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Examining Caregiver Appraisal of Functional Capacity in Family Members with Dementia

Catherine Verrier Piersol
Virginia Commonwealth University

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A dissertation submitted in partial fulfillment of the requirements for the degree of
Doctor of Philosophy at Virginia Commonwealth University

by

Catherine Verrier Piersol
B.S., Tufts University, 1982
M.S., Boston University, 1988

Director: Al Copolillo, PhD, OTR/L, FAOTA
Chair and Professor, Department of Occupational Therapy
School of Allied Health Professions

Virginia Commonwealth University
Richmond, Virginia
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Abstract

EXAMINING CAREGIVER APPRAISAL OF FUNCTIONAL CAPACITY IN FAMILY MEMBERS WITH DEMENTIA

By Catherine Verrier Piersol, Ph.D.

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy at Virginia Commonwealth University.

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Major Director: Al Copolillo, PhD, Professor, Department of Occupational Therapy

The vast majority of persons with Alzheimer's disease and related dementias live at home and are cared for by families or close friends/neighbors. An essential element to daily care decisions is the caregiver's appraisal of function in the family member with dementia. This dissertation comprises three separate papers exploring caregiver appraisal of functional capacity, using secondary data from a study conducted at Thomas Jefferson University of 88 patient-caregiver dyads, funded by the Alzheimer's Association (L. Gitlin, PhD, principal investigator; Grant # IIRG-07-28686). The caregivers were primarily female (88.6%), white (77.3%), and spouses (55.7%), with a mean age of 65.8. All caregivers had a high school education or higher and had provided care from 6 months to 22 years. The majority of the participants with dementia

were female (52.3%) and white (76.1) with a mean age of 81.7. Their scores on the MMSE ranged from 10 to 28 (M = 17.7, SD = 4.6, N = 87).

The first paper examined construct and interrater reliability of the Functional Capacity Card Sort (FCCS), a tool designed to measure subjective caregiver appraisal. Using spearman's rank correlations the FCCS was found to be statistically associated with the Caregiver Assessment of Function and Upset scale (r = .43, $p < 0.0001$, N = 86) and not statistically associated with the Neuropsychiatric Inventory scale (r = -.14, p = .16, N = 86), supporting convergent and discriminant validity respectfully. Kendall's coefficient of concordance revealed a strong agreement among caregivers in the ranking of the six cards of the FCCS, Kendall W (5, 72) = 0.83, p = .0001, supporting interrater reliability of the FCCS.

The second and third paper demonstrated the utility of the FCCS in distinguishing three groups of caregivers based on their estimation of functional capacity in the person with dementia compared to a gold standard occupational therapy assessment. Fifty-two (61%) of the caregivers overestimated function, 19 (22%) caregivers underestimated function, and 15 (17%) were concordant with the standardized assessment. Further analysis explored personal and home environment factors in relation to caregiver appraisal. The Kruskal-Wallis test showed cognitive status in the person with dementia (H (2, N = 85) = 3.67, p = .16) and caregiver depressive symptoms (H (2, N = 86) = 1.35, p = .51) were not associated with the caregiver's appraisal of functional capacity in the person with dementia. Linear regression and proportional odds logistic regression, adjusted for cognitive status in the person with dementia, did not reveal a relationship between caregiver appraisal and the number of observed home hazards [F (1, N = 86) = .01, p = .94] or the unmet needs reported by the caregiver [Wald $\chi 2$ (1, N = 86) = .95, p = .33],

respectively. Linear regression showed a trend towards the hypothesis that caregiver concordant/underestimation of functional capacity have greater home adaptations compared to caregiver overestimation [F (1, N = 86) = 3.06, p = .08]. The papers in totality demonstrate the utility of the FCCS to assess caregiver appraisal and interpret level of estimation, which can guide the therapeutic approach and treatment plan by an occupational therapist or other health professional. Further understanding of caregiver appraisal and associated factors is critical to providing best practice in dementia care. Limitations and future directions for research are discussed.

Chapter I: Introduction

Alzheimer's Disease and Related Dementia

During the 20th century, the population of older people (age 65 and older) increased from 3 million to 37 million, with the oldest old (age 85 and over) increasing from just over 100,000 in 1900 to 5.3 million in 2006 (Federal Interagency Forum on Aging-Related Statistics, 2008). Based on the United States baby boomer generation, it is projected that there will be 71.5 million older people by 2030 and 21 million oldest old by 2050 (Federal Interagency Forum on Aging-Related Statistics, 2008). This rising prevalence "affects many aspects of our society, challenging policymakers, families, businesses, and health care providers, among others, to meet the needs of aging individuals" (Federal Interagency Forum on Aging-Related Statistics, 2008, p. 2). Advancing age being the greatest risk factor for Alzheimer's disease, the prevalence of Alzheimer's disease and related dementia (ADRD) is rising, with estimations that the number of older people with ADRD will reach 7.7 million by 2030. This is close to a 50 percent increase from the 5.4 million older people currently affected with dementia (Alzheimer's Association, 2012). The incidence of dementia is likely to increase to 13.2 million in the United States by the year 2050 (Hebert, Scherr, Bienias, Bennett, & Evans, 2003) and to 106.8 million globally (Brookmeyer, Johnson, Ziegler-Graham, & Arrighi, 2007).

ADRD refers to a set of diseases for which dementia is the primary symptom. Alzheimer's disease is the most common type of dementia, accounting for 60 to 80 percent of

cases (Alzheimer's Association, 2012); however, there is a body of evidence from longitudinal and autopsy studies indicating that many people with dementia demonstrate behavioral symptoms and anatomical brain abnormalities associated with more than one type of dementia (Schneider, Arvanitakis, Bang, & Bennett, 2007; Jellinger, 2007). Dementia is a set of symptoms characterized by a decline in intellectual function that limits an individual's ability to manage and perform daily activities (Kawas, 2003; Mace & Rabins, 2011), and can include the manifestation of dementia-related neuropsychiatric symptoms including agitation, apathy, anxiety and disinhibition (Lyketsos et.al., 2011). In addition, most individuals with Alzheimer's disease have neuropsychiatric symptoms, with agitation-type behaviors presenting in early, middle, and late stages and apathy reported as the most persistent behavior across all stages (Lyketsos et al., 2011).

The course of the disease ranges from eight to ten years; with some individuals living up to 20 years post diagnosis. The symptoms progress from mild memory loss to more severe functional limitations, at which point an individual can no longer perform daily activities (Bullock, 2004; Sadik & Wilcox, 2003). The progressive decline in cognitive processes and functional ability impact the life of the person with dementia, the families and others that provide care, as well as the health care delivery system (Plassman, et al., 2007). The World Health Organization (WHO) and Alzheimer's Disease International (ADI) recognize dementia as a public health priority and assert the need to increase knowledge and awareness of dementia and improve care and support for both individuals with dementia and their caregivers (World Health Organization & Alzheimer's Disease International, 2012).

The Role of Families in the Care of People with Dementia

Family caregiving is described as the act of assisting an individual one cares about who is chronically ill or disabled and no longer able to care for him/herself (National Family Caregivers Association, 2010). A report by the Institute of Medicine (IOM), based on a review of the evidence, states that informal caregivers "provide a large amount of long-term care services to families and friends, and will continue to be a significant part of the health care workforce" (IOM, 2008, p. 29). A survey of 1,297 randomly selected adults providing care to individuals 50 years of age or older, conducted by the National Alliance for Caregiving (NAC) and the American Association for Retired Persons (AARP) showed 65.7 million Americans are family caregivers, i.e. 29% of the population (NAC & AARP, 2009). The most prevalent reason reported by caregivers for needing to provide care was "Alzheimer's/Confusion" (30%), which is an increase from 25 percent in 2004 (NAC & AARP, 2009, p. 17). In 2011 greater than 15 million Americans provided over 17 billion hours of unpaid care to individuals with dementia. The annual monetary value of the care provided by families or informal caregivers is reported to be in excess of $210 billion (Alzheimer's Association, 2012).

The vast majority of people with Alzheimer's disease and related dementias live at home, are cared for by families or close friends/neighbors, and require supervision or assistance with daily activities (Alzheimer's Association, 2012; Family Caregiver Alliance, 2006). Caregivers play a vital role in the safety and well-being of family members with dementia. As caregivers, family members must determine the amount and type of oversight or assistance necessary for the person to perform activities of daily living (ADL), such as getting washed and dressed and eating a meal, and instrumental activities of daily living (IADL), such as managing medications,

preparing meals, and shopping. When compared to those caring for older people without dementia, family caregivers of people with dementia are more likely to provide assistance with daily activities, including getting in and out of bed, using the toilet, managing incontinence, bathing, and eating (Alzheimer's Association, 2012).

Caregiver Appraisal of Functional Capacity in People with Dementia

Accurate appraisal by caregivers of their family member's capacity to perform daily activities is an essential element in the overall responsibilities of caregiving. Family reports are often sought by health care providers to gain an understanding of the patient's functional capacity, which can drive the intervention plan. The information about daily function gathered from close family members has been viewed as particularly important in dementia care since patients with cognitive impairment tend to overestimate their ability to perform daily activities (Karagiozis, Grey, Sacco, Shapiro, & Kawas, 1998; Kiyak, Teri, & Borson, 1994; Loewenstein et al., 2001).

The concept of appraisal is described in the psychology literature as a cognitive process used to mediate emotional reactions (Lazarus & Folkman, 1984; Lazarus, 1993). Cognitive appraisal is "largely evaluative, focused on meaning or significance, and takes place continuously during waking life" (Lazarus & Folkman, 1984, p. 31). Cognitive appraisal theory asserts that under comparable conditions people react with different emotions and actions based on personal and environmental characteristics (Lazarus, 1993). This theory posits appraisal as the cognitive mediator for stress reactions. Drawing on this concept, caregiver appraisal is operationally defined for this dissertation as the cognitive process caregivers go through to estimate the functional capacity of the person with dementia. Caregivers must estimate the

functional capacity of the person with dementia and react accordingly, by providing a range of care from general oversight to hands on assistance. Essentially, caregiver appraisal serves as the mediator for the actions caregivers take in providing daily care.

Functional capacity in the person with dementia is usually assessed by interviewing the caregiver with dementia (Suh, Ju, Yeon, & Shah, 2004). However, the accuracy of caregiver appraisal when compared to direct assessment has been found to be inconsistent, with caregivers over and under estimating functional ability of the person with dementia (Karagiozis et al., 1998; Doble, Fisk, & Rockwood, 1999; Zanetti, Geroldi, Frisoni, Bianchetti, & Trabucchi, 1999; Arguelles, Loewenstein, Eisdorfer, & Arguelles, 2001; Loewenstein et al., 2001; Davis, Martin-Cook, Hynan, & Weiner, 2006). Disparity between subjective appraisal and objectively measured functional capacity of the person with dementia can lead to inappropriate oversight and management by the caregiver. Caregivers who overestimate or underestimate the abilities of the person with dementia may place the person with dementia in situations that exceed or fall below the person's functional capacity. Health care providers need to be able to accurately judge whether the caregiver's estimation of function is in concordance with a standardized assessment of function. Interpretation of caregiver estimation of function is best achieved through comparison of the caregiver's subjective appraisal and a health professional's evaluation using a standardized measure.

To meet this need, the Cognitive Disabilities Model (Allen & Blue, 1998) was used to develop the Functional Capacity Card Sort (FCCS), a new tool designed to measure subjective caregiver appraisal of functional ability in the person with dementia. The levels of function used to develop the FCCS correspond with the cognitive levels of the Cognitive Disabilities Model.

Thus, the subjective caregiver appraisal rating on the FCCS can be compared to the score on the Allen Diagnostic Module (Earhart, 2006), a standardized test derived from the Cognitive Disabilities Model. In doing so, caregivers can be placed into one of three possible categories: 1) concordant estimation (appraisal rating is concordant with standardized assessment); 2) over estimation (appraisal rating is higher than standardized assessment); or 3) under estimation (caregiver appraisal is lower than standardized assessment). The FCCS offers occupational therapists the ability to determine a caregiver's accuracy in appraising the functional capacity of the family member with dementia. This can guide targeted intervention planning.

Proposed Papers using Secondary Data Analysis

Chapters II, III, and IV of this dissertation comprise three papers that examine caregiver appraisal of functional capacity using secondary data analysis from a study conducted at Thomas Jefferson University (TJU) entitled "Health-Related Quality of Life of Individuals with Dementia and their Caregivers in the Home" (QOL Study), funded by the Alzheimer's Association (L. Gitlin, PhD, Principal Investigator; Grant # IIRG-07-28686). Chapter II introduces the Functional Capacity Card Sort, including its development, content validity and preliminary examination of its psychometric properties. Factors associated with caregiver appraisal and its concordance with standardized assessment are explored in Chapter III. Chapter IV examines caregiver appraisal in relation to conditions of the home environment. Each chapter is written as a separate paper. As such, the sections of each paper include similar supporting literature, variables, and measures, and the Tables and Figures are numbered by paper rather than using continuous numbering throughout the dissertation. An overview of the aims and hypotheses for each paper follows.

Psychometric evaluation of the Functional Capacity Card Sort.

The first paper is an initial psychometric examination of the FCCS and provides a detailed description of its development and established content validity. The study examined the tool's construct validity and interrater reliability. To study convergence and discriminant validity, Spearman's rank correlation procedure was used to test the relationship between caregiver appraisal ratings of functional capacity on the FCCS with measures that are conceptually related and unrelated respectively. It was hypothesized that there would be a positive statistically significant association between the caregiver rating on the FCCS and the Caregiver Assessment of Function and Upset (Gitlin, et al., 2005) and no statistically significant association between the FCCS and the Neuropsychiatric Inventory (Cummings et al., 1994). To determine interrater reliability, Kendall's *W* statistic was used to calculate the degree to which different caregivers identified consistent rankings of the FCCS cards. The hypothesis stated there would be a strong agreement among the caregivers in ranking the order of the FCCS cards from low to high functional capacity.

Factors associated with caregiver appraisal of functional capacity in people with dementia.

The second paper demonstrates the utility of the FCCS in distinguishing three types of caregiver estimation. The analysis initially categorized caregivers based on the FCCS rating of functional capacity by caregivers compared to the score on a standardized assessment administered to the person with dementia by an occupational therapist. The comparison yielded a three level categorical variable called caregiver concordance status, which served as the dependent variable. Using a Kruskal-Wallis test, this study examined the differences among the

three groups on two independent variables: cognitive status in the person with dementia and depressive symptoms in the caregiver. It was hypothesized that higher cognitive status in the person with dementia would be significantly associated with caregiver over estimation of functional capacity in the person with dementia and that higher caregiver depressive symptoms would be significantly associated with caregiver under estimation of functional capacity.

Home environmental conditions and caregiver appraisal of functional capacity in people with dementia.

The third paper examines caregiver appraisal in relation to physical attributes of the home environment that hinder or support an individual's safety and function. In this study, caregiver concordance status was considered the independent variable. The dependent variables, all relating to the home environment, were 1) home hazards and 2) adaptations observed by an occupational therapist during a formal home assessment, and 3) unmet needs reported by the caregiver through therapist initiated interview questions. Linear regression, adjusted for cognitive status in the person with dementia, was used to examine the relationship between caregiver concordance status, and home hazards and adaptations. It was hypothesized that caregiver overestimation would result in greater observed home hazards, and caregiver under estimation and concordant estimation would result in greater observed home adaptations. Proportional odds logistic regression was used to analyze the relationship between concordance status and caregiver reported unmet needs. It was hypothesized that caregiver under estimation would have greater caregiver reported unmet needs.

Summary

National statistics indicate the prevalence of dementia is rising throughout the United States and worldwide (Alzheimer's Association, 2012; Alzheimer's Disease International, 2009; Hebert et al., 2003). Along with this increase in the number of people with dementia comes a proliferation of families having to assume direct care responsibilities. Family caregivers are challenged to manage the daily responsibilities of caregiving and provide a safe home environment so people with dementia can remain at home for as long as possible. In their role as caregivers, families must make daily decisions regarding the amount and type of care they provide. Inherent in the decision-making is an appraisal process in which caregivers estimate the functional ability of their family member with dementia; thus caregiver appraisal mediates care decisions and actions. When compared to a standardized assessment, caregivers may be concordant with the direct assessment or may under estimate or overestimate functional capacity in the person with dementia. This dissertation establishes the validity and reliability of the Functional Capacity Card Sort and its use in determining concordance with standardized assessment followed by an examination of caregiver concordance in relation to selected personal and environmental variables.

Chapter II: Psychometric Evaluation of the *Functional Capacity Card Sort*: Measuring Caregiver Appraisal of Functional Capacity in Persons with Dementia

Families play a vital role in the safety and well-being of their relatives with dementia. The vast majority of persons with Alzheimer's disease and related dementias live at home, are cared for by family caregivers, and require supervision or assistance with daily living activities (Alzheimer's Association, 2012; Family Caregiver Alliance, 2006). As caregivers, family members must subjectively judge the amount and type of oversight necessary for the person with dementia in the areas of activities of daily living (ADLs), such as eating, bathing and dressing; and instrumental activities of daily living (IADLs), such as preparing meals, managing finances and medications, and shopping. The caregiver's provision of daily care for the person with dementia increases over the disease trajectory, suggesting a change in their appraisal of functional ability and need.

Caregiver appraisal of functional capacity is an essential element to care decisions and impacts activity engagement, function and safety of the family member with dementia. Caregivers must estimate the functional capacity of the person with dementia and react accordingly, by providing a range of care from general oversight to hands on assistance. Disparity between the caregiver's appraisal and standardized assessment of functional capacity can be an indication that the caregiver is providing inappropriate oversight and management of daily activities. Caregivers who do not accurately judge their family member's function, may

over or under estimate the person's capabilities, which can have an impact on the safety, function, and well-being of the person with dementia . Caregivers who overestimate the person's functional ability, that is, their subjective judgment leads them to believe the person can do more than he or she is capable of (e.g. staying home alone, using the stove, taking a bath), may not provide adequate supervision or hands on assistance. This may place the person with dementia at a risk for potential harm. In contrast, caregivers who underestimate functional ability may provide superfluous care, thereby restricting the person's participation in daily activities and contributing to excess disability (Yury & Fisher, 2007; Rogers et al., 2000).

A family report of everyday function and the assistance required with activities of daily living is often sought by occupational therapists and other health care providers in order to understand the abilities of the relative with dementia. This report can drive intervention planning and care recommendations. Family member report has been viewed as a particularly important proxy in dementia care, as the person with the cognitive impairment tends to overestimate functional capacity (Karagiozis, Grey, Sacco, Shapiro, & Kawas, 1998; Kiyak, Teri, & Borson, 1994). However, the accuracy of family appraisal when compared to direct assessment of functional ability has been found to be inconsistent (Karagiozis et al., 1998; Doble, Fisk, & Rockwood, 1999; Zanetti, Geroldi, Frisoni, Bianchetti, & Trabucchi, 1999; Argüelles, Loewenstein, Eisdorfer, & Argüelles, 2001; Loewenstein et al., 2001; Davis, Martin-Cook, Hynan, & Weiner, 2006). A mechanism to effectively and efficiently determine whether a caregiver's estimation is concordant or discordant with a standardized assessment offers health care providers the opportunity to educate and train caregivers to maximize function and ensure safety in the person with dementia. The Functional Capacity Card Sort addresses this need.

The Functional Capacity Card Sort (FCCS) was developed for use in a cross-sectional study, entitled Health Related Quality of Life in Individuals with Dementia (QOL Study), conducted at Thomas Jefferson University (Gitlin, 2011; Grant # IIRG 07-28686; Piersol, Herge, & Gitlin, 2011). The study examined the prevalence of modifiable factors, including home hazards, fall risk, and functional capacity and the relationship between these factors and quality of life indicators in a person with dementia as perceived through self and proxy report (Gitlin, 2011). The QOL study used performance-based assessments to measure functional capacity of the person with dementia that are based on a hierarchy of cognitive abilities theorized in the Cognitive Disabilities Model (Allen & Blue, 1998). Using this hierarchy of cognitive ability, the FCCS was developed to measure caregiver appraisal of functional capacity in persons with dementia. The caregiver rating was compared to the score on the standardized Allen Diagnostic Module-2 (Earhart, 2006), which is administered to the person with dementia, in order to determine the concordance between caregiver appraisal rating and standardized evaluation score. This paper describes the development of the FCCS and the phases involved in establishing content validity, followed by preliminary psychometric results examining the validity and reliability of this new tool.

Cognitive Disabilities Model

The Cognitive Disabilities Model (Allen, 1985, 1987; Allen & Blue, 1998) is a framework for understanding and interpreting functional capacity in people with cognitive impairment using a hierarchy that denotes the person's cognitive abilities and the cognitive demands of the activity (Pollard & Olin, 2005). Cognitive ability is described as observable behaviors that correspond with a hierarchy of underlying cognitive processes. Cognitive

demands are the characteristics of an activity that affect cognitive processing within specific contexts. The model describes the complex and dynamic interactions between a person's cognitive abilities and the context in which functional performance takes place, referred to as functional cognition. As such, cognitive disability is described from a functional perspective. The model does not address distinct cognitive functions such as memory and attention, but rather how these cognitive functions work together towards a person's capacity to perform daily occupations.

The cognitive processing underlying functional cognition is conceptualized using an information processing paradigm (Allen, 1985; Levy, 1998; Levy & Burns, 2005) which explains how information is acquired, stored, retrieved, and used for activity performance within a given context. The model asserts that a person will not be able to meet cognitive activity demands within a particular context that are above his or her cognitive ability. For example, if a woman with dementia can only locate objects that are within her visual field, she will not be aware of items that are stored in a bathroom cabinet. In order for the woman to utilize the items, they would need to be placed within her line of sight.

The theoretical underpinning of the cognitive disabilities model is Piaget's developmental theory and is reflected in the model's hierarchical continuum of cognitive ability. This hierarchy is referred to as the Allen Cognitive Levels. The Allen Cognitive Level (ACL) scale consists of six levels that describe hierarchical cognitive ability with functional capacity indications, ranging from lowest to highest (Allen, 1999; Pollard & Olin, 2005), with a level six representing highest function. Within each ACL there are sequential modes of performance that further distinguish patterns of behaviors, forming an ordinal scale that represents the ability to notice and react

appropriately to increasingly complex activity and environmental demands (Allen, Blue & Earhart, 1995; Pollard & Olin, 2005). There are five even-numbered modes (0, 2, 4, 6, and 8) for Allen Cognitive Levels 1 to 5. The level and mode are represented by a decimal format in which the first number represents the cognitive level and the second number represents the mode of performance. For example 4.2, indicates level "4", mode "2". The scale should be interpreted along a continuum of abilities and does not imply that the intervals between levels and modes are equal. The levels and modes are used to predict functional capacity and determine the amount of assistance required to perform a particular task (Allen, 1987). Appendix A identifies the hallmark feature of each cognitive level and performance mode with a description of the pattern of behavior within cognitive levels 1 to 5 (Allen, 1999).

The cognitive level and mode is determined by administering the Allen assessment battery. The score represents a person's functional capacity to meet specific cognitive activity demands, which reflects the person's "best ability to function within the activity demands of desired occupations" (Allen et al., 2007, p.8). The score implies inclusion of all of the skills and behaviors up to that cognitive level and mode of performance. For interpretation in clinical settings, the distinguishing features of the modes within each level can be placed into "high" and "low" categories of behaviors. These categories distinguish the higher and lower functional patterns of behavior within each level (Earhart, 2009). The Cognitive Disabilities Model and battery of Allen assessments are considered standard practice in occupational therapy (McCraith, Austin, & Earhart, 2011).

Grounded in the Cognitive Disability Model, the FCCS is used in conjunction with the Allen assessment battery to interpret caregiver concordance with the standardized assessment.

The FCCS yields an appraisal rating which reflects the caregiver's estimation of functional capacity, on a 6 point scale from lowest (1) to highest function (6). The caregiver rating on the FCCS is then compared to the score of the person with dementia on the Allen Diagnostic Module (ADM-2) (Earhart, 2006). To determine the concordance status, the ADM-2 score is converted to the same six point scale as the FCCS. The conversion process is depicted in Appendix B. Three types of concordance status result from this comparison. Concordant estimation indicates the FCCS caregiver rating is consistent with the ADM-2 score, implying the caregiver is accurately appraising functional capacity in the person with dementia. Overestimation occurs if the FCCS rating is higher than the ADM-2 score, indicating the caregiver is inaccurately judging the person with dementia at a higher level of functional capacity than the standardized test score. And finally, under estimation is determined if the FCCS rating is lower than the ADM-2 score, indicating the caregiver is inaccurately judging the person to be functioning at a lower level than the ADM-2 score.

Study Purpose and Research Questions

The purpose of this study was to advance the development of the FCCS by examining its psychometric properties, specifically construct validity and inter-rater reliability. To evaluate construct validity, convergent validity was examined using the Caregiver Appraisal of Function and Upset (CAFU). This is a proxy measure conceptually related to functional capacity measured by the FCCS, on which caregivers appraise the functional independence of their family member with dementia (Gitlin et al, 2005). Discriminant validity was examined using the Neuropsychiatric Inventory (NPI), a proxy measure conceptually unrelated to functional capacity, on which caregivers report the frequency and severity of neuropsychiatric symptoms in

the person with dementia (Cummings, 1997). To examine the reliability of the FCCS, inter-rater reliability was examined by measuring the degree to which caregivers consistently ranked the FCCS cards from low to high function. The analysis determined the strength of agreement among caregiver rankings.

The following research questions and hypotheses guided this study:

1. What is the relationship between caregiver appraisal of functional capacity on the FCCS and caregiver appraisal of functional independence on the CAFU? (Convergent validity)?

Hypothesis 1: There will be a significant positive association between caregiver appraisal on the FCCS and CAFU.

2. What is the relationship between caregiver appraisal of functional capacity on the FCCS and caregiver report of neuropsychiatric symptoms on the Neuropsychiatric Inventory (NPI)? (Discriminant validity)

Hypothesis 2: Caregiver appraisal of functional capacity on the FCCS will not be significantly associated with caregiver report of neuropsychiatric symptoms on the NPI.

3. What is the level of agreement among caregivers who rank the six cards of the FCCS in order from low to high function? (interrater reliability)

Hypothesis 3: There will be agreement among caregivers in ranking the order of six cards of the FCCS from low to high functional capacity.

Literature Review

The cognitive and physical function of individuals with dementia deteriorates over time impacting the ability to perform daily activities. Approaches to the assessment of functional ability in this population include self-report by the person with dementia, subjective caregiver

appraisal or proxy report, and objective measures administered by health care providers or trained personnel (Zanetti et al, 1998; Zank & Frank, 2002; Arlt, et al., 2008). Objective assessment of function comprises performance-based assessments that measure ability to execute specific daily tasks such as telling time and money management (Wadley, Harrell, & Marson, 2003; Cullum et al., 2001) and assessments that measure functional capacity given the demands of an activity within an environment (Allen et al, 2007; Earhart, 2006; Fisher & Bray Jones, 2010). In addition, neuropsychological testing assesses deficits in processing over a variety of cognitive domains (Salmon & Bondi, 2009). The results of cognitive testing and performance-based assessments provide fundamental evaluation findings for the development of appropriate intervention and caregiver education.

Determining caregiver judgment of function in the family member with dementia provides valuable information for research (Suh, Ju, & Shah, 2004) and offers practitioners data to drive their intervention plan. Family caregiver appraisal of function indirectly measures the functional status of the person with dementia and level of assistance needed, and offers insight into caregiver subjective perceptions. Family caregiver appraisal scales include the Blessed Dementia Rating Scale (Blessed, Tomlinson, & Roth, 1968); the Dementia Severity Rating Scale (Clark & Ewbank, 1996; Xie, et al., 2009); the Older Americans Resources and Services (OARS) Activities of Daily Living scale (Doble & Fisher, 1998); and the Disability Assessment of Dementia (Gelinas, Gautheir, McIntyre, & Gauthier, 1998; Feldman et al., 2001). These caregiver proxy scales are subjective and may not be concordant with direct assessment of functional capacity in the person with dementia, which would require a comparison between scores. Comparisons of caregiver scales with performance based, standardized assessments of

the person with dementia are difficult due to incompatible foci and scaling properties (Doble, Fisk & Rockwood, 1999).

With the intent to make valid comparisons between caregiver or informant report and objective assessment of function, corresponding measures have been developed. The Functional Activities Questionnaire (FAQ) was designed for both self and informant report of older adults, and entails 10 items that measure instrumental activities of daily living on a 4 point integer scale (Pfeiffer, Kurosaki, Harrah, Chance, & Filos, 1982). In order to make comparisons, Karagiozis et al. (1998) developed the Direct Assessment of Functional Abilities (DAFA) to measure the same items queried on the FAQ. Score comparisons showed that subjects with dementia performed significantly worse on direct assessment than they had predicted by self-report. Overestimation of abilities by subjects with dementia was positively correlated with dementia severity. In contrast, caregivers tended to slightly underestimate the abilities of the subjects with dementia; however the difference between the FAQ and DAFA scores was not significant. Interpretation of the item comparisons on the FAQ and the DAFA is limited, as there are inconsistencies between certain items, which make it difficult to draw conclusions.

Zanetti et al. (1999) investigated the level of agreement between direct and performance-based assessment of function in persons with very mild and mild dementia and family caregiver proxy report (N = 111). Four items from the Direct Assessment of Functional Status (DAFS) (Loewenstein et al., 1989) and two from the seven-item Physical Performance Test (PPT) (Reuben & Siu, 1990) were used to assess the person with dementia. Caregiver appraisal was assessed using basic and instrumental activities of daily living items from the Barthel Index (Mahoney & Barthel, 1965) and Lawton scales (Lawton & Brody, 1969). Caregivers were asked

to report dependence or independence with six ADL/IADL items (dressing, toileting, walking, telephone use, shopping, and managing money). Caregiver report of walking yielded the strongest association with actual performance of the person with dementia. The researchers reported a moderate to good agreement for dressing, and moderate agreement for telephone use, shopping and money use. For toileting no association was found. Disagreement between caregiver ratings and performance-based assessment was affected by caregiver burden, specifically restrictions on caregiver time. In addition, caregivers with higher depressive symptoms tended to underestimate the functional ability of the person with dementia.

Loewenstein et al. (2001) compared family caregiver perception of functional abilities with direct assessment of study participants with dementia (N = 72) using eight of the DAFS items. Family caregiver appraisal was determined using a set of questions taken from the Caregivers Perceptions of Functional Status scale (CPFS), an unpublished scale that has not yet been psychometrically tested. The analysis used items on the CPFS that corresponded to the DAFS items. The results showed that caregivers accurately predicted the functional performance of the study participants who were not impaired. In contrast, caregivers significantly over estimated the ability to tell time, identify currency, make change, and utilize eating utensils in study participants with dementia. A higher score on the Mini Mental Status Examination (MMSE) of the person with dementia was associated with caregiver overestimation, while caregiver depressive symptoms was not found to be significantly associated with under or over estimation of functional performance in study participants with dementia.

Impaired ability to manage finances is an early sign of Alzheimer's disease (Overman & Stoudemire, 1988). Wadley et al. (2003) directly measured the ability of persons with

Alzheimer's disease and control participants to handle financial matters using the Financial Capacity Instrument (FCI; Marson et al., 2000), in which participants performed 20 financial management tasks which were then scored for accuracy. The FCI results were compared to self and informant reports using an author developed scale which maps onto the FCI. Individuals with Alzheimer's disease and family caregiver dyads (n = 20) were compared to control/control informant dyads (n = 23). The findings showed high levels of consistency and accuracy among the control and informant dyads. Participants with Alzheimer's disease who inaccurately reported their financial abilities consistently overestimated their ability, while caregivers who inaccurately appraised financial ability were found to both over and under estimate their family member's functional ability.

The Functional Independence Measure (FIM) was used to determine the correlation between caregiver-reported and observation-derived FIM scores (Cotter, Burgio, Roth, & Gitlin, 2002). Caregiver description of level of dependence in ADL performance by the family member with dementia and predicted duration of assistance was compared to observation ratings using videotaped analysis of seven ADL items from a modified version of the FIM Self-Care subscale (Granger, Hamilton, Keith, Zielezny, & Sherwin, 1986). Caregivers initially estimated the amount of assistance they would provide their family member to complete each ADL item and the duration of assistance time, after which, videotaped observations of each ADL interaction between caregiver and family member were completed. The findings showed that caregivers accurately described the amount of assistance they provided to their family member and overestimated the duration of assistance time. As discussed by the researchers, the significant correlation between caregiver report of assistance and the observed assistance did not

necessarily reflect the actual functional ability of the person with dementia, which was not assessed. The findings "reflect what caregivers allow the patients to do, rather than what the patients are truly able to do" (p .44).

An attempt to address this limitation was done in a subsequent study using the same dataset and adding a third FIM score derived by an occupational therapist watching the videotapes (Cotter, Burgio, Roth, Gerstle, & Richardson, 2008). The third score was compared to the caregiver-reported and observation-derived FIM scores. This study found that the three ratings were significantly correlated, supporting the original finding of agreement between caregiver and observation derived ADL ratings. Both studies concluded that caregivers can accurately provide information about what they do to assist the person with dementia during ADL performance. However the amount of assistance caregivers provide may not reflect the actual functional capacity of the person with dementia.

Objective assessment is preferable when evaluating the functional capacity of an individual with dementia. In addition, ascertaining caregiver appraisal can provide valuable information with regard to their perceptions and understanding. The literature reveals that caregivers or informants are inconsistent in the accuracy of their assessment of function in individuals with dementia. A limitation in practice and research with regard to the interpretation of caregiver appraisal is the lack of reliable and valid subjective or proxy assessment tools that can be directly compared to objective assessments. The Functional Capacity Card Sort in conjunction with the Allen assessment battery, a gold standard assessment of functional capacity, offers a psychometrically sound approach to determining caregiver accuracy.

Content Development of the Functional Capacity Card Sort

The FCCS is administered to family caregivers prior to administering the Large Allen Cognitive Level Screen (LACLS-5) (Allen et al., 2007; Kehrberg, Kuskowski, Mortimer, & Shoberg, 1992) and the Allen Diagnostic Module (ADM-2) (Earhart, 2006) to the person with dementia. Following standardized procedures, each FCCS card is presented to the caregiver one at a time; all cards remain in consideration throughout the administration process. Caregivers are guided through a deductive reasoning process in order to choose the card that best describes their family member's functional capacity. Development of the FCCS and administration instructions included four phases over an 18 month period: (1) development, (2) field testing, (3) refinement, and (4) confirmation. The intent of these structured phases was to establish content validity of the tool and to formalize the administration protocol.

Development.

The FCCS was developed using the Cognitive Disabilities Model, which asserts a hierarchy of cognitive abilities and activity demands, and describes the ability to perform daily activities given the complex interactions between cognitive ability and the context in which the activity takes place (Allen & Blue, 1998). The craft-based standardized assessments are designed to measure and interpret a person's capacity to perform ADLs and IADLs. Thus it was important that the FCCS use a familiar daily activity on which the hierarchy of cognitive abilities and activity demands could be mapped. The self-care activity of "washing self" was chosen, as this activity had universal application and allowed for the development of clear statements distinguishing the hallmark features of the Allen Cognitive Levels (Allen, Blue & Earhart, 1995). Each description on the FCCS cards maps onto a distinct cognitive level and reflects the

hierarchy of functional capacity. Of all possible ADL tasks, washing self was chosen because the subtasks can effectively be used to describe the hierarchy of cognitive ability and activity demands reflected in the Allen Cognitive levels.

The author, in collaboration with another expert in the Cognitive Disability Model and Allen assessment battery constructed a 12 item card sort (version 1) consisting of cards describing "washing self" with the intent to reflect 12 cognitive levels and modes. The first card described the ability to wash self for an individual at Allen Cognitive Level 2, at the high Modes of Performance (2.6 and 2.8). Cards 2 to 11 (10 cards) described the ability to wash self for an individual functioning at each distinct Allen Cognitive Level and Mode of Performance from 3.0 to 4.8. The twelfth card described the ability to wash self for an individual at Allen Cognitive Level 5, at the low Modes of Performance (5.0, 5.2 and 5.4).

The card item descriptions were reviewed by occupational therapists with expertise in the Cognitive Disabilities Model and Allen diagnostic battery (n = 5). An author developed Content Validity Questionnaire for Experts was designed in which the experts were asked to accurately identify the intended Allen Cognitive Level and Mode of Performance for each card and provide recommendations to enhance the clarity of the card descriptions. The questionnaire and instructions were delivered and returned via e-mail and United States Postal Service.

Responses were entered into an Excel spreadsheet for analysis. A mean accuracy percentage was calculated across raters as follows. First, for each rater, the number of accurate responses (correct identification of intended Allen Cognitive Level) was divided by the number of cards reviewed and multiplied by 100 to determine each rater's percent accuracy. Second, the mean of the percent accuracy and standard deviation across raters were calculated. Based on a

low mean accuracy score (*M* = 46%, *SD* = .13; Appendix C) and recommendations by the panel, Version 2 of the FCCS was developed by collapsing cards 2 to 11 into four cards describing Allen Cognitive Levels 3 and 4 for both low and high Modes of Performance. The descriptions of cards 1 and 12 remained the same.

Field testing.

The protocol for administration of the FCCS was established. Version 2 of the card item descriptions were reviewed by a new panel of expert occupational therapists (n = 7), using the same questionnaire resulting in a high mean accuracy score (*M* = 100%, *SD* = 0; Appendix C). This outcome supported a high level of content validity by the experts. The six card version moved to field testing. Appendices B1 and B2 summarize the results from each phase. Version 2 was administered by trained occupational therapists to family caregivers (N = 24) participating in a cross-sectional study conducted at Thomas Jefferson University (Gitlin, 2011; Grant # IIRG-07-28686). Using an author developed Content Validity Questionnaire for the Caregiver, caregivers were asked to rank the six cards from 1 (lowest level of function/most dependent) to 6 (highest level of function/most independent), resulting in fair accuracy, M = 74%; SD = .34 (Appendix C). On the same questionnaire, caregivers were asked to rate four items addressing difficulty and clarity of use on a scale from 1 (not difficult and very clear) to 3 (very difficult and not clear). As presented in Appendix D, caregivers (n = 24) reported the tool was not difficult to use (*M* = 1.33, *SD* = ± .56), the final card was not difficult to choose (*M* = 1.58, *SD* = .65); the directions were clear (*M* = 1.12, *SD* = .34); and the statements were clear (*M* = 1.12, *SD* = .34).

Refinement.

Based on comments from the Phase 2 expert panel, minor modifications to card format and administration procedures were made, which resulted in the final version of the FCCS. This version was reviewed by three previous expert occupational therapists and two new expert occupational therapists (n = 5) using the same expert questionnaire. Consistent with Phase 2, the accuracy remained high (*M* = 100%; *SD* = 0; Appendix C), confirming a high level of content validity by the experts. In total, the three versions of the FCCS were reviewed 16 times by 14 different expert occupational therapists.

In this phase, the FCCS and caregiver questionnaire were administered to additional caregivers (n = 22) participating in the same study, resulting in improved accuracy from Phase 2 (*M* = 81%; *SD* = .28, Appendix C). Caregiver ratings of usability and clarity resulted in similar findings as in Phase 2 (Appendix D), indicating the FCCS is clear and not difficult to use.

Confirmation.

Using the Content Validity Questionnaire for Experts, the final card item descriptions were reviewed by occupational therapy graduate students trained in the Cognitive Disabilities Model and Allen diagnostic battery (n = 10). The students were asked to identify the intended Allen Cognitive Level after reading each card, which resulted in high mean accuracy, *M* = 93, *SD* = .14 (Appendix C). The final version of the FCCS and the caregiver questionnaire were then administered to an additional set of caregivers (n = 26) with improved accuracy, *M* = 94%; *SD* = .16 (Appendix C), and clarity and ease of use remained positive (Appendix D).

The final item descriptions on the individual cards of the Functional Capacity Card Sort are depicted in Appendix E. The FCCS tool includes six cards, size 4” X 11”, and the

administration instructions. The front side of the card is the description of the washing activity, which is displayed to the caregiver. The print is large and easy to read, using upper case letters to distinguish the hallmark features of the cognitive level and the key actions of performing the activity. For administration purposes, the back side of each card includes the following three items: (1) the order in which the card should be presented, (2) the caregiver appraisal rating score, and (3) the associated Allen Cognitive Levels.

Over four phases of validity testing, each description on the FCCS cards were systematically reviewed and reported by experts to be consistent with the Allen Cognitive Levels, thus supporting the tool's content validity. In addition, caregiver report of both the tool's ease of use and clarity of instructions was found to be high. As a tool for measuring subjective caregiver appraisal, the FCCS has utility in both practice and research.

Methods

Description of data set.

To examine construct validity, data was obtained from the cross-sectional study entitled Health-related Quality of Life in Individuals with Dementia Living at Home (QOL Study), funded by the Alzheimer's Association (Gitlin, 2011; Grant # IIRG-07-28686) and conducted over an 18 month period from February 2009 to October 2010 (N=88). To examine inter-rater reliability of the FCCS, data was obtained from a subset of caregiver participants who participated in Phases 2 to 4 of the content validity process (N = 72). Data collection was completed at three points in time within a two week period. An initial telephone interview was completed by a trained interviewer, followed by two home sessions conducted by a trained occupational therapist (N = 4).

Participants.

The QOL Study was approved by the Institutional Review Board (IRB) at Thomas Jefferson University. Written informed consent was obtained from caregiver participants, and verbal consent was obtained from participants with dementia. The caregiver inclusion criteria were: (1) 21 years of age or older (male or female); (2) live with or in close proximity to the family member with dementia; (3) speak English; (4) provided care for a minimum of 6 months; and (5) self-identify as providing the most day to-day coordination of hands-on care for the person with dementia. The criteria for participants with dementia were: (1) Mini Mental State Examination (MMSE) score above 10 (if 24 or above, confirmation of diagnosis was obtained from caregiver); (2) live at home; and (3) speak English. People with dementia who were bed-bound and unresponsive were excluded from the study, as were their caregivers.

Measures.

Caregiver Appraisal of Function and Upset (CAFU). The CAFU is a valid and reliable 15 item instrument for evaluating caregiver report of functional dependence in activities of daily living (ADL) and instrumental activities of daily living (IADL) in the person with dementia. It also measures caregiver reaction (upset) to the individual's level of dependence in ADL and IADL. The instrument has good internal consistency and convergent and discriminant validity (Gitlin et al., 2005). It includes two indices, eight IADL items (telephone, shopping, meal preparation, housework, laundry, travel, medicine, and finances) and seven ADL items (bathing, dressing upper body, dressing lower body, toileting, grooming, eating, and getting out of bed). Caregivers are asked about the amount of help their family member requires for each item on a scale from 1 (most help) to 7 (no help). An ADL and IADL score is derived. Higher scores

indicate less help needed to perform the activity, thus greater functional independence in the person with dementia. For this study, the ADL index of the CAFU was used in the analysis, in order to be consistent with the type of activity being assessed in the FCCS. The CAFU was administered to the caregiver on the telephone by the trained interviewer.

Neuropsychiatric Inventory (NPI). The NPI measures frequency and severity of behavioral symptoms in individuals with dementia in 12 domains including delusions, hallucinations, agitation, dysphoria, anxiety, apathy, irritability, euphoria, disinhibition, aberrant motor behavior, night-time behavior disturbances, and appetite and eating abnormalities (Cummings, 1997). The caregiver is asked to report the frequency (1=occasionally/less than once per week to 4=very frequently/daily or essentially continuously present) and severity (1=mild/produces little distress in the patient to 3=severe/very disturbing to the patient and difficult to redirect) of each item. The NPI demonstrates high inter-rater reliability and construct validity (Cummings et al., 1994). In this study, the score for each domain was derived by multiplying the frequency by severity of behavioral occurrence scores. The final NPI score was calculated by totaling the scores for each behavior domain, with higher scores indicating greater symptomatology. The NPI was administered to the caregiver in the home by the trained occupational therapist.

Content Validity Questionnaire. The author-developed questionnaire was used for the content validity phase of development, in which caregivers were asked to rank the six cards in the correct order from lowest to highest ability to function. The occupational therapist recorded the order in which the FCCS cards were ranked by the caregiver on a specially designed data

table. The Content Validity Questionnaire was administered to the caregiver in the home by the trained occupational therapist.

Data analysis.

Institutional Review Boards at Thomas Jefferson University and Virginia Commonwealth University approved this secondary analysis study. The analysis and interpretation of results were completed at Thomas Jefferson University with consultation from a biostatistician. Data were analyzed with SAS® 9.3 using nonparametric statistical procedures as they do not require normal distribution or variance assumptions with regard to study population and can be used with ordinal data.

At the $\alpha = 0.05$ level of significance, construct validity was tested using Spearman's rank correlation with the sample of 88 participants. To evaluate convergent validity of the Functional Capacity Card Sort, the Spearman correlation coefficient was calculated between the caregiver score on the FCCS and caregiver score on the ADL section of the Caregiver Assessment of Function and Upset. To evaluate discriminant validity, the correlation coefficient between the caregiver score on the FCCS and caregiver score on the NPI was calculated. To examine inter-rater reliability with respect to the agreement between caregiver ranking of the six FCCS cards, the strength of the agreement among caregivers was calculated using the Kendall's *W* statistic at the $\alpha = 0.05$ level of significance. Kendall's *W*, also referred to as Kendall's coefficient of concordance, is used for assessing agreement among raters and ranges from 0 (no agreement) to 1 (complete agreement). Higher agreement indicates higher inter-rater reliability.

Results

Sample characteristics.

Table 1 shows the demographic characteristics of the study sample. The caregivers in the QOL study were primarily female (88.6%), white (77.3%), and spouses (55.7), with a mean age of 65.8 years. All caregivers had a high school education or higher, and had provided care from 6 months to 22 years. Most participants with dementia were female (52.3%) and white (76.1%) with a mean age of 81.7. The MMSE scores ranged from 10 to 28 (M = 17.7, SD = 4.6, N = 87). All of the 6 participants who scored above the 24 cut off score for dementia had a physician's diagnosis of Alzheimer's disease or related dementia.

Table 1

Caregiver and Person with Dementia Demographics

	Caregiver (N=88)					Person with Dementia (N=88)				
	M	*SD*	Range	*n*	%	*M*	*SD*	Range	*n*	%
Age	65.8	12.2	38.0 - 89.0			81.7	8.0	56.0 - 97.0		
Gender										
Female				78	88.6				46	52.3
Male				10	11.4				42	47.7
Race										
White				68	77.3				67	76.1
Non-white				20	22.7				21	23.9
Years Caregiving	5.1	3.5	0.5 - 22.0							
MMSE[a]						17.7	4.6	10.0 – 28.0		
Relationship to Person with dementia										
Spouse				49	55.7					
Non-spouse				39	44.3					
Education										
High school				2	2.3					
> High school				86	97.7					

Note: M = Mean. SD = standard deviation. MMSE = Mini Mental Status Exam. [a] = N=87

Construct validity.

The dot plot in Figure 1 shows the correlation between FCCS scores and CAFU ADL scores. Spearman's correlation test showed that caregiver appraisal of functional capacity on the FCCS was significantly associated with caregiver report of functional independence on the CAFU, which supports the first hypothesis. As shown in Table 2, there is a moderately positive association between the two variables ($r = .43$, $p < 0.0001$, $N = 86$), providing evidence for convergent validity of the FCCS.

Figure 1. Scatter Plot Correlation between Functional Capacity Card Sort (FCCS) and Caregiver Assessment of Function and Upset-Activity of Daily Living (CAFU-ADL) Score

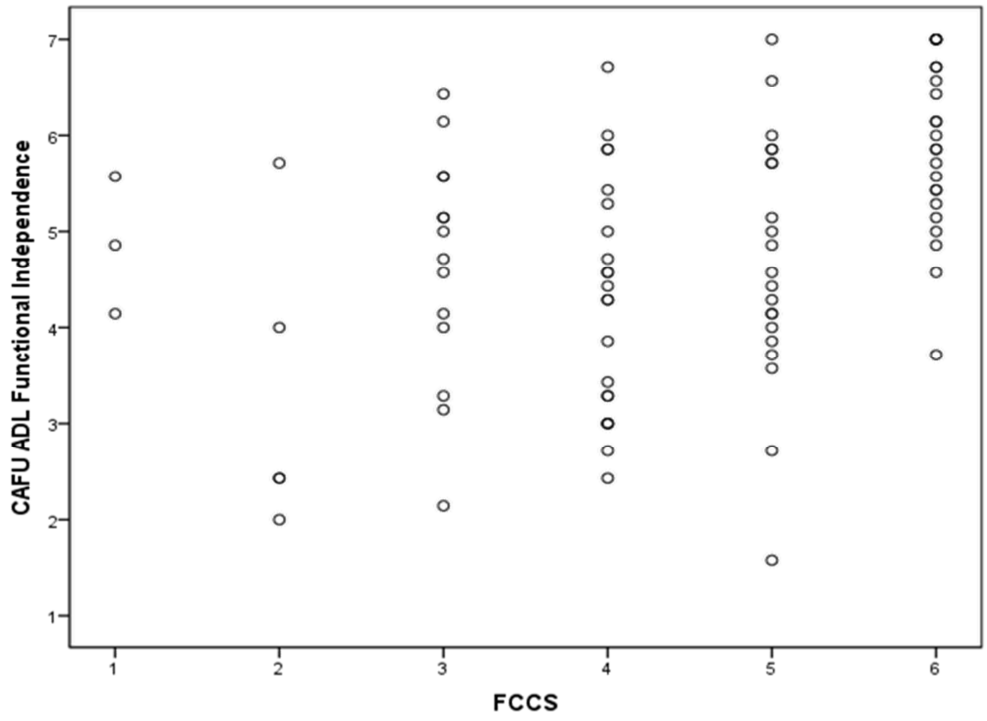


Table 2

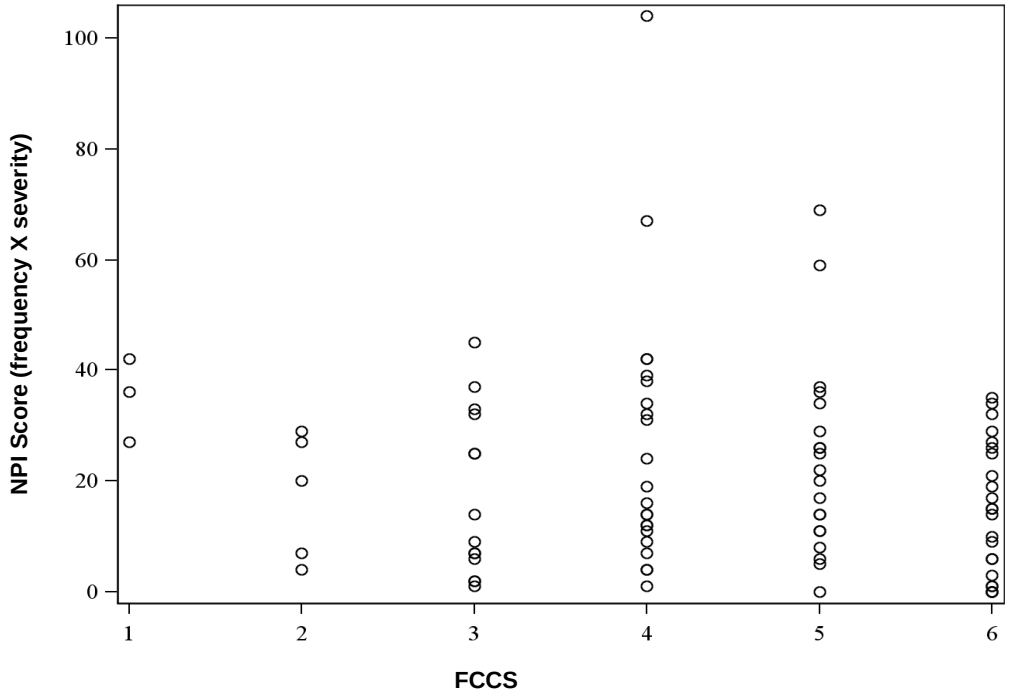
Correlations between the Functional Capacity Card Sort and CAFU and NPI (N = 86)

Validity Test Variables	FCCS	*p*
CAFU (ADL items)	0.43	<.0001
NPI	-0.14	.19

Note: FCCS = Functional Capacity Card Sort; CAFU = Caregiver Appraisal of Function and Upset; ADL = Activities of Daily Living; NPI = Neuropsychiatric Inventory

The dot plot in Figure 2 shows the correlation between FCCS scores and NPI scores (frequency X severity). Supporting the second hypothesis, the Spearman's correlation test showed that the caregiver score on the FCCS was not significantly associated with the score on the NPI. Table 2 shows a weak negative association between the two constructs (r = -.14, *p* = .16, N = 86), providing evidence for discriminant validity of the FCCS.

Figure 2. Scatter Plot Correlation between Functional Capacity Card Sort (FCCS) and Neuropsychiatric Inventory (NPI)



Interrater reliability.

Kendall's coefficient of concordance revealed a strong agreement among caregivers in the ranking of the six cards of the FCCS, Kendall W (5, 72) = 0.83, p = .0001, supporting the third hypothesis. As shown in Table 3, the rows represent the FCCS card number and the columns represent the caregivers' ranking of the card. Results support interrater reliability of the FCCS among caregivers. The mean rankings for each card showed the greatest

Table 3

Interrater Reliability of the FCCS by Caregivers (N = 72)

				Card Ranking											
				1		2		3		4		5		6	
		M	*SD*	n	%	n	%	n	%	n	%	n	%	n	%
FCCS Card Number	1	1.20	0.75	65	90.3	3	4.1	2	2.8	0	0	2	2.8	0	0
	2	2.01	0.59	5	6.9	65	90.3	0	0	1	1.4	0	0	1	1.4
	3	1.24	0.76	2	2.9	0	0	55	76.4	11	15.3	2	2.8	2	2.8
	4	3.93	0.73	1	1.4	1	1.4	10	13.9	53	73.6	4	5.6	3	4.1
	5	4.86	0.66	0	0	2	2.8	1	1.4	6	8.3	59	81.9	4	5.6
	6	5.74	0.75	0	0	0	0	4	5.6	1	1.4	5	6.9	62	86.1

Note: M = Mean. *SD* = standard deviation. FCCS = Functional Capacity Card Sort.

agreement at the lowest level of function with 90.4% agreement among caregivers (Card 1/Rank 1), M = 1.20, SD = 0.75; and highest level of function with 86.1% agreement among caregivers (Card 6/Rank 6), M = 5.74, SD = 0.75. The least agreement occurred with the middle levels of function at 76.4% agreement (Card 3/Rank 3), M = 3.23, SD = 0.76, and 74% agreement (Card 4/Rank 4), M = 3.93, SD = 0.73).

Discussion

In this study, preliminary psychometric properties of the FCCS were examined. The FCCS, a tool for assessing caregiver appraisal of functional ability in the person with dementia, is comprised of six cards, each describing the activity of "washing self" from low to high level of functional capacity. Appendix C provides a description of each FCCS card. The FCCS tool was based on the Cognitive Disabilities Model in order to provide a systematic approach for determining the accuracy of caregiver appraisal through comparisons of caregiver ratings with a standardized assessment. Based on this comparison caregiver appraisal of functional capacity in the person with dementia can be labeled as concordant estimation, overestimation, or underestimation. Interpreting the concordance status of the caregiver offers practitioners clinical data that can be used to inform the approach and content of caregiver education and skill-building, and promote participation and safety in daily activities for the person with dementia. For example, caregivers who are overestimating functional capacity would require education in safety precautions, home environmental modifications, and skill-building to ensure their family member's safe and thorough performance of daily activities. Under estimators would require education about how to adjust their oversight and assistance and skill-building to allow the person with dementia to perform at the highest potential. Finally, concordant estimators would benefit from validation of their accurate appraisal and skill-building to promote ongoing provision of appropriate care.

Prior to this study, content validity of the FCCS was established through an extensive process that spanned 18 months, and was conducted as part of a cross-sectional study on quality of life in people with dementia living at home (Gitlin, 2011). Over the four phases involved in

this process, the item descriptions on each card were systematically reviewed and reported by experts. They reported these to be consistent with the Cognitive Disabilities Model, specifically the Allen Cognitive Levels, thus supporting the tool's content validity. In addition, caregivers reported high satisfaction with the utility and clarity of the tool. As a result, there is strong evidence that the FCCS reflects consistent theoretical tenets of the Cognitive Disability Model, supporting its use in conjunction with the ADM-2.

The purpose of this study was to advance the development of the tool by examining construct validity and inter-rater reliability. Utilizing an existing data set, the findings support convergent validity of the FCCS, as demonstrated by the moderately strong statistically significant correlation between caregiver FCCS ratings and the CAFU, a conceptually related measure. Discriminant validity was demonstrated by the statistically insignificant and weak correlation between the FCCS and the NPI, a conceptually unrelated measure. The interrater reliability of the FCCS was also examined by calculating the concordance between caregiver rankings of the order of the six FCCS cards. The analysis revealed a strong agreement among caregivers in their ranking of the six cards from low to high level of ability to wash. Descriptive statistics showed that caregivers were more able to accurately identify the highest and lowest descriptions of functional capacity, which clearly distinguish between independent and dependent performance. There was less agreement among caregivers for card descriptions that depicted middle levels of function, where distinguishing features are less obvious.

As described previously, measures to assess caregiver or proxy report of function in the person with dementia do exist (Blessed, Tomlinson, & Roth, 1968; Clark & Ewbank, 1996; Xie, et al., 2001; Gelinas, Gautheir, McIntyre, & Gauthier, 1998; Feldman et al., 2001; Doble &

Fisher, 1998). However, to determine the accuracy of the proxy report, the caregiver's appraisal would best be compared to a standardized assessment. Because researcher developed measures typically assess specific ADL or IADL tasks, generalization to daily function is limited (Wadley, Harrell, & Marson, 2003; Cullum et al., 2001; Pfeiffer et al, 1982). The FCCS provides a theory based tool for which descriptions of functional capacity map onto the Allen Cognitive Levels, allowing for interpretation of caregiver estimation of function across the disease trajectory.

Caregiver appraisal is a complex process that must change as the disease progresses. The ability of the caregiver to accurately appraise functional capacity may be complicated by a plethora of subjective conditions as the disease progresses. A range of subjective conditions that may vary at different points in time impact the caregiver's ability to clearly and objectively evaluate functional abilities in the person with dementia. Using the FCCS to quantify caregiver appraisal of functional capacity and interpret concordance status allows occupational therapists to more effectively assess caregiver knowledge and estimation of function, thus promoting a customized approach to family education and training.

Limitations of the study center on the sample and use of secondary data. Since the sample size for this study was relatively small, the results need to be confirmed in a larger, more diverse sample of caregiver and person with dementia dyads. All of the caregivers in the data set had a high school education, with close to 98% reporting additional schooling. As such, the sample of caregivers was well educated, which may have positively impacted their ability to understand and interpret the card descriptions. In addition, the caregivers were from one geographic region in the United States, which may impact the results. The use of a secondary data set limited the availability of additional measures from which to test convergent and

discriminant validity. Further psychometric testing is needed to provide additional evidence of construct validity, as well as criterion-related validity.

In conclusion, the FCCS is an easy to administer assessment that has been shown to be well received by caregivers and user friendly. The outcomes of this study demonstrate that the FCCS is a valid and reliable tool for use in practice and research. As a clinical tool, it offers occupational therapists using the Allen assessment battery a compatible addition to their assessment tool kit. In addition, a host of personal characteristics and environmental conditions may contribute to the accuracy of caregiver appraisal as functional capacity in the person with dementia declines. The FCCS can be used in future research to examine variables associated with caregiver appraisal. Mapping caregiver appraisal across the disease process would contribute to a better understanding of the multifaceted nature of appraisal and further guide the development of caregiver intervention.

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Appendix A

Hierarchy of Allen Cognitive Levels and Modes of Performance

ACL (Hallmark Feature)	Mode	Pattern of Behavior
1: Automatic Actions (Locating stimuli)	.0	Withdrawing from stimuli
	.2	Responding to stimuli
	.4	Localizing stimuli
	.6	Moving in bed
	.8	Raise body part
2: Postural Actions (Spontaneous motor actions)	.0	Overcome gravity
	.2	Stand and use righting actions
	.4	Walk
	.6	Walk to identified location
	.8	Use railings and grab bars for support
3: Manual Actions (Sustaining actions on objects)	.0	Grasps objects
	.2	Distinguishing between objects
	.4	Sustain actions on objects
	.6	Notes effects of actions on objects
	.8	Use all objects and sense completion of an activity
4: Goal-Directed Actions (Completing a goal)	.0	Sequence self through steps of an activity
	.2	Differentiate between parts of an activity
	.4	Complete a goal
	.6	Scan the environment
	.8	Memorizes new steps
5: Exploratory Actions (Self-directed learning)	.0	Learn to improve effects of actions
	.2	Improve the fine details of actions
	.4	Engage in self-directed learning
	.6	Consider social standards
	.8	Consult with other people
6: Planned Actions (Self-initiated motor actions occur with planning)	.0	Planned actions

Note: ACL = Allen Cognitive Level. From "Structures of the Cognitive Performance Modes", by C. K. Allen, 1997. Copyright 1997 by Allen Conferences.

Appendix B

Conversion of Allen Diagnostic Module-2 Score

ADM-2 Score (high/low pattern of behavior)	Converted ADM-2 Score for Comparison with FCCS
2.6 or 2.8 (High 2)	1
3.0, 3.2 or 3.4 (Low 3)	2
3.6 or 3.8 (High 3)	3
4.0, 4.2 or 4.4 (Low 4)	4
4.6 or 4.8 (High 4)	5
5.0, 5.2 or 5.4 (Low 5)	6

Note: ADM-2 = Allen Diagnostic Module-2. ACL = Allen Cognitive Level. FCCS = Functional Capacity Card Sort.

Appendix C

Expert and Caregiver Accuracy of Cognitive Levels

Phase	Panel of Experts [c] N = 24			Family Caregivers [e] N = 72		
	Accuracy (%)			Accuracy (%)		
	n	*M*	*SD*	n	*M*	*SD*
1[a]	5	45	.13	NA	NA	
2[b]	7	100	0	24	74	.34
3[b]	5[d]	100	0	22	81	.28
4[b]	10	93	.14	26	94	.16

Note: [a]12 Cards. [b]6 Cards. [c]Panel members were asked to read card descriptions and label Allen Cognitive Level; Phases 1, 2, and 3 consisted of expert occupational therapists in the Allen diagnostic battery; Phase 4 consisted of occupational therapy graduate students trained in the battery. [d]Three of the five experts were second time reviewers. [e]Family caregivers were asked to rank cards from lowest to highest function.

Appendix D

Caregiver Reported Difficulty and Clarity

		(1)		(2)		(3)		(4)	
Phase	n	Difficulty using tool[a]		Difficulty choosing card[a]		Clarity of directions[b]		Clarity of statements[b]	
		M	*SD*	*M*	*SD*	*M*	*SD*	*M*	*SD*
2	24	1.33	.56	1.58	.65	1.12	.34	1.12	.34
3	22	1.36	.58	1.54	.67	1.13	.35	1.12	.42
4	26	1.23	.43	1.50	.58	1.11	.33	1.11	.33

Note: [a]3 point scale (1=not at all difficult, 2=somewhat difficult; 3=very difficult). [b]3 point scale (1=very clear, 2=somewhat clear; 3=not at all clear).

Appendix E

Functional Capacity Card Sort Card Descriptions

Card Rank	Allen Cognitive Level (Modes)	Card Description
1	High 2 (2.6, 2.8)	Your family member… DOES NOT WASH; SITS while being washed; MAY HOLD washcloth if handed washcloth; DOES NOT MOVE washcloth.
2	Low 3 (3.0, 3.2, 3.4)	Your family member… DOES NOT WASH; SITS while being washed; HOLDS washcloth if handed washcloth; MOVES washcloth WITHOUT PURPOSE.
3	High 3 (3.6, 3.8)	Your family member… WASHES WITH SUPERVISION; MISSES ALL PARTS of the body that can't be seen; DOES NOT NOTICE that the floor is wet and may slip; STOPS WASHING if the soap runs out; DOES NOT ASK for help.
4	Low 4 (4.0, 4.2, 4.4)	Your family member… WASHES WITH SUPERVISION; MAY MISS SOME PARTS of the body that can't be seen (e.g. back of legs); DOES NOT NOTICE that the floor is wet and may slip; DOES NOT AUTOMATICALLY get more soap if the soap runs out; ASKS for help.
5	High 4 (4.6, 4.8)	Your family member… Washes INDEPENDENTLY; DOES NOT COMPLETE all the steps of washing if interrupted; MAY OR MAY NOT NOTICE that the floor is wet and may slip; ASKS FOR REASSURANCE (e.g. "Am I doing this right?"); MAY OR MAY NOT AUTOMATICALLY get more soap if the soap runs out; TELLS you when there is no more soap.
6	Low 5 (5.0, 5.2, 5.4)	Your family member… Washes INDEPENDENTLY; COMPLETES all steps even if interrupted by something; NOTICES that the floor is wet and avoids slipping; DOES NOT ASK FOR REASSURRANCE; AUTOMATICALLY gets more soap independently if the soap runs out.

Note: ACL = Allen Cognitive Level

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Chapter III: Factors Associated with Caregiver Appraisal of Functional Capacity in People with Dementia

The majority of people with Alzheimer's disease and related dementias (ADRD) live at home and are supported by family or other informal caregivers who are responsible for providing appropriate oversight and assistance (Alzheimer's Association, 2012; Family Caregivers Association, 2011). Families provide 80 percent of care delivered in the home environment (Alzheimer's Association, 2012), which requires care related responsibilities that are often ambiguous and unfamiliar. Caregivers engage in a multitude of tasks that primarily focus on the well-being of the person with dementia (Hasselkus & Murray, 2007). They face unexpected challenges, including the decline in cognitive and physical function of the person with dementia and emergence of behavioral symptoms, resulting in fluctuations in their own physical and emotional health and well-being (Brodaty & Donkin, 2009). Providing care can have adverse health consequences, including high rates of depression (Pinquart & Sorenson, 2003; Kovinsky et al., 2003).

Greater than 15 million Americans provide unpaid care to individuals with dementia. The Alzheimer's Association (2012) reports that most caregivers are women (60%), aged 55 or older (56%), married (66%), and have less than a college degree (67%). Over half of caregivers are the primary breadwinners of the household (55%), and nearly half are employed full or part time outside the home (44%). The term "sandwich generation" is used to describe 26% of caregivers

who are simultaneously caring for their children and a parent living in their home (MetLife Mature Market Institute, 2006; Spillman & Pezzin, 2000).

Individuals who assume these responsibilities have been described as the "hidden patient" (Emlet, 1996, p. 255; Hill, 2003, p. 1682) because they are perceived solely as providers of care, not as individuals who may be in need of care themselves. Caregivers often lose sight of the importance of their own quality of life, physical health, and social participation, as well as the actions necessary for illness prevention and health maintenance. All of these contribute to the ability to provide appropriate care. Many typical health-related behaviors, such as preventive routines and compliance with prescribed medical regimes, may not be followed or appropriately managed due to the overload of caregiver responsibilities (Baldwin, Kleeman, Stevens, & Rasin, 1989; Steadman, Tremont & Davis, 2007).

Throughout the course of the disease, caregivers are required to gauge the amount of supervision and hands-on assistance necessary to allow for appropriate participation in daily activities and ensure safety. In addition, proxy reports by family members are viewed as particularly important in dementia care, as individuals with cognitive impairment tend to overestimate their functional capacity (Karagiozis, Grey, Sacco, Shapiro, & Kawas, 1998; Kiyak, Teri, & Borson, 1994). And yet, even the accuracy of caregiver appraisal is inconsistent (Karagiozis et al., 1998; Doble, Fisk, & Rockwood, 1999; Zanetti, Geroldi, Frisoni, Bianchetti, & Trabucchi, 1999; Argüelles, Loewenstein, Eisdorfer, & Argüelles, 2001; Loewenstein et al., 2001; Davis, Martin-Cook, Hynan, & Weiner, 2006). When a caregiver's estimation of a person's capacity is inaccurate, the person with dementia may be placed in situations that compromise safety, and exceed or fall below their functional capacity, thus facilitating or

compromising safety, function, and well-being. For example, caregivers who overestimate the individual's functional capacity may provide inadequate supervision or hands on assistance, posing safety risk to the person with dementia. Alternately, caregivers who underestimate function may provide superfluous care, thereby restricting participation in daily activities by the person with dementia.

To determine the accuracy of caregivers' reports of functional capacity, their judgments have been compared to objective testing of actual performance (Doble, et al., 1999; Karagiozis et al., 1998; Loewenstein et al, 2001; Argüelles, et al., 2001; Cotter, Burgio, Roth, Gerstle, & Richardson, 2008; Davis et al, 2006; Wadley, Harrell, Marson, 2003; Zanetti et al, 1999). Through this comparison, caregiver accuracy is interpreted as concordant (in agreement) or discordant (in disagreement) with actual performance (Argüelles, et al., 2001). Critical to the interpretation of caregiver concordance are the measures used to assess caregiver appraisal of function and the actual functional capacity of the person with dementia. In order to accurately interpret caregiver appraisal, the Functional Capacity Card Sort (FCCS), a new instrument that measures caregiver appraisal of functional capacity in the person with dementia, was used for this study. The FCCS was developed based on the Cognitive Disability Model (Allen & Blue, 1998) and reflects the same Allen Cognitive Levels as the Allen Diagnostic Module-2 (ADM-2), a gold standard assessment of functional capacity administered by an occupational therapist. By comparing the caregiver rating on the FCCS and the standardized score on the ADM-2, caregiver appraisal can be characterized by three types of concordance status: concordant estimation, overestimation, or underestimation.

Using retrospective analysis, this study examined the differences among these three types of caregiver appraisal in relation to cognitive status in the person with dementia and depressive symptoms in the caregiver. These two variables were chosen, as studies typically include them when examining factors associated with concordance or discordance between proxy ratings and objective ratings; and the findings thus far are mixed. An association has been reported between higher Mini Mental Status Exam (MMSE) scores (greater cognitive function) and caregiver report of both overestimation (Loewenstein et al., 2001; Doble et al., 1999) and underestimation (Argüelles et al., 2001) of functional capacity in individuals with dementia. In contrast, Karagiozis et al. (1998) and Davis et al. (2006) reported no significant relationship between cognitive status and caregiver concordance or discordance. An association was reported between caregiver depressive symptoms and their underestimation of functional capacity in the person with dementia (Argüelles et al., 2001; Zanetti et al., 1999). However, other researchers found no significant relationship between these variables (Loewenstein et al., 2001; Davis et al., 2006).

Study Purpose and Research Questions

Given these findings, the need for further examination of caregiver concordance in relation to cognitive status and caregiver depression was identified, in order to either further substantiate or challenge current evidence. In addition, the development of the FCCS and its utility with the ADM-2 offered a new, systematic approach to determining caregiver concordance. As families play an increasingly important role in the care of people with dementia living at home, this study sought to answer two research questions:

1. What is the relationship between cognitive status in the person with dementia and caregiver concordant status (concordant estimation, underestimation, and overestimation)?

2. What is the relationship between caregiver depressive symptoms and caregiver concordance status?

Conceptual Framework and Hypotheses

The study's hypotheses were developed using the Person-Environment-Occupation Model (PEO) (Law et al., 1996) which draws key concepts from the Competence-Environmental Press Model (Lawton & Nahemow, 1973) and the Stress-Health Process Model (Pearlin et al., 1981). These two models posit engagement in daily activities and personal characteristics of the caregiver and person with dementia as interconnecting with the environmental contexts.

The Person-Environment-Occupation Model.

The Person-Environment-Occupation Model (PEO) (Law et al., 1996) provides an overarching framework for understanding the relationship between personal factors, environmental features, and the capacity of the person with dementia to perform activities of daily living (ADL) and instrumental activities of daily living (IADL). The PEO model describes a dynamic transaction between characteristics of the person, the demands and supports within his or her living environments, and the occupations in which he or she engages as an ongoing process that drives occupational performance over the lifespan (Law et al., 1996). The *person* is described as having unique physiological, psychological, and cognitive characteristics; the *environment* as physical, social, societal, and cultural components; and *occupations* as the person's social roles and the activities and tasks that make up those roles (Law et al., 1996). Occupational performance is the outcome of the transaction between the personal, environmental, and occupational characteristics, and is influenced when there is transformation in one or more of these domains. The environment may hinder or support occupational

performance depending on the personal capacities of the person and the demands of the occupation or activity in which he or she participates.

Based on this model, an individual with dementia with higher cognitive ability living within a familiar environment that supports his or her performance of daily routines may be judged inaccurately by the caregiver as functioning at a higher level than formal testing would reveal. Caregivers would be less likely to identify deficits, as the individual with dementia is successfully functioning within a familiar environment. Thus, it was hypothesized that higher cognitive status in the person with dementia living at home would be significantly associated with caregiver overestimation of functional capacity in the person with dementia, but not concordant or underestimation.

The Stress Process Model.

The Stress Process Model (Pearlin et al., 1990) offers a framework for understanding stressors that can potentially influence caregiver beliefs and influence his or her appraisal of functional capacity in their family member with dementia, subsequently driving caregiver action. The model describes an interactive, multidimensional process comprising four domains: personal context, stressors, mediators of stress, and outcomes of stress (Pearlin et al., 1990). Given personal context, caregivers evaluate whether their stressors pose a potential threat and whether they have sufficient coping capabilities (mediator of stress). If caregivers perceive the stressors as threatening and their coping resources as inadequate, they will experience increased depression, anxiety and other threats to health and well-being (outcome). Conversely caregivers who perceive their coping resources as adequate will experience less stress.

Based on this model, caregivers who perceive the stress of providing care as a potential threat to their well-being and feel they cannot cope may experience depression. This lowered emotional state may impact the caregiver's appraisal process in estimating the functional capacity of the person with dementia. Studies have shown an association between caregiver depression and appraisal of function, with caregivers who report depressive symptoms under estimating function (Argüelles, et al., 2001; Zanetti, at al., 1999). For this study, it was hypothesized that higher caregiver depressive symptoms would be significantly associated with caregiver underestimation of functional capacity in the person with dementia, but not concordant or overestimation.

Literature Review

Due to the nature of the disease, people with dementia progressively decline in cognitive and physical function, which necessitates the involvement of caregivers. Family caregivers must appraise their family member's functional capacity and make decisions about the level of assistance to provide. In addition, health professionals often depend on the caregiver's estimation to determine the abilities of their patient with dementia, although caregiver appraisal may not be accurate. To address these issues, there is a growing body of literature investigating caregiver appraisal of patient function and other health domains, including their concordance with proxy ratings and direct assessment.

Caregiver appraisal of function and other health domains in people with dementia.

In a cross-sectional study, Arlt, Hornung, Eichenlaub, Jahn, Bullinger, and Petersen (2008) compared the ratings of family caregivers, clinicians, and people with dementia with regard to cognitive impairment, depression, and health-related quality of life of the person with

dementia. The findings revealed a significant association between caregiver ratings of cognitive status in the person with dementia and clinician derived scores. However, there was no significant association between self-reported ratings of cognitive status by the person with dementia and clinician ratings. There was a high correlation between depression ratings by the clinician, caregiver and person with dementia.

Zank and Frank (2002) compared the ratings of family caregivers and adult day center staff with regard to their perceptions of activities of daily living (ADL) performance, and memory and behavioral problems in the person with dementia at two time points 6 months apart. Cross-sectional results revealed significant differences between the caregiver and staff ratings of ADL performance, and memory and behavior problems, with family caregivers reporting greater ADL deficits and memory and behavior problems compared to staff. The differences between family caregiver and staff ratings were greater when subjective caregiver burden was high, indicating the influence of caregiver burden on the appraisal process. Longitudinal analysis revealed that the relationships between staff and caregiver ratings remained consistent over 6 months with a perceived decline in ADL performance of the person with dementia. This study compared two subjective ratings by caregivers and staff and found that caregivers under estimated ADL performance (indicated more ADL deficits) compared to staff. However an objective measurement of ADL performance was not obtained. The authors indicate a concern that they did "not know whether the professional's or the family caregiver's ratings reflect reality" (p. 164).

Cotter, Burgio, Roth, and Gitlin (2002) compared caregiver report of dependence in ADL performance and predicted duration of assistance to observation ratings. They used videotaped

analysis of seven ADL items on a modified version of the FIM Self-Care subscale (Granger, Hamilton, Keith, Zielezny, & Sherwin, 1986). Caregivers were initially asked to estimate the amount of assistance they would provide their family member to complete each ADL item and the duration of assistance time. Then videotaped observations of each ADL interaction between caregiver and family member with dementia were completed. The findings revealed a statistically significant correlation between caregiver-reported and observation-derived levels of assistance, although family members overestimated the amount of assistance time. The researchers acknowledged that the interpretation of the results was limited, as the study did not objectively assess the actual functional ability of the person with dementia. The findings "reflect what caregivers allow the patients to do, rather than what the patients are truly able to do" (p .44).

A subsequent study attempted to address this limitation using the same dataset and adding a third FIM score derived by an occupational therapist watching the videotapes (Cotter, Burgio, Roth, Gerstle, & Richardson, 2008). This third score was compared to the caregiver-reported and observation-derived FIM scores. This study found that the three ratings (caregiver-reported, observation-derived, and occupational therapist FIM score) were significantly correlated, supporting their original finding of agreement between caregiver and observation derived ADL ratings. These two studies concluded that caregivers can accurately provide information about what they do to assist the person with dementia during ADL performance; however, the amount and type of assistance caregivers provide may not indicate the ability of the person with dementia. The caregiver may have been overestimating or underestimating functional capacity and providing excessive or insufficient assistance.

Caregiver appraisal of function and concordance with direct assessment and related factors.

As suggested by Cotter et al. (2008), the amount of assistance caregivers provide may not reflect the actual functional capacity of the person with dementia. To address this issue, studies have been conducted that compare caregiver appraisal of functional capacity with direct assessment in order to determine caregiver concordance or accuracy. Ala, Berck and Popovich (2005) assessed the ability of people with dementia to accurately recall personal information, including their name, caregiver name, address, and telephone number, and the caregiver's estimation of ability in the person with dementia. Caregivers of individuals with moderate dementia (MMSE score 10-25), were the most likely to inaccurately judge performance. Similar to other studies, the greatest proportion of caregivers who were discordant with objective assessment ratings overestimated the functional capacity of the person with dementia. Wadley et al. (2003) found that people with dementia overwhelmingly overestimated their financial abilities compared to their caregivers, who were just as likely to overestimate as underestimate.

Further studies have specifically examined caregiver concordance and discordance with direct or objective assessment in relation to other variables, most prevalently caregiver depression and cognitive impairment in the person with dementia. Zanetti et al. (1999) investigated the level of agreement between family caregiver proxy report and direct performance-based assessment of function in people with mild dementia. Caregivers were asked to report dependence or independence in specific activities of daily living. Four scales from the Direct Assessment of Functional Status (DAFS) (Loewenstein et al., 1989) and two tests from the seven-item Physical Performance Test (PPT) (Reuben & Siu, 1990) were used for

performance-based assessment. The assessment score and caregiver proxy report were compared in six activities: dressing, toileting, walking, telephone use, shopping, and money use. The strongest association between caregiver report and actual performance was found with walking. The researchers reported a moderate to good agreement for dressing, and moderate agreement for telephone use, shopping and money use, with no agreement for toileting. Analysis revealed that disagreement between caregiver ratings and performance-based assessment was affected by caregiver burden, specifically the restrictions on caregiver time. Moreover, caregivers with higher depressive symptoms tended to underestimate the functional ability of the person with dementia.

Doble et al. (1999) compared objective, performance-based assessment of individuals with dementia using the Assessment of Motor and Process Skills (AMPS) (Fisher, 1997) with categorical summary ratings of competency (competent, at risk, or impaired) by occupational therapists and family informant ratings using an adapted version of the Older Americans Resources and Services (OARS) (Doble & Fisher, 1998). Forty-six percent of caregivers were discordant with occupational therapist ratings and consistently overestimated the ADL function of their family members. Caregiver overestimation of function was found to be more prevalent with higher cognitive status in the person with dementia; however, no association was found with other variables including caregiver gender, relationship to person with dementia, amount of daily contact, or living arrangement.

Two studies using a modified version of the DAFS investigated caregiver bias in predicting the ability of the person with dementia to perform eight daily activities (reading a clock, preparing a letter for mailing, identifying currency, counting currency, balancing a

checkbook, making change for purchase, brushing teeth, and eating skills). Measures that directly compared performance of the person with dementia and caregiver judgment were used (Argüelles, Loewenstein, Eisdorfer, & Argüelles, 2001; Loewenstein et al., 2001). For study participants with dementia who did not display impairment when performing the eight tasks, caregivers were concordant with actual performance. However caregivers tended to overestimate the ability to read a clock, identify currency, make change, and utilize eating utensils in participants with dementia who did not accurately perform each task (Loewenstein et al., 2001). Similarly, Argüelles et al. (2001) found that a significant proportion of caregivers overestimated the ability of the person with dementia to read a clock, count currency, make change, brush teeth, and use eating utensils. Studies found dissimilar findings regarding cognitive status in the person with dementia, with Loewenstein et al., (2001) reporting an association between higher cognitive status and overestimation of function and Argüelles et al. (2001) reporting an association between higher MMSE score and underestimation. Argüelles et al. (2001) found that lower scores on the Center for Epidemiology Studies – Depression scale (CES-D) was significantly associated with overestimation of function in the person with dementia, $F (1, 66) = 8.70$, $p = < 0.05$), whereas Lowenstein et al. (2001) found no statistically significant difference between CES-D scores and over or underestimation of function.

In a study of 49 well-educated dyads, of which 45 were spouses, Davis, Martin-Cook, Hynan, and Weiner (2006) compared caregiver estimation of function in the person with dementia to an objective measurement of instrumental ADLs to determine a discrepancy score. Other factors were measured as potential sources for variance, including cognitive status and neuropsychiatric behaviors in the person with dementia, and depression, self-efficacy,

resentment, and satisfaction with the caregiving experience in the caregiver. A discrepancy score of 10 points or greater indicated significant clinical difference. Just over sixty-three percent of caregivers were within 10 points of the objective ratings, indicating an accurate prediction of functional performance in the person with dementia. Of the 18 dyads whose discrepancy score showed significant clinical difference, 11 caregivers overestimated and 7 underestimated functional ability of the person with dementia. There was, however, no correlation between the discrepancy score and other factors measured. These well-educated caregivers tended to accurately appraise functional capacity in their spouse with dementia when their subjective assessment was compared to objective measures, and caregiver appraisal was relatively unaffected by cognitive and psychosocial factors. Inconsistent with other studies, this study did not find a relationship between caregiver depression and discordant caregiver appraisal.

A study by Dassel and Schmitt (2008) sought to determine if executive function skills in spouse caregivers influenced the accuracy of their appraisal of function in the spouse with mild cognitive impairment (MCI) or mild to moderate Alzheimer's disease (AD; N = 40 dyads). A caregiver and patient version of the Test of Everyday Functional Abilities (Cullum et al, 2001) was administered and compared to determine an ADL difference score, which fell on a continuum from -1 to +1, with the score of 1 indicating perfect agreement between the caregiver and direct assessment scores. Caregiver executive function was a significant predictor of ADL difference scores ($\beta = 0.33$, $p = .04$), and caregivers with higher executive function were more accurate in rating their spouse's function. Caregivers with lower executive function skills tended to underestimate functional disability in the person with dementia, which can be interpreted for this study as an overestimation of functional capacity.

The literature reveals inconsistent findings with regard to factors associated with caregiver appraisal of functional capacity and discrepancies that exist between the subjective ratings of caregivers and objective or standardized assessment of the people with dementia. This retrospective study sought to further examine caregiver depressive symptoms and cognitive status in the person with dementia, two factors that have been reported in the literature. A limitation of other studies is the lack of validity of the measures used to compare subjective and objective ratings. This study used compatible, theory-based measures to determine the concordance between subjective caregiver report on the FCCS and objective assessment on the ADM-2, a gold standard assessment within occupational therapy.

Methods

Description of data set.

Data was obtained from the cross-sectional study entitled *Health-related Quality of Life in Individuals with Dementia Living at Home* (QOL Study), funded by the Alzheimer's Association (Gitlin, 2011; Grant # IIRG-07-28686) and conducted over an 18 month period from February 2009 to October 2010 (N=88). Data collection was completed at three points in time within a two week period. An initial telephone interview was completed by a trained interviewer, followed by two home sessions conducted by a trained occupational therapist (N=4).

Participants.

The QOL study was approved by the Institutional Review Board (IRB) at Thomas Jefferson University. Written informed consent was obtained from caregiver participants, and verbal consent was obtained from participants with dementia. The caregiver inclusion criteria were: (1) 21 years of age or older (male or female); (2) live with or in close proximity to the

family member with dementia; (3) speak English; (3) have provided care for a minimum of 6 months; and (4) self-identify as providing the most day to-day coordination of hands-on care for the person with dementia. The criteria for participants with dementia were: (1) Mini Mental State Examination (MMSE) score above 10 (if 24 or above, confirmation of diagnosis was obtained from caregiver); (2) live at home; and (3) speak English. People with dementia who were bed-bound and unresponsive were excluded from the study, as were their caregivers.

Measures.

Caregiver concordant status. The Functional Capacity Card Sort (FCCS) and the Allen Diagnostic Module – 2 (ADM-2) were used jointly to determine caregiver concordance status. Type of concordance status is measured categorically as follows: (0) concordant estimation (FCCS rating and ADM-2 converted rating are consistent); (1) over estimation (FCCS rating is higher than the ADM-2 converted rating); and (-1) under estimation (FCCS rating is lower than the ADM-2 converted rating).

The FCCS was developed to measure caregiver appraisal of functional capacity. It has good content validity and utility (Piersol, Herge, & Gitlin, 2010). The first paper of this dissertation reports preliminary psychometric findings showing moderate convergent validity ($r = 0.43$, $p < .0001$, $N = 86$), strong discriminant validity ($r = -0.14$, $p = .19$, N - 86) and strong interrater reliability, (Kendall W (5, 72) = 0.83, $p = .0001$). The FCCS consists of six large print cards that map to the Allen Cognitive Levels (Allen & Blue, 1998). Caregivers are guided through a deductive reasoning process to choose the card that best describes the functional capacity of their family member with dementia. The final caregiver rating is on a six-point scale, from 1 to 6, reflecting lowest to highest functional capacity respectively. The FCCS was

administered to the caregiver in the home by a trained occupational therapist prior to the administration of the Allen Diagnostic Module – 2 (ADM-2).

The ADM-2 (Earhart, 2006) assesses functional cognition; the complex and dynamic interactions between a person's cognitive abilities and the context in which functional performance takes place, thus linking cognitive processing with the demands of the activity and the environment (Pollard & Olin, 2005). Individuals were asked to complete a pre-determined craft activity designed to include a range of activity demands that vary in difficulty and problems to solve. The ADM-2 has moderate interrater reliability (Bar-Yosef, Weinblatt, & Katz, 1999) and is positively correlated with screening scores on the Allen Cognitive Level Screen - 5 (Roitman & Katz, 1996). Scoring tables are used to determine the individual's Allen Cognitive Level. The ADM-2 characterizes capabilities over a hierarchy of cognitive levels and modes from lowest function (profound disability) to highest function (intact executive functioning). The ADM-2 was administered to the person with dementia in the home by a trained occupational therapist. The resulting score was converted to a six-point rating, from 1 to 6, reflecting lowest to highest functional capacity respectively in order to be compared to the FCCS rating.

Cognitive status of person with dementia. Cognitive status of the person with dementia was measured using the Mini Mental State Examination (MMSE) administered in the home. The MMSE is one of the most extensively used tools to assess cognitive status (Folstein, Folstein, & McHugh, 1975). Exam items assess orientation to time and place, attention, calculation, recall, and language. The measure demonstrates high inter-rater and test-retest reliability, as well as concurrent and discriminant validity (Tombaugh & McIntyre, 1992). Items are summed on a scale ranging from 0 to 30, with higher scores indicating better cognitive status. Indicative of

cognitive deficits compatible with dementia, the conventional cut off score of ≤ 24 was used for eligibility in this study.

Depressive symptoms of caregiver. Depressive symptoms of the caregiver were measured using the Center for Epidemiologic Studies – Depression scale (CES-D); administered on the phone. The CES-D is a valid and reliable screening instrument to measure common symptoms of depression that have occurred over the past week, such as poor appetite, hopelessness, pessimism, and fatigue (Radloff, 1977). Twenty items are rated on a 4-point Likert scale indicating the frequency with which symptoms were experienced and are summed to compute a total score, ranging from 0 (rarely or none of the time; < 1 day) to 3 (most or almost all of the time; 5-7 days). The possible range of scores is 1 to 60. Scores are summed across items, with higher scores indicating greater depressive symptomatology. A cutoff score of 16 or greater identifies individuals at risk for clinical depression, with good sensitivity and specificity and high internal consistency (Lewinsohn, Seeley, Roberts, & Allen, 1997).

Data Analysis.

IRB approval was obtained from Thomas Jefferson University, Philadelphia, PA and Virginia Commonwealth University, Richmond, VA for a secondary data analysis. Data were analyzed with SAS® 9.3. Analysis and interpretation of results were completed at Thomas Jefferson University in consultation with a biostatistician. The statistical analysis used nonparametric procedures as they do not require normal distribution or variance assumptions with regard to study population and can be used with ordinal or nominal data.

Descriptive statistics were used to characterize the sample and determine the distribution of caregivers in each concordance status group. A Kruskal-Wallis one-way analysis of variance

was used to compare demographic characteristics among the three concordance status groups to determine the need for any covariates in testing the hypotheses. The Kruskal-Wallis test was used to determine whether cognitive status in the person with dementia and caregiver depression accounted for differences between concordance status groups using an alpha level of < .05. The plan included a post hoc pairwise comparison with a Bonferroni correction if significant differences were found in order to test the directional component of the hypotheses.

Results

Sample characteristics.

This study used cross sectional data from 88 home-dwelling people with dementia and their caregivers who participated in the QOL study. As indicated in Table 1, the caregivers were primarily female (88.6%), white (77.3%), and spouses (55.7%), with a mean age of 65.8. All caregivers had a high school education or higher, and had provided care from 6 months to 22 years. Their scores on the CES-D varied widely, ranging from 0 to 42 (M = 11.4, SD = 9.7, N = 88). Based on the cut off score of 16, a small proportion of the caregivers were at risk for clinical depression (n = 26, 29.5%). The majority of caregiver participants did not have depressive symptoms (n = 62, 70.5%). Most participants with dementia were female (52.3%) and white (76.1%) with a mean age of 81.7. The MMSE scores ranged from 10 to 28 (M = 17.7, SD = 4.6, N = 87). Because of the inclusion criteria for the original study (MMSE score greater than 10), the sample did not include participants with severe dementia. The largest proportion of the participants with dementia had moderate dementia with scores ranging from 10 to 20 on the MMSE (n = 61, 70.5%). Twenty six participants with dementia (29.5%) had mild dementia with

Table 1

Caregiver and Person with Dementia Demographics

	Caregiver (*N*=88)					Person with Dementia (*N*=88)				
	M	*SD*	Range	*n*	%	*M*	*SD*	Range	*n*	%
Age	65.8	12.2	38.0 - 89.0			81.7	8.0	56.0 - 97.0		
Gender										
Female				78	88.6				46	52.3
Male				10	11.4				42	47.7
Race										
White				68	77.3				67	76.1
Non-white				20	22.7				21	23.9
Years Caregiving	5.1	3.5	0.5 - 22.0							
Relationship to Person with dementia										
Spouse				49	55.7					
Non-spouse				39	44.3					
Education										
High school				2	2.3					
> High school				86	97.7					
MMSE[a]						17.7	4.6	10.0 – 28.0		
CES-D	11.4	9.7	0.0 - 42.0							

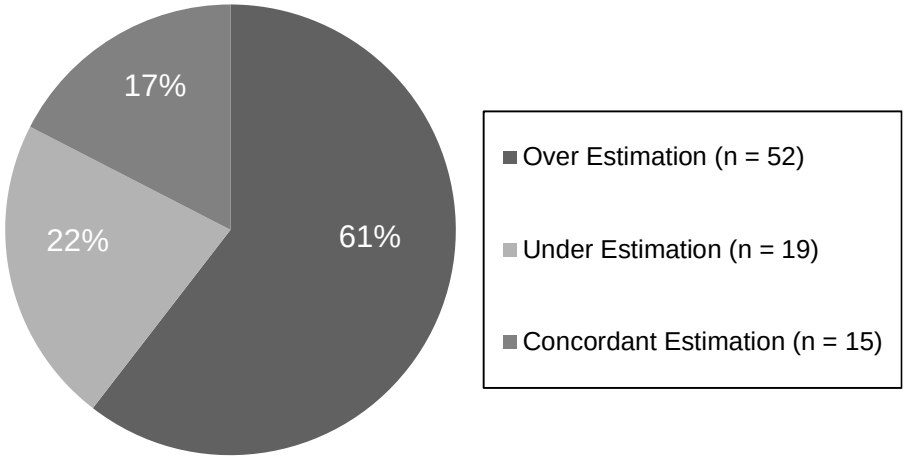
Note: *M* = Mean. *SD* = standard deviation. MMSE = Mini Mental Status Exam. CES-D = Center for Epidemiologic Studies-Dementia scale. [a] N=87

scores of 21 or above. Of this group, all of the 6 participants who scored above the 24 cut off score had a physician's diagnosis of Alzheimer's disease or related dementia.

Caregiver distribution among concordance status groups.

Caregiver concordance is determined by comparing the caregiver rating on the FCCS to the result of the standardized ADM-2 assessment administered to the person with dementia. Analysis revealed that 71 (83%) of the caregivers were discordant with the standardized assessment. Breaking down this discordant group into overestimation and underestimation groups, as seen in Figure 1, 52 (61%) of caregivers overestimated functional capacity in the person with dementia, 19 (22%) caregivers underestimated, and 15 (17%) were concordant estimators.

Figure 1. Distribution of caregiver estimation of functional capacity in the person with dementia derived by comparing the Functional Capacity Card Sort rating and the adjusted Allen Diagnostic Module-2 rating



Differences among caregiver concordant status groups.

The comparison of demographic characteristics among the three concordance status groups revealed no significant associations as presented in Table 2, therefore covariates were not included in the statistical analysis. MMSE median and mean scores and standard deviations (person with dementia) and the CES-D (caregiver) were initially calculated for the three caregiver concordant status groups. These distributions are provided in Table 3. The Kruskal-Wallis one-way analysis of variance test was then used to compare the differences between the three concordance status groups for each variable.

Relationship between cognitive status and caregiver concordant status. There was no statistically significant difference on the MMSE scores among the three groups, H (2, N = 85) = 3.67, p = .16. Because no significant difference was found, the post hoc test pairwise comparison was not done. Thus, the first hypothesis that higher cognitive status would be associated with caregiver overestimation

Table 2

Demographic Comparisons among Concordance Status Groups

Variable	Caregiver Concordance Status Groups (N = 86)						Kruskal- Wallis test
	Concordant Estimation n = 15		Under Estimation n = 19		Over Estimation n = 52		
	M	*SD*	*M*	*SD*	*M*	*SD*	
Age (CG)	70.1	11.8	65.0	14.5	65.1	11.5	$\chi^2(2, N = 86) = 2.11, p = .35$
Age (PWD)	80.1	9.3	83.4	6.8	81.2	8.1	$\chi^2(2, N = 86) = 1.54, p = .46$
Years of caregiving	6.1	5.8	5.1	2.5	4.8	2.9	$\chi^2(2, N = 86) = 0.49, p = .78$
	n	%	*n*	%	*n*	%	
Gender (CG) Female	11	73	17	89	48	92	$\chi^2(2, N = 86) = 4.06, p = .13$
Male	4	27	2	11	4	8	
Gender (PWD) Female	7	47	12	63	27	52	$\chi^2(2, N = 86) = 1.03, p = .60$
Male	8	53	7	37	25	48	
Race (CG) White	14	93	14	74	38	73	$\chi^2(2, N = 86) = 2.83, p = .24$
Non-White	1	7	5	26	14	27	
Race (PWD) White	14	93	15	79	36	69	$\chi^2(2, N = 86) = 3.84, p = .15$
Non-White	1	7	4	21	16	31	
Relationship Spouse	13	87	14	74	39	75	$\chi^2(2, N = 86) = 0.76, p = .68$
Non-spouse	2	4	5	26	13	25	

Note: M = Mean. *SD* = standard deviation. CG = caregiver. PWD = person with dementia.

Table 3

Distribution of MMSE and CES-D Scores across Caregiver Concordance Status Groups

Measure	Total Sample (N = 88)			Caregiver Concordance Status Groups (N = 86)								
				Concordant Estimation			Under Estimation			Over Estimation		
	Mdn	*M*	*SD*	*Mdn*	*M*	*SD*	*Mdn*	*M*	*SD*	*Mdn*	*M*	*SD*
MMSE	17	17.7	4.6	18	19.1	5.3	19	18.9	5.1	17	16.9	4.0
CES-D	9	11.4	9.7	9	9.6	6.5	11	14.4	12.4	8	10.4	9.0

Note: Mdn = Median *M* = Mean. *SD* = standard deviation. MMSE = Mini Mental Status Exam. CES-D Center for Epidemiologic Studies – Depression Scale

was not supported. The descriptive data reveals that the highest mean score on the MMSE was with the concordant estimation group. The results show that, for this sample, the level of cognitive impairment in the person with dementia was not associated with the caregiver's appraisal of functional capacity.

Relationship between caregiver depression and caregiver concordant status. The Kruskal-Wallis test was not statistically significant for the CES-D, showing no difference in caregiver depression symptoms among the three concordance status groups, H (2, N = 86) = 1.35, p = .51. Because no significant difference was found, the post hoc test pairwise comparison was not done. For this sample, caregiver mood was not statistically associated with appraisal of functional capacity.

Discussion

This retrospective study placed caregivers into three distinct groups based on the concordance between their rating of functional capacity in the person with dementia and a standardized assessment rating. Caregivers were identified as concordant estimators, over

estimators, or under estimators. Unique to this study was the combination of tools employed to determine caregiver concordance status. The FCCS and the ADM-2, both grounded in the Cognitive Disability Model (Allen & Blue, 1998), provided the ratings from which to compare and determine caregiver concordance status. The majority of caregivers in the sample were discordant with the standardized assessment (n = 71, 83%), indicating they inaccurately estimated functional capacity in their family member with dementia compared to the score on the ADM-2, a standardized test administered by an occupational therapist. This is similar to the findings of Wadley et al. (2003) showing limited validity of caregiver report of financial ability and counters findings showing the validity and clinical utility of caregiver proxy reports (Cotter, et al., 2008; Davis, 2006).

Of the discordant group of caregivers, the majority overestimated the functional capacity of their family member. That is, the caregiver subjective rating on the FCCS was higher than the converted rating on the ADM-2. In contrast, Zank and Frank (2002) found that caregivers reported more deficits in ADL performance than formal caregivers. This can be interpreted as caregiver underestimation of function, although no standardized assessment was conducted to determine actual functional capacity. A tendency for under estimation of functional capacity of patients with dementia, often described as excess disability, was found in staff in adult day centers (Yury & Fisher, 2007) and skilled nursing facilities (Rogers, et al., 1999).

The results of this study suggest that caregivers of people with dementia living within a familiar home environment overestimate functional capacity when compared to standardized assessment. These results are similar to some previous findings (Argüelles et al., 2001; Doble et al., 1999; Loewenstein et al., 2001) and contrary to others (Karagiozis et al. (1998). The familiar

home environment may provide a structure for maximizing competence in the person with dementia, which may be inaccurately judged by caregivers as a higher level of functional capacity than standardized testing would detect. Over estimation of function poses a safety risk for the person with dementia, as the caregiver may not provide appropriate supervision or assistance during daily activities.

Consistent with empirical evidence, it was hypothesized that higher cognitive status in the person with dementia would be significantly associated with caregiver overestimation of function, which was not supported in the analysis. The results suggest that caregiver appraisal of functional capacity is relatively unaffected by the cognitive status of the person with dementia, as measured by the MMSE. These results are in agreement with two studies that found caregiver accuracy of patient function was unrelated to the severity of the subject's dementia, as measured by the MMSE (Karagiozis et al., 1998; Davis et al, 2006). However, other studies consistently found that higher cognitive ability in the person with dementia was associated with caregiver overestimation of functional ability (Loewenstein, et al., 2001; Argüelles et al., 2001; Doble et al., 1999; Wadley et al, 2003), as did a study addressing informant reports of specific cognitive functions (Kemp, Brodaty, Pond, & Luscombe, 2002). Analyzing concordance status by level of dementia (mild and moderate) using cut off scores on the MMSE may be considered in post-hoc analysis.

One possible explanation for this study's non-significant finding between the three groups of caregivers is low statistical power, a limitation in retrospective studies that use secondary data analysis and potential risk for Type II error. In response to the insignificant finding, a post hoc power analysis for MMSE was completed, which revealed a power of .75 to

reject the null hypothesis of no difference in MMSE, if the mean MMSE in the overestimation group (n = 52) was 3 points higher than in the other two group. The American College of Physician reports a change of 3 points in the MMSE is clinically significant (Qaseem et al., 2008). Approximately 105 subjects would have been necessary to achieve the commonly accepted power of .80 with an effect of this size. Although power is close to this cut off point, this hypothesis was under powered.

Caregiver depression has been shown to be associated with the concordance of caregiver appraisal with direct assessment (Argüelles et al., 2001; Zanetti, et al., 1999). It was hypothesized that higher caregiver depression would be associated with underestimation of functional capacity in the person with dementia. The analysis did not support the hypothesis, similar to the findings of Davis et al. (2006) who found no significant effect of caregiver depressive symptoms on the accuracy of caregiver appraisal. As with the first hypothesis, there was a potential risk for a Type II error, due to low power. Again, a power analysis revealed the hypothesis was powered at .52 to reject the null hypothesis of no difference in CES-D, if the mean CES-D in the under estimation group (n = 19) was 6 points higher than in the other two groups. Schultz et al. (2002) report a change of 6 points in the CES-D is clinically significant. Approximately 172 subjects would have been necessary to achieve the commonly accepted power of .80 with an effect of this size. Thus it is possible that the analysis was unable to detect a significant difference between concordance status groups with regard to caregiver depressive symptoms.

In addition to the calculated low statistical power of the data set, there are other limitations to this study. First, the small sample size limited the number of caregivers ultimately

placed in one of the three groups of concordance status. The difference in number between the over estimation group (n = 52) and concordance group (n = 15) was 37. This difference may have limited the potential for statistically significant findings. Future research with a larger sample size allowing for an even distribution of caregiver concordance status would be valuable. Second, with regard to the independent variables, the MMSE and CES-D are widely used in research to measure patient cognitive impairment and caregiver depressive symptoms. However the QOL study data set only included participants with mild to moderate dementia (score of 10 or above on the MMSE) and CES-D scores that were primarily below the cut-off point of 16, indicating limited presence of depressive symptoms among participants.

The use of the Allen Diagnostic Module-2 in combination with the FCCS offered a unique approach to determining caregiver accuracy in the appraisal of functional capacity. This is the first study to utilize these tools as an outcome measure, which offers an easy and direct approach to determining concordant, over or under estimation of function. The occupational therapy based Assessment of Motor and Processing Skills (Fisher & Bray Jones, 2010) has also been used in this capacity, but the calculations and analysis required for comparison with the measurement of caregiver appraisal are cumbersome (Doble et al., 1999). The ADM-2 in combination with the FCCS offers clinicians and researchers a theory-based tool to determine the accuracy of caregiver appraisal that is easy to administer and interpret. The results show that the Functional Capacity Card Sort in concert with the Allen Diagnostic Module-2 effectively distinguish three concordance status groups, which has utility in future research and clinical practice.

Looking towards the future, questions remain with regard to the factors that predict caregiver appraisal of functional capacity and the influence of the environment in which the person lives. A longitudinal design in which these variables could be measured over an extended time period would offer insights into the evolving nature of caregiving and the perceptions of those who provide care. Although the empirical evidence has most prevalently examined cognitive and depressive symptoms in relation to caregiver appraisal of function, other variables have been explored and warrant additional investigation. These include caregiver burden, and quality of life of both caregiver and person with dementia. Another factor related to the emotional state of the caregiver is denial that a family member has dementia. Denial of the disease and its progression may influence caregiver appraisal of functional capacity and care decisions. For example, a caregiver who does not believe her/his family member has cognitive impairment may overestimate functional capacity and place the family member at risk for harm by not providing appropriate oversight or assistance with daily activities. In addition, a factor that could not be considered in this secondary analysis was the cognitive status of the caregiver. This could be an issue of concern, especially when the caregiver is an elder spouse.

In conclusion, the empirical evidence is divided with regard to the relationship between caregiver appraisal of functional capacity and associated factors. Exploring the impact of additional caregiver factors on the appraisal of functional capacity will inform clinical practice, as the caregiver is an essential team member in the care of patients with dementia. The health profession must consider the patient with dementia and the caregiver as a dyad. Therefore the assessment and intervention process should include tools that evaluate and treat both individuals.

Further understanding of caregiver appraisal and associated factors is critical to providing best practice in dementia care.

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Chapter IV: Home Environmental Conditions and Caregiver Appraisal of Functional Capacity in People with Dementia

The notion of aging in place has become prevalent in the vernacular of today's culture, as the majority of Americans prefer to remain active within their communities as they age (AARP, 2006). The Centers for Disease Control and Prevention (CDC) defines aging in place as the "ability to live in one's own home and community safely, independently, and comfortably, regardless of age, income, or ability level" (http://www.cdc.gov/healthyplaces/terminology.htm). A growing body of evidence provides common sense, creative solutions for remaining at home by addressing the sensory motor changes that naturally occur with aging (Wahl, 2003). However, with the cognitive and behavioral changes of Alzheimer's disease or related dementia (ADRD) an individual's capacity to remain at home independently is compromised, necessitating home adaptations to promote safety and reduce risk for injury (Hurley et al., 2004; Corcoran & Gitlin, 2001). Based on an ecological framework, people with dementia progressively become unable to interact with the home environment to perform daily activities and to interpret natural environmental cues, like daylight or placement of objects that support performance of daily activities (Lawton & Nahemow, 1973; Law et al., 1996). For people with dementia, the process of safely aging in place includes the involvement of a caregiver.

An estimated 60 to 70 percent of older adults with ADRD live at home (Alzheimer's Association, 2012), and it is projected that the home will continue to be the predominant living

space for people with dementia (Wahl & Gitlin, 2003). The home environment has a greater effect on the function and safety of people with dementia than on cognitively intact individuals (van Hoof, Kort, van Waarde, & Blom, 2010). In addition, people with dementia may have altered sensitivities to characteristics of the physical environment including light, temperature, and sound, which can affect functional ability and behavior (van Hoof, Kort, Duijnste, Rutten, & Hensen, 2010). With the changes in people with dementia, caregiver responsibilities change too. The home environment is reported to have an impact on the decisions and actions of the caregiver to ensure the safety, accessibility, and independence of the person with dementia (Olson, Hutchings, & Ehrenkrantz, 1999). Therefore this study examined the relationship between caregiver appraisal of functional capacity in the person with dementia and the physical conditions of the home environment.

As functional capacity declines in people with dementia, the home environment can have an increasingly greater impact on their participation in valued and necessary daily activities. A relationship has been shown between cognitive status in the person with dementia and physical attributes of the home environment in that low scores on the Mini Mental Status Examination were associated with fewer hazards and more adaptations (Gitlin, Schinfeld, Winter, Corcoran, Boyce, & Hauck, 2002). Physical structures and objects within the environment that typically do not present a safety risk may become hazards. For example, placing lotions, deodorants, or other potentially toxic liquids on the bathroom vanity allows for easy access, but also presents a safety hazard for people with dementia, who may be confused and erroneously ingest the substance with negative consequences. Adaptations to the living space, such as adaptive equipment in the bathroom, can minimize safety risk and facilitate function (Gitlin et al., 2002). In addition,

environmental or equipment needs that are unmet can impede a caregiver's ability to provide quality care. For instance, a shower chair or grab bar would facilitate the caregiver's ability to provide a safe environment and appropriate care for the person with dementia. Thus, the home environment potentially comprises hazards, adaptations, and unmet needs that may threaten or support the function and safety of the person with dementia

As people with dementia age at home, they require increasingly more supervision and assistance which is typically provided by a family member or close friend (Alzheimer's Association, 2012). The responsibility for identifying and taking action to remove hazards and to implement adaptations to ensure safe participation in daily activities often falls on the caregiver. Underlying these caregiver actions is an appraisal of functional capacity of the person with dementia. Such appraisal is essential as a guide to decision making relating to daily care. For this study, appraisal is defined as the cognitive process of caregivers to estimate the functional capacity of the person with dementia. Based on their appraisal and subsequent actions, caregivers may facilitate or compromise the safety, function, and well-being of the person with dementia within the home environment.

Greater than 15 million family caregivers provide unpaid care to people with dementia. It is estimated that most caregivers are women (60%), aged 55 or older (56%), married (66%), and have less than a college degree (67%). Over half of caregivers are the primary breadwinners of the household (55%), and nearly half (44%) are employed full or part time outside the home (Alzheimer's Association, 2012). It is estimated that family caregivers provide over 17 million hours of care per year, an average of almost 22 hours of care per week (Alzheimer's Association, 2012), with an economic value totaling $210.5 billion. Evidence shows that the effects of caring

for someone with dementia can be overwhelmingly burdensome and stressful, and often results in depressive symptoms and anxiety disorders (Schulz & Martire, 2004). As a result of the daily responsibilities of caregiving, family members, often described as the "hidden patient" (Emlet, 1996, p. 255; Hill, 2003, p. 1682), may experience fluctuations in their physical health and emotional well-being (Baldwin, Kleeman, Stevens, & Rasin, 1989; Steadman, Tremont & Davis, 2007). This, in turn, may influence their ability to accurately appraise the capabilities of the person with dementia and actions regarding the type of care and oversight necessary to ensure function and safety.

Studies show that caregivers often misjudge functional ability (Doble, Fisk & Rockwood, 1999; Loewenstein et al., 2001; Argüelles, Loewenstein, Eisdorfer, & Argüelles, 2001; Wadley, Harrell, & Marson, 2003; Zanetti, Geroldi, Frisoni, Bianchetti, & Trabucchi, 1999, Karagiozis et al, 1998), with studies revealing discrepancies between caregiver appraisal and objective assessment of function. Caregivers who over or underestimate the functional ability of the person with dementia may place the individual in situations that exceed or fall below the person's functional capacity, respectively. For example, caregivers who overestimate the capacity may not provide adequate supervision or hands on assistance, and may not take action to remove or modify potential hazards within the home, posing a safety risk to the person with dementia. On the contrary, caregivers who underestimate function may provide superfluous care, thereby restricting participation in daily activities by the person with dementia. The relationship between caregiver appraisal of functional capacity and conditions of the home environment that support and hinder safety and function in the person with dementia has not been explicitly explored.

Study Purpose and Research Questions

The study examined caregiver appraisal of functional capacity in the family member with dementia in relation to observed hazards and adaptations within the home and caregiver reported needs. The study utilized cross-sectional data collected as part of a study conducted at Thomas Jefferson University (Gitlin, 2011). Caregiver appraisal of functional capacity was measured and compared to a standardized assessment administered by an occupational therapist to determine the concordance status between the two measures. This comparison yielded three types of concordance status: concordant estimation (caregiver appraisal consistent with standardized assessment); over estimation (caregiver appraisal higher than standardized assessment); and under estimation (caregiver appraisal lower then standardized assessment). Three home environment variables were collected for analysis: (1) hazards observed by an occupational therapist, (2) adaptations observed by an occupational therapist, and (3) unmet needs reported by the caregiver based on two items: i) did the person with dementia have physical difficulty getting into/out of home/rooms, and ii) did the caregiver need assistive devices to provide care to the family member.

The following research questions guided this study:

1. What is the relationship between the number of observed home hazards and caregiver concordance status?
2. What is the relationship between the number of observed adaptations within the home and caregiver concordant status?
3. What is the relationship between caregiver reported unmet environmental needs in the home and caregiver concordance status?

Conceptual Framework and Hypotheses

The conceptual framework for this study is grounded in human ecology, in which individual characteristics and experiences interconnect with environmental contexts. The Person-Environment-Occupation Model (PEO) (Law et al., 1996) which draws key concepts from the Competence-Environmental Press Model (Lawton & Nahemow, 1973) guided the inquiry process. The transaction between personal competence and environmental press (the forces or influences of the environment that evoke a response or action), as described by Lawton and Nahemow (1973) can be viewed as either promoting or restricting behavior and mastery. A fit between the abilities of an individual and demands of the environment promotes adaptive behavior. In contrast, a poor fit between abilities and environments, may impact negatively on performance. The PEO Model provides a framework from which to examine the relationship between caregiver appraisal of functional capacity as measured by concordance status and specific conditions of the home environment, as measured by occupational therapist observation and caregiver report.

The PEO Model (Law et al., 1996) describes the dynamic transaction between the person, the environments in which the person lives, and the occupations in which the person engages as an ongoing process that drives occupational performance over the lifespan (Law et al., 1996). The *person* is described as having unique physiological, psychological, and cognitive characteristics; the *environment* as physical, social, societal, and cultural components; and *occupations* as the activities and tasks in which a person engages over the life span that make up individual roles (Law et al., 1996). Personal factors influence the way in which the person interacts with the environment and the performance of daily activities. The environment directly

influences behavior and, conversely, is influenced by behavior or action. It is considered to be more amenable to modification than personal characteristics. Occupations serve to meet a person's intrinsic need for self-maintenance, expression, and satisfaction, and change within the context of personal roles and the environment. Occupational performance is the outcome of the transaction between the personal, environmental, and occupational characteristics, and is influenced when there is transformation in one or more of these domains. For example, when the cognitive and physical capacities of individuals decline, the environment may hinder or support their occupational performance depending on the demands of the activity or occupation in which they engage.

Within this framework, family caregivers are considered a component of the social environment for the person with dementia and thus have the potential to impact occupational performance. For this study, it was hypothesized that caregiver appraisal, as described by its concordance with standardized assessment of functional capacity, would be associated with characteristics of the home environment, controlling for cognitive status in the person with dementia. Specifically, three hypotheses were tested. First, caregivers who overestimated functional capacity would not interpret the environment as hazardous and thus, would not change the environment or remove hazards. *Therefore it was hypothesized that the caregiver overestimation group would have a greater number of observed home hazards compared to caregiver concordant estimation and underestimation groups.* Second, caregivers who were concordant with standardized assessment and underestimated functional capacity would interpret the environment as hazardous for the person with dementia and thus would make modifications to the environment. *Therefore, it was hypothesized that the caregiver underestimation and*

concordant estimation groups would have a greater number of observed home adaptations compared to the caregiver overestimation group. Third, caregivers who underestimate functional capacity would identify navigational difficulties and the need for assistive devices, and thus would report unmet needs within the home. *Therefore, it was hypothesized that the caregiver underestimation group would have greater caregiver reported unmet needs when compared to the caregiver concordant estimation and overestimation groups.*

Literature Review

The vast majority of people with dementia live at home and thus interact heavily with the physical environment (Calkins, 2011). The domain of environmental gerontology serves as a platform for the study of home environments. Environmental gerontology addresses "the description, explanation, and modification or optimization of the relation between the elderly person and his or her environment" (Wahl & Weisman, 2003, p. 616). The literature merges theoretical and practical evidence to support the interconnection of personal, functional, and psychosocial factors with characteristics of the home environment. Understanding these linkages is an important direction for research and can advance the development of targeted home environment intervention (Gitlin, 2003; van Hoof, Kort, van Waarde, & Blom, 2010). Gitlin, Mann, Tomit, & Marcus (2001) investigated the types of environmental problems older adults encountered at home and correlated these with personal, psychosocial, and functional factors. The results revealed an average of 13 environmental problems that were a barrier to safe and independent performance of daily activities. Factors most strongly associated with environmental problems were age (younger), gender (female), race (minority), health (having pain), and

functional status (greater physical disability). Similar research has not been reported specifically about the homes of people with dementia.

Caregivers of people with dementia witness decline in cognitive and physical abilities, experience change in relationship, and confront direct care challenges, including problem behaviors, all of which can interfere with the daily function and safety of their family member. These factors often necessitate the provision of supervision and hands on assistance to allow for the individual's safe participation in daily activities. In addition, caregivers must make decisions about the physical characteristics and nature of the home environment as it relates to their provision of care. Adaptations to the home are often necessary, but may not be made until an injury or critical event has occurred. The home environment literature provides an understanding of caregiver motivation to make changes and adherence to recommendations, as well as, design features that support provision of care within the home context.

Lach and Chang (2007) explored the motivation of caregivers to make environmental changes in the home. Through focus group interviews, emerging themes embodied important factors that represent barriers or facilitators for caregiver action regarding environmental change. Caregivers expressed that they might not make recommended changes or home modifications even though they knew they should. The greatest barrier to taking action was described as "difficulty knowing what changes to make and then deciding when the right time to make them was" (Lach & Chang, 2007, p. 1004). This statement highlights the relationship between caregiver appraisal and home environmental conditions. Knowing the right time to make changes or adaptations may be based on the caregiver's appraisal of their family member's functional capacity. Their appraisal of declining function may necessitate taking action.

Involvement of professionals for recommendations, advice, and "giving them a push" (p. 1003) emerged as facilitators of initiating changes within the home environment.

Adherence of caregivers to specific recommendations for home modifications (Sheldon & Teaford, 2002) and skill-building strategies (Chee, Gitlin, Dennis, & Hauck, 2007) vary. In one study, caregivers implemented at least 40% of the therapist's recommendations, and the general reasons given for failure to implement were that they "did not see the need," or "did not think it would work" (Sheldon & Teaford, 2002, p. 80). Modifiable factors associated with caregiver adherence to recommendations included better physical health, greater treatment exposure, more problem areas addressed by the intervention, and more active skill-building techniques. The strongest predictor of adherence was number of contacts with the interventionist. Also, caregivers with better physical health used more strategies than those reporting poor health. In this study, cognitive status and problem behaviors in the person with dementia were not statistically significant predictors of caregiver adherence (Chee et al., 2007).

The importance of a safe and supportive environment emerges through caregiver narratives. Olsen, Hutchings and Ehrenkrantz (1999) analyzed home-based dementia care and its environmental context as seen through the eyes of family caregivers. This qualitative study explored whether home design features facilitated or hindered caregivers in providing appropriate care to the family member with dementia. Ninety caregivers were interviewed. Eight design features identified as making caregiving easier were one-level living, adequate space, simple layout, open floor plan, privacy, safe and accessible bathroom, safe kitchen, and safe access to outdoors. The absence of these design features were labeled as detrimental to care. Similarly, optimal home features including architecture, interior design, indoor environment, and

technology have been described (Day, Carreon, & Stump, 2000; Van Hoof & Kort, 2009). Most recently, Van Hoof and Kort (2009) presented the results of a comprehensive literature review on the characteristics and needs of people with dementia and data from focus groups with experts in aging and home modification. Key features supporting function and promoting a safe environment were an open floor plan, familiar furniture, proper lighting and thermal comfort, and appropriate adaptive equipment. Preplanned spaces for people with dementia may provide an optimal setting; however, for individuals remaining in their homes, the responsibility for home modifications often falls on the caregiver.

Previous studies have sought to understand the nature of the home environment for individuals with dementia through the experiences and reports of caregivers and observation of the impact of architectural/design features on daily activities and safety. The motivation of caregivers to take action and their adherence to professional recommendations generally reveals a commitment to ensure the safety of their family member. However, a clearer understanding of the relationship between caregiver characteristics and the home environment is warranted. Specifically, no studies have analyzed the impact of caregiver appraisal of functional capacity in the person with dementia on certain conditions of the home environment that facilitate or hinder safety and function. To address this gap, this retrospective study sought to examine how three home conditions, 1) number of observed home hazards, 2) number of observed adaptations, and 3) caregiver reported environmental unmet needs, are related to concordance between caregiver appraisal and standardized, professionally assessed functional capacity.

Methods

Description of data set.

Data was obtained from the cross-sectional study entitled *Health-related Quality of Life in Individuals with Dementia Living at Home* (QOL Study), funded by the Alzheimer's Association (Gitlin, 2011; Grant # IIRG-07-28686) and conducted over an 18 month period from February 2009 to October 2010 (N=88). Data collection was completed at three points in time within a two week period. An initial telephone interview was completed by a trained interviewer, followed by two home sessions conducted by a trained occupational therapist (N=4).

Participants.

The QOL study was approved by the Institutional Review Board (IRB) at Thomas Jefferson University. Written informed consent was obtained from caregiver participants, and verbal consent was obtained from participants with dementia. The caregiver inclusion criteria were: (1) 21 years of age or older (male or female); (2) live with or in close proximity to the family member with dementia; (3) speak English; (3) had provided care for a minimum of 6 months; and (4) self-identify as providing the most day to-day coordination of hands-on care for the person with dementia. The criteria for participants with dementia were: (1) Mini Mental State Examination (MMSE) score above 10 (if 24 or above, confirmation of diagnosis was obtained from caregiver); (2) live at home; and (3) speak English. People with dementia who were bed-bound and unresponsive were excluded from the study, as were their caregivers.

Measures.

Home environmental condition. Characteristics of the home were measured using the Home Environmental Assessment Protocol (HEAP), which has been shown to have adequate inter-rater reliability and convergent validity (Gitlin et al., 2002). The HEAP measures specific dimensions of the physical home environment that support or hinder the ability of people with dementia to function safely. The battery is administered by walking with the caregiver through the home to each area in which the person with dementia spends time during a typical day. Areas of the home that the person with dementia never goes into are not included. The battery uses structured observation and probing questions to derive ratings for up to seven areas of the home. The HEAP was administered with the caregiver in the home. For this study, three indices were used: (1) number of observed hazards (e.g. throw rug, access to harmful objects); (2) number of observed adaptations (e.g. structural renovation, installation of grab bar); and (3) caregiver reported unmet home needs. "Unmet needs" was measured by asking caregivers two questions: (1) did their family member have physical difficulty using or getting into/out of home/rooms (yes/no), and (2) did they need assistive devices to provide care to their family member (yes/no). A sum of total number of unmet needs (0, 1 or 2) was derived. A score of "0" indicated no unmet needs; a score of "1" or "2" indicated a positive response to one or both of the questions. This index is a categorical variable.

Caregiver concordant status. The Functional Capacity Card Sort (FCCS) and the Allen Diagnostic Module – 2 (ADM-2) were used jointly to determine caregiver concordance status. Type of concordance status is measured as follows: (0) concordant estimation (FCCS rating and ADM-2 converted rating are consistent); (1) overestimation (FCCS rating is higher than the

ADM-2 converted rating); and (-1) underestimation (FCCS rating is lower than the ADM-2 converted rating).

The FCCS was developed to measure caregiver appraisal of functional capacity. It has good content validity and utility (Piersol, Herge, & Gitlin, 2010). Paper 1 of this dissertation reports preliminary psychometric findings showing moderate convergent validity ($r = 0.43$, $p < .0001$, $N = 86$), strong discriminant validity ($r = -0.14$, $p = .19$, N - 86), and strong interrater reliability (Kendall W (5, 72) = 0.83, $p = .0001$). The FCCS consists of six large print cards that map to the Allen Cognitive Levels (Allen & Blue, 1998). Caregivers were guided through a deductive reasoning process to choose the card that best described the functional capacity of their family member with dementia. The final caregiver rating is on a six-point scale, from 1 to 6, reflecting lowest to highest functional capacity respectively. The FCCS was administered to the caregiver in the home prior to administration of the Allen Diagnostic Module-2.

The ADM-2 (Earhart, 2006) assesses functional cognition; the complex and dynamic interactions between a person's cognitive abilities and the context in which functional performance takes place, thus linking cognitive processing with the demands of the activity and the environment (Pollard & Olin, 2005). Individuals were asked to complete a pre-determined craft activity designed to include a range of task demands that vary in difficulty and problems to solve. The ADM-2 has moderate interrater reliability (Bar-Yosef, Weinblatt, & Katz, 1999) and is positively correlated with screening scores on the Allen Cognitive Level Screen - 5 (Roitman & Katz, 1996). Scoring tables are used to determine the individual's Allen Cognitive Level. The ADM-2 characterizes capabilities over a hierarchy of cognitive levels and modes from lowest function (profound disability) to highest function (intact executive functioning). The

ADM-2 was administered to the person with dementia in the home. The ADM-2 score was converted to a six-point rating, from 1 to 6, reflecting lowest to highest functional capacity respectively.

Cognitive status of the person with dementia. The cognitive status of the person with dementia was measured using the Mini Mental State Examination (MMSE), administered to the individual in the home. The MMSE is one of the most extensively used tools to assess cognitive status (Folstein, Folstein & McHugh, 1975). Exam items assess orientation to time and place, attention, calculation, recall, and language. The measure demonstrates high inter-rater and test-retest reliability; as well as concurrent and discriminant validity (Tombaugh & McIntyre, 1992). In this study, items were summed on a scale ranging from 0 to 30, with higher scores indicating better cognitive status. The conventional cut off score of ≤ 24 was used for eligibility.

Data analysis.

IRB approval was obtained from Thomas Jefferson University, Philadelphia, PA and Virginia Commonwealth University, Richmond, VA for secondary data analysis. Data were analyzed with SAS® 9.3. The analysis and interpretation of the results were completed at Thomas Jefferson University in consultation with a biostatistician.

Initially, descriptive statistics were used to characterize the sample, concordance status groups, and distribution of home characteristics across the groups. For the two continuous dependent variables, it was hypothesized that caregiver overestimation would have greater observed home hazards when compared to all other caregivers, i.e., caregiver concordant and overestimation; and caregiver concordant and underestimation would have greater adaptations when compared to overestimation, controlling for cognitive status in the person with dementia.

Thus, the three concordance status groups were collapsed into two estimation groups: caregivers who overestimated and those who did not overestimate (concordant and underestimation). Linear regression was then used to model the association between the two-level categorical independent variable (overestimating and not overestimating) and the dependent variables (observed home hazards and adaptations), adjusting for cognitive status.

For the ordinal dependent variable (reported unmet environmental needs), it was hypothesized that underestimation would have greater unmet needs when compared to concordant and overestimation when controlling for cognitive status. As with the analyses above, the null hypothesis was that each estimation group would have the same reported unmet environmental needs. Again, the three concordance status groups were collapsed into two groups: caregivers who underestimated and caregivers who did not underestimation (concordant and overestimation). Proportional odds logistic regression was used to model the association between the two-level categorical independent variable and unmet environmental needs, adjusting for cognitive status. An alpha level of .05 was used for all statistical tests.

Results

Sample characteristics.

Data used for this study was from 88 home-dwelling people with dementia and their caregivers who participated in the QOL study. As indicated in Table 1, the caregivers were primarily female (88.6%), white (77.3%), and spouses (55.7%), with a mean age of 65.8. All caregivers had a high school education or higher, and had provided care from 6 months to 22 years. The majority of participants with dementia were female (52.3%) and white (76.1%) with a mean age of 81.7. The MMSE scores ranged from 10 to 28 (M = 17.7, SD = 4.6, N = 87).

Table 1

Caregiver and Person with Dementia Demographics

	Caregiver (*N* = 88)					Person with Dementia (*N* = 88)				
	M	*SD*	Range	*n*	%	*M*	*SD*	Range	*n*	%
Age	65.8	12.2	38.0 - 89.0			81.7	8.0	56.0 - 97.0		
Gender										
Female				78	88.6				46	52.3
Male				10	11.4				42	47.7
Race										
White				68	77.3				67	76.1
Non-white				20	22.7				21	23.9
Years Caregiving	5.1	3.5	0.5 - 22.0							
MMSE[a]						17.7	4.6	10.0 – 28.0		
Relationship to Person with dementia										
Spouse				49	55.7					
Non-spouse				39	44.3					
Education										
High school				2	2.3					
> High school				86	97.7					

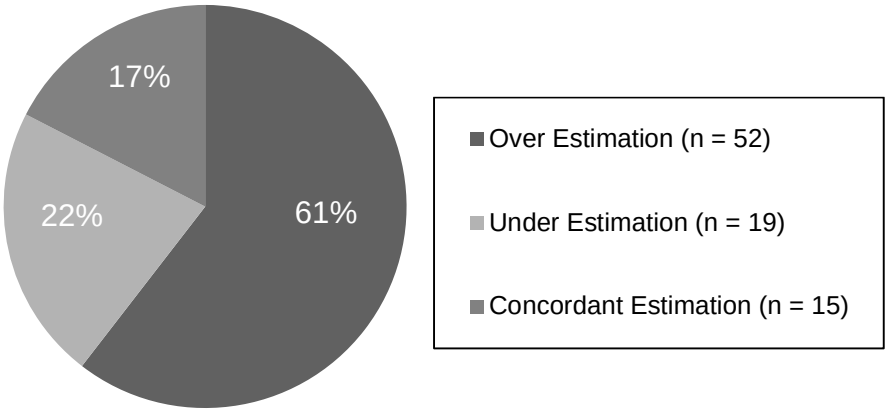
Note: *M* = Mean. *SD* = standard deviation. MMSE = Mini Mental Status Exam. [a] = N=87

Because of the inclusion criteria for the original study (MMSE score greater than 10), the sample did not include participants with severe dementia. The largest proportion of the participants with dementia had moderate dementia with scores ranging from 10 to 20 on the MMSE (n = 62, 70.5%). Twenty six participants with dementia (29.5%) had mild dementia with scores of 21 or above. Of this group, all of the 6 participants who scored above the 24 cut off score had a physician's diagnosis of Alzheimer's disease or related dementia.

Caregiver distribution among concordance status groups.

Caregiver concordance was determined by comparing the caregiver rating on the FCCS with the result of the standardized ADM-2 assessment administered to the person with dementia, which is adjusted for the comparison. Figure 1 shows that 52 (61%) of the caregivers

Figure 1. Distribution of caregiver estimation of functional capacity in the person with dementia derived by comparing the Functional Capacity Card Sort rating and the adjusted Allen Diagnostic Module-2 rating



overestimated functional capacity in the person with dementia, 19 (22%) caregivers underestimated, and 15 (17%) of the caregivers were concordant estimators.

Home environmental conditions among caregiver concordant status groups.

The QOL Study data set included the number of observed home hazards and adaptations, and caregiver reported unmet needs, as measured by the HEAP. Table 2 provides the frequency distribution of the three variables in the total sample. Mean scores and standard deviations of the number of home hazards and adaptations, and the frequency of 0, 1, or 2 unmet needs were calculated for the three caregiver concordant status groups, as shown in Table 2. Number of home hazards ranged from 1 to 27; and number of adaptations ranged from 0-23. Most caregivers reported zero unmet needs. The concordant estimation group had the greatest number of hazards, whereas the underestimation group had the greatest number of adaptations. The mean number of home hazards was slightly greater in the group of caregivers who were

concordant estimators (*M* = 8.9). In the concordant estimation group, 66.7 percent of the caregivers reported zero unmet needs (e.g. answered "no" to both questions on HEAP).

Table 2

Mean Home Hazards and Adaptations and Frequency of Unmet Needs across Caregiver Concordance Status Groups

Item	Total Sample			Caregiver Concordance Status Groups (*N* = 86)								
				Concordant Estimation (*n* = 15)			Under Estimation (*n* = 19)			Over Estimation (*n* = 52)		
	(*N* = 88)											
	Mdn	*M*	*SD*	*Mdn*	*M*	*SD*	*Mdn*	*M*	*SD*	*Mdn*	*M*	*SD*
Hazards	6	8.1	5.2	8	8.9	6.3	8	7.5	4.3	6	7.9	5.1
Adaptations	5	5.4	4.1	5	5.7	4.5	6	6.6	4.9	4	4.9	4.1
	n	%		*n*	%		*n*	%		*n*	%	
0 unmet needs	42	48.3		10	66.7		8	42.1		23	44.2	
1 unmet need	31	35.6		3	20.0		7	36.8		21	40.4	
2 unmet needs	14	16.1		2	13.3		4	21.1		8	15.4	

Note: Mdn = Median. *M* = Mean. *SD* = standard deviation.

Relationship between caregiver concordance status and home environmental conditions observed by occupational therapist.

Linear regression was used to test the first two hypotheses, using an alpha level of .05. The three concordance status groups were collapsed into a two level categorical variable (estimation groups), adjusting for cognitive status in the person with dementia. The two caregiver estimation groups were: overestimating and not overestimating (concordant/ underestimation). Table 3 provides the frequency distribution of hazards and adaptations for the two groups. For both hypotheses the two level estimation group was the independent variable.

Table 3

Mean Home Hazards and Adaptations across Caregiver Estimation Groups

Item	Overestimation (n = 52)			Concordant/Underestimation (n = 34)		
	Mdn	*M*	*SD*	*Mdn*	*M*	*SD*
Hazards	6	7.9	5.1	8	8.1	5.3
Adaptations	4	4.9	3.7	6	6.2	4.7

Note: Mdn = Median. *M* = Mean. *SD* = standard deviation.

In the first hypothesis, the number of home hazards observed by the occupational therapist was the dependent variable. The second hypothesis tested the number of observed adaptations as the dependent variable.

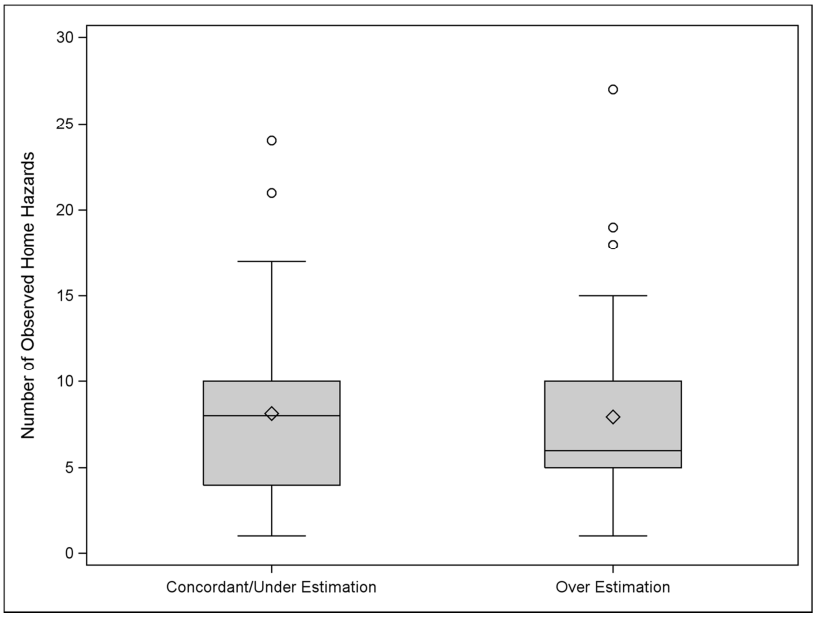
Concordance status and number of observed home hazards. With regard to home hazards there was no significant difference among the two groups, F (1, N = 86) = .01, p = .94. Thus the first hypothesis that caregiver overestimation of functional capacity in the person with dementia would be associated with a significantly greater number of hazards compared to caregiver concordant/underestimation was not supported. The box plot in Figure 2A shows the distribution of observed home hazards for each concordance status group.

Concordance status and number of observed home adaptations. The second hypothesis that caregiver concordant/underestimation of functional capacity would be associated with a significantly greater number of adaptations than caregiver overestimation was not supported. Although there was no significant statistical difference among the two groups, F (1, N = 86) = 3.06, p = .08, the results are in the predicted direction. As shown in Table 3, the mean number of home adaptations was greatest with caregivers who did not overestimate

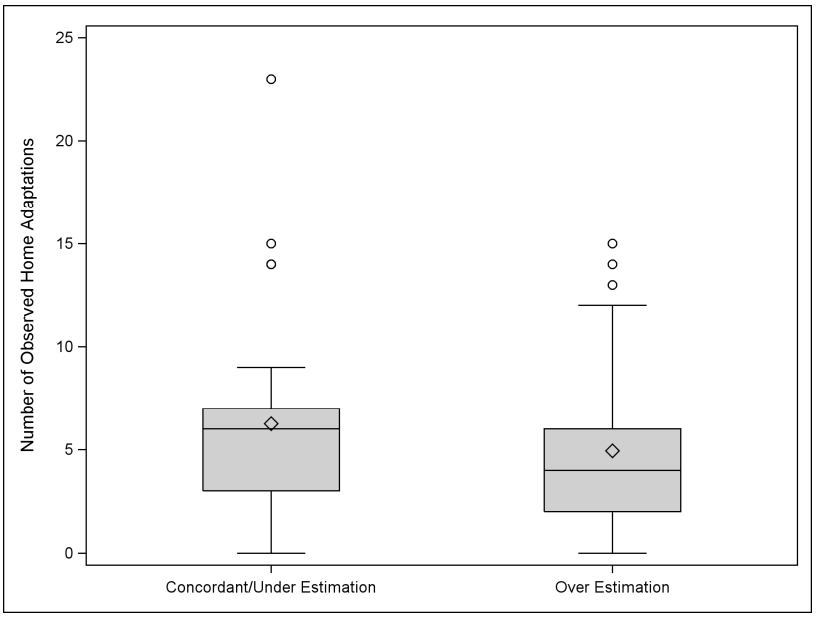
(concordant/underestimation), showing a trend towards the hypothesis. Figure 2B shows the distribution of observed home adaptations among the groups.

Figure 2. Box Plot Distributions for Home Hazards (A) and Adaptations (B) by Caregiver Estimation Group

A.



B.



Relationship between caregiver concordance status and unmet needs reported by caregiver.

Finally, proportional odds logistic regression was used to test the third hypothesis, using an alpha level of .05. The three concordance status groups were collapsed into a two level categorical independent variable (estimation groups) and adjusting for cognitive status in the person with dementia. For this analysis the two estimation groups were: underestimating and not underestimating (concordant/overestimation). Table 4 provides the frequency of unmet needs for the two groups. The odds of having greater unmet needs was not statistically different among the estimation groups, thus hypothesis 3 was not supported, Wald $\chi 2$ (1, N = 86) = .95, p = .33.

Table 4

Frequency of Unmet Needs across Caregiver Estimation Groups

Item	Underestimation (n = 19)		Concordant/Overestimation (n = 67)	
	n	*%*	*n*	*%*
0 unmet needs	8	42.1	33	49.3
1 unmet need	7	36.8	24	35.8
2 unmet needs	4	21.1	10	14.9

As displayed in Figure 3, the descriptive data reveals that most caregivers reported having no unmet needs, followed by the report of one unmet need. For caregivers who reported one and two unmet needs, caregivers who underestimated functional capacity in their family member with dementia were most likely to report one and two unmet needs compared to those caregivers who did not overestimate (concordant/over estimation); with greatest difference between the groups in the report of two unmet needs.

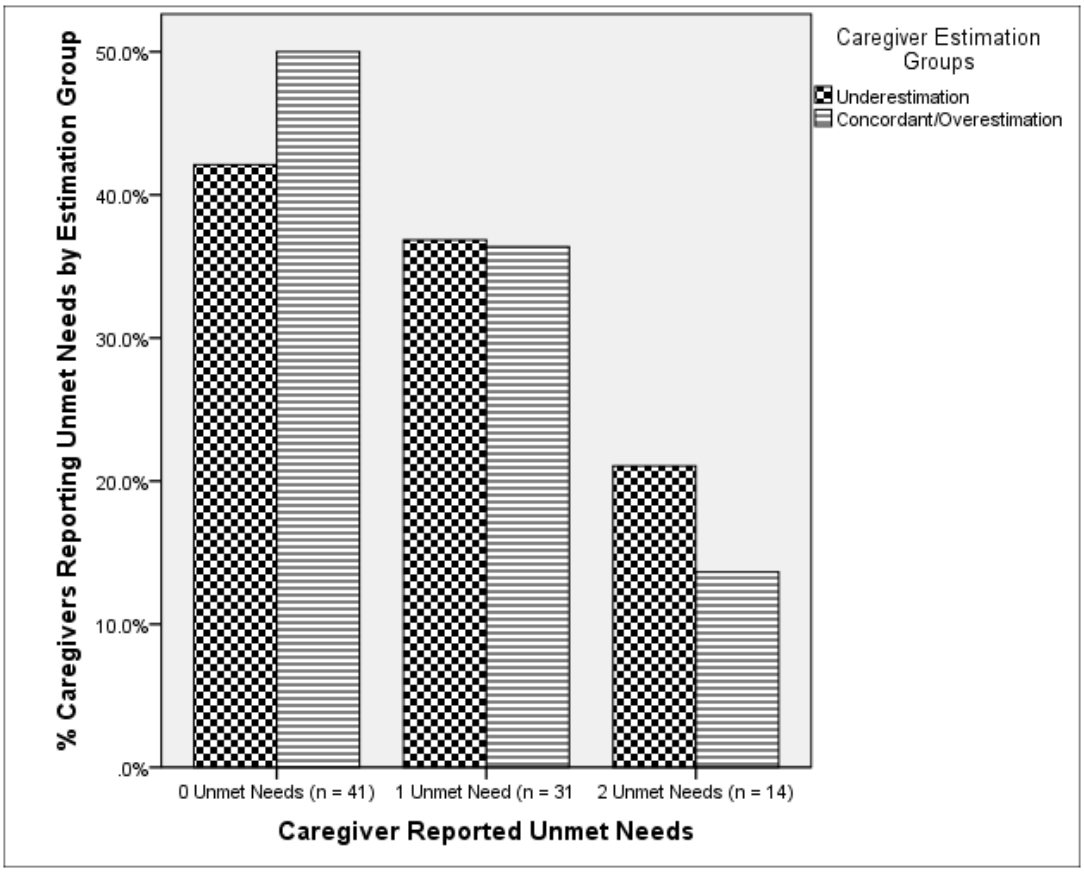


Figure 3. Caregiver reported unmet needs by estimation group (N = 86)

Discussion

The rising prevalence of Alzheimer's disease and related dementia and the percentage of those who live at home, drive the need to better understand characteristics of the home environment. The home environment plays an important role in the functioning and care of people with dementia, as decreasing personal competence requires greater reliance on the living environment (Lawton & Nahemow, 1973; Law et al., 1996), of which the caregiver is a part. For the person with dementia, the caregiver has control over the structure, condition, and effect the home environment has on their function and safety. The factors that play a role in people with

dementia remaining at home include the person's functional capacity and health, environmental characteristics of the home, and knowledge, skills, and actions of the caregiver. This study examined whether caregiver appraisal of functional capacity in the person with dementia was associated with home environmental factors. Appraisal was considered a cognitive process caregivers go through to estimate the functional capacity of their family member with dementia. Subjective appraisal by caregivers has been shown to be inconsistent with direct or performance based assessment. The nature of this inconsistency was addressed in this study by placing caregivers in groups based on a comparison of their appraisal of functional capacity in the person with dementia and standardized assessment. Initial descriptive statistics revealed that caregiver overestimation was the largest group (n = 52), followed by caregiver underestimation (n = 19) and caregiver concordant estimation (n = 15).

It was hypothesized that the type of caregiver estimation of functional capacity, that is whether caregiver overestimation or concordant/underestimation, would be associated with characteristics of the home environment. For this analysis, the three caregiver groups were collapsed into two estimation groups. The HEAP provided three indices that captured characteristics of the home environment, including the number of hazards and adaptations observed by occupational therapists, and the unmet needs reported by caregivers based on two probing questions that ask the caregiver to identify difficulty in navigating the home and need for assistive devices.

Inferential statistical analysis revealed no significant differences between the two types of caregiver estimation groups with regard to observed home hazards and caregiver reported unmet needs. For the hypothesis that caregivers who accurately appraise and underestimate functional

capacity in their family member with dementia would have greater home adaptations, the results were not statistically significant, but were in the predicted direction. Although, the results suggest that caregiver appraisal of functional capacity is not a factor when considering conditions of the home environment, there was a trend indicating that caregivers who accurately appraise or underestimate functional capacity do take action to make adaptations within the home. Further examination to test this hypothesis is warranted.

In addition, other potential influences on the environment must be explored. Factors that were not taken into consideration include the caregiver's knowledge about dementia and motivation to address environmental issues. Lach and Chang (2007) report that caregivers did not make environmental changes even though they knew they should. In addition, it is not known whether caregivers had been provided with information about hazards and recommendations for adaptations by a health professional. Adherence to recommendations has been shown to be associated with caregiver health, treatment exposure, and skill-building (Chee et al., 2007). Future investigation into caregiver appraisal of function as a predictor of home environmental characteristics should consider other caregiver factors, such as motivation and adherence.

Within the sample, more caregivers reported zero unmet needs, compared to one or two unmet needs. Unlike the hazard and adaptation indices, this index measures the subjective report of caregivers; consequently, other factors may have influenced their response, such as financial status, time providing care, and willingness to share personal information. Ensuring the physical home is safe and resolving unmet environmental needs within the home are salient to successful aging in place for people with dementia. Questions remain as to what factors impact the

condition of the physical home environment and potentially lead to home adaptations for people with dementia. These questions point to the need for further research.

Study limitations center on the relatively small sample size and the use of secondary data analysis. The sample size limited the number of caregivers in the underestimation and concordant/overestimation groups. For the proportional odds regression, the size of the two groups was an issue. Using post-hoc analysis it was determined that with the sample sizes of 19 and 67 and assuming an overall distribution of 50% zero unmet needs, 35% one unmet need and 15% two unmet needs, there was 80% power to detect only large odds ratios (4.1 or greater). The observed odds ratio in the data was 1.6. Given the distribution of concordance status, a much larger sample is needed to detect what may be significant differences. Furthermore, the number and variety of home environmental features initially explored in the data collection process was limited. A greater array of environmental design features, similar to, for example, those used by van Hoof and Kort (2009) and including such items as open floor plans, familiar furniture, proper lighting, and appropriate adaptive equipment may have allowed for greater determination of absence or presence of adaptations, hazards, and unmet needs.

Looking to the future, research with a larger sample size which allows for an improved distribution of caregiver concordance status would enable a better distinction between groups. It would be equally interesting to explore if and how caregiver appraisal of functional capacity changes over time and the impact on environmental features. Given that the nature of appraisal relates to how caregivers think, it would be interesting to employ qualitative research methods to explore caregiver experiences about their reasons for making changes in the environment and analyze the themes that emerge from each of the caregiver concordance status groups. Finally,

as the home is the primary residential setting for people with dementia and family members constitute the majority of informal caregivers, more research is needed to determine the factors that contribute to home environmental conditions that promote safety, function, and quality of life of the person with dementia, and their family caregivers.

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Chapter V: Conclusion

The incidence of Alzheimer's disease and related dementias is rising to 13.2 million in the United States by the year 2050 (Hebert, et al., 2003) and 106.8 million globally (Brookmeyer, et al., 2007). Families play a critical role in the daily participation, safety, and well-being of people with dementia, as most people with dementia are living at home (Alzheimer's Association, 2012). Health care providers lack the tools to effectively assess caregiver perceptions and judgments, yet caregivers are at the forefront of making daily care decisions for people with dementia. In their role, caregivers are faced with daily, often moment to moment, decisions regarding the type and amount of assistance to provide their family member and the need for home environmental modifications. The decisions they make are informed in large part by the caregiver's appraisal of functional ability in their family member with dementia. In addition, health professionals often depend on the proxy reports of caregivers to determine the functional capacity of the person with dementia in light of the tendency for patients to overestimate their abilities (Karagiozis, Grey, Sacco, Shapiro, & Kawas, 1998; Kiyak, Teri, & Borson, 1994). The three papers that comprise this dissertation center on the process of caregiver appraisal as a critical element in understanding the perceptions of family caregivers in dementia care. The three papers utilized secondary analysis of a data set from a study funded by the Alzheimer's Association (Gitlin, 2011; Grant # IIRG-07-28686).

The first paper introduced the Functional Capacity Card Sort (FCCS), a new tool to assess caregiver appraisal of functional capacity and examined its psychometric properties. The FCCS offers occupational therapists and other health care providers a method for measuring the judgment of caregivers and comparing it to a gold standard to determine concordance. As noted previously, there is a shortage of tools that offer such a comparison. Caregiver estimation of functional capacity, which is either concordant with or an overestimation or underestimation of the gold standard, offers health care providers valuable insight into the caregiver's knowledge. The psychometric testing of the FCCS reported here, supports its convergent and discriminant validity, and inter rater reliability. These preliminary results are promising and provide a foundation for further testing. The FCCS can be used in practice as a tool to help develop the care plan for both the patient with dementia and the family member.

Using the data collected from the FCCS and the Allen Diagnostic Module-2 (ADM-2), the purpose of the second and third paper was to explore concordance status in relationship to personal characteristics and specific conditions of the physical home environment. The results of the second paper revealed that cognitive status of the person with dementia and caregiver depressive symptoms did not influence the type of estimation caregivers made about the functional capacity in the person with dementia. Similarly, the results did not show caregiver appraisal as influencing the structure of the home environment. A significant relationship was not found between the level of caregiver appraisal and observed hazards and adaptation, or reported unmet environmental needs. As previously discussed, there was the potential for a Type II error due to low power to detect a significant difference between the three concordance status groups. These papers are the first to use the FCCS as a measure of caregiver appraisal. Although

the findings in the second and third paper did not support the hypotheses, there remain clear implications for practice and future research.

Implications for Practice

The instruments used to measure functional capacity were effective for determining caregiver estimation. Comparison between the caregiver FCCS rating and the standardized ADM-2 score of the person with dementia revealed that the majority of family members in the sample overestimated the capacity of the person with dementia. Overestimation can place the person with dementia at risk for safety issues. If caregivers are underestimating the functional ability of the person for whom they care, they may not provide necessary oversight or assistance during daily activities. For example, a caregiver may leave their family member at home alone when he or she does not have the capacity to problem solve a solution if something unexpected were to occur. In addition, an overestimation of functional capacity by the caregiver could lead a person with dementia to continue driving beyond their ability to do so.

Quantifying caregiver appraisal of functional capacity can guide the therapeutic approach and treatment plan by an occupational therapist or other health professional. The FCCS is an easy to administer tool that is acceptable to caregivers. Having both the family member's estimation of function and the score on the standardized assessment provides the practitioner with empirical data to share with the family and health care team. This data can drive the delivery of family training that includes education about what the person can do and how the caregiver may need to modify the task or environment to enable occupational performance. Consequently the caregiver, who is leaving their family member at home or continuing to let him

or her drive, may gain an understanding of capacities and limitations of their family member, which can influence their care decisions.

Occupational therapy intervention that is driven by caregiver concordant status offers families a systematic approach to provide caregiver education and skill-building. For example, caregivers who are overestimating functional capacity would require education in safety precautions, home environmental modifications, and skill-building to ensure the family member's safe and thorough performance of daily activities. Under estimators would require education about how to adjust their oversight and assistance and skill-building to allow the person with dementia to perform at the highest potential. Finally, concordant estimators would benefit from validation of their accurate appraisal and skill-building to promote ongoing provision of appropriate care.

Critical to the intervention process is the caregiver's willingness to learn and implement strategies and make modifications to the home environment. The Transtheortical Model of Change (Prochaska & Velicer, 1997) offers a conceptual framework for understanding caregiver readiness to learn and make changes in caregiving approaches. The framework suggests that changing behaviors is complex, requiring individuals to make incremental cognitive and behavioral change at different levels of readiness. Caregivers with low levels of readiness may need fundamental education about the disease process prior to being ready to learn specific care strategies. Whereas, caregivers with high levels of readiness tend to be receptive to treatment suggestions and demonstrate the ability to initiate and implement care strategies. Understanding the caregiver's readiness level and identifying concordance status can inform the approach to

intervention. Further research would offer insights into how caregiver readiness to change the approach to care and modify environmental factors may influence the accuracy of appraisal.

Measuring hazards and adaptations within the home is critical to the provision of care. The third study used the Home Environmental Assessment Protocol (Gitlin et al., 2002) to capture this data. The HEAP provides a comprehensive method to assess home conditions that hinder or support function and safety in the person with dementia. Human factors research asserts that there will be increasingly more reliance on caregiver training with regard to increasing efficiency, safety and comfort within the home environment (Charness & Holley, 2001), Therefore, a systematic approach to the assessment of environmental structures and caregiver reported unmet needs within the environment can promote a tailored approach to caregiver education and training in environmental strategies that promote function and safety. The FCCS, ADM-2, and HEAP offer practitioners valid and reliable tools to assess and interpret caregiver judgment, patient function, and home environmental features, all of which contribute and support best practice in dementia care.

Directions for Future Research

With regard to the FCCS, additional psychometric testing is necessary to examine its validity and reliability. In addition, the FCCS in conjunction with the ADM-2 provide an approach to determining caregiver estimation which can be utilized in subsequent studies. Further investigation using the FCCS and ADM-2 to assess caregiver appraisal of functional capacity and its association with other characteristics of the caregiver and person with dementia is warranted. Cognitive appraisal theory (Lazarus & Folkman, 1984) can guide future inquiry into the emotional factors, such as stress and burden, which have been shown to contribute to

caregiver appraisal of functional capacity and care decisions (Zanetti, 1999; Razani, 2007). Prospective studies using the FCCS and ADM-2 to measure caregiver appraisal and concordance status must consider the necessary sample size to establish appropriate power.

The third paper reports the first study to explore the concordance between caregiver appraisal and standardized assessment in relation to the physical home environment. Based on the theoretical constructs of the Person Environment Occupation Model (Law et al., 1996), it was hypothesized that overestimation and underestimation of functional capacity would be associated with the number of hazards and adaptations observed in the home and the unmet needs reported by caregivers, which was not supported. As discussed previously, the non-significant findings may have been due to low statistical power. Evidence exists that there may be a relationship between caregiver appraisal and action, as Lach and Chang (2007) reported the greatest barrier to caregiver action in making changes within the home environment was deciding when it was the "right time" (p. 1004). Knowing the "right time" may reflect the caregiver's appraisal of functional capacity in the person with dementia. However caregiver decisions to remove a hazard or make an adaptation in the home may be driven by other factors. Sheldon and Teaford (2002) reported the main reasons caregivers gave for not implementing recommended adaptations were not thinking there was a need or not thinking the adaptation or device would work. Of interest for further research is the decision making of caregivers with regard to appraisal of functional capacity and appraisal of environmental need, which may be different modes of thinking.

The experiences of caregivers as they go through the process of appraising the abilities of the person for whom they are caring needs more study. Qualitative research methods to explore the narratives of caregivers over time as they make decisions about the care they provide would

contribute further to the literature and have implications for future research questions and hypothesis development. In summary, through a better understanding of the caregiver appraisal process and the personal and environmental factors that are associated with caregiver overestimation or under estimation of functional capacity, targeted caregiver intervention can be developed and tested.

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Vita

Catherine Verrier Piersol was born August 8, 1959, in Boston, Massachusetts, and is a citizen of the United States of America. She received a Bachelor of Science in Occupational Therapy from Tufts University, Boston, MA in 1982 and a Master of Science in Occupational Therapy from Boston University in 1988. Her Master's Thesis was a qualitative study exploring the clinical reasoning of occupational therapists. She has practiced as an occupational therapist for 30 years. For the past 18 years, she has worked in the community and home health arenas with a focus on dementia care and family caregiver education. She has been teaching in higher education since 1996 with faculty appointments at Harcum College, Bryn Mawr, PA and Philadelphia University, Philadelphia, PA. Currently, she is an assistant professor in the Department of Occupational Therapy at Thomas Jefferson University, Philadelphia, PA. She assumed the position of Clinical Director of Jefferson Elder Care in March, 2008 to develop and implement specialized home-based clinical services and professional training programs in the areas of dementia care and aging in place. She has participated in numerous research projects as an interventionist testing non-pharmacological interventions for patients with dementia and their family members. She was the project director for the research study from which the data set was used for this dissertation. Her publications include a textbook called *Occupational Therapy in Home Health Care,* which is widely used by students and practitioners.