dahan-Oliel, Mazer, Gelinas, Dobbs & Lefebvre, 2010; Innes, Page, & Cutler, 2015; Levasseur et al., 2015; Nimrod & Shrira, 2014; Parisi et al., 2015). Policy and funding support for ways of providing befriending services, ideally including valued activities, needs to be offered at the community level. Such services need to provide practical and emotional support in a context of more accessible and easy-to-navigate environments, including transportation services to enable older adults with memory loss to travel in order to participate in valued activities.

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Study 2. Effects of Dyadic Discrepancy in Awareness of Mild Cognitive Impairment on Caregiver's Well-being

Introduction

Persons with mild cognitive impairment (PwMCIs) are often embedded in a dyadic context with a care partner (CP). The interdependence of care dyads includes both PwMCIs' and their CPs' evaluations of the PwMCIs' cognitive and behavioral deficits. Both the PwMCIs and their primary CPs may overlook a gradual and subtle decline in the PwMCI's cognitive abilities, and the two may have different perceptions of the extent of the cognitive and behavioral deficits. Thus, it is important to understand the interpersonal aspects of the mild cognitive impairment (MCI) caregiving experience.

For these reasons, researchers of cognitive impairment (i.e., MCI, dementia) have paid considerable attention to understanding patient and caregiver appraisal of the illness, but their efforts have focused mostly on the question of whether PwMCIs' assessment of their deficits are sufficiently accurate to be used in medical interventions as compared to assessments by other informants (usually CPs) (e.g., Galeone, Pappalardo, Chieffi, & Carlomagno, 2011; Vogel et al., 2004). However, regardless of the accuracy of PwMCIs' illness assessment, PwMCIs' and CPs' dyadic illness representations have their own important implications because of their effect on the dyads' collaborative actions for illness management or the individual's psychological adjustment (Berg & Church, 2007).

Chronic illness researchers have studied the association between the congruence of illness presentation and adjustment in care dyads, but the results are complex. This complexity involves not only the context of different illnesses but also characteristics such as whose illness representation is more positive or the extent to which those with the illness and their caregivers differ (Berg & Upchurch, 2007). For example, caregivers who perceive the illness as more severe than their patients do may benefit the care dyads' coping and adjustment by encouraging behavioral actions to deal with the stress, however, the caregivers may feel more stressed by the dissimilarity of dyadic illness representations and patients' underestimation of illness severity (e.g., Figueiras & Weinman, 2003; Heijmans, de Ridder, & Bensing, 1999). Such results emphasize the importance of understanding the contextual aspects of dyadic illness representations as they relate to patients' and caregivers' outcomes. However, in the literature of MCI and early dementia, there has been little research on PwMCIs' and CPs' congruent or discrepant illness representations and their effects on caregiving outcomes. A systematic understanding of MCI care dyadic views and their effects is needed for developing targeted interventions aimed at promoting greater awareness of MCI among PwMCIs and their caregivers and encouraging teamwork approaches to MCI management. Guided by tenets from the caregiving stress process framework of Pearlin, Mullan, Semple, and Skaff (1990), the purpose of this paper is to examine the discrepancy between PwMCIs' and CPs' perceptions of PwMCIs' memory loss symptoms, and the effects of such dyadic discrepancy on CPs' caregiving burden.

Mild Cognitive Impairment

Mild cognitive impairment refers to deficits in cognitive abilities that are noticeable to relatives, but are not severe enough to interfere with activities of daily living (Petersen, 2004). Although MCI is a construct under debate because of its unstandardized definition, diagnostic criteria, and treatment protocol, it is regarded as an abnormal cognitive decline beyond that associated with normal aging. Also, MCI often precedes Alzheimer's disease and other dementias, so the conversion rate of people with MCI to Alzheimer's disease is significantly higher compared to the rate of people without MCI (Burns & Morris, 2008). Estimates suggest that persons diagnosed with MCI develop dementia at a rate of about 10%–15% a year (Alzheimer’s Association, 2013), and the prevalence of MCI is approximately 10%–20 % among people aged 65 and older (Alzheimer’s Association, 2015).

Discrepancy in Dyadic Perceptions of Mild Cognitive Impairment

PwMCIs are often embedded in a dyadic context that involves a CP. The interdependent nature of this dyadic context influences PwMCIs’ and CPs’ appraisals of PwMCIs’ MCI symptoms, and they may have either similar or discrepant perceptions of the cognitive impairment. MCI care dyadic appraisals can reflect PwMCIs’ and CPs’ awareness of PwMCIs’ symptoms, PwMCIs’ cognitive or behavioral abilities and functioning, and impairment in specific domains (Clare, Markova, Roth & Morris, 2011). For example, PwMCIs and their CPs may attribute cognitive impairment to normal aging or simple forgetfulness, or they may have different views regarding the progress of the illness or the extent of the deficits.

Researchers on MCI or early dementia have examined dyadic perceptions by measuring individual illness representations by persons with cognitive impairment and their caregivers (e.g., Clare et al., 2012a, 2012b; McIlvane, Popa, Robinson, Houseweart, & Haley, 2008). The main focus of the previous studies has been on patients’ unawareness of their cognitive decline, raising questions about whether their illness representations are reliable and accurate compared to those of their care partners. The main finding was that persons with MCI and dementia have a tendency to underestimate their deficits (Arlt, et al. 2008, Onor, Negro, & Aguglia, 2006; McIlvane et al., 2008; Galeone et al., 2011; Salmon et al., 2006). However, researchers have also reported results that were not consistent with this finding (e.g., Farias, Mungas, & Jagust, 2005; Kalbe et al., 2005; Lingler, Terhorst, Schulz, Gentry, & Lopez, 2016). Studies on discrepancy among care dyads across different severities of cognitive impairment found that PwMCIs did not under-report (Farias et al., 2005) but even overestimated their impairment compared to their caregivers' assessment, while patients with dementia underestimated their deficits (Kalbe et al., 2005). As such, previous research on PwMCIs' and CPs' illness representations focused on examining the objectivity of PwMCIs' assessments of their own deficits by comparing them with their CPs' assessments.

An important point that should not be overlooked regarding dyadic illness representation research is the discrepancy itself in patients' and their caregivers' perception of the cognitive impairment. The similarity or difference in dyadic illness perception could provide meaningful information to understand PwMCIs' and CPs' MCI care-related experiences, because the variance in dyadic perception of patients' illness is known to be related to illness management, care-related coping, and psychological and physical well-being (Berg & Church, 2007). Even though it is important to understand the collective features of dyadic illness perception, surprisingly, little research in MCI and early dementia has investigated the discrepancy (or similarity) of dyadic appraisal within MCI care dyads, or its related outcomes or correlates. A quantitative study by Savla, Wang, Roberto, and Blieszner (2016) found that discrepancy of MCI care dyadic appraisals differed across specific domains of cognitive and behavioral abilities and types of care dyads (spouse CPs vs. adult child CPs). A qualitative analysis of the same dataset by Roberto, Blieszner, McCann, and McPherson (2011) revealed that the coping strategies and abilities of PwMCIs and their family care partners varied depending on the extent to which they similarly acknowledged PwMCIs' deficits. That is, PwMCIs and their families who dismissed the memory loss as due to aging did not consider the use of memory-helping strategies. A 20-month longitudinal study (baseline and 12- and 20-month follow-ups) found consistency in the degree of discrepancy of impairment perception between people with early-stage dementia and their caregivers. The caregivers' moods and stress levels remained stable as well (Clare et al., 2012b). A different degree of dyadic discrepancy occurred in different areas of patients' functioning, such that discrepancy concerning patients' daily activities was greatest, followed by differing views of memory and socio-emotional functioning. Although this study revealed longitudinal trajectories in perception discrepancy and in caregivers' well-being, the association between them was not estimated.

As such, in the literature on care dyads' perceptions of patients with MCI and early dementia, the degree or characteristics of discrepancy of dyadic illness appraisals have been studied to some extent. However, there has been little discussion about how discrepant views by a care recipient and a caregiver are related to the caregiver's outcomes. Indirectly, information from findings in the literature outside of cognitive impairment care has revealed complexity regarding the impact of the care dyad's illness representation on the caregiver's adjustment and well-being. Research has found similar dyadic appraisals of an illness not only helpful to the patient's recovery and the care dyad's coping and psychological adjustment, but also undesirable, because caregivers and patients become careless and fail to take proper actions to manage the illness and psychological stress (Berg & Upchurch, 2007; Figueiras & Weinman, 2003; Heijmans et al., 1999). Additionally, Heijmans et al. (1999) commented that the effect of similarities in the illness representations between patient and caregiver may differ by illness.

The evidence from previous studies suggests that associations may exist between dyadic discrepancies of illness perceptions and caregivers' outcomes in the MCI caregiving context. By examining this association, the current study will add to systematic understanding of the characteristics of MCI care dyadic views and the effects of perceptual similarities and differences, which could help to develop targeted interventions aimed at promoting greater awareness of MCI among PwMCIs and their caregivers and encouraging a family teamwork approach to MCI management. In particular, the purpose of the current study was to examine types and magnitude of discrepancies in PwMCIs' and CPs' ratings of PwMCIs' memory-related deficits, and their associations with the CPs' caregiving burden.

Theoretical Background

Pearlin et al.'s (1990) caregiving stress model was applied to understand the MCI caregiving context. The caregiving stress model describes a multiple and complex process that affects caregiving outcomes. Pearlin and colleagues paid attention to *background and context* (e.g., socioeconomic status) that lead to considerable individual variability in caregiving outcomes. They also used the concept of *primary* and *secondary stressors,* depending on the source of the stressors. Primary stressors are associated with care recipients' cognitive deteriorative status and problematic behavioral pattern, and their dependency on caregivers, which determines the caregiving workload. As a result of the care demands caused by the primary stressors, caregivers may also experience secondary stressors involving role conflicts and role strains (e.g., family conflict, job versus caregiving role conflict, economic problems, and constraint on social life and outside activities). Secondary stressors also include intrapsychic strains, in which caregivers experience a decline in the level of self-esteem and competence. Additionally, Pearlin and colleagues postulated the role of mediators in the relationship between caregiving stressors and caregiving outcomes. Coping strategies or social support are considered as mediators in the model, able to attenuate or reinforce caregiving negative outcomes such as depression, anxiety and perceived burden.

Research questions and directions were developed using this stress model as a theoretical framework for the current study. Particularly, this study focused on the role of dyadic illness representation and proposed its mediating role to increase or decrease CPs' caregiving burden. When PwMCIs and their family caregivers particularly agree on PwMCI's cognitive and behavioral abilities, CPs are expected to have a more positive caregiving experience involving less burden and more adjustments.

Finally, this study examined the assumption that CPs with similar dyadic appraisals of their PwMCIs' deficits would report less caregiving burden over time. The specific study aims are to examine:

Aim 1: Whether CPs perceive PwMCIs' memory and functioning deficits as more negative than do PwMCIs.

Aim 2: Whether CPs' different levels of caregiving burden are *associated* with the type of dyadic discrepancy in perceptions of PwMCIs' memory and functioning deficits.

> Hypothesis associated with Aim 2: CPs with similar dyadic illness representations report lower caregiving burden those with different dyadic illness representations.

Aim 3: Whether CPs' caregiving burden over time is *predicted* by dyadic discrepancy in the perceptions of PwMCIs' memory and functioning deficits.

Method

Procedure

The original study was conducted by the Virginia Tech MCI research team to examine responses to the diagnosis of MCI among families, with the approval of the Institutional Review Board (IRB) of Virginia Tech. This study had three waves of annual data collection utilizing mixed methods (i.e., scale-based questionnaires and open-ended interview questions). Elders (age 60+) who had been diagnosed with MCI by clinical professionals were recruited at six memory clinics in six cities. The protocol that the clinical professionals used to assess MCI included five criteria developed by Petersen and colleagues (1999): (a) complaint of memory loss, (b) normal functioning in daily life, (c) normal ability of cognition, (d) memory loss abnormal for age, (e) non-existence of dementia. Mini-Mental State Examination (MMSE; Folstein, Folstein, & McHugh, 1975) and Clock Drawing Task (Royall, Cordes, & Polk, 1998) were also used for further assessment. The clinic team omitted dementia cases, utilizing the guideline of the Diagnostic and Statistical Manual IV-R (DSM-IV-R), and other health problems-based memory loss using different instruments (e.g., Katz's index (Katz, Ford, Moskowitz, Jackson, & Jaffe, 1963); Barthel's index (Mahoney & Barthel, 1965). The clinic team invited the elders who were qualified to participate in the MCI study and the research team followed up with them and also asked them to identify their primary care partner (the person who was most engaged in their lives), who was then invited to participate. PwMCIs and CPs had separate face-to-face interviews conducted by a doctoral-level researcher or a social worker, in their homes or at the clinic. During the interviews, PwMCIs and CPs answered open-ended questions and completed questionnaires. A total of 125 PwMCI and CP dyads participated in the first wave of the study. Of the total, 59% of PwMCIs and 68% of CPs completed the second wave interview. In the third wave, 34% of PwMCIs and 42% of CPs completed the interviews.

Sample

The current study was approved by the Virginia Tech IRB. It used data from two interviews with PwMCI-CP dyads. The independent variable was based on the Deficit Awareness Scale (DAS), which was administered at either the first or the second interview (baseline). Of the 125 original dyads in the sample, complete dyadic data on the DAS were available for 62 dyads. At the follow-up interview (10 to 28 months after baseline, *M* = 18.90, *SD* = 5.47), dyadic data on the DAS were available for 28 PwMCI-CP pairs.

Measures

Deficit Awareness Scale (DAS). The independent variable was derived from the DAS (Green, Goldstein, Sirockman, & Green, 1993), which PwMCIs and CPs completed at baseline and follow-up. This questionnaire was designed to assess perceptions of functioning in four cognitive and behavioral areas, including remote memory, recent memory, attention, and performance of daily activities. Remote memory estimates ability to remember information and events covering the PwMCI's whole life (e.g., names of family members and friends, childhood events, school-based learning), and recent memory is about acquiring new information involving events on previous days and names of people the PwMCI just met. Attention assesses the PwMCI's ability to concentrate on a single object or thought (e.g., solving an arithmetic problem, following a conversation, ignoring distracting noises). Performance of daily activities addresses how well PwMCIs can accomplish practical activities to manage their lives and achieve a desirable quality of life (e.g., driving safely and balancing the checkbook). Each domain has four items and respondents rate cognitive or behavioral abilities using a 5-point scale ranging from 1 (Very good) to 5 (Very poor). Mean ratings for each of four subscales and an overall mean rating were calculated. Higher scores indicate worse assessment of the PwMCI's symptoms (Baseline: Cronbach's $\alpha = 0.88$ for PwMCIs; 0.86 for CPs; Follow-up: Cronbach's $\alpha = 0.84$ for PwMCIs; 0.92 for CPs).

Zarit Burden Interview Scale. The dependent variable was the CP score on the Zarit Burden Interview Scale – Screening Version (Bédard et al., 2001), measured at baseline and follow-up. CPs reported caregiving-related strains on 4 items (e.g., Do you feel that because of the time you spend with your relative, you don't have enough time for yourself? Do you feel stressed between caring for your relative and trying to meet other responsibilities work or family?), using a 5-point scale ranging from 0 (Never) to 4 (Nearly always). CPs' total sum scores out of a possible total of 16 were computed and higher scores indicate more burden. The internal consistencies of this scale were acceptable (Cronbach's $\alpha = 0.90$ for baseline; 0.81 for follow-up).

Data Analysis

Descriptive statistics including level of CPs' caregiving burden were first computed to characterize the study sample. To investigate the individual perspectives on PwMCIs' deficits and level of agreement within the dyads, I computed descriptive statistics of PwMCI- and CP-reported DAS scores, *t*-tests (for examining mean differences), and intra-class correlation coefficients (for examining agreement within dyads) for each domain of DAS. Particularly, to examine care-dyadic discrepancy in the evaluation of cognitive and behavioral functioning, *discrepancy scores* were generated by subtracting CPs' mean scores from PwMCIs' mean scores on each DAS subscale and the overall DAS mean score. Thus, discrepancy scores close to 0 reflect the dyads having similar perceptions of PwMCIs' abilities. Larger positive discrepancy scores signify that PwMCIs viewed their cognition and behaviors as worse than did CPs. In contrast, larger negative discrepancy scores indicated that CPs regarded PwMCIs' abilities as worse than did PwMCIs. For each domain of DAS, the mean and standard deviation of the raw discrepancy scores at baseline and follow-up were computed.

Using these raw discrepancy scores at baseline, *discrepancy groups* were created to contextualize the direction of dyadic discrepancy (i.e., which PwMCIs and CPs rated PwMCIs' deficits more negatively or did both rate the deficits similarly?). For the variable of *discrepancy* *group,* the standard deviation of mean discrepancy scores at baseline was used to classify three types of discrepancy group (Similar; CP negative; CP positive). In each of four DAS domains and overall DAS, if the dyad's discrepancy score was less than -0.5 SD, the dyad was classed in the group of CPs having a more negative view than PwMCIs of PwMCIs' behaviors; if the dyad's discrepancy score was greater than 0.5 SD, then this case fell into the group of CPs having more positive assessment than PwMCIs. When a discrepancy score fell between -0.5 SD and 0.5 SD, it was included in the group of CPs and PwMCIs having similar views. Descriptive statistics of PwMCI- and CP-reported DAS by the discrepancy group and the number of dyads belonging to each discrepancy were computed.

To examine whether the level of CP caregiving burden at baseline differed across the three discrepancy groups, one-way analysis of variance (ANOVA) and post hoc tests were used. Regression analyses were used to investigate the effect of dyadic discrepancy on change in the CPs' caregiving burden from baseline to follow-up. Employing regression analyses utilizing the continuous variable (raw discrepancy scores) was more appropriate in this case rather than ANOVA utilizing the categorical variable (discrepancy groups). This is because regression analyses permitted examining the associations of dyadic discrepancy and CP burden at baseline within the small sample of 28 CPs who completed the caregiving burden questionnaire at follow-up, out of 62 dyads who responded to the DAS at baseline. For this small number of CP responses, using raw discrepancy scores as a continuous variable was better than dividing them by discrepancy group, which would yield an even smaller number of CPs in each group.

PwMCIs' Mini-Mental State Examination scores measured by clinicians were considered as a control variable at first because PwMCIs' deteriorations in cognitive health are known to affect CPs' caregiving stress and burden (e.g., Pearlin et al., 1990) However, since PwMCIs'

MMSE scores had low variability and no discrepancy group differences, they were not controlled.

Results

Descriptive Statistics of the Study Sample

The sample employed in this study comprised 62 care dyads (62 PwMCIs and their 62 primary informal CPs). As shown in Table 2.1, the mean age of PwMCIs was 75 years (*SD* = 7.51), and most of them were men (74%). In contrast, CPs' mean age was 8 years lower than that of PwMCIs and almost all CPs were women (97%). PwMCIs' MMSE mean score was 26.3 (*SD* = 2.96), which indicated a fairly high level of cognitive functioning. Eighty-two percent of CPs were living with their PwMCI. Their relationship to PwMCI was primarily spouse (72.13% of CPs), followed by adult child (14.75%).

Pearson and Spearman correlations were examined to determine PwMCI or CP characteristics listed in Tables 2.2 and 2.3 that were associated with the discrepancy types (derived from baseline data) or discrepancy scores (at baseline and follow-up). For PwMCIs' and CPs' ratings of PwMCIs' deficits, no PwMCI characteristics were associated with discrepancy type in any DAS subscales or the overall DAS. Among CPs' characteristics, marital status was associated with discrepancy type in Performance of daily activities [r_s (61) = - 0.31, $p = 0.02$] and overall DAS [r_s (61) = - 0.26, $p = 0.05$]. CPs' age was also significantly correlated with discrepancy type in remote memory [r_s (62) = -0.25, $p = 0.05$]. F-test or chi-square test were conducted to identify significant differences in each of the PwMCIs' and CPs' characteristics that showed significant correlation coefficients by discrepancy type (i.e., CP positive; Similar; CP negative). CPs' age did not differ by type of discrepancy of dyads' ratings on PwMCI's remote memory [F (2, 61) = 1.93, *ns*]. CPs' marital status did not significantly differ by type of discrepancy on overall DAS, [$\chi^2(2, 61) = 4.05$, *ns*] but significantly differed by type of discrepancy on Performance of daily activities [$\chi^2(2, 61) = 6.87$, $p = 0.03$]. Although CP's marital status showed a significant difference, this factor was not included in further analysis (i.e., ANOVA) as a factor assumed to be related with discrepancy types. This is because the group differences were not consistent across all DAS scales and the number of those who were not married in each type of discrepancy group was too small (Range = 2 to 5).

Aim 1: Descriptive Statistics and Agreement between PwMCIs' and CPs' Ratings of PwMCIs' Deficits

Descriptive statistics of DAS ratings and discrepancy scores, and paired-sample mean comparison tests on DAS are shown in Table 2.4. According to the mean scores of DAS, PwMCIs rated their remote memory, attention, performance of daily activities, and overall DAS between Good and Fair; and CPs evaluated PwMCIs' attention, performance of daily activities and overall DAS as between Good and Fair. However, PwMCIs did not function well in terms of recent memory, as reported by both PwMCIs and CPs (ratings between Fair and Poor). Except for remote memory, CPs tended to view PwMCI's cognitive and behavioral abilities as worse than did PwMCIs. Paired *t*-tests were also conducted to compare means of both PwMCIs' and CPs' for overall DAS and each subscale. On average, PwMCIs' and CPs' ratings did not differ significantly, but there was a significant difference in the deficits of daily activities, marked by CPs' higher ratings. For follow-up, CPs reported significantly higher levels of PwMCIs' deficit in attention and daily activities than PwMCIs did.

Table 2.4 also shows results from intraclass coefficients for baseline and follow-up. Intraclass correlation coefficients showed that agreement between PwMCIs' and CPs' ratings of PwMCIs' MCI-related deficits was small to medium at both baseline (Range = 0.22 – 0.36) and follow-up (Range = 0.37 – 0.66). Intraclass coefficients for all DAS areas and overall DAS at follow-up increased compared to those at baseline, which means PwMCIs and CPs came to have more concordant perceptions of PwMCIs' deficits. Recent memory showed the largest increase and remote memory revealed the least increase.

Aim 2: Association of CPs' Burden and Discrepancy Type

Table 2.5 and Figure 2.1 reveal results from ANOVA that examined difference in the means of the CPs' caregiving burden by discrepancy group. Mean CP caregiving burden differed significantly among the three types of discrepant views of PwMCIs' deficits. In overall DAS, CPs' burden differs by discrepancy group [*F* (2, 58) = 4.92, *p* = 0.01]. According to post hoc analysis using the Bonferroni post hoc criterion for significance, CPs' mean burden score for the CP negative group (*M*=4.83, *SD*=2.44) was significantly higher than for the CP positive group (*M*=1.79, *SD*=2.64) [*F* (2, 58) = 4.92, *p* = 0.01]. The effect of discrepancy type was not significant in remote memory [*F* (2, 59) = 1.49, *p* = 0.23]. For recent memory, CPs' burden ratings were significantly different by discrepancy group [*F* (2, 59) =4.90, *p* = 0.01]. Post hoc comparison revealed that CPs in the CP negative group (*M*=5.47, *SD*=2.60) reported significantly more burden than CPs in the CP positive group (*M*=2.23, *SD*=3.30) [*F* (2, 59) = -3.24, *p* = 0.01]. There was a trend that CPs in the CP negative group reported more burden than CPs in the Similar group [*F* (2.59) = - 1.94, *p* = 0.09]. Regarding attention, the CP burden differs by discrepancy type [*F* (2, 59) =3.30, *p* = 0.04]. However, post hoc analysis using the Bonferroni criterion did not indicate burden level differences between discrepancy types at a 0.05 significance level. There was a trend that CPs in the CP negative group rated more burden than CPs in the Similar group [*F* (2, 59) = -2.05, *p* = 0.07]. For performance of daily activities, ANOVA indicated significant differences in CPs' burden level by discrepancy type [*F* (2, 58) =

4.45, p = 0.02]. Post hoc comparisons using the Bonferroni criterion indicated that CPs' mean burden score for the CP negative group (*M*=4.84, *SD* =2.87) was significantly higher than for the similar group (*M*=2.54, *SD*=2.58), [*F* (2, 58) = -2.30, *p* = 0.02].

Aim 3: Effect of Dyadic Discrepancy on CPs' Caregiving Burden Over Time

Multiple regression analyses were performed to evaluate whether discrepancies at baseline between CPs' and PwMCIs' ratings of PwMCIs' deficits in overall DAS and all four areas of DAS significantly contributed to explaining CP caregiving burden at follow-up. CPs' follow-up caregiving burden was regressed on raw discrepancy scores in overall DAS and each domain of DAS, controlling for CPs' baseline caregiving burden (Table 2.6). A significant effect was found for attention, in which larger discrepancy scores (PwMCIs' higher ratings and CPs' lower ratings on PwMCIs' deficits) at baseline predicted a higher level of CPs' caregiving burden at follow-up ($\beta = 1.16, p = 0.03$). However, raw discrepancy scores at baseline in overall DAS and the other individual DAS dimensions did not contribute to explaining CPs' follow-up burden at a significant level.

Discussion

Aim 1: Dyadic Discrepancy in Perceiving PwMCIs' Deficits

As to the characteristics of the discrepancy between PwMCIs' and CPs' perceptions of PwMCIs' illness, care dyads' views of PwMCIs' cognitive and behavioral deficits varied to different extents in different domains (domain-specificity). Regarding agreement between PwMCIs' and their CPs' ratings of PwMCIs' deficits, low levels of agreement were found at baseline across overall DAS and individual DAS domains, and these increased to medium levels at follow-up. Previous studies on MCI and dementia support the domain-specificity of dyadic discrepancy of illness perception (e.g., Green et al., 1993; Kaszniak, DiTraglia, & Trosset, 1993;

Leicht, Berwig, & Gertz, 2010). While previous studies using samples of dementia care dyads have consistently reported the discrepancy pattern for remote memory in which caregivers or other informants perceived more deficits than did care receivers, the current study found the opposite pattern. In people with dementia with progressed cognitive impairment, their remote memory deficit may be more easily recognized by their caregiver. However, MCI memory deficits appear at a subtler level. Furthermore, remote memory involves remote life experiences which are more likely to be recalled privately by PwMCIs than observed by their CPs who help with PwMCIs' instrumental care needs. For this reason, remote memory deficits among the PwMCIs of the current study may be harder for their caregivers to detect.

Aim 2: Discrepancy Type and Caregiving Burden

This study demonstrated that the level of CPs' caregiving burden differed by the characteristics of dyadic discrepancy, depending on whether the CP and PwMCI had similar appraisals, or whose appraisal (CPs vs. PwMCIs) was more positive or negative (Aim 2). Overall, CPs who had more positive views than or similar views as their PwMCIs reported significantly lower levels of burden than those who had negative views. However, there was no significant difference in burden level between CPs who had similar views as their PwMCIs and those who had more positive views. While these findings partially support the hypothesis for Aim 2 (CPs with a similar dyadic illness representation report a lower caregiving burden than those with different dyadic illness representation), they also provide evidence that CPs with more positive views of PwMCIs' deficits had a similar association with caregiving burden level. Overall, these findings suggest that CPs' caregiving burdens were associated with the MCI patient and caregiver dyad context of how they concurrently perceive MCI patients' health status. For MCI patients and their care partners, a concordant understanding of the patient's status and the care partner's perception that the memory impairment is not too advanced are associated with a positive caregiving experience.

One finding in this study was the existence of domain specificity in the associations between CP burden and care dyads' discrepancy type. In recent memory, attention, and daily activities, and in overall DAS, CPs rating their PwMCIs' deficits as more severe reported significantly more caregiving burden. However, such association was not found for remote memory. The reason for this unexpected finding is not clear, but it may be due to the nature of remote memory. Remote memory in DAS involves PwMCIs' ability to remember information learned in the past (Green et al., 1993). The questionnaire items in this domain asked the extent to which the PwMCI remembered the names of PwMCI's family members and friends, events from their childhood, and what they learned in school. Such information concerns one's private and fundamental memories that characterize one's life. Fading of such memories may be more likely to be noticed by PwMCIs than by CPs. For this reason, CPs may not relate PwMCIs' remote memory loss to their caregiving burden as much as they do PwMCIs' losses in the other domains. Deficits in recent memory, attention, and daily activities may be more problematic to CPs than deficits in remote memory. Abilities in recent memory, attention, and daily activities are more relevant and necessary for performing everyday activities, so deficits in such domains may stand out more to CPs and require CPs' help.

An additional finding in the domain of daily activities was that CPs who had similar evaluation as PwMCIs reported the lowest caregiving burden, compared to those who had either more positive or more negative views than did the PwMCIs. Although the caregiving burden difference between the CPs with a more positive view and those with a similar view was not statistically significant, which may be due to the small number of dyads in the CP positive group, the mean difference in those CPs' reported caregiving burden was large. This result also may be explained by the domain specificity (different domains have different associations). Different from the domain of recent memory and attention, which assess PwMCIs' cognitive abilities, the domain of daily activities focuses on PwMCIs' behavioral abilities required for driving, balancing the checkbook, and managing life. When PwMCIs have difficulty accomplishing such activities, this affects more than only the PwMCI's mind and cognitive level. PwMCIs need CPs to be physically with them to meet the PwMCI's instrumental and objective needs, which requires CPs' labor and time investment. Discrepancy in PwMCIs' and CPs' evaluations on PwMCIs' performance of daily activities may make it difficult for them to agree on the extent of care that the PwMCIs want to receive from caregivers and that caregivers want to provide to the PwMCIs. These findings support that associations of CPs' caregiving burden and care dyad discrepancy present differently depending on the domains of cognitive and behavioral abilities.

Aim 3: Causal effect of Dyadic Discrepancy on Caregiving Burden Over Time

Examination of the effect of dyadic discrepancy at baseline on CPs' caregiving burden was conducted using regression analyses with a relatively small sample. In the cross-sectional data analyses mentioned previously, significant associations between discrepancy type and CP caregiving burden were found in overall DAS and three individual domains of DAS. However, only in attention, the baseline discrepancy predicted CPs' caregiving burden at follow-up in two-time point data analyses (Aim3).

When PwMCIs perceived their own attention ability as worse than did their CPs, the CPs were more likely to have a higher burden at follow-up. Several explanations can be posited. First, PwMCIs' negative evaluation of their health status may lead them to begin earlier to pay more attention to their condition and to invest more energy and time in managing MCI, which also may require CPs’ attention and help. For example, PwMCIs with a negative evaluation of their illness may try to acquire more information about MCI and seek medical assistance and external support to take care of their illness. Meanwhile, their CPs who had a more positive evaluation of their PwMCIs’ status may think the PwMCI is over-reacting to the illness and may not agree with the PwMCI’s effort. This discordance, marked by negative PwMCI and positive CP, may ultimately lead to an increase in CPs’ stress and unpleasant caregiving burden. Another possible explanation for the same finding, the effect of dyadic discrepancy of PwMCI’ attention on CPs’ burden in the future, is that CPs with better assessment of PwMCI’s attention may underplay the deficits. CPs’ positive views deter them from being alert to PwMCI’s conditions and taking action to manage the illness by seeking information and medical assistance or making long-term plans. A previous analysis of the same data revealed that CPs who overlooked or did not readily acknowledge PwMCI’s deficits tended to minimize or ignore memory-related problems and used resignation (“MCI is a normal part of aging”) as a coping strategy (Roberto et al., 2011). As a result, timely and constructive actions to comprehend the PwMCI’s cognitive and physical conditions and manage the deficits could be delayed. Delaying the planning and development of coping strategies means care partners may be unprepared to cope with aggravating situations, leading to a higher burden.

Conclusions

The current study shed light on the discrepancy between PwMCIs’ and CP’s perceptions of PwMCI’s deficits in multiple cognitive and behavioral areas, and the relationship between the care dyads’ collective appraisal of MCI and the care partners’ adjustment (i.e., MCI-related burden). Differential results for DAS cognitive and behavioral domains support the notion of domain-specificity of MCI-related cognitive and behavioral abilities. The level of CPs’ caregiving burden differed by the characteristics of dyadic discrepancy, depending on whether CP and PwMCI had a similar appraisal, or whose appraisal (CP vs. PwMCI) was more positive or negative. These findings highlight the importance of understanding variability in the extent and context of care dyadic discrepancy regarding multiple areas of PwMCI's functioning. Because this variability influences care partners' perceived burden in different directions, interventions for care partners need to take account their care dyads' level of awareness and understanding of cognitive impairment.

The relatively small number of PwMCI-CP dyads at follow-up limited the ability to examine the influence of multiple predictors on CP's burden, so the analysis should be replicated with a more dyads. Further, longitudinal research could also examine how coping enacted by PwMCI vs CP varies according to the nature of dyadic discrepancy in perceptions of cognitive functioning and affects caregiver's and patient's outcomes.

Notwithstanding limitations associated with a small sample, this study has important implications for PwMCIs and CPs to manage the PwMCIs' illness and choose appropriate treatment options. Since there are various domains of cognitive and behavioral competence associated with MCI, the CPs may not judge the PwMCIs' overall ability by looking at only one aspect of the PwMCIs' specific deficit. In addition, disagreement between PwMCIs and CPs on the PwMCIs' certain symptoms may not necessarily lead to similar discrepancies in other areas. PwMCIs and CPs need to communicate closely with each other over the various domains of the PwMCIs' condition; the advice of healthcare professionals is a great help in this process. These efforts can also help PwMCIs and CPs choose the appropriate treatment or social services for MCI management, as well as the intensity of care provided to PwMCIs. In particular, this study emphasizes a dyadic perspective on illness understanding, different from previous studies that have underscored PwMCIs' individual accurate awareness of their illnesses. In this point, this study suggests that PwMCIs and CPs should have more conversation and attention regarding each other's thoughts on cognitive functioning so that the PwMCIs and the CPs have the same understanding of the PwMCIs' condition. In addition, caregiving support and appropriate interventions are needed to keep the CPs from being too pessimistic about the given situation and the PwMCIs' condition. These efforts will help the CPs not to be overwhelmingly exhausted on the long caregiving journey and able to maintain or improve their well-being.

Study 2 References

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Conclusions

Summaries and Implications

Based on the conceptual framework of the resilience model, the current studies examined the role of protective factors in improving the well-being of people with dementia or MCI and caregivers in their cognitive impairment experiences. The first study examined how neighborhood social cohesion perceived by community-living PwDs affected their participation in valued activity and well-being. The second study examined how CPs' well-being changed when care dyads had similar or different perceptions of the PwMCIs' illness severity. These two studies provide valuable findings of the resilience processes in people with cognitive impairment and their caregivers involving the relationships that interconnect various personal, interpersonal, and environmental factors.

Study1 particularly showed how neighborhood social cohesion encouraged individuals' participation in valued activities, which eventually increased their quality of life. Furthermore, this study examined whether this perception was equally shared by typical elders and elders with cognitive impairment. The ratings of the cognitive impairment group on neighborhood social cohesion, number of valued activities participated in, and quality of life were lower overall than those of the typical group, but the positive effects of neighborhood social cohesion and participation in valued activities occurred without any significant difference between the two groups of elders. That is, the effect of neighborhood social cohesion on quality of life through valued activities is not attenuated among participants with cognitive impairment. However, the more important issue here is that this series of positive effects might be harder for PwDs to initiate because neighborhood social cohesion, which could be a trigger of this positive pathway, is perceived by PwDs as lower initially. These findings imply the potential impact of the community and neighborhood environment on PwDs' lives, and suggest importance of discussing integration of PwDs into the community instead of segregating them. When PwDs live in a community with poor understanding of dementia and lower acceptance and optimism toward PwDs, they may be more likely to experience emotional alienation from the community, leading to reduced motivation for social engagement. In addition, communities with such bias against people with dementia might be less likely than supportive communities to have adequate social services and programs, easy-to-navigate public transportation systems, and convenient amenities that could encourage PwDs' social engagement.

The study findings have important implications for researchers, practitioners, and policymakers. In order to reduce the emotional exclusion that PwDs may experience from the community, it is necessary to raise public awareness and understanding of dementia and make efforts to eliminate the stigma of dementia at the community level. In addition, social or meaningful activities that meet the various levels of physical and cognitive abilities of PwDs should be provided, with attention to diverse options that reflect their preferences. It is important to help PwDs remain socially active by replacing their former roles and activities with those they can manage and enjoy, to sustain and improve their well-being. Leisure or valued activities highlighted in the current study not only provide physical and cognitive stimulation, but also enable older adults to experience social intimacy and emotional support. Finally, to increase the accessibility of PwDs to these activities, it is also necessary to check and expand the social infrastructure related to mobility (e.g., transportation). This effort will help to finally achieve "dementia-friendly communities (WHO, 2012, p. 88)" in which people recognize dementia as a disability and the normalization of dementia is realized by integrating PwDs as members of community without any discrimination.

Study 2 showed the interpersonal aspect of dementia caregiving in which shared illness representations between PwMCIs and their CPs were related with the CPs' perceived caregiving burden. In the domains related to the cognitive ability of PwMCIs, CPs who had views that were more positive than or similar to those of their PwMCIs reported significantly lower levels of burden than those who had negative views. In the domain of PwMCIs' everyday behavioral ability, CPs who had evaluations similar to those of PwMCIs reported the lowest level of caregiving burden. These findings highlight the importance of understanding that the extent and context of concordance or discrepancy in PwMCIs’ and CPs’ dyadic illness appraisals varied across multiple areas of the PwMCIs’ functioning, and were significantly associated with the CPs' well-being. Thus, this study provides evidence that PwMCIs’ and their CPs’ perceptions of the PwMCIs’ illness-related deficits is not a unitary construct, so it is important to examine both PwMCIs' and CPs' perceptions, and their concordance or discrepancy in those perceptions across the multiple domains related to MCI symptoms. Particularly, perceptions on PwMCIs' cognitive ability and daily living performance need to be examined separately. In addition, the finding that dyadic appraisals of PwMCIs’ symptoms were related with the well-being of CPs shows that the CPs’ well-being is not merely a matter of personal level but also had an interpersonal aspect.

This study emphasizes a dyadic perspective on illness understanding, different from previous studies that have underscored PwMCIs' individual accurate awareness of their illnesses. In this point, this study suggests that PwMCIs and CPs should have more conversation and attention regarding each other's thoughts on the illness so that the PwMCIs and the CPs have the same understanding of the PwMCIs' condition. In addition, there are various areas of cognitive and behavioral competence associated with MCI, CP may not be able to judge the overall competence of PwMCI by looking at only one aspect of the PwMCIs’ specific deficit. Also, differences of opinion between PwMCIs and CPs for a particular symptom of the PwMCIs may not necessarily cause similar discrepancies in other areas. For these reasons, PwMCIs and CPs need to try to understand the abilities of the PwMCIs in various cognitive and behavioral domains; the advice of healthcare professionals is a great help in this process. These efforts can help PwMCIs and CPs choose the appropriate treatment or social services for MCI management, as well as the intensity of care provided to PwMCIs.

Limitations and Future Directions

Although the current studies provided valuable findings regarding dementia care and protective factors, there are limitations and suggestions that need to be addressed by future research. The studies in this dissertation deal with data on elders with different levels of dementia symptoms. In the first study, PwDs were identified using a relatively comprehensive concept of dementia which included a broad range of cognitive impairment, and they were compared with typical older people who did not have cognitive impairment. In the second study, people with MCI, a pre-dementia stage, were selected as the study sample. The severity of cognitive impairment must be considered when interpreting the results of the current studies, because PwDs' cognitive and behavioral abilities and related life styles may vary across the severity of the illness. Particularly, the first study used only self-reported data, which excluded the more severely impaired older people; this may make the study estimates less accurate. In addition, the NHATS dementia classification scheme (Kasper et al., 2013) used in the first study is not a validated medical diagnosis, so some of the participants may be misclassified.

Second, both studies were based mainly on cross-sectional data. Of course, the second study looked at the changes in the caregiving burden of the caregivers using baseline and follow-up data, but there were not many CPs available for follow-up. For this reason, the current studies are insufficient to draw conclusions about causal directions or transitions regarding dementia care. Considering gradualism in the progression of dementia, dementia care experiences might change in responding to altering demands of care, availability of care resources, PwDs' and caregivers' personal growth and adjustment. For this reason, longitudinal study designs are recommended to capture the stability and change in various aspects of dementia care. Particularly, it may be worthwhile to examine how dementia experience changes following PwDs’ dementia progression.

As a suggestion for future research, even though the current studies provide a start to connect the concept of resilience with dementia care, more scholarly efforts are needed to create theoretical frameworks linking the two areas. As noted by Smith and Hayslip (2012), although the construct of resilience has secured a place in research literature of later life, far too little attention has been paid to theory in resilience study. Furthermore, the issue of a weak theoretical foundation generates other critical constraints in the development of valid measures and instruments, and clinical applications. Therefore, there is an urgent need to establish a theoretical framework for the experience of chronic illness, including dementia.

Contributions and Conclusions

Despite these limitations, the current research extends knowledge of dementia care by exploring the usefulness of the concept of resilience in dementia experiences. The concept of resilience, which indicates people's capability of using resources in difficult circumstances in order to adapt to the situation, prevent negative influences, and eventually achieve positive outcomes (Kaplan, 2005; Rutter, 2007; Wright & Masten, 2006), has given a new perspective to the literature of dementia experience and care. This allows the current study to focus on how PwDs and caregivers can manage or overcome the difficult life adversity of dementia, which is the other facet of dementia care research beyond the negative aspects that have been mainly studied so far.

In addition, this research not only addressed dementia care and well-being as an issue at the PwDs' or caregivers' individual level of analysis, but also addressed community and care dyadic interpersonal levels of analysis. Therefore, the first study suggested that when dementia-friendly communities with high neighborhood social cohesion exist, PwDs can improve their quality of life through more active social activities. The second study found that the well-being of the caregivers improved when the PwMCIs and caregivers had a similar illness representation, or when the caregivers rated the PwMCIs more positively than the PwMCIs themselves did. These findings of the dementia experience with consideration of the contexts in which PwDs and caregivers are embedded may be useful for developing multidimensional interventions that consider the various levels of context surrounding the PwDs and caregivers, rather than simply perceiving dementia as a personal matter.

Dementia gradually changes people’s lives, and in many cases, caregivers stay by them, watching over and providing care for a long time. Considering the nature of serious memory loss, dementia may represent an insurmountable risk. Once cognitive impairment manifests in a person, a complete cure is almost impossible and the symptoms of the illness usually worsen to the point of severity. Moreover, it often requires long periods of illness management with growing extent and cost for PwDs themselves and their caregivers. However, the very fact that dementia is accompanied by so many insurmountable risks suggests that more research is needed on dementia care with a focus on resilience. This focus will be helpful to search for better strategies to help PwDs and their caregivers get through the long and demanding journey of dementia care. The situation of dementia is challenging for both PwDs and their caregivers, but encouragement and help from the larger community may foster positive adaptation to complement negative outcomes. In sum, the findings of this dissertation emphasize the need to continue research related to dementia care resilience.

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Introduction & Conclusion

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Tables and Figures

Table 1.1.

Demographic Characteristics and Descriptive Statistics by Total Sample and Group

	Total Sample	Normal	Cognitive Impairment			
	N=5974 (weighted: 28307372)	*n*=4763 (23953253,84%)	*n*=1211 (4354119, 16%)			
Variable	% or M (SE)	% or M (SE)	% or M (SE)	χ2/*t*	*p*	Alpha
Demographic Characteristics						
Age						
Age in years	74.49 (0.09)	73.78 (0.10)	78.40 (0.25)	17.47	<0.001	
Sex						
Female	55.15	55.74	51.93	4.28	0.039	
Race/ethnicity						
White, non-Hispanic	82.55	84.95	69.46	84.64	<0.001	
Education						
College level or higher	52.26	55.97	32.05	161.70	<0.001	
Whether receiving mobility help						
Yes	6.93	5.01	17.37	187.09	<0.001	
Functioning Limitations						
# of ADL&IADL limitations	1.36 (0.03)	1.09 (0.03)	2.83 (0.11)	15.47	<0.001	
Descriptive Statistics						
Neighborhood social cohesion						0.74
Know well	1.22 (0.01)	1.22 (0.01)	1.24 (0.03)	0.62	0.536	
Willing to help	1.49 (0.01)	1.51 (0.01)	1.38 (0.02)	-5.10	<0.001	
Can be trusted	1.54 (0.01)	1.56 (0.01)	1.45 (0.02)	-4.45	<0.001	
Participation in Valued Activities						0.48
Total # of participated valued activities	2.67 (0.01)	2.76 (0.02)	2.18 (0.04)	-14.18	<0.001	
None	3.14	2.02	9.21	63.02	<0.001	
Total 1 activity	10.45	9.06	18.06			
Total 2 activities	26.75	26.16	29.93			
Total 3 activities	35.36	36.21	30.73			
Total 4 activities	24.30	26.54	12.06			
Visiting in person with friends and family	88.48	90.45	77.76	117.47	<0.001	
Attending religious services	58.66	59.42	54.77	6.58	0.010	
Participating in organized activities	38.96	42.23	21.25	132.87	<0.001	
Going out for enjoyment	81.12	84.20	64.86	188.82	<0.001	
Quality of life						0.63
Life has meaning and purpose	1.83 (0.01)	1.85 (0.01)	1.71 (0.02)	-7.64	<0.001	
Feel confident and good about self	1.84 (0.01)	1.86 (0.01)	1.71 (0.02)	-7.98	<0.001	
Like living situation	1.80 (0.01)	1.82 (0.01)	1.71 (0.02)	-5.74	<0.001	

Note. t-tests were conducted for age, functioning limitations, neighborhood social cohesion, total # of participated valued activities, and quality of life

Table 1.2.

Summary of Inter-correlations between Study Variables by Group

	1	2	3	4	5	6	7
1 COH1: Know well		$.540^{**}$	$.353^{**}$	$.082^{**}$	$.079^{**}$	$.095^{**}$	$.091^{**}$
2 COH2: Willing to help	$.552^{**}$		$.587^{**}$	$.126^{**}$	$.169^{**}$	$.164^{**}$	$.181^{**}$
3 COH3: Can be trusted	$.392^{**}$	$.503^{**}$		$.160^{**}$	$.124^{**}$	$.165^{**}$	$.255^{**}$
4 ACT	$.133^{**}$	$.220^{**}$	$.182^{**}$		$.235^{**}$	$.233^{**}$	$.185^{**}$
5 QOL1: Life has meaning and purpose	$.100^{**}$	$.125^{**}$	$.124^{**}$	$.224^{**}$		$.514^{**}$	$.371^{**}$
6 QOL2: Feel confident and good about self	$.103^{**}$	$.111^{**}$	$.121^{**}$	$.179^{**}$	$.463^{**}$		$.436^{**}$
7 QOL3: Like living situation	$.102^{**}$	$.130^{**}$	$.138^{**}$	$.164^{**}$	$.294^{**}$	$.318^{**}$	

$^{*}p < .05$. $^{**} p < .01$.

Notes. Typical group shown below the diagonal and cognitive impairment group shown above the diagonal. COH = Neighborhood social cohesion; ACT = Number of participated valued activities; QOL = Quality of life

Table 1.3.

Confirmatory Factor Analyses

	Normal (*n*=4763)			Cognitive Impairment (*n*=1211)		
Path	*B*	*SE(B)*	*β*	*B*	*SE(B)*	*β*
Neighborhood social cohesion						
COH1: Know well	0.89	0.03	0.65 ***	0.72	0.05	0.59 ***
COH2: Willing to help	1.00	0.00	0.84 ***	1.00	0.00	0.90 ***
COH3: Can be trusted	0.72	0.03	0.61 ***	0.76	0.06	0.66 ***
Participation in valued activities						
ACT	1.00	0.00	1.00	1.00	0.00	1.00
Quality of life						
QOL1: Life has meaning and purpose	0.99	0.06	0.65 ***	0.82	0.08	0.64 ***
QOL2: Feel confident and good about self	1.00	0.00	0.70 ***	1.00	0.00	0.78 ***
QOL3: Like living situation	0.80	0.06	0.47 ***	0.77	0.08	0.58 ***
Model fit indices						
Model S-Bχ2 (32)	217.74			156.10		
RMSEA	0.04			0.06		
CFI	0.96			0.92		

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

Note. COH = Neighborhood social cohesion; ACT = Number of participated valued activities; QOL = Quality of life

Table 1.4.

Regression Coefficients and Standard Errors by Group

	Typical (n=4763)			Cognitive Impairment (n=1211)		
Path	*B*	*SE(B)*	*β*	*B*	*SE(B)*	*β*
Neighborhood social cohesion						
Age	0.00	0.00	0.04 *	0.01	0.00	0.07 †
Female	0.05	0.02	0.05 **	0.02	0.05	0.02
White, non-Hispanic	0.18	0.03	0.12 ***	0.20	0.05	0.14 ***
College or higher education	0.05	0.02	0.04 *	0.06	0.05	0.04
Number of ADL&IADL disability	-0.03	0.01	-0.12 ***	-0.02	0.01	-0.11 **
Participation in valued activities						
Neighborhood social cohesion	0.39	0.03	0.21 ***	0.18	0.06	0.10 **
Age	0.00	0.00	0.00	-0.01	0.01	-0.08 *
Female	0.31	0.03	0.16 ***	0.27	0.07	0.12 ***
White, non-Hispanic	0.08	0.04	0.03 *	0.32	0.08	0.13 ***
College or higher education	0.39	0.03	0.19 ***	0.46	0.08	0.19 ***
Number of ADL&IADL disability	-0.11	0.01	-0.23 ***	-0.09	0.01	-0.25 ***
Quality of life						
Participation in valued activities	0.06	0.01	0.24 ***	0.10	0.02	0.26 ***
Age	0.00	0.00	-0.01	0.01	0.00	0.12 **
Female	-0.03	0.01	-0.07 **	-0.05	0.03	-0.05
White, non-Hispanic	-0.04	0.01	-0.05 **	-0.06	0.04	-0.06
College or higher education	0.02	0.01	0.04 *	0.04	0.03	0.05
Number of ADL&IADL disability	-0.03	0.00	-0.25 ***	-0.04	0.01	-0.28 ***
Model fit indices						
Model S-Bχ2 (33)	273.84			183.90		
RMSEA	0.04			0.06		
CFI	0.95			0.90		

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

Note. Participation in valued activities = number of activities in which a participant engaged in the last month (Range: 0-4)

Table 1.5.

Testing for Invariance between Typical and Cognitive Impairment Groups

Model	Invariance	Constraints	Comparison	Retained?	S-Bχ2	*df*	c	ΔS-Bχ2	Δ*df*	*p*	RMSEA	CFI	ΔRMSEA	ΔCFI
1	Configural invariance	Unconstrained	-	-	455.46	66	1.35	-	-	-	0.045	0.938	-	-
2	Measurement invariance	All factor loadings	1 vs 2	Y	461.65	70	1.39	12.91	4	0.012	0.043	0.937	0.002	0.001
3	Structural invariance	Path: COH →ACT	2 vs 3	Y	469.20	71	1.39	7.69	1	0.006	0.043	0.936	<0.001	0.001
4	Structural invariance	Path: ACT → QOL	3 vs 4	Y	472.30	72	1.39	3.41	1	0.065	0.043	0.936	<0.001	<0.001

Note. COH = Neighborhood social cohesion; ACT = Number of participated valued activities; QOL = Quality of life; S-Bχ2= Satorra-Bentler adjusted chi-square; c = Satorra-Bentler scaling correction factor; ΔS-Bχ2= adjusted chi-square difference test

Table 2.1.

Sociodemographic Characteristics of PwMCIs and CPs

Variable and category	PwMCI Total (*n*=62)	CP Total (*n*=62)
Age (in years), M (SD)	75 (7.51)	67 (11.05)
Sex, n (%)		
Female	16 (25.81)	60 (96.77)
Race, n (%)		
White	38 (61.29)	42 (67.74)
African American	22 (35.48)	20 (32.26)
Other	2 (3.22)	0 (0.00)
Ethnicity, n (%)		
Hispanic/Latino	0 (0.00)	0 (0.00)
Education, n (%)		
High school/GED and below	30 (48.38)	23 (37.10)
Vocational college	2 (3.23)	7 (11.29)
College	22 (35.48)	20 (32.26)
Graduate/professional school	8 (12.90)	12 (19.35)
Monthly income, n (%)		
<$1000	6 (10.17)	7 (12.73)
$1000-$1999	16 (27.12)	14 (25.45)
$2000-$3999	19 (32.20)	19 (34.55)
$4000-$6999	12 (20.34)	8 (14.55)
>$7000	6 (10.17)	7 (12.73)
CP and PwMCI live together, n (%)		51 (82.26)
Marital status		
Married or partnered	44 (70.97)	49 (79.03)
Not married	18 (29.03)	13 (20.97)
Relationship to PwMCI		
spouse or partner		44 (70.97)
parent or stepparent		10 (16.13)
brother or sister		2 (3.23)
other relative		1 (1.61)
friend		5 (8.06)
MMSE, M (SD)	26.13 (2.96)	
Caregiving Burden at baseline		3.79 (3.07)
Caregiving Burden at follow-up (*n*=31)		4.61 (2.69)

Table 2.2.

Pearson's Correlations

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
1 CP Remote at BL																				
2 CP Recent at BL	.448**																			
3 CP Attention at BL	.526**	.412**																		
4 CP Daily at BL	.389**	.451**	.398**																	
5 PwMCI Remote at BL	.361**	.203	.145	.066																
6 PwMCI Recent at BL	.257*	.317*	.084	.088	.539**															
7 PwMCI Attention at BL	.113	.181	.248	.133	.551**	.434**														
8 PwMCI Daily at BL	.102	.225	.148	.219	.375**	.439**	.556**													
9 CP DAS Mean at BL	.731**	.767**	.740**	.788**	.237	.230	.228	.219												
10 PwMCI DAS Mean at BL	.256*	.303*	.195	.163	.751**	.790**	.796**	.784**	.287*											
11 Discrepancy Remote at BL	-.611**	-.238	-.360**	-.301*	.518**	.222	.364**	.225	-.469**	.402**										
12 Discrepancy Recent at BL	-.161	-.580**	-.279*	-.308*	.290*	.589**	.219	.186	-.456**	.421**	.394**									
13 Discrepancy Attention at BL	-.356**	-.206	-.649**	-.233	.310*	.270*	.576**	.311*	-.448**	.461**	.589**	.407**								
14 Discrepancy Daily at BL	-.291*	-.258*	-.281*	-.747**	.230	.212	.327*	.486**	-.557**	.397**	.463**	.400**	.498**							
15 Discrepancy DAS Mean at BL	-.429**	-.424**	-.495**	-.550**	.415**	.437**	.470**	.456**	-.632**	.561**	.747**	.734**	.793**	.803**						
16 CP Burden at BL	.244	.418**	.339**	.329**	-.052	-.048	-.056	.112	.437**	-.006	-.268*	-.398**	-.330**	-.266*	-.408**					
17 CP Burden at FL	-.029	-.016	-.141	.107	.199	-.217	.284	.347	-.005	.160	.187	-.215	.399*	.103	.144	.607**				
18 PwMCI Age	.020	.053	.021	.288*	-.147	-.163	.043	-.018	.143	-.091	-.143	-.185	.016	-.293*	-.208	.090	.174			
19 PwMCI MMSE	-.100	-.106	-.217	-.171	-.101	.078	-.080	-.259*	-.177	-.116	.007	.154	.118	.110	.120	-.388**	-.210	-.295*		
20 CP Age	.140	.076	-.064	-.012	-.122	-.113	-.130	-.259*	.051	-.205	-.232	-.162	-.048	-.135	-.192	-.118	.020	.330**	.029	

Note. BL=baseline; FU=follow-up; DAS=Deficit Awareness Scale; * $p<.05$; ** $p<.01$

Table 2.3.

Spearman's Rank Correlations

	Remote DISC group at BL	Recent DISC group at BL	Attention DISC group at BL	Daily DISC group at BL	DAS mean DISC group at BL	PwMCI sex	PwMCI race	PwMCI educ	PwMCI income	PwMCI marital status	CP sex	CP race	CP educ	CP income	CP living with PwMCI	CP marital status	CP relationship to PwMCI
CP Remote at BL	-.561**	-.172	-.365**	-.300*	-.396**	-.178	-.264*	-.208	-.102	.080	.288*	-.098	-.144	-.141	.096	.166	-.033
CP Recent at BL	-.232	-.605**	-.191	-.247	-.388**	-.264*	-.137	.079	.231	.220	-.018	-.212	-.131	.153	.111	.148	-.141
CP Attention at BL	-.291*	-.233	-.605**	-.224	-.421**	-.027	-.015	-.189	-.099	-.077	-.013	.105	-.129	.093	.009	-.114	.105
CP Daily at BL	-.265*	-.325*	-.170	-.586**	-.551**	-.001	-.052	.002	.081	-.071	.018	-.061	-.044	.080	-.228	.025	.114
PwMCI Remote at BL	.467**	.131	.259*	.318*	.412**	.004	-.092	-.313*	-.281*	-.133	.239	.087	-.131	-.102	.115	-.075	.100
PwMCI Recent at BL	.109	.384**	.214	.123	.276*	-.229	-.233	-.073	.000	.053	.208	-.135	.041	.127	.134	.077	-.122
PwMCI Attention at BL	.423**	.132	.473**	.343**	.408**	.171	-.058	-.290*	-.153	-.239	.229	.121	-.048	.005	.030	-.163	.300*
PwMCI Daily at BL	.361**	.085	.364**	.546**	.488**	.068	-.058	-.307*	-.094	-.227	.229	.047	-.069	.077	.068	-.302*	.283*
CP DAS Mean at BL	-.407**	-.459**	-.411**	-.465**	-.594**	-.122	-.159	-.052	.036	.048	.063	-.097	-.144	.066	-.047	.101	.014
PwMCI DAS Mean at BL	.432**	.237	.391**	.433**	.512**	.004	-.115	-.302*	-.155	-.189	.255*	.046	-.073	.068	.096	-.202	.194
Discrepancy Remote at BL	.938**	.273*	.531**	.495**	.692**	.181	.119	-.005	-.135	-.166	-.095	.128	.049	.051	.017	-.235	.116
Discrepancy Recent at BL	.198	.917**	.304*	.240	.534**	.013	-.104	-.096	-.148	-.123	.200	.042	.177	-.022	.049	-.030	0.000
Discrepancy Attention at BL	.599**	.273*	.943**	.455**	.661**	.169	-.019	-.066	.036	-.148	.136	0.000	.119	.027	-.001	-.032	.155
Discrepancy Daily at BL	.483**	.336**	.403**	.915**	.810**	.024	.023	-.139	-.089	-.014	.128	.088	.030	.005	.199	-.238	.057
Discrepancy DAS Mean at BL	.702**	.558**	.660**	.774**	.935**	.113	.050	-.104	-.126	-.154	.128	.116	.149	.005	.125	-.248	.125
CP Burden at BL	-.221	-.395**	-.317*	-.232	-.402**	-.240	-.243	-.024	.091	.141	-.052	-.275*	-.225	-.005	-.024	.044	-.066
CP Burden at FL	.407*	-.284	.311	.229	.238	-.037	-.238	.184	.015	.079	-	-.208	-.048	.067	0.000	.074	.048
PwMCI Age	-.119	-.238	.018	-.250	-.208	-.048	-.127	-.064	-.091	.008	-.100	-.002	.072	.097	-.260*	.137	.023
PwMCI MMSE	-.065	.146	.028	.143	.158	.038	-.045	.315*	.029	.115	-.251	-.019	.266*	.089	.058	.080	-.154
CP Age	-.251*	-.094	-.062	-.102	-.163	-.401**	-.249	.071	.068	.503**	.051	-.228	-.187	-.260	.216	.452**	-.474**
Remote discrepancy group at BL		.232	.518**	.490**	.630**	.210	.146	-.072	-.092	-.188	-.093	.133	.041	.113	.010	-.242	.173
Recent discrepancy group at BL			.318*	.238	.499**	.059	-.060	-.096	-.112	-.114	.115	.059	.211	-.041	.138	-.049	.009
Attention discrepancy group at BL				.376**	.613**	.116	-.025	-.016	.071	-.119	.092	-.049	.157	.025	-.003	-.009	.121
Daily discrepancy group at BL					.755**	.133	.104	-.158	-.111	-.090	.054	.162	-.013	-.003	.149	-.311*	.145
DAS mean discrepancy group at BL						.112	.047	-.084	-.159	-.162	.081	.124	.213	-.009	.139	-.256*	.126
PwMCI sex							.551**	-.059	-.262*	-.841**	-.310*	.618**	.133	.040	-.402**	-.692**	.859**
PwMCI race								-.225	-.199	-.476**	-.216	.815**	-.081	-.019	-.299*	-.452**	.487**
PwMCI education									.553**	.264*	-.282*	-.296*	.503**	.365**	-.106	.213	-.273*
PwMCI monthly income										.371**	-.156	-.400**	.341**	.625**	.107	.326*	-.394**
PwMCI marital status											.084	-.623**	-.078	.013	.354**	.718**	-.917**
CP sex												-.069	-.204	-.291*	.154	.130	-.057
CP race													-.090	-.093	-.402**	-.577**	.634**
CP education														.353**	-.110	.006	.002
CP monthly income															-.094	.096	-.103
CP live in same home with PwMCI																.279*	-.408**
CP marital status																	-.832**
CP relationship to PwMCI																	

Note. BL=baseline; FU=follow-up; DAS=Deficit Awareness Scale; DISC=Discrepancy; * *p*<.05; ** *p* <.01

Table 2.4.

PwMCI-CP Agreement in Awareness of PwMCIs' Deficits (N=62 pairs for Baseline, 28 pairs for Follow-up)

DAS subscale	PwMCI *M* (*SD*)	CP *M* (*SD*)	PwMCI - CP Discrepancy Score *M* (*SD*)	*t* value	*p*	Intraclass Correlation Coefficient
Baseline						
Overall DAS	2.46 (0.588)	2.61 (0.629)	-0.15 (0.73)	1.57	0.123	0.29 *
Remote memory	2.12 (0.603)	1.95 (0.652)	0.17 (0.71)	-1.88	0.065	0.36 **
Recent memory	3.13 (0.863)	3.17 (0.856)	-0.05 (1.00)	0.37	0.714	0.32 *
Attention	2.46 (0.699)	2.57 (0.751)	-0.11 (0.89)	1.00	0.322	0.25 †
Daily activities	2.16 (0.790)	2.77 (1.039)	-0.61 (1.16)	4.12	<0.001	0.22 †
Follow-up						
Overall DAS	2.73 (0.561)	2.95 (0.748)	-0.22 (0.63)	-1.84	0.077	0.56 **
Remote memory	2.44 (0.678)	2.31 (0.841)	0.13 (0.81)	0.83	0.413	0.44 *
Recent memory	3.34 (0.933)	3.44 (0.827)	-0.10 (0.73)	-0.71	0.485	0.66 **
Attention	2.59 (0.566)	2.99 (0.951)	-0.40 (0.91)	-2.35	0.027	0.38 *
Daily activities	2.58 (0.693)	3.10 (1.044)	-0.52 (1.02)	-2.68	0.013	0.37 †

Note. DAS=Deficit Awareness Scale; *t*= value of *t*-statistics; † *p*<.10; * *p*<.05; ** *p* <.01

Table 2.5.

One-Way Analysis of Variance of CPs' Burden at Baseline by DAS Discrepancy Group

DAS subscale	Total			Discrepancy group										
				CP negative			Similar			CP positive				
	n	*M*	*SD*	%	*M*	*SD*	%	*M*	*SD*	%	*M*	*SD*	*F*	*p*
Overall DAS	61	3.72	3.045	38	4.83	2.443	39	3.79	3.323	23	1.79	2.636	4.92	0.011
Remote memory	62	3.79	3.068	23	4.29	2.644	44	4.26	3.096	34	2.86	3.214	1.49	0.233
Recent memory	62	3.79	3.068	27	5.47	2.601	52	3.53	2.862	21	2.23	3.295	4.90	0.011
Attention	62	3.79	3.068	35	5.09	2.287	39	3.04	3.085	26	3.13	3.538	3.30	0.044
Daily activities	61	3.72	3.045	41	4.84	2.868	46	2.54	2.575	13	4.38	3.889	4.45	0.016

Note. DAS=Deficit Awareness Scale

Table 2.6.

Regression Model Predicting CPs' Caregiving Burden (N=31)

	Overall			Remote memory			Recent memory			Attention			Daily activities		
	β	*t*	*p*	*β*	*t*	*p*	*β*	*t*	*p*	*β*	*t*	*p*	*β*	*t*	*p*
CP burden at FU															
Discrepancy score at BL	0.90	1.47	0.152	0.88	1.54	0.135	-0.20	-0.40	0.691	1.16	2.36	0.025	0.40	1.16	0.256
CP burden at BL	0.59	4.33	<0.001	0.58	4.29	<0.001	0.55	3.81	0.001	0.53	4.09	<0.001	0.59	4.24	<0.001

Note. BL=baseline; FU=follow-up; *β*: standardized regression coefficient; *t*: tests whether the value of the regression coefficient is significantly different from 0; *p*: significance value of t-test.

Supplementary Table 2.7.

Descriptive Statistics of DAS Scores by Discrepancy Group (N=62)

DAS	CP negative						Similar						CP positive					
			PwMCI		CP				PwMCI		CP				PwMCI		CP	
	n	%	*M*	*SD*	*M*	*SD*	*n*	%	*M*	*SD*	*M*	*SD*	*n*	%	*M*	*SD*	*M*	*SD*
Overall DAS	23	38	2.16	0.56	3.01	0.56	24	39	2.51	0.59	2.55	0.57	14	23	2.89	0.28	2.06	0.32
Remote memory	14	23	1.76	0.49	2.45	0.57	27	44	2.01	0.53	2.05	0.58	21	34	2.50	0.57	1.50	0.49
Recent memory	17	27	2.65	0.81	3.82	0.77	32	52	3.18	0.85	3.18	0.67	13	21	3.62	0.69	2.31	0.60
Attention	22	35	2.09	0.66	3.11	0.56	24	39	2.49	0.66	2.50	0.60	16	26	2.92	0.52	1.94	0.66
Daily activities	25	41	1.71	0.64	3.50	1.01	28	46	2.32	0.67	2.36	0.69	8	13	2.97	0.83	1.92	0.71

Note. DAS=Deficit Awareness Scale

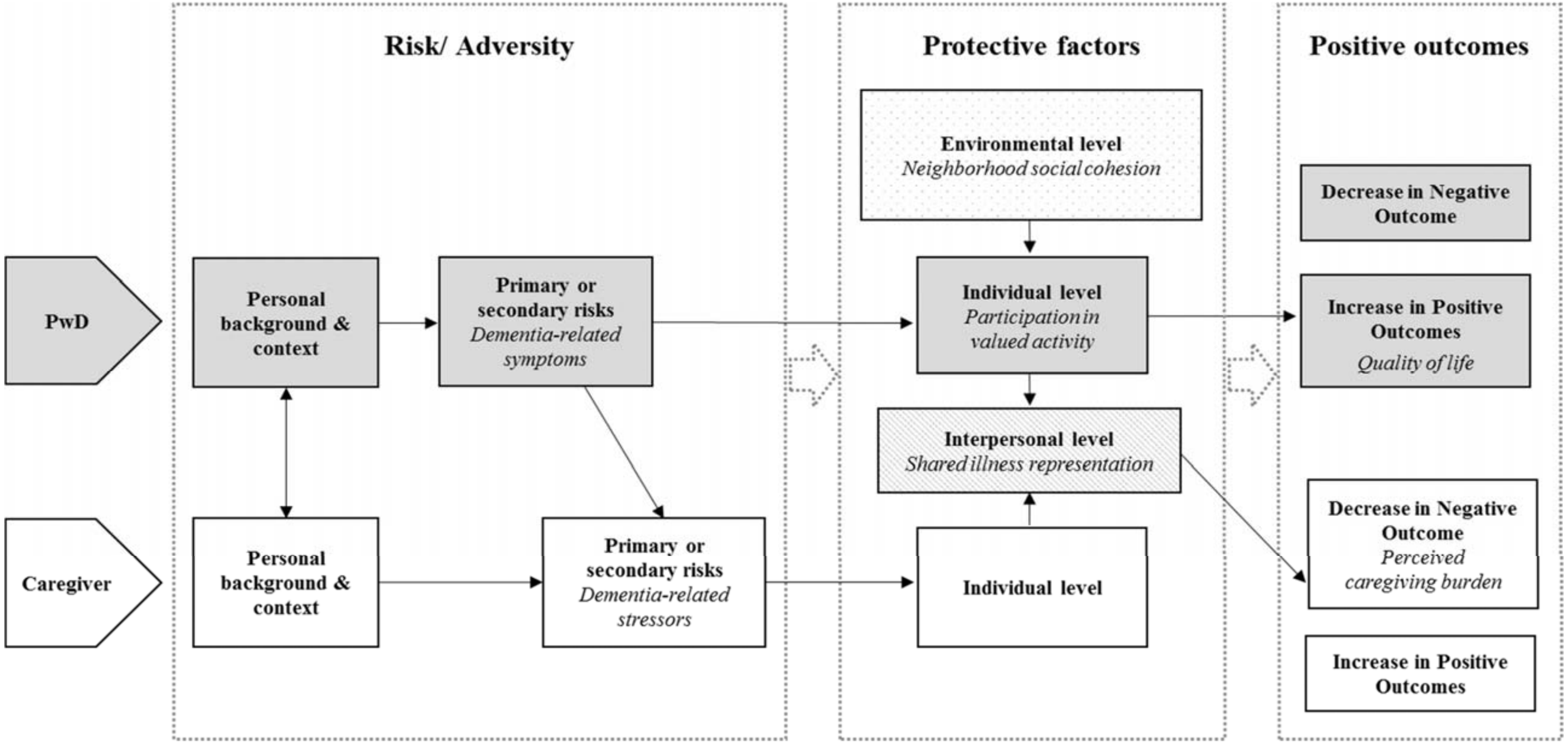


Figure 1. Resilience model of people with dementia (PwDs) and caregivers (adapted from Smith & Hayslip, 2012; Pearlin et al., 1990). Bold font displays original constructs; italic font displays variables emerging from this research. Gray shade displays PwDs' variables and no shade displays caregivers' variables. Slanted line pattern indicates interpersonal-level variable and dot pattern indicates environmental level variable.

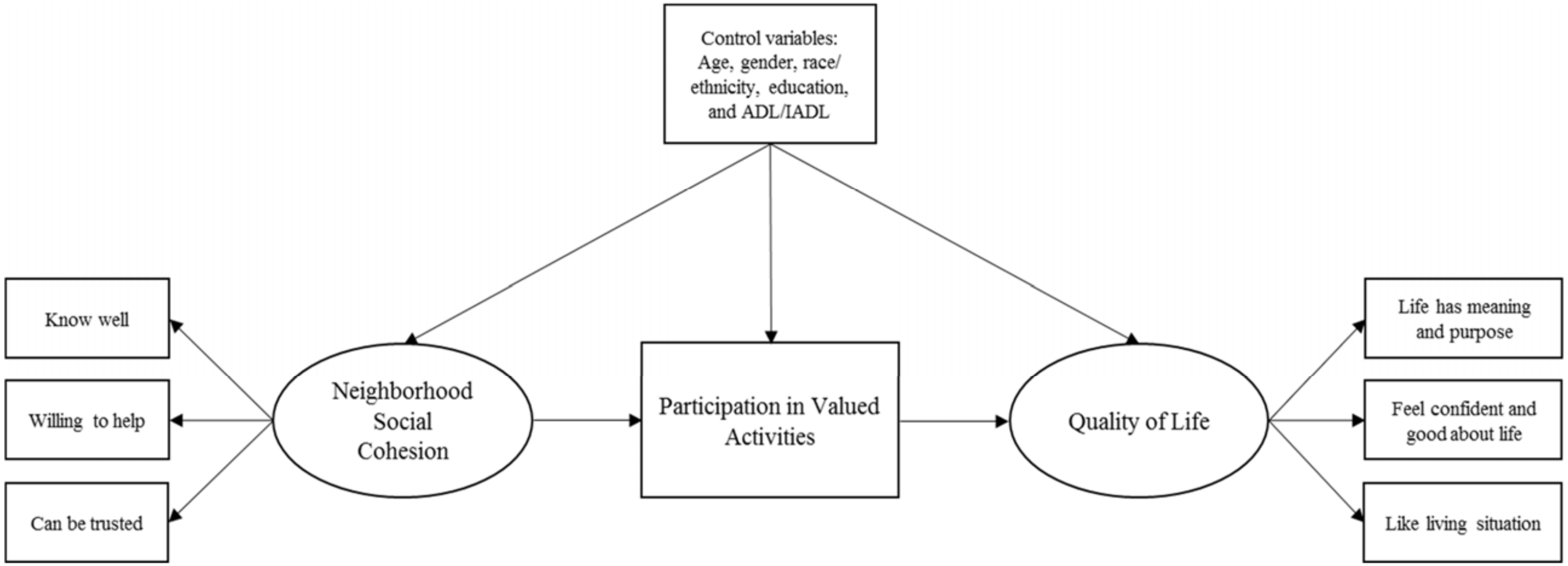


Figure 1.1. Constructed Model

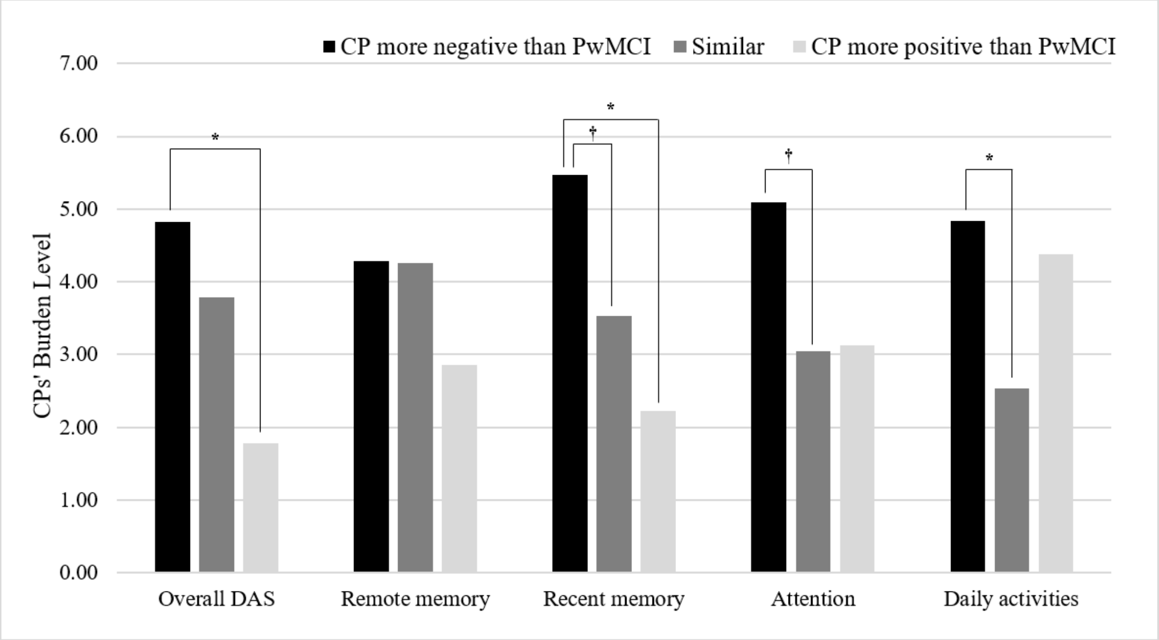


Figure 2.1. Mean CP Caregiving Burden at Baseline by DAS Discrepancy Group. Significance levels are results from post hoc tests (*N*=62 pairs from Baseline data; † *p* < .10; * *p* <.05)

Appendix

A. Study 2 measures

Deficit Awareness Scale

No.	Item
1	Elder's ability to remember the names of family members
2	Elder's ability to remember the names of friends
3	Elder's ability to remember events from her/his childhood
4	Elder's ability to remember things s/he learned in school
5	Elder's ability to remember the names of people s/he just met
6	Elder's ability to remember what happened to her/him yesterday
7	Elder's ability to remember what s/he has read
8	Elder's ability to remember new phone numbers
9	Elder's ability to do simple arithmetic problems in her/his head
10	Elder's ability to concentrate on a task over a period of several minutes
11	Elder's ability to follow a conversation
12	Elder's ability to ignore distracting noises around her/him
13	Elder's ability to drive safely
14	Elder's ability to drive without getting lost
15	Elder's ability to balance the checkbook
16	Elder's ability to manage her/his life and responsibilities on her/his own

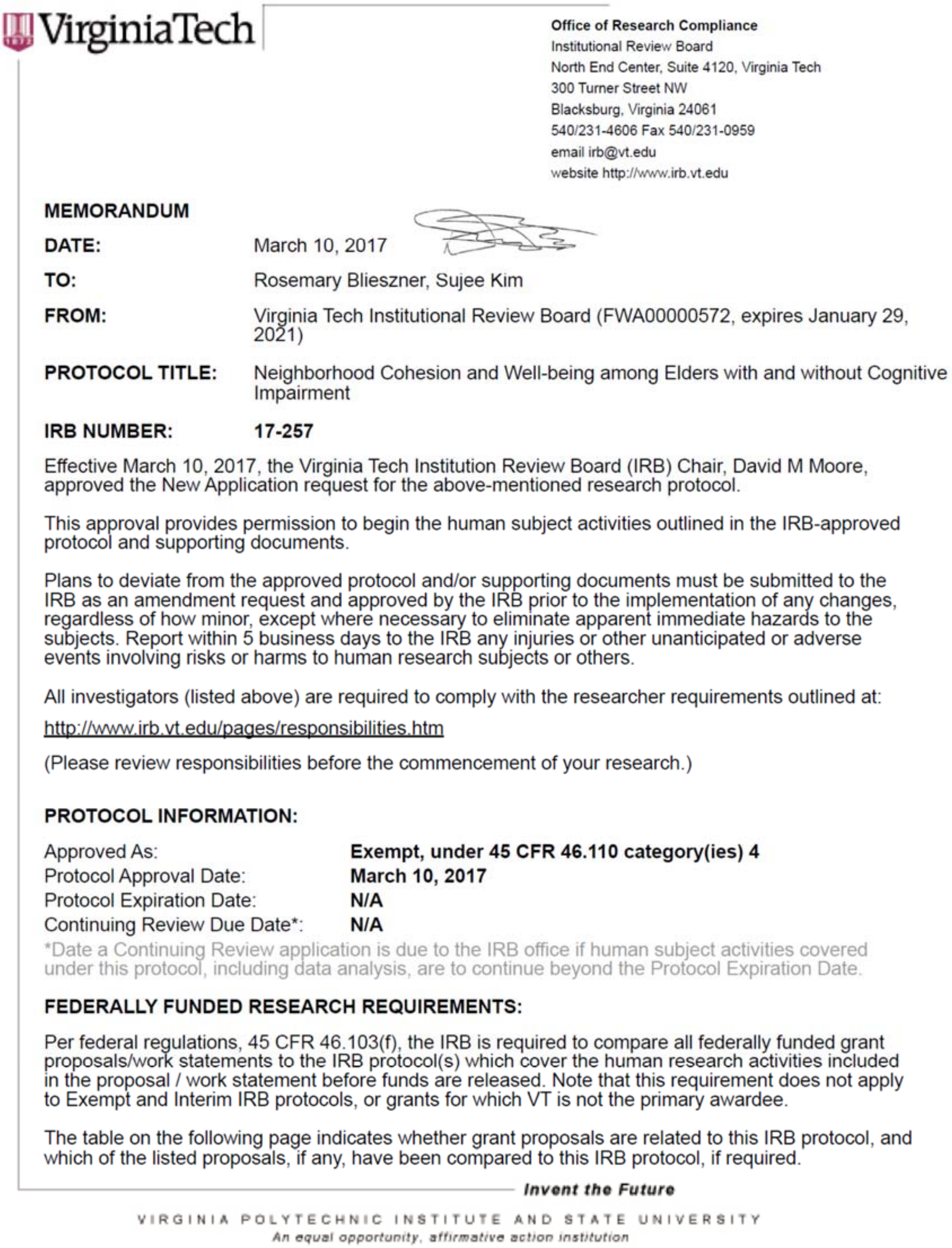
Response options:
1 = Very good 2 = Good 3 = Fair 4 = Poor 5 = Very poor

Burden Interview Scale

No.	Item
1	Do you feel that because of the time you spend with your relative, you don’t have enough time for yourself?
2	Do you feel stressed between caring for your relative and trying to meet other responsibilities (work/family)?
3	Do you feel angry when you are around your relative?
4	Do you feel that your relative currently affects your relationship with family members and friends in a negative way?

5	Do you feel strained when you are around your relative?
6	do you feel that your health has suffered because of your involvement with your relative?
7	Do you feel that you don’t have as much privacy as you would like because of your relative?
8	Do you feel that your social life has suffered because you are caring for your relative?
9	Do you feel that you have lost control of your life since your relative’s illness?
10	Do you feel uncertain about what to do about your relative?
11	Do you feel you should be doing more for your relative?
12	Do you feel you could do a better job in caring for your relative?
Response options: 0 = Never 1 = Rarely 2 = Sometimes 3 = Quite frequently 4 = Nearly always	

B. IRB Approval Letters



VirginiaTech

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Blacksburg, Virginia 24061
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website http://www.irb.vt.edu

MEMORANDUM

DATE: March 10, 2017

TO: Rosemary Blieszner, Sujee Kim

FROM: Virginia Tech Institutional Review Board (FWA00000572, expires January 29, 2021)

PROTOCOL TITLE: Neighborhood Cohesion and Well-being among Elders with and without Cognitive Impairment

IRB NUMBER: **17-257**

Effective March 10, 2017, the Virginia Tech Institution Review Board (IRB) Chair, David M Moore, approved the New Application request for the above-mentioned research protocol.

This approval provides permission to begin the human subject activities outlined in the IRB-approved protocol and supporting documents.

Plans to deviate from the approved protocol and/or supporting documents must be submitted to the IRB as an amendment request and approved by the IRB prior to the implementation of any changes, regardless of how minor, except where necessary to eliminate apparent immediate hazards to the subjects. Report within 5 business days to the IRB any injuries or other unanticipated or adverse events involving risks or harms to human research subjects or others.

All investigators (listed above) are required to comply with the researcher requirements outlined at:

http://www.irb.vt.edu/pages/responsibilities.htm

(Please review responsibilities before the commencement of your research.)

PROTOCOL INFORMATION:

Approved As:	**Exempt, under 45 CFR 46.110 category(ies) 4**
Protocol Approval Date:	**March 10, 2017**
Protocol Expiration Date:	**N/A**
Continuing Review Due Date*:	**N/A**

*Date a Continuing Review application is due to the IRB office if human subject activities covered under this protocol, including data analysis, are to continue beyond the Protocol Expiration Date.

FEDERALLY FUNDED RESEARCH REQUIREMENTS:

Per federal regulations, 45 CFR 46.103(f), the IRB is required to compare all federally funded grant proposals/work statements to the IRB protocol(s) which cover the human research activities included in the proposal / work statement before funds are released. Note that this requirement does not apply to Exempt and Interim IRB protocols, or grants for which VT is not the primary awardee.

The table on the following page indicates whether grant proposals are related to this IRB protocol, and which of the listed proposals, if any, have been compared to this IRB protocol, if required.

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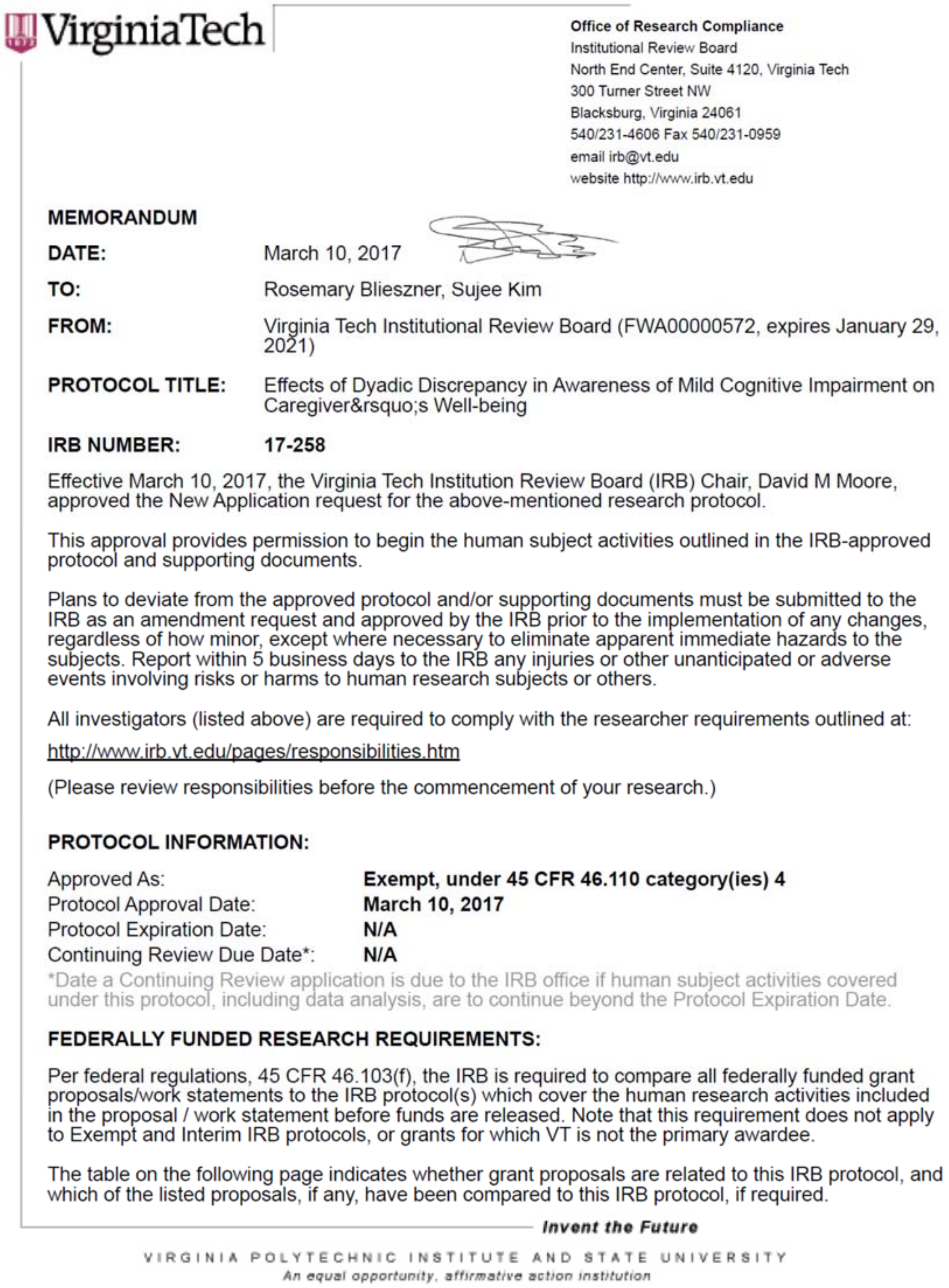

VirginiaTech

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website http://www.irb.vt.edu

MEMORANDUM

DATE: March 10, 2017

TO: Rosemary Blieszner, Sujee Kim

FROM: Virginia Tech Institutional Review Board (FWA00000572, expires January 29, 2021)

PROTOCOL TITLE: Effects of Dyadic Discrepancy in Awareness of Mild Cognitive Impairment on Caregiver’s Well-being

IRB NUMBER: **17-258**

Effective March 10, 2017, the Virginia Tech Institution Review Board (IRB) Chair, David M Moore, approved the New Application request for the above-mentioned research protocol.

This approval provides permission to begin the human subject activities outlined in the IRB-approved protocol and supporting documents.

Plans to deviate from the approved protocol and/or supporting documents must be submitted to the IRB as an amendment request and approved by the IRB prior to the implementation of any changes, regardless of how minor, except where necessary to eliminate apparent immediate hazards to the subjects. Report within 5 business days to the IRB any injuries or other unanticipated or adverse events involving risks or harms to human research subjects or others.

All investigators (listed above) are required to comply with the researcher requirements outlined at:

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(Please review responsibilities before the commencement of your research.)

PROTOCOL INFORMATION:

Approved As:	**Exempt, under 45 CFR 46.110 category(ies) 4**
Protocol Approval Date:	**March 10, 2017**
Protocol Expiration Date:	**N/A**
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