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How Well Do Your Family Members Know You? The Relationship Between Informant Report and Cognitive Performance of Older Adults

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by

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We the undersigned committee, having examined the submitted doctoral research project, "How Well Do Your Family Members Know You? The Relationship Between Informant Report and Cognitive Performance of Older Adults" by Mairy Yousif, M.S. hereby indicates its unanimous approval.

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Abstract

Title: How Well Do Your Family Members Know You? The Relationship Between Informant Report and Cognitive Performance of Older Adults

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Introduction: Given the clear impact and prevalence of dementia on the aging population, there is a need for greater research and understanding in this area. As the dementia progresses, medical providers rely heavily on caregiver and family member reports of the patient's functioning and other aspects of their care. Therefore, it is important to know how accurate caregivers and family members are in judging their loved ones' cognitive and physical strengths and weaknesses. This study aims to expand upon these previous studies by comparing caregiver/collateral reports of cognitive and functional status on the DSRS to neuropsychological tests and an objective measure of adaptive functioning and exploring whether the informant-rating on the DSRS is able to predict neuropsychological test scores. Furthermore, this study aims to determine whether caregivers are more or less accurate depending on which stage of the disease process their loved one is in.

Method: Participants were referred for a brief neuropsychological evaluation (BNE) by their medical provider to help clarify diagnosis and inform treatment and recommendations. The most common referrals were due to concerns about memory and/or other cognitive changes. Patients' caregivers complete the Dementia Severity Rating Scale (DSRS) during the intake appointment, the DSRS is administered by the licenced social worker. Diagnostic impressions were made by a multidisciplinary team

that included a neurologist, a geriatrician or a geriatric nurse practitioner, a neuropsychologist, a pharmacist, a social worker, and clinical psychology doctoral students. The multidisciplinary team utilized medical histories, brain imaging, social histories, and neuropsychological test data to inform diagnosis. 282 participants were administered brief neuropsychological evaluations (BNE) as well as the Dementia Severity Rating Scale (DSRS) at their intake appointment. After removing individuals who did not meet diagnostic criteria for inclusion, a total of 254 participants were included in the current study. Among them, 151 patients were diagnosed with dementia (60.3% female, M = 80.61, SD = 6.54), 64 patients were diagnosed with Mild Cognitive Impairment (MCI; 57.8% female, M = 78.59, SD = 6.95), and 39 were diagnosed with Normal Cognition (NC; 53.8% female, M = 76.64, SD = 7.13.

Results: The overall DSRS score was statistically different among diagnostic groups. Specifically, scores from the AD group were significantly higher than both MCI and NC groups, and those from the MCI group were significantly higher than the NC group. Correlation analysis revealed that overall DSRS scores were negatively and significantly correlated with overall TFLS score, suggesting that as DSRS score increases, TFLS score decreases. A linear regression indicated that the DSRS score statistically significantly predicted the TFLS score, accounting for 9.9% of the variance. Further correlations revealed a statistically significant negative correlation between total DSRS and MoCA score, suggesting that as DSRS scores increase (i.e., indicating poorer functioning), MoCA scores decrease (i.e., indicating poorer global cognitive functioning). Correlations among neuropsychological measures of executive functioning with total DSRS score suggested that as DSRS score increases, measures

of executive functioning indicate poorer overall functioning, such that a higher DSRS score is correlated with greater time to complete TMT-B, more perseverative errors on M-WCST, fewer correctly completed categories on M-WCST, and fewer correct items on Stroop Color-Word subtest. The degree of agreement between total TFLS and overall DSRS scores revealed that the differences among caregivers who had contact with the patient less than one day per week, one day per week, two days per week, three to four days per week, and 5 or more days per week were not statistically significant. Similarly, there was no significant difference among the degree of agreement between the TFLS and the caregiver's relationship with the patient.

Conclusion: Ultimately, the results of the study showed that collateral reporters using the DSRS were able to accurately distinguish between NC, MCI, and dementia groups. Additionally, the DSRS accurately predicted functional status when compared to an objective measure of adaptive functioning, but only accounted for 9.9% of the variance. It was also reasonably related to neuropsychological measures of global cognitive functioning and executive functioning. However, there was no difference in the accuracy of the DSRS dependent on the collateral reporter's relationship to the patient, nor how many days per week the collateral reporter spends time with the patient. Therefore, individuals who complete the DSRS for the patient provide information that agrees with the TFLS to the same degree despite their relationship to the patient or how much time they spend with the patient. This finding suggests that information obtained from caregivers via clinical interviews may also be equally accurate regardless of how much time the caregiver spends with the patient. Indeed, it appears that the accuracy of collateral reports received from caregivers and family

members is not dependent on the nature of the relationship with the patient or the number of days per week spent together.

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Chapter 1: Introduction

As the number of older adults continues to rise, there is an increased need to understand the complexity in working with and providing care for older adults. United States population trends suggest that by 2050, the population of older adults aged 65 and older is expected to grow from about 46 million to almost 90 million (Colby & Ortman, 2019). With increased life expectancies, there is greater opportunity for older adults to have fulfilled lives with family and friends. Simultaneously, greater life expectancies increase the likelihood of health concerns, including developing neurodegenerative diseases such as dementia. Dementia is the umbrella term which describes an impaired ability to remember, think or make decisions that interferes with completing everyday activities (Alzheimer's Association, 2022). The underlying cause of dementia is typically a result of a neurodegenerative disease process which results in the gradual worsening of symptoms over the course of years due to progressive brain damage (Alzheimer's Association, 2022). There are several etiologies of dementia including Alzheimer's disease, vascular dementia, Lewy body dementia, and frontotemporal dementia. The prevalence of dementia in older adults aged 65 and older was 5 million in 2014 and is projected to be nearly 14 million by 2060 (CDC, 2019).

When an individual begins to experience memory loss and other forms of cognitive decline (i.e., processing speed, attention, visuospatial skills, executive functioning), it can be a very challenging time for all involved in the patient's care. The consequences of cognitive decline as a result of a neurodegenerative disease typically include higher medical cost and cost of living. Patients with dementia tend to need much care as their disease progresses. Many individuals will require in-home

care or move into an assisted living facility. In 2022, Alzheimer's and other dementias will cost the nation $321 billion; these costs are estimated to reach nearly $1 trillion by 2050 (Alzheimer's Association, 2022).

Given the clear impact and prevalence of dementia on the aging population, there is a need for greater research and understanding in this area. Important research in this area includes, but is not limited to, understanding the difference between healthy aging and clinically meaningful cognitive decline, the development of mild cognitive impairment, how activities of daily living are impacted throughout the disease process, and the risk factors of the various etiologies of dementia. In addition to this, it's important to recognize that individuals with dementia tend to lack insight into their cognitive deficits as their disease progresses; as a result, they rely on their caregivers to speak with their medical providers (Heilman, 1991). Therefore, in addition to the learning more about the individuals who are impacted by dementia, learning about their caregivers is also an important factor. As the disease progresses, medical providers rely heavily on caregiver and family member reports of the patient's functioning and other aspects of their care. Consequently, it is important to know how accurate caregivers and family members are in judging their loved ones' cognitive and physical strengths and weaknesses.

Chapter 2: Study Purpose

To accomplish this goal, the purpose of this study is to utilize data from caregivers and family members regarding their loved ones' cognitive functioning (i.e., memory, speech and language, recognition of family members, orientation to time, orientation to place, ability to make decisions) as well as their ability to perform various activities of daily living (i.e., social and community activity, home activities and responsibilities, personal care, eating, control of urination and bowels) to determine the accuracy of caregiver reports. Activities of daily living (ADLs) are important in determining a patient's clinical presentation when determining whether an individual has MCI or dementia. Providers utilize ADL measures along with observations and collateral information from caregivers to determine patients' functional status. However, due to the lack of insight of many demented individuals, physicians and other healthcare workers must rely heavily on caregiver reports to determine patients' functional status. Therefore, determining the accuracy of caregiver reports is an important factor in diagnosing dementia in older adults.

Chapter 3: Literature Review

Cognitive Aging:

As individuals age, there is a typical, and even expected degree of cognitive change that is considered to be normal and does not represent a clinically meaningful decline or impairment. Early theorists in the field of cognitive aging have suggested that there is a single explanation for most of the cognitive decline seen among older adults (Salthouse, 2004). Salthouse (1996) proposed a theory suggesting that processing-speed is the primary mechanism of cognitive change which precedes and triggers all other cognitive declines. He posited that impairments are the result of two mechanisms that are influenced by processing speed: the limited time mechanism and the simultaneity mechanism. The limited time mechanism suggests that due to slower processing speed, cognitive operations cannot be successfully completed in the available time. Therefore, it is assumed that more complex operations will be impacted given the time an individual takes to perform the simple operations that precede it. This is referred to as the complexity effect (Salthouse, 1996). For example, completing a complex task, such as The Stroop Task, in which an individual is asked to name the ink color of a word that is printed in a different colored ink (e.g., the word "red", printed in blue ink), may be more challenging for older adults as a consequence of slower processing speed. The second mechanism, the simultaneity mechanism, explains how information can be lost due to slower processing speed. Salthouse (1996) explains that given slow processing speed, products of early processing may be lost by the time that later processing is completed. Given these mechanisms, the cascade of cognitive decline that can stem from slowed processing speed becomes more apparent.

It can then be theorized that slowed processing speed can impact all other areas of cognitive functioning including learning and memory, attention and processing speed, executive functioning, and language.

However, more recent literature suggests that one process does not account for all cognitive slowing (Zelinski et al., 2011). Alternatively, older adults exhibit cognitive aging in many domains of cognition independent of any single factor. It is thought that age impacts various aspects of cognitive functioning (Zelinski et al., 2011). The literature in the field suggests that various types of memory are negatively impacted by age. Despite popular opinion, some researchers suggest that these declines begin in early adulthood; in fact, Salthouse (2004) suggest that subtle cognitive changes can be seen in as early as the 20s. Several studies have indicated that among these, source memory is affected by cognitive aging (Luo et al., 2008); that is, older adults have difficulty remembering the source of information (e.g., who told them a story). Similarly, the ability to recall and retrieve specific facts (e.g., names) typically declines with age. Additionally, episodic memory (i.e., autobiographical memory) shows lifelong declines as an individual ages (Harada et al., 2013). On the other hand, semantic memory (i.e., memory for facts and knowledge) remains relatively better preserved in older adults (Luo et al., 2008), and only shows late life declines (Harada et al., 2013). Furthermore, nondeclarative (implicit) memory, or memory that is encoded outside of a person's awareness, is typically unaffected by age. Examples of implicit memory include driving a car (procedural memory), becoming hungry when you smell pizza (classical conditioning), using a stimulus (e.g., the color green) to recall something else (e.g., grass), and becoming sensitized to a fear through repeated

exposure (non-associative learning). Understanding how healthy older adults fare across the cognitive domains can aid in our understanding of clinically meaningful cognitive decline which is likely to progress in the context of neurodegenerative diseases.

Learning and Memory

There are several explanations for the aforementioned age-related memory changes including slowed processing speed (Salthouse, 1996), difficulty ignoring information that is irrelevant, and decreased use of strategies to improve learning and memory (e.g., stimulus rehearsal) (Harada et al., 2013). Cognitive psychology literature also offers a possible explanation for the difference in the age-related decline among declarative and nondeclarative memories. Procedural and other types of implicit memory are thought to be different and distinct from explicit (episodic and semantic) memory in terms of acquisition, retrieval, forgetting, and the role of consciousness. Squire (1992) as described by Rutherford et al. (2012) notes various differences among declarative and non-declarative memory. This researcher notes that there is a single memory system responsible for retrieval of both facts and events. The main difference noted among explicit and implicit memory systems is that declarative memory enters consciousness whereas implicit memory does not. Because of this automaticity of implicit (procedural) memories, they are more resistant to forgetting when compared to semantic and episodic memory. The way in which these memories are acquired also differ. Once learned, implicit memories become automatic (i.e., riding a bike) whereas explicit memories are learned such that they must be retrieved consciously and intentionally.

Processing Speed/Simple Attention

Processing speed is the speed at which cognitive processes are performed, including motor speed. As previously noted, it is well established that processing speed declines with age (Salthouse, 1992). While this is undisputed, there appears to be some differences of opinion as to the importance of the motor slowness and reaction time. Many theorists believe that motor slowing impacts cognitive slowing that is exhibited by older adults (Salthouse, 2000). However, contrary to this thought, Rush (2006) conducted an experiment in which differences among younger and older adults were observed on processing speed tasks, despite controlling for age-related motor slowing, suggesting that older adults experience slower mental processing speed independent of motor skills. A similar process within this cognitive domain is attention, which is the set of cognitive processes that allow an individual to focus on a particular event while also avoiding distracting stimuli. Studies show that simple attention, with the exception of simple auditory attention (including tasks that involve working memory), does not typically decline with age (Harada et al., 2013). Similar to Salthouse (1994), some researchers believe that the declines in simple attention as observed on various tasks evidence a decline in older adults due to their processing speeds demands rather than deficits specifically in simple attention (Gilsky, 2007). Similarly, older adults typically do not have difficulty with tasks of sustained attention (i.e., vigilance tasks) (Gilsky, 2007). On the other hand, divided attention, or the ability to focus on multiple things simultaneously, is associated with significant age-related declines, particularly when the demands of two tasks are high (Gilsky, 2007).

Executive Functioning

Executive functions are the higher-level thinking processes that are responsible for individuals' ability to problem solve, organize, plan, self-monitor, and regulate emotions (Gilbert et al., 2008). The region of the brain that is thought to be responsible for these various skills is the prefrontal cortex (PFC) (Gilbert et al., 2008). Concept formation, abstraction, and mental flexibility decline with age, specifically after the age of 70 (Harada et al., 2013). The purposed explanation for this is that older adults tend to think more concretely than younger adults. Similarly, inhibition is negatively affected by age, such that older adults have a difficult time inhibiting an automatic response when asked to produce a novel response (e.g., on the Stroop task). However, executive abilities requiring a speeded motor component exhibited the largest decline with age (Harada et al., 2013).

Speech and Language

Tasks that measure speech and language are typically spared among older adults and do not decline as individuals age. In fact, there is evidence to suggest that older adults have more extensive vocabularies and improved discourse abilities (Gilsky, 2007). However, older adults do experience more frequent word finding difficulties and tend to exhibit circumlocution (i.e., using many words when few will suffice). Other changes in language abilities as individuals age include a decline in verbal fluency among older adults. However, tasks of verbal fluency are typically timed and therefore include a processing speed component in addition to language. Additionally, visual confrontational naming ability (i.e., naming a familiar object when

shown a picture of it) tends to remain stable in adults and begins to decline at around age 70 (Harada et al., 2013).

Visuospatial Skills

Similar to language abilities, visuospatial abilities, including object perception (i.e., recognizing familiar items or faces) and spatial perception (i.e., understanding the placement of objects as it relates to other objects) tend to remain stable as individuals age (Harada et al., 2013). Conversely, visual construction skills (i.e., the ability to put together parts to create something new) do decline over time. Outside of standardized testing, age-related deficits in this skill could impact individuals' ability to perform various tasks such as assembling furniture from a box of parts.

Consequences of Cognitive Aging

While the cognitive declines observed among adults are fairly broad, begin in early adulthood, and are cumulative across lifespan, they do not necessarily have great negative consequences to an individual's life (Salthouse, 2004). In other words, despite the negative effects of cognitive aging, many healthy older adults are able to continue to perform daily activities and generally continue all other routine tasks. There are several potential proposed reasons for this including personality characteristics, reduction of environmental demands, altering activities, and use of the experience and knowledge that comes with age (Salthouse, 2004). It is argued that factors other than cognitive ability, such as personality characteristics (e.g., motivation, persistence), are required to complete various activities which are impervious to cognitive aging. Additionally, modifying activities to reduce physical or cognitive demands might allow older adults to function normally and continue to perform many routine daily

tasks, as few situations require individuals to perform at their maximum levels. Similarly, modifying activities to reduce the cognitive demand required also aids older adults in continuing to function normally and complete daily activities. For example, many older adults alter their driving to reduce safety concerns (e.g., avoiding left turns, avoiding highways). Finally, it is plausible that the wisdom that comes with age reduces the need for novel problem-solving skills (Salthouse, 2004). Their experience may reduce their need to utilize their full cognitive load to complete various tasks. Therefore, while cognitive aging plagues the majority of older adults, many healthy individuals are able to continue performing many of their daily activities.

Despite the fact that some degree of age-related cognitive change is normal and subtle enough that it does not interfere with most daily tasks, many older adults still express concerns about cognitive changes as they age (Salthouse, 2004). For example, Weaver Cargin et al. (2008) assessed 100 healthy older adults for cognition, mood, and general health factors. They found that among the complaints reported by older adults, the most strongly and frequently reported problems were related to memory, specifically memory for names, but also for actions (e.g., forgetting what has been read, forgetting where an object was left). Participants also noted subjective difficulty with information retrieval and made complaints surrounding difficulties with concentration and distractibility. It was also found that nondemented older adults with no objectively measurable memory decline report cognitive complaints that are similar to those exhibiting documented memory declines (based on objective neuropsychological assessment data). Therefore, simply obtaining self-reported symptoms without also conducting a formal assessment of cognition may lead to

diagnostic errors. Additionally, mood symptoms (i.e., depression, anxiety, general mental health) were most strongly associated with cognitive complaints. Complaints of cognitive decline among older adults are important as those regarding memory declines have aided in the prediction of dementia (Weaver Cargin et al., 2008). Specifically, individuals with memory complaints have an increased risk of developing Mild Cognitive Impairment, which is thought to be the transitional clinical presentation preceding dementia or overt dementia (Peña-Casanova, 2012).

Risk Factors for Neurodegenerative Diseases:

Since healthy older adults undergo a mild degree of normal cognitive decline as they age, the next logical inquiry is: what makes some more susceptible to pathological cognitive decline? In other words, what are the risk factors for clinically meaningful cognitive decline which represents more than just normal aging? There are several factors that are thought to be risk factors for neurodegenerative disease in older adults including genetic factors, demographics, physical activity, use of substances, as well as various comorbidities. From a genetic perspective, those who carry the Apolipoprotein E (APOE) gene are thought to have an increased risk for dementia, specifically those with the APOE e4 allele (Gatz et al., 1997). In fact, those with a family history of dementia have an increased risk of developing dementia; however, this is only true among those who are APOE e4 carriers (Huang, et al., 2004). Despite these individuals having an elevated risk for developing AD, only 50% of those with AD carry the APOE e4 allele (Chen et al., 2009).

Demographic characteristics, such as age, sex, and education also impact an individuals' likelihood of developing dementia. The literature in this field suggests that

the risk of dementia significantly increases with age (Chen et al., 2009). In fact, age is the largest risk factor for dementia with the risk doubling every 5 years after the age of 65 (Rafferty et al., 2018). This association is found among all subtypes of dementia including AD. There is also thought to be a difference among the sexes as it pertains to developing dementia, in that the incidence of AD is higher in women than in men after the age of 85; however, similar findings are not seen among diagnoses of vascular dementia (VaD) (Chen et al., 2009). Researchers have attempted to explain the sex differences among men and women, in part by suggesting that women are at greater risk due to their increased lifespans (e.g., Mielke, 2008). Finally, education as a risk factor for dementia is thought to support the "use it or lose it" phenomenon, which suggests that maintaining the survival of new neurons (including those that are produced in adulthood) requires learning, or "using it" (Rea, 2017). Research also suggests that those with a lower education level are at increased risk of developing dementia (Orrell, et al., 1995). This likely contributed to the idea that brain teasers/puzzles (e.g., crossword puzzles, sudokus, etc.) might aid in maintenance of cognitive functioning with age. Similarly, those who engage in physical activity are associated with a 30-50% reduction in cognitive decline (Chen et al., 2009), suggesting that exercise might be a protective factor against developing dementia.

Other factors believed to increase the risk of developing dementia include the use of substances such as tobacco, drugs, and alcohol. Tobacco use is thought to be a risk factor for developing dementia (Chen et al., 2009). Similarly, those with a history of tobacco use are also at an increased risk of developing dementia, apparently due to the associated cardiovascular risk factors. Several drugs have also been linked to the risk

of dementia, such as benzodiazepines. Meanwhile, other types of drugs may actually be protective in developing dementia, such as statins and nonsteroidal anti-inflammatory drugs (NSAIDS); however, these findings are mixed (Chen et al., 2009). Estrogen is also thought to be a protective factor. Alcohol use shows mixed findings regarding its association with dementia, as several studies have reported both the protective properties as well as its risk factors for older adults developing dementia (Chen et al., 2009). However, many studies have maintained consensus that heavy alcohol use increases the risk of developing dementia.

Medical comorbidities, such as cardiovascular risk factors, are also thought to be associated with the development of dementia. Cardiovascular risk factors (e.g., hypertension, hyperlipidemia, diabetes) are thought to increase the risk of dementia, specifically vascular dementia (Knopman, et al., 2001). Cardiovascular risk factors do not present the same risk for other types of dementia such as AD. However, those who exhibit a cognitive impairment associated with a vascular etiology are more likely to develop dementia roughly five years following a cerebrovascular incident (Chen et al., 2009). Similarly, there is a positive correlation between body mass index (BMI) and dementia, such that as BMI increases, so does the risk of developing dementia. Other comorbidities such as various infections (i.e., human immunodeficiency virus and hepatitis C) have also been reported to be associated with an increased risk of developing dementia (Chen et al., 2009).

Mild Cognitive Impairment:

Given our greater understanding of risk factors of clinically significant cognitive decline, there has been a shift in the diagnosis and treatment of dementia, with greater

focus on early detection and intervention. Therefore, it has become increasingly important to identify clinically meaningful cognitive impairment in its earliest stages, prior to the development of dementia. As an individual's cognitive decline progresses beyond the realm of normal cognitive aging, he/she may meet criteria for a Mild Cognitive Impairment (MCI) (Peterson, et al., 1999), the stage between normal aging and the more serious decline of dementia. Throughout history, there have been various terms used to describe the cognitive functioning of those who exhibit a measurable cognitive decline that does not meet criteria for a dementia. For example, in the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5), mild neurocognitive disorder (NCD) is a diagnostic category that is essentially the equivalent of MCI. The diagnostic criteria for mild NCD suggests that individuals must evidence modest cognitive decline below their premorbid cognitive functioning; however, the cognitive decline does not interfere with their capacity for independence in everyday activities, including complex activities of daily living (e.g., management of finances and medication) (American Psychological Association, 2017). Additionally, mild NCD is thought to have similar etiologies to dementia. In the DSM-V, a specification of the etiology is required. The potential etiologies of mild neurocognitive disorder are Alzheimer's disease, frontotemporal lobar degeneration, Lewy body disease, vascular disease, traumatic brain injury, substance/medication use, prion disease, Parkinson's disease, Huntington's disease, or multiple etiologies (American Psychological Association, 2017).

The previous notion of MCI focused primarily on memory impairments, whereas the current understanding of MCI is divided into two subtypes, amnestic MCI

and nonamnestic MCI. Amnestic MCI is for those with a singular memory impairment as well as a memory impairment in addition to other cognitive impairments. Whereas nonamnestic MCI characterizes those with non-memory impairment cognitive decline (Peterson, 2016). Additionally, for both amnestic and nonamnestic MCI, there is a distinction of single domain or multiple domain, such that if only a single cognitive domain is impacted, the clinical impression would include "single domain" or "multiple domain" if declines are observed in multiple cognitive domains (Gauthier, et al., 2006). For example, if an individual only exhibits notable decline in the learning and memory domain, he/she would receive a diagnosis of amnestic MCI, single domain. Whereas those who exhibit a decline in in learning and memory in addition to the executive functioning and language domains, would receive a diagnosis of amnestic MCI, multiple domain.

Petersen (2016) reviewed multiple studies on MCI and estimated that the overall prevalence among individuals over the age of 60 is likely in the 12% to 18% range. Additionally, of those classified with MCI of a neurodegenerative etiology, AD is the most likely underlying etiology or disease. As previously noted, there are numerous terms for MCI that have been used in the past 40 decades. One such common term is "prodromal AD". This came from the notion that MCI is the steppingstone to dementia, most commonly AD. The Alzheimer's Disease Neuroimaging Initiative (ADNI) has conducted research over the past several decades regarding MCI that progresses to AD. Their data suggest that those who are clinically classified as amnestic MCI, have medial temporal lobe atrophy on Magnetic Resonance Imaging (MRI), and exhibit a hypometabolic pattern consistent

with AD on F-fluorodeoxyglucose positron emission tomography (FDG-PET), are most likely to progress from MCI to AD (Petersen, 2016).

Activities of Daily Living:

An examination of activities of daily living (ADLs) is an important factor in a patient's clinical presentation when determining differentiating between MCI and dementia. ADLs are tasks that most young, healthy individuals can perform independently complete and are used as an indicator of a person's functional status (Edemekong et al., 2021). ADLs are classified as either basic ADLs (BADLs) or instrumental ADLs (IADLs). BADLs affect an individual's ability to care for themselves and include ambulating, feeding, dressing, personal hygiene, continence, and toileting (Edemekong et al., 2021). Ambulating is assessed as the ability for an individual to walk independently. Similarly, feeding and dressing are assessed as the ability for an individual to feed oneself and select appropriate clothing and dress, respectively. Personal hygiene describes one's ability to appropriately bathe and groom as well as maintaining dental hygiene, nail, and hair care. Finally, continence and toileting refer to one's ability to control bladder and bowel function and appropriately using the toilet and cleaning oneself, respectively.

Conversely, IADLs are more complex activities often involving more complex thinking skills, including organizational skills. IADLs are often the tasks that individuals begin asking for help when they become too difficult and include transportation and shopping, managing finances, shopping and meal preparation, housecleaning and maintenance, managing communication with others, and managing medications (Edemekong et al., 2021). Transportation and shopping involve

organizing transportation and procuring groceries. The ability to pay bills and manage financial assets are involved in managing finances. Meal preparation and home maintenance involve all tasks required to prepare a meal and cleaning and maintaining a home, respectively. Using telephone and email are an important aspect of managing communication. Finally, managing medications involves the ability to take medications as directed. Consideration of complex or instrumental activities of daily living is essential in determining whether a patient should be diagnosed with MCI or dementia. For example, two individuals with similar patterns of cognitive impairment might either be diagnosed with MCI or dementia depending on the degree to which they are also having difficulty with IADLs. Those whose cognitive impairment is interfering with IADLs are more likely to be diagnosed with dementia, whereas those with adequate adaptive functioning would be diagnosed with MCI.

The ability to perform many ADLs often requires a combination of cognitive, motor (e.g., balance, dexterity), and perceptual abilities (Mlinac et al., 2016). Furthermore, Lewis et al. (2007) suggest that executive control functioning (i.e., complex thinking involving problem solving, reasoning, planning, and cognitive flexibility) is an accurate predictor of functional abilities in older adults, such that executive control dysfunction predicts lapses in the ability to perform IADLs. As a full neuropsychological evaluation is not always readily available to determine a patient's functional status, providers utilize ADL measures along with observations, self-report, and collateral information from caregivers. Self-report measures of functional status are convenient, easy to administer, and provide useful information when the patient is cognitively intact. However, these tools may be inappropriate when the patient's

disease is progressed to the point of a lack of insight into their deficits (Mlinac et al., 2016). Similarly, informant rating scales are used frequently, but can provide biased information impacted by caregiver stress/burden (Mlinac et al., 2016). Additionally, the informant's ratings are only as good as their level of knowledge or awareness of how the patient is functioning. For example, if a family member who lives out of town and sees the patient infrequently is the one who completes these rating scales then the informant-report provided by this individual may not be accurate.

Additionally, objective measures are necessary when self- or collateral-reported information regarding daily functioning is of questionable validity, or nonexistent.-Such tools provide an alternative to self-, and informant-report measures of ADLs to provide a more objective measure of an individual's ADLs (Mlinac et al., 2016). The Texas Functional Living Scale (TFLS) and Independent Living Scales (ILS) are examples of such measures. In these objective measures, patients are asked to perform various activities that mimic IADLs that they are required to perform in their day to day lives. Common examples of such tasks include using a calendar, writing a check, remembering to remove candy from a bottle (i.e., mimicking medication management), health and safety, etc. Research indicates that a combination of self-report (including caregiver report) and performance-based measures of ADLs are the best way for providers to fully appreciate a patient's functional status (Mlinac et al., 2016).

Dementia:

As previously stated, an individual's functional status is often a major determining factor in their clinical presentation of MCI or dementia. Dementia is an umbrella term

encompassing various cognitive and functional symptoms (e.g., areas of cognitive dysfunction, difficulty performing activities of daily living, etc.) with various etiologies. The diagnosis of dementia (or major NCD as classified by the DSM-V) suggests that an individual evidences significant cognitive decline compared to their premorbid cognitive functioning, which interferes with their capacity for independence in everyday activities, including complex activities of daily living (e.g., management of finances and medication) and do not occur exclusively in the context of delirium (American Psychological Association, 2017). The potential etiologies of major NCD are Alzheimer's disease, frontotemporal lobar degeneration, Lewy body disease, vascular disease, traumatic brain injury, substance/medication use, prion disease, Parkinson's disease, Huntington's disease, or multiple etiologies (American Psychological Association, 2017). The two most common etiologies of dementia (Alzheimer's disease and vascular dementia) will be described in further detail as a detailed description of all etiologies is outside the scope of this paper.

Alzheimer's disease (AD) involves a neurodegenerative (and progressive) disease process and is the most common etiology of dementia, accounting for 60-80% of all dementias (Alzheimer's Association, 2022). The progression of this disease involves long-lasting asymptomatic phase, followed by a predementia phase (i.e., amnestic MCI), and finally the dementia stage (Parnetti, et al., 2019). In order to standardize the assessment and diagnosis of AD, The Consortium to Establish a Registry for Alzheimer's Disease (CERAD) developed various practices and criteria for the diagnosis of AD (Fillenbaum, 2008). The main components of the CERAD assessment consist of the clinical battery, neuropsychological battery, neuropathology battery,

neuroimaging battery, behavior rating scale for dementia, family history assessment, services assessment, autopsy resources, and educational brochures (Fillenbaum, 2008). Ultimately, however, the CERAD diagnostic criteria for AD is made postmortem and is used to refine the assessment and diagnosis premortem. The postmortem criteria include the presence of neuritic plaques (NP) by silver or thioflavin S strains in areas of maximum density in the middle frontal gyrus, superior and middle temporal gyri, and inferior parietal lobule (Markesbery, 1997). CERAD proposes that the NP can be classified by age (i.e., less than 50, 50 to 75, and over 75) in order for an accurate diagnosis of AD to be made (Markesbery, 1997). Although the exact cause of AD is not definitively understood, the presence of extracellular beta-amyloid deposits (in senile plaques) and intracellular neurofibrillary tangles (paired helical filaments) are associated with AD (Imbimbo, 2005). In addition to age, gender, and family history, vascular risk factors such as hypertension, smoking, ischemic heart disease, atrial fibrillation, increased cholesterol, diabetes, and obesity have also been implicated in the presence of Alzheimer's disease (O'Brien et al., 2015). From a neuropsychological perspective, the primary cognitive deficit is related to memory with amnestic symptoms being the most common presentation of AD (Peña-Casanova, 2012). On tasks assessing episodic memory (i.e., list learning, paragraph recall, visual memory), such as the California Verbal Learning Test (CVLT), individuals with AD struggle most with retrieval of previously encoded information. In other words, information that is learned is lost following a delay when the patient is asked to spontaneously recall the information, in addition to cued recall and recognition of the information (Peña-Casanova, 2012).

Vascular dementia is the second most common etiology of dementia, accounting for approximately 15% of cases (O'Brien et al., 2015). Similar to the CERAD neuropathological criteria for AD, there exists neuroimaging diagnostic criteria for vascular dementia. The National Institute of Neurological Disorders and Stroke (NINDS) and the Association Internationale pour la Recherche et l'Enseignement en Neurosciences (AIREN) suggest utilizing a comprehensive diagnostic process including history and physical, radiological, and pathological examinations (van Straaten et al., 2003). The NINDS-AIREN criteria for vascular dementia include a rating system for various lesions in the brain (e.g., large-vessel strokes in the inferior medial temporal lobe) (van Straaten et al., 2003). Risk factors of vascular dementia include age and stroke. In fact, having a stroke increases one's chances of developing dementia in the long-term, with 20-25% of individuals developing delayed dementia. Individuals who develop dementia following a stroke also tend to have increased age, low education, female sex, vascular risk factors, multiple strokes, and both global and medial temporal atrophy on imaging (O'Brien et al., 2015). While these risk factors for vascular dementia have commonalities with those for Alzheimer's disease, the clinical presentation of the two differ, and the presentation of vascular dementia tends to be far more variable than that of Alzheimer's disease (O'Brien et al., 2015). In the case of stroke or multi-infarct dementia, the location of the stroke likely impacts the clinical presentation as each area of the brain serves different functions and has differing behavioral correlates. As subcortical vascular pathology is frequently seen, the associated cognitive processes are often affected (i.e., attention, information processing, and executive functions). In addition to neuropsychological testing,

accurate diagnosis of vascular dementia requires brain imaging that supports the presence of cerebrovascular disease in the brain (i.e., white matter lesions, lacunes, infarcts) (O'Brien et al., 2015).

Although dementia is incurable, management includes treating comorbidities (e.g., vascular risk factors), addition of medication, providing support to the patient and caregivers, and maximizing independence (O'Brien et al., 2015). The Food and Drug Administration (FDA) has approved five pharmacologic therapies for the treatment of dementia. These include cholinesterase inhibitors (i.e., donepezil, galantamine, and rivastigmine) as well as the neuropeptide-modifying agent, memantine (Raina et al., 2008). However, research shows mixed effectiveness of drug therapy for use in patients with dementia, with the use of cholinesterase inhibitors and memantine at best resulting in clinically marginal improvement in measures of cognition and global assessment of dementia (Raina et al., 2008).

Poor Insight in Dementia:

Self-awareness in addition to accurate awareness of one's abilities is beneficial in many aspects of life, specifically for those who have a neurodegenerative disease such as dementia. Without self-awareness, those who fall ill due to physical and mental ailments have trouble understanding their capabilities and limitations. As part of their disease process, individuals with neurodegenerative diseases often experience anosognosia. Those who exhibit anosognosia, tend to lack awareness regarding the impact of their illness (Heilman, 1991). However, there is a distinction between verbal, explicit denial of an illness (i.e., anosognosia) and indifference or lack of genuine concern regarding one's deficit (i.e., anosodiaphoria) (Heilman, 1991). Importantly,

anosognosia is a symptom of a neurological disease process rather than a purposeful dismissal or denial of deficits. Rosen, 2011 suggest that anosognosia may be the consequence of a specific impairment (e.g., Anton's syndrome) or due to a potential disconnection between the language regions of the brain to the other regions, which could prevent those with anosognosia from expressing knowledge of their deficits.

Therefore, a common clinical observation and characteristic of individuals with Alzheimer's disease and other dementias is that these individuals tend to have poor insight and awareness regarding the degree of their cognitive and functional deficits (Robertsson et al., 2007). Patients diagnosed with dementia also tend to be poor historians when providing information to their medical providers regarding their functional status, in that they tend to overestimate their ability to perform various activities (Robertsson et al., 2007). Although this is typically unintentional, it can be problematic as inaccurate information regarding functional abilities can result in misdiagnosis as well as inappropriate treatment recommendations, and increased risk of safety hazards at times. Providers are often able to determine that individuals with dementia lack insight into their deficits based on contradictory caregiver reports. Robertsson et al. (2007) suggest that when a caregiver's opinion differs from the patient's, the opinion of the caregiver typically has preferential right to judge the level of the person's insight. In general, caregivers are given the ability to judge the care recipient based on the present deficits or symptoms, severity of deficits or symptoms, the cause of the deficit or symptoms, the consequence of the deficits in everyday life, and the ways to compensate for their deficits or symptoms. As a result, providers must put a lot of weight on the opinion of caregivers. Therefore, it is imperative to

understand how accurate caregivers' perceptions are, specifically given the literature that suggests that caregivers also tend to misperceive their patients' symptoms at times (i.e., pain) (Redinbaugh et al., 2002).

Dourado et al. (2014) sought to operationalize anosognosia by testing the effectiveness of a measure of awareness of disease in individuals with dementia (i.e., the Assessment Scale of Psychosocial Impact of the Diagnosis of Dementia [ASPIDD]). Ultimately, they found correlations among functional disability and unawareness of disease. This result provides further evidence for the theory that people with dementia show unawareness for memory dysfunction and ADL deficits, which may be related to executive dysfunction (Dourado et al., 2014). Unawareness of ADL deficits poses a great safety risk for these individuals as they may not see a reason to retire from potentially dangerous behaviors (e.g., driving, cooking). This lack of awareness and potential disregard for safety may increase caregiver burden (Dourado et al., 2014).

Caregiver Reports:

As noted above, due to the lack of insight of many demented individuals, physicians and other healthcare workers rely heavily on caregiver reports regarding their functioning. Hackett et al., (2020) sought to examine informant bias among caregivers of individuals who were diagnosed with MCI. Participants were included from an extensive national database (National Alzheimer's Coordinating Center), and the sample size was quite large (N=4,284). Hackett et al. (2020) utilized the Functional Activities Questionnaire (FAQ) as the measure of informant-reported adaptive functioning, which is a 10-item questionnaire that was given to the informants at one

point in time. The researchers analyzed the relationships between participant variables (i.e., participant age, sex, and GDS score) with the mean FAQ (informant rating), and sought to determine which informant variables attributed to higher FAQ scores (lower-rated adaptive functioning among participants). The authors concluded that higher FAQ scores were more common among informants who cohabitated with the participant, were paid caregivers, spouses, adult children, and those with higher education. Notably, this finding was observed even after controlling for demographics, cognition, and depressive symptoms of the individual with MCI.

DSRS:

The Dementia Severity Rating Scale (DSRS) is an informant-based multiple-choice questionnaire that assesses the severity of the major functional and cognitive domains implicated in AD. Clark et al., 1996 developed the DSRS as an easy to administer and convenient measure to assess a patient's ability to function in their home environment. At the DSRS's inception, Clark et al. (1996) performed an experiment in which they administered the DSRS to caregivers of patients diagnosed with probable AD and definite AD (i.e., confirmed by autopsy). They sought to compare DSRS scores to various neuropsychological tests from the CERAD battery (i.e., verbal fluency, Boston naming, word list, construction praxis, and clock drawing) as well as a CERAD score (i.e., a combined score calculated by the researchers for patients with probable AD, in which they summed the raw scores of various tests from the CERAD battery). The study aim was to establish the psychometric properties of the DSRS. Ultimately, Clark et al. (1996) reported that the DSRS demonstrated high concurrent validity as evidenced by its high correlation with other measures (e.g., the DSRS and Mini Mental

Status Exam [MMSE] had a correlation of -0.77). The DSRS's correlation with the combined CERAD score was -0.73, which is high for a caregiver-based measurement of functional status (Clark et al., 1996). The DSRS also demonstrated high test-retest reliability (0.90) and interrater reliability (>0.87). Ultimately, Clark et al. (1996) concluded that the DSRS is a practical and easy-to-use measure of severity in dementia.

Moelter et al. (2015) subsequently utilized the DSRS to predict Clinical Dementia Rating (CDR) scores. The CDR is a semi-structured interview which is a commonly used dementia staging instrument. The CDR assesses 6 domains of cognitive and functional performance (i.e., orientation, judgement and problem solving, community affairs, home and hobbies, and personal care) applicable to AD and related dementias. Moelter et al. (2015) administered both the CDR and DSRS to individuals in four diagnostic groups: AD (n=612), non-AD dementia (n=97), MCI (n=133), and controls (n=110). Linear regressions found that DSRS scores strongly predict scores on the CDR. This was an important outcome as the CDR is a lengthy semi-structured interview that relies heavily on clinical judgement for administration and scoring. Therefore, if an easy-to-administer brief questionnaire (i.e., DSRS) is able to predict CDR scores, the same information could be more easily attained.

Additionally, Mitchell et al. (2015) sought to determine the ability of the DSRS to differentiate cognitively healthy individuals from those diagnosed with MCI, and those diagnosed with AD. The DSRS was administered primarily to spouses or adult children of patients. The researchers found that within the normal control and AD groups, the DSRS correlated to more tests from the neuropsychological battery when compared to

MCI groups. Mitchell et al. (2015) rationalized this finding by explaining that caregivers may have an easier time accurately rating those who are not at all impaired or far more impaired compared to those "in-between" with an MCI diagnosis who are not expected to be as severely impaired as those with dementia. Additionally, those diagnosed with MCI may have the ability to compensate for the deficits using compensatory strategies, thereby "fooling" raters. Additionally, like Clark et al., (1995), Mitchell et al., (2015) found that the DSRS had good construct reliability as it was highly related to the FAQ and other self- and collateral- reports of dementia severity.

Study Aims:

This study aims to expand upon these previous studies by comparing caregiver/collateral reports of cognitive and functional status on the DSRS to neuropsychological tests and an objective measure of adaptive functioning, and exploring whether the informant-rating on the DSRS is able to predict neuropsychological test scores. Furthermore, this study aims to determine whether caregivers are more or less accurate depending on which stage of the disease process their loved one is in. For example, caregivers or family members may be more accurate later in the disease process when deficits are more apparent (i.e., late-stage dementia) and less accurate in the earlier stages (i.e., MCI). Previous studies (i.e., Mitchell et al. 2015) with similar aims used only those diagnosed with AD, while the current study aims to combine all dementia diagnoses in addition to AD diagnoses. As noted above, given the lack of insight that many individuals with dementia have, may physicians and other medical providers tend to put much weight on caregiver opinion of cognitive

and functional status. Therefore, it is imperative that research is conducted to elucidate the accuracy of caregiver reports. Additionally, exploring unique caregiver characteristics (i.e., the amount of time caregivers spend with the patient and their relationship to the patient) will provide novel information in the field of accurate caregiver reporting. Outcomes of this research study will aid in informing healthcare professionals in the reliability of caregiver report.

Chapter 4: Study Hypotheses

Objective 1.

To explore how caregiver/collateral reports of cognitive and functional status on the DSRS compares among diagnostic groups ranging from dementia to MCI, to normal cognition.

Hypothesis 1.

The overall DSRS score will differ among groups such those in the dementia groups will have higher scores than those with MCI, and those with MCI will have higher scores than those with normal cognition.

Objective 2.

To explore how caregiver/collateral reports of cognitive and functional status on the DSRS predicts objective scores of adaptive functioning.

Hypothesis 2.

Higher overall DSRS scores (indicating worse overall adaptive functioning) will predict lower scores on objective measures of adaptive functioning (indicating worse overall adaptive functioning), as measured by the Texas Functional Living Scales (TFLS).

Objective 3.

To explore how caregiver/collateral reports of cognitive and functional status on the DSRS relates to objective scores of executive functioning.

Hypothesis 3.

Overall DSRS scores will be negatively correlated with global cognitive functioning as measured by the Montreal Cognitive Assessment (MoCA) as well as

measures of executive functioning (i.e., Modified-Wisconsin Card Sorting Task, Trail Making Test-B, Stroop Color-Word Interference).

Objective 4.

To measure whether the degree of agreement between caregiver/collateral reports of cognitive and functional status on the DSRS and an objective measure of neuropsychological functioning is dependent upon how often caregivers/collateral informants spend time with the patient.

Hypothesis 4.

Caregivers who reside with the patient and see them 5 or more days per week will provide more collateral reports that do not differ from objective neuropsychological test data compared to collateral reporters who see the patient less frequently.

Objective 5.

To measure whether the degree of agreement between caregiver/collateral reports of cognitive and functional status on the DSRS and an objective measure of neuropsychological functioning is dependent upon caregivers/collateral informants' relationship to the patient.

Hypothesis 5.

Spouses will provide more collateral reports that do not differ from objective neuropsychological test data compared to collateral reporters who possess a different relationship to the patient.

Chapter 5: Methods and Procedures

Data Collection

This study utilized both archival as well as prospective data collected at the Health First Memory Disorder Clinic (HFMDC) in Melbourne, Florida between 2020 and 2022. Inclusion criteria included patients who had undergone a brief neuropsychological evaluation (BNE) including the DSRS as a part of their diagnostic procedure. In addition to reviewing neuropsychological test data, a review of records revealed which patients' caregivers were administered the dementia severity rating scale by a licensed social worker at their intake visit. Inclusion criteria also included those who were given a diagnosis of cognition within normal limits, mild cognitive impairment, or dementia (i.e., Alzheimer's dementia, vascular dementia, Lewy body dementia, mixed dementia, dementia unspecified). See below for further details regarding diagnostic procedures. Those who were given other cognitive diagnoses (i.e., unspecified neurocognitive disorder) were excluded from the study. This study received approval from Florida Institute of Technology's institutional review board.

Measures

This study utilized archival and prospective data derived from standard clinically administered cognitive and diagnostic tests. The following tests were administered to all patients: Supraspan Serial List Learning Task; Brief Visual Memory Test, Revised (BVMT-R); Digit Span subtest of the Wechsler Adult Intelligence Scale, 4th Edition (WAIS-IV); Clock Drawing Task; Trail Making Test (TMT) A & B; Golden Stroop Test (Stroop); Modified Wisconsin Card Sorting Test (M-WCST); Controlled Oral Word Association Task (COWAT), phonemic and

semantic; Boston Naming Test-15 (BNT-15); Comprehension and Repetition subtests of the Western Aphasia Battery (WAB); Narrative Writing Sample of the Boston Diagnostic Aphasia Examination (BDAE); Texas Functional Living Scale (TFLS); Geriatric Anxiety Inventory (GAI); Geriatric Depression Scale (GDS) in addition to the DSRS. The TFLS total raw score was utilized as an objective measure of adaptive functioning in participants for statistical analyses. Similarly, measures of Executive functioning (i.e., M-WSCT, TMTB, and Stroop Color-Word) were utilized for the statistical analyses.

DSRS

The Dementia Severity Rating Scale (DSRS) is an informant-based multiple-choice questionnaire that assesses the severity of the major functional and cognitive domains implicated in AD. The caregiver rates the patient in 11 categories: 6 assessing cognitive functioning and 5 measuring functional status. The domains of cognitive functioning include memory, speech and language, recognition of family members, orientation to time, orientation to place, and ability to make decisions. Assessment of functional status includes social and community activity, home activities and responsibilities, personal care – cleanliness, eating, control of urination and bowels, and ability to get from place to place (Clark et al., 1996). Patients are rated in each category using a Likert scale beginning with "0" describing normal ability in each category and increasing up to 6, indicating the severest form of impairment in each category. For example, the category of "Memory" ranges from "0" which is "normal memory" to 6 which is "does not remember even the most basic things" (Clark et al., 1996). The DSRS is scored by adding the score for each section. The total score ranges

from 0 to a maximum score of 54. Interpretation of the DSRS suggests that scores ranging from 0 to 18 suggest mild impairment, 19 to 36 suggest moderate impairment, and 37-54 suggest severe impairment. See appendix A for a copy of the DSRS questionnaire.

MoCA

The MoCA (Nasreddine et al., 2005) is a widely used cognitive screener used to measure global cognitive functioning. It examines cognitive functioning via various domains, including visuospatial/executive, naming, memory, attention, language, abstraction, delayed recall, and orientation. The maximum total raw score that can be obtained is 30. The MoCA utilizes age correction by adding 1 point for individuals with 12 years or fewer formal education. Higher scores indicate more intact global cognitive functioning.

TFLS

The TFLS (Cullum et al., 2001) is an objective measure of adaptive functioning which measures IADL skills. It contains 21 items and is divided into 4 subtests: Time, Memory and Calculation, Communication, and Memory. Tasks include drawing hands on a clock, calculating monetary change, demonstrating how to write a check. Individuals can attain a maximum total score of 50. A higher raw score suggests more intact adaptative functioning.

M-WCST

The M-WCST (Greve, 2001) is a briefer version of the Wisconsin Card Sorting Test-128 and is a novel problem-solving task and measures mental flexibility within the executive functioning domain. The M-WCST utilizes 48 cards in addition to 4 key

cards. Each deck card and key card has 1 to 4 colored shapes. Examinees are asked to sort cards from the deck to the key cards according to certain rules (i.e., color, form, number). After 6 correct responses, the examinee is prompted of a rule-change and is asked to match the cards based on another rule. This continues until the examinee sorts all 6 categories or the deck is depleted. Several scores emerge from the M-WCST (i.e., number of categories correct, number of perseverative errors, number of total errors, and percent of perseverative errors).

The Stroop Task

The Color Word Stroop Task (Golden et al., 1978) presents participants with color words printed in different colored ink (i.e., RED printed in green) and measures inhibition and cognitive interference. The examinee has a maximum of 45 seconds to respond to as many items as he/she is able to. The number of correct responses is summed. A higher raw score indicates better performance on this task.

TMT-B

TMT-B is a commonly used neuropsychological instrument used to measure executive functioning, psychomotor speed, visual search, and attention. Examinees are asked to draw a line connecting the dots in alphanumeric order, switching back and forth between numbers and letters (e.g., 1-A-2-B-3-C and so on thorough L-13). The task is timed and is discontinued when the examinee reaches 13 or after 300 seconds. A higher raw score (i.e., seconds) indicates poorer performance on the task.

Procedures

Participants were referred for a BNE by their geriatrician and/or medical provider to help clarify diagnosis and inform treatment and recommendations. The

most common referrals were due to concerns about memory and/or other cognitive changes. Patients' caregivers complete the DSRS during the intake appointment, the DSRS is administered by the licenced social worker. All neuropsychological testing was completed by Clinical Psychology doctoral students from Florida Institute of Technology and supervised by a doctoral-level licensed and board-certified neuropsychologist. In addition, all testing followed standard procedures of the neuropsychological tests, including standardized administration and scoring.

Diagnostic impressions were made by a multidisciplinary team that included a neurologist, a geriatrician or a geriatric nurse practitioner, a neuropsychologist, a pharmacist, a social worker, and clinical psychology doctoral students. The multidisciplinary team utilized medical histories, brain imaging, social histories, and neuropsychological test data to inform diagnosis. Review of patient records indicated participant inclusion into each diagnostic group: AD, MCI, and NC. Patients were diagnosed with AD using Tenth Revision of the International Classification of Diseases and Related Health Problems (ICD-10) diagnostic criteria. Those who were given MCI diagnoses were diagnosed using Peterson (2004) criteria. For example, the criteria for amnestic-MCI (a-MCI) include a memory complaint corroborated by an informant, measured memory impairment using objective measures, generally preserved global cognitive functioning, and largely intact functional activities (Peterson, 2004). Finally, participants were placed in the NC group if test results fell within the normal range across all domains and they had intact instrumental activities of daily living.

Participants

A total of 282 participants were administered BNEs and given the DSRS at their intake appointment. Out of these patients, 28 did not meet diagnostic criteria for inclusion in this study (i.e., they were diagnosed with unspecified neurocognitive disorder). After removing individuals who did not meet diagnostic criteria for inclusion, a total of 254 participants were included in the current study. Among them, 151 patients were diagnosed with dementia (60.3% female, M = 80.61, SD = 6.54), 64 patients were diagnosed with Mild Cognitive Impairment (MCI; 57.8% female, M = 78.59, SD = 6.95), and 39 were diagnosed with Normal Cognition (NC; 53.8% female, M = 76.64, SD = 7.13). Of those diagnosed with dementia (n = 151), 53.0% were diagnosed with Alzheimer's Disease, 27.2% were diagnosed with dementia of undetermined etiology, 13.9% were diagnosed with dementia of mixed etiology (e.g., Alzheimer's and Vascular), 4.6% were diagnosed with Vascular Dementia, and 1.3% were diagnosed with Dementia with Lewy Bodies. Of those diagnosed with MCI, 68.8 were diagnosed with MCI, amnestic type with the remainder (31.2%) diagnosed with MCI, non-amnestic type. The average education level was 13.59 (SD = 2.64 for the dementia group, 14.36 (SD = 2.20) for the MCI group, and 13.69 (SD = 2.56) for the NCI group. Among the 254 patients, a majority of them self-identified as being Caucasian/White (88.1%), with the remaining patients self-identifying as African American/Black (8.6%), Asian (1.3%), Native American (1.3%), or No Response (1.3%). Only 4.6% identified as having Hispanic ethnicity. See Table 1 for a description of patient demographics by diagnostic group.

Data Analyses

Data was analyzed using the statistical software SPSS, Version 28. Differences in DSRS scores among diagnostic categories was analyzed using ANOVA followed up with t-tests for each diagnostic group. Regressions were utilized to determine whether or not the DSRS predicts scores on various neuropsychological tests and objective measures of adaptive functioning. Similarly, comparisons among DSRS scores and scores on various neuropsychological tests and objective measures of adaptive functioning were analyzed using Pearson correlations. The degree of agreement between the DSRS and other measures as it relates to how often caregivers interact with the patient was analyzed using ANOVA comparing the degree of agreement between the two tests with how often the caregiver sees the patient. A similar ANOVA was utilized to determine the degree of agreement between the DSRS and another measure depending on the relationship of the caregiver (i.e., spouse, child, etc.).

Chapter 6: Results

Diagnostic Group and Demographic Factors. A one-way ANOVA was used to determine whether there were significant differences among gender, years of education, race, ethnicity, and age among the three diagnostic groups (i.e., dementia, mild cognitive impairment, and normal cognition). There was no significant difference among years of education across the dementia group (M = 13.59, SD = 2.64), MCI group (M = 14.36, SD = 2.20), and NC group (M = 13.69, SD = 2.56) [$F(2, 251)$ = 2.135, p = .120]. Similarly, there was no significant difference among gender across the diagnostic groups [$F(2, 251)$ = .273, p = .761]. Race and ethnicity also did not produce significant differences among the diagnostic groups [$F(2, 250)$ = 1.096, p = .336], [$F(2, 251)$ = .034, p = .967], respectively. Dissimilarly, there was a significant difference in age across the diagnostic groups [$F(2, 251)$ = 6.137, p = .002], such that those in the dementia group were significantly older (M = 80.61, SD = 6.54), followed by the MCI group (M = 78.59, SD = 6.95), and then the NC group (M = 76.64, SD = 7.13).

DSRS by Diagnostic Group. A one-way Welch ANOVA was conducted to determine whether the DSRS score differed across diagnostic categories (i.e., Dementia, MCI, NC). Participants were classified into three groups: Dementia (n = 151), MCI (n = 64), and NC (n = 39). DSRS score was normally distributed for the Dementia and MCI groups, as assessed by Shapiro-Wilk's test (p>0.05). While the NC was not normally distributed, a decision was made to conduct a one-way ANOVA as non-normality does not affect Type 1 error rate sustainably and the one-way ANOVA can be considered robust to non-normality (Maxwell, et al., 2004). The assumption of

homogeneity of variances was also violated, as assessed by Levene's Test of Homogeneity of Variance (p = .046). The overall DSRS score was statistically different among diagnostic groups, Welch's $F(2, 101.882) = 31.590$, $p < .001$. Overall DSRS score was highest in the Dementia group (M = 12.90, SD = 5.94), followed by the MCI group (M = 8.25, SD = 4.51), and then the NC group (M = 6.74, SD = 0.76). See Figure 1 for a comparison of DSRS scores by diagnostic groups.

T-tests were then conducted to determine whether DSRS scores were significantly greater in the Dementia group compared to the MCI group, and in the MCI group compared to the NC group. The assumption of homogeneity of variances was again violated (Dementia group and MCI group), as assessed by Levene's test for equality of variances (p = .022). Therefore, a Welch t-test was conducted to determine whether there were differences in overall DSRS scores between the Dementia group and the MCI group. There was a statistically significant difference in overall DSRS scores between the Dementia group and MCI group, with the Dementia group scoring higher than the MCI group, M = 4.65, 95% CI [3.17, 6.12], $t(151.315) = 6.229$, $p <$ .001. There was homogeneity of variances for overall DSRS scores for the MCI group and NC group, as assessed by Levene's test for equality of variances (p = .414). Therefore, an independent-samples t-test was run to determine if there were differences in overall DSRS scores between the MCI group and NC group. There was a statistically significant difference in overall DSRS scores between the MCI group and NC group, with the MCI group scoring higher than the NC group, M = 1.51, 95% CI [-.35, 3.37], $t(100) = 1.610$, p = .05. Therefore, this result supports the first hypothesis that DSRS scores would differ among the diagnostic groups, such that those

diagnosed with dementia would score higher than those diagnosed with MCI, and those diagnosed with MCI would score higher than those with NC.

DSRS and Adaptive Functioning. A Pearson's product-moment correlation was calculated to assess the relationship between DSRS and TFLS scores across the entire study population. There was a statistically significant, moderate negative correlation between DSRS and TFLS scores in this population, $r(247) = -.32$, $p < .001$, with DSRS explaining 10% of the variation in TFLS score. This suggests that as DSRS score increases, TFLS score decreases. See Table 2 for the means and standard deviations of overall DSRS and total TFLS scores by diagnostic group.

A linear regression was then calculated to determine whether DSRS scores predict total TFLS scores. To assess linearity a scatterplot of DSRS scores against average TFLS scores with superimposed regression line was plotted. Visual inspection of these two plots indicated a linear relationship between the variables. There was homoscedasticity and normality of the residuals. The prediction equation was: TFLS score = 42.04 – 0.41 * DSRS score. The DSRS score statistically significantly predicted the TFLS score, $F(1, 243) = 26.817$, $p < 0.001$, accounting for 9.9% of the variation in the TFLS score with adjusted R^2 = 9.6%. Therefore, the regression equation can be used to predict the TFLS score based on the DSRS score such that the DSRS score leads to a 0.41-point, 95% CI [-.333, -.149] decrease in TFLS score. Predictions were made to determine mean TFLS scores for people who scored 18 and 36 on the DSRS, which are the upper-bound scores within the mild and moderate classifications, respectively. For a DSRS score of 18, mean TFLS scores would be approximately 34.61 (95% CI, 33.13 to 36.10). For a DSRS score of 36, mean TFLS

scores would be approximately 27.19 (95% CI, 23.12 to 31.27). This finding supports the second hypothesis that higher overall DSRS scores predict lower scores on objective measures of adaptive functioning, as measured by the TFLS.

DSRS and Global Cognitive Functioning. A Pearson's product-moment correlation was calculated to assess the relationship between overall DSRS score and overall MoCA score. There was a statistically significant, small negative correlation between total DSRS and MoCA score, $r(253) = -.27, p < .001$, with DSRS scores explaining 7% of the variation in MoCA scores. This suggests that as DSRS scores increase (i.e., indicating poorer functioning), MoCA scores decrease (i.e., indicating poorer global cognitive functioning). This result partially supports the third hypothesis as a small negative correlation was seen among overall DSRS score and MoCA scores.

DSRS and Executive Functioning. Pearson's product-moment correlations were also calculated to assess the relationship between overall DSRS score and measures of executive functioning, including the number of correctly sorted categories on the M-WCST, number of perseverative errors on the M-WCST, number of correct Stroop Color-Word subtest items, and total time to complete TMT-B. There was a statistically significant, small negative correlation between total DSRS and number of correctly completed categories on M-WCST, $r(231) = -.25, p < .001$, with DSRS scores explaining 6% of the variation in number of categories. Similarly, there was a statistically significant, small negative correlation between overall DSRS score and total raw score on Stroop Color-Word subtest, $r(241) = -.22, p < .001$, with DSRS scores explaining 5% of the variation in the number of correct Stroop Color-Word subtest items. Meanwhile, a statistically significant, moderate positive correlation was

observed between overall DSRS score and number of seconds to complete TMT-B, $r(241) = 0.32$, $p < .001$, with DSRS explaining 10% of the variation in total time to complete TMT-B. Additionally, a statistically significant, small positive correlation was observed between overall DSRS score and number of perseverative errors on M-WCST, $r(214) = 0.28$, $p < .001$, with DSRS explaining 8% of the variation in number of perseverative errors. While the direction of the correlation coefficients differs, all the correlations performed support the third hypothesis that as DSRS score increases, measures of executive functioning indicate poorer overall functioning, such that a higher DSRS score is correlated with greater time to complete TMT-B, more perseverative errors on M-WCST, fewer correctly completed categories on M-WCST, and fewer correct items on Stroop Color-Word subtest. See Table 3 for the means, standard deviations, and correlations of overall DSRS score with neuropsychological tests measuring global cognitive functioning, executive functioning, and adaptive functioning.

Degree of Agreement and Contact with Patient. In order determine whether the degree of agreement between caregiver/collateral reports of cognitive and functional status on the DSRS and an objective measure of neuropsychological functioning is dependent upon how often caregivers/collateral informants spend time with the patient, a degree of agreement variable between the TFLS and DSRS scores was created. The steps to create this variable are as follows: First, the TFLS was reverse-scored such that the number of errors (rather than correct items) was coded. This was completed to ensure that the overall DSRS score would be positively correlated with the TFLS (e.g., higher scores on both measures would indicate greater

difficulties), so that they could be more easily compared. Next, a common denominator was chosen for the overall DSRS score and reverse-scored TFLS score (i.e., 100), so that the two variables could be put onto the same scale. Then, a degree of freedom value was determined by subtracting the overall DSRS score out of 100 and reverse-scored TFLS score out of 100. The absolute value of this subtraction was used as the degree of agreement between the overall DSRS score and the TFLS score, with a smaller value indicating greater agreement between these two variables.

A one-way ANOVA was subsequently conducted to determine whether the degree of agreement value between the DSRS and TFLS differed depending on the level of contact the collateral reporter has with the patient. Participants were classified into five groups: less than one day per week (n = 11), one day per week (n = 12), two days per week (n = 16) three to four days per week (n = 26), or 5 or more days per week (n = 166). There was homogeneity of variances, as assessed by Levene's test of homogeneity of variances (p = .626). The differences among those who had contact with the patient less than one day per week (M = 11.76, SD = 12.12), one day per week (M = 16.57, SD = 11.92), two days per week (M = 9.22, SD = 7.67) three to four days per week (M = 9.94, SD = 10.36), and 5 or more days per week (M = 12.75, SD = 10.64) were not statistically significant, $F(4, 226) = 1.231$, p = .298. Similarly, an independent-samples t-test was conducted to determine whether the degree of agreement between the TFLS and the DSRS scores differed between collateral reported who live with the patient (n = 138) and those who do not (n = 99). The assumption of homogeneity of variances was met as assessed by Levene's test for equality of variances (p = .245). There was no statistically significant difference in the

degree of agreement between the TFLS and DSRS scores and whether the collateral reporter lived with the patient (M = 12.41, SD = 9.95) and those who did not live with the patient (M = 12.70, SD = 11.71), M = .28, 95% CI [-2.50, 3.07], $t(235) = .210$, p = .84. A post-hoc independent-samples t-test was conducted to determine whether the degree of agreement between the TFLS and the DSRS scores differed between collateral reported who reported that they saw the patient five or more days per week (n = 166) and those who did not (n = 65). The assumption of homogeneity of variances was met as assessed by Levene's test for equality of variances (p = .690). There was no statistically significant difference in the degree of agreement between the TFLS and DSRS scores and whether the collateral reporter reported seeing the patient more than five days per week (M = 12.75, SD = 10.64) and those who reported seeing the patient fewer than five days per week (M = 11.30, SD = 10.49), M = -1.45, 95% CI [-4.51, 1.61], $t(229) = -.934$, p = .35. These findings do not support the fourth hypothesis that individuals who have more contact with the patient would provide more accurate information of the patient's functional status.

Degree of Agreement and Relationship. A one-way ANOVA was conducted to determine whether the degree of agreement between the DSRS and TFLS differed depending on the nature of the collateral reporter's relationship with the patient. Participants were classified into six groups: spouse (n = 102), sibling (n = 8), child (n = 100) other family (n = 12), friend (n = 13), or other (n = 7). There was homogeneity of variances, as assessed by Levene's test of homogeneity of variances (p = .401). The differences between spouses (M = 12.73, SD = 10.55), siblings (M = 9.64, SD = 5.81), children (M = 12.99, SD = 11.73) other family (M = 10.04, SD = 8.67), friend (M =

11.74, *SD* = 8.08), or other (*M* = 18.40, *SD* = 9.60) were not statistically significant, *F*(6, 236) = .742, *p* = .616. Similarly, an independent-samples t-test was conducted to determine whether the degree of agreement between the TFLS and the DSRS scores differed between collateral reporters who identified as the patient's spouse (*n* = 102) and those who do not identify as the patient's spouse (*n* = 141). The assumption of homogeneity of variances was met as assessed by Levene's test for equality of variances (*p* = .807). There was no statistically significant difference in the degree of agreement between the TFLS and DSRS scores and whether the collateral reporter identified as the patient's spouse (*M* = 12.73, *SD* = 10.55) or did not identify as the patient's spouse (*M* = 12.77, *SD* = 10.87), *M* = -.49, 95% CI [-2.80, 2.70], *t*(241) = -0.35, *p* = .97. This does not support the fifth hypothesis that spouses will provide more collateral reports that do not differ from objective neuropsychological test data compared to collateral reporters who possess a different relationship to the patient.

Chapter 7: Discussion

Impact of Study

The purpose of this study was to utilize data from caregivers and family members regarding their ratings of their loved ones' cognitive functioning as well as their loved ones' actual ability to perform various activities of daily living to determine the accuracy of caregiver reports. Given that many patients diagnosed with dementia experience anosognosia and have limited insight into their deficits, medical providers often look to a patient's caregiver to obtain an accurate medical, social, and psychological histories. These collateral reports are often used to determine a patient's functional status and are therefore integral in a diagnosis of dementia. Therefore, determining the accuracy of caregiver reports is an important factor in diagnosing dementia in older adults.

A total of 254 patients were divided into three groups based on their diagnosis (dementia, MCI, or NC). Results of the study indicated no significant differences in education level, gender, race, nor ethnicity among the three diagnostic groups, indicating that such factors did not impact patients being given a certain diagnosis. However, age did have a significant effect among the three groups. Given that the risk of dementia significantly increases with age (Chen et al., 2009), this was an expected result as the older a patient is, the more likely they are likely to be diagnosed with dementia.

The first hypothesis sought to explore how caregiver/collateral reports of cognitive and functional status as measured by the DSRS compares among diagnostic groups ranging from dementia to MCI to normal cognition. It was hypothesized that

the overall DSRS score would differ among groups such those in the dementia groups will have higher scores than those with MCI, and those with MCI will have higher scores than those with normal cognition. The results of the study supported this hypothesis as significant differences were observed among the three groups with the dementia group having the highest mean overall DSRS score, followed by the MCI group, and then the NC group. This indicates that on average, collateral reporters of patients diagnosed with dementia rated them as more impaired when compared with the MCI and NC groups. Similarly, on average, collateral reporters of patients diagnosed with MCI rated them as more impaired when compared to the NC groups. Therefore, via the DSRS, collateral reporters are able to distinguish the level of a patient's impairment based on their diagnostic group. Providers are therefore suggested to consider including the DSRS as an indicator of impairment for patients suspected to have dementia who are not able to provide an accurate history due to the progression of their disease.

The second hypothesis sought to explore whether caregiver/collateral reports of cognitive and functional status on the DSRS can predict objective scores of adaptive functioning, such that higher overall DSRS scores (indicating worse overall adaptive functioning) would predict lower scores on objective measures of adaptive functioning (indicating worse overall adaptive functioning), as measured by the Texas Functional Living Scales (TFLS). Results of the study also supported this hypothesis. Specifically, results indicated that as DSRS score increases (suggesting poorer adaptive functioning), TFLS score decreases (suggesting poorer adaptive functioning). Results also indicated that overall DSRS scores may predict TFLS scores with reasonable

accuracy, accounting for 9.9% of the variance. This finding supports the idea that caregivers are able to provide a fairly accurate description of functional status among their family members. This was true for both patients who were diagnosed with dementia (and have limited insight), in addition to MCI and NC groups. Therefore, informant reports of ADL dysfunction were reasonably consistent with clinical measures of ADLs (i.e., TFLS), suggesting that informants may provide useful clinical information to healthcare providers. The regression equation predicted a mean TFLS raw score of approximately 34.61 for those in the highest range of mild based on overall DSRS score (overall DSRS of 18). Similarly, those who scored in the highest range of moderate based on the overall DSRS score (overall DSRS of 34) predicted a TFLS raw score of approximately 27.19. However, the highest overall DSRS score observed in this sample was 27 (the total possible score on the DSRS is 54), indicating only moderate impairment as measured by the DSRS. This suggests that even patients who were diagnosed with dementia did not meet the severe classification based on the DSRS. Therefore, this indicates that further research may need to be conducted in order to evaluate the interpretation of a wider range of scores on the DSRS including those in the more severely impaired ranges.

The third hypothesis explored how caregiver/collateral reports of cognitive and functional status on the DSRS relates to objective scores of global and executive cognitive functioning. It was hypothesized that overall DSRS scores would be negatively correlated with global cognitive functioning as measured by the Montreal Cognitive Assessment (MoCA) as well as measures of executive functioning (i.e., Modified-Wisconsin Card Sorting Task, Trail Making Test-B, Stroop Color-Word

Interference). Results indicated that the overall DSRS score did have a small negative correlation with the total MoCA score, suggesting that as DSRS scores increase (i.e., indicating more impairment), MoCA scores decrease (i.e., indicating poorer global cognitive functioning). This suggests that caregivers and collateral reporters provision of information on the DSRS does relate to and somewhat accurately reflect patients' overall cognitive functioning. Similarly, results of the study indicated that as DSRS score increases (i.e., indicating more impairment), measures of executive functioning indicate poorer overall executive functioning. In other words, overall DSRS score was correlated with greater time to complete TMT-B, more perseverative errors on M-WCST, fewer correctly completed categories on M-WCST, and fewer correct items on Stroop Color-Word subtest. Again, this suggests caregiver/collateral reports on the DSRS relate to and somewhat accurately reflect the degree of executive dysfunction as measured by these tests. It was not expected that the DSRS would be highly correlated with the MoCA, M-WCST, TMT-B, or Stroop CW, as they are not measuring the exact same constructs. The DSRS does not measure executive functioning, for example, and it is not intended to. However, because executive functioning is needed to perform some ADLs, and the DSRS has questions about ADLs, this might explain why there is a modest relationship between these two variables.

The fourth hypothesis sought to measure whether the degree of agreement between caregiver/collateral reports of cognitive and functional status on the DSRS and an objective measure of neuropsychological functioning as measured by the TFLS is dependent upon how often caregivers/collateral informants spend time with the

patient. It was hypothesized that caregivers who reside with the patient and see them 5 or more days per week would provide collateral reports that are more similar to objective neuropsychological test data compared to collateral reports from caregivers who see the patient less frequently. However, results of the study did not show a significant difference in the degree of agreement among the DSRS and TFLS based on how often the caregiver saw the patient. Participants in this sample were rated on the DSRS by caregivers who saw them from less than 1 day per week to 5 or more days per week, and all of the caregivers who reported living with patients (n = 138) also reported seeing the patients 5 or more days per week. Therefore, a comparison was made between the degree of agreement among TFLS and DSRS scores and whether or not patients lived with their caregiver; however, this was also not significant. These results indicated that those who provide collateral reports for patients were just as accurate as one another and seeing the patient more or less often or living with the patient did not impact their ability to more accurately report cognitive or functional abilities in their relatives/friends. This was a surprising result as it was hypothesized that more time spent with the patient would yield DSRS and TFLS scores that are more similar compared to collateral reporters who do not live with the patient. It is plausible that this the case as anyone who is asked to fill out the DSRS for the patient likely has a vested interest in the patient's wellbeing. These informants are the ones accompanying the patient to a healthcare appointment and therefore have knowledge about the patient's cognitive and functional status. Additionally, these individuals likely have access to other people in the patient's life (e.g., spouse, children, etc.) and are able to speak about and ask questions about what the patient is/is not able to do in

situations where they may not have as much personal experience with the patient directly. Ultimately, these factors may contribute to informant reporters who see the patient less often yielding similar degrees of discrepancy between DSRS and TFLS scores as compared to informant reporters who see the patient almost every day or live with the patient.

Similar to the fourth hypothesis, the fifth hypothesis sought to measure whether the degree of agreement between caregiver/collateral reports of cognitive and functional status on the DSRS and an objective measure of neuropsychological functioning is dependent upon caregivers/collateral informants' relationship to the patient. It was hypothesized that spouses would provide more collateral reports that do not differ from objective neuropsychological test data compared to collateral reporters who possess a different relationship to the patient. Results indicated that the collateral reporter's relationship to the patient did not impact the degree of agreement between the DSRS and TFLS scores. Participants in this sample had the DSRS completed by individuals who were related to the participant (e.g., spouse, sibling, child, etc.) or unrelated (e.g., friend, roommate, case worker, etc.). Again, this was an unexpected result as it was thought that those identified as spouses of patients would provide information that agreed more with the TFLS than those who did not identify as spouses. The results of the fourth and fifth hypotheses suggest that all individuals who completed the DSRS are equally accurate in providing information about the patient's functional or cognitive status regardless of their relationship and frequency of contact. Again, it is plausible that individuals who accompany a patient to a medical appointment know enough about the patient's cognitive or functional status and or are

able to ask other family members if they do not have personal experience. On the contrary, due to an increased life expectancy, a growing number of spouses transition into the role of caregiver when one spouse develops dementia (Braun, et al., 2009). Research on the accuracy of informant reporting suggests that family caregivers of individuals diagnosed with dementia (often spouses) may have a tendency to overreport cognitive and functional deficits (Kemp et al., 2002). There are several reasons why this may be the case. If the collateral reporter knows that a patient is impaired in one area, they may assume that he/she is impaired in all areas. On the other hand, caregivers who experience caregiver stress may exaggerate a patient's impairments as a cry for help. Ultimately, these factors may contribute to informant reporters who have a close relationship with the patient (i.e., spouses) yielding similar degrees of discrepancy between DSRS and TFLS scores compared to informant reporters who have a more distant relationship to the patient.

Limitations and Future Research

There are several limitations of the current study. One significant limitation is that there was no true control group. All of the participants were patients of the Health First Memory Disorder Clinic and presented to the clinic with cognitive (primarily memory) concerns. Therefore, even though they performed well on cognitive testing and had no difficulties managing instrumental activities of daily living, they are still not true controls as they have memory concerns. Individuals diagnosed with normal cognition within this sample may not be equivalent to older adults from a community sample with no memory concerns, as all participants in this study presented to a memory clinic with a cognitive complaint. A true control group may have mean overall DSRS groups

that are closer to 0, whereas this sample had a NC group with a mean overall DSRS score of 6.74. A community sample of older adults with normal cognition would allow a better comparison among the 3 groups, allow for exploration of the DSRS cutoff scores, and potentially aid in developing new cutoff scores for the DSRS.

Given that the sample was obtained from a memory clinic, all data and diagnoses were made for clinical purposes including treatment planning and providing patients and caregivers with relevant recommendations. Therefore, one interdisciplinary group (i.e., geriatrician, neurologist, neuropsychologist, pharmacist, social worker, and clinical psychology students) made all of the diagnoses. Ideally, a research study with methodology similar to this study would benefit from multiple groups reviewing the data independently and coming to a consensus regarding diagnosis. Having more than two interdisciplinary groups determining a diagnosis for each participant and using the common diagnosis would allow for more confidence in the accuracy of the given diagnosis. This would ensure that participants are placed in the correct group (i.e., NC, MCI, Dementia).

Relatedly, given that the diagnosis is made by a multidisciplinary group, who each provide different input from various disciplines (i.e., medicine/radiology, social work, neuropsychology, pharmacy, social work), a diagnosis is not made solely using neuropsychological test data. However, this study only compared DSRS scores to neuropsychological test data. It may have been beneficial to incorporate other variables into the study and compare them to the DSRS, such as medical history, social history, impressions of brain imaging, and pharmaceutical confounds (e.g., polypharmacy).

Additionally, having more information regarding caregiver factors may be beneficial, such as factors related to caregiver stress.

Future research should replicate this study with a true control group (i.e., a sample of individuals with normal cognition who are recruited from the community). Furthermore, it would be beneficial for future studies to obtain multiple opinions on each participants' diagnoses in order to more confidently group participants in each group. Additionally, future studies can compare the DSRS to other factors that are important in making a dementia diagnosis (e.g., medical/social history, brain imaging, etc.) rather than just neuropsychological test data. Future research should also continue to look at the individual items of the DSRS (not just the overall DSRS score) and assess whether there are correlations among the items and other neuropsychological tests to help differentiate which cognitive domains may be more relevant within each item. It would also be beneficial to explore new qualitative cut-offs for each of the DSRS descriptors (i.e., mild, moderate, severe). As the current study showed that even patients diagnosed with dementia never reached the severe category, indicating that the current cutoffs for the descriptors may not be capturing "severe" dementia. Additionally, separating the DSRS scores by cognitive and adaptive scores may be beneficial. This may provide greater confidence when comparing the DSRS to neuropsychological tests of cognitive and adaptive functioning.

Conclusion

The DSRS is an informant-based multiple-choice questionnaire that assesses the severity of the major functional and cognitive domains implicated in AD. It is a brief tool that is easy to administer by many providers. The caregiver rates the patient

in 11 categories: 6 assessing cognitive functioning and 5 measuring functional status. The DSRS provides information to clinicians regarding these domains. As previously mentioned, a significant component of accurately diagnosing dementia is utilizing data from caregivers and family members regarding their loved ones' cognitive functioning as well as their ability to perform various activities of daily living. Given that many patients diagnosed with dementia experience anosognosia and have limited insight into their deficits, medical providers often look to a patient's caregiver to obtain an accurate medical and psychosocial histories. Additionally, these collateral reports are often used to determine a patient's functional status as well. Therefore, obtaining caregiver collateral reports is integral in a diagnosis of dementia. The present study sought to determine the accuracy of collateral reporters.

Ultimately, the results of the study showed that collateral reporters using the DSRS were able to accurately distinguish between NC, MCI, and dementia groups. Additionally, the DSRS was somewhat able to accurately predict functional status when compared to an objective measure of adaptive functioning, accounting for 9.9% of the variance. It was also reasonably related to neuropsychological measures of global cognitive functioning and executive functioning. However, there was no difference in the accuracy of the DSRS dependent on the collateral reporter's relationship to the patient, nor how many days per week the collateral reporter spends time with the patient. Therefore, individuals who complete the DSRS for the patient provide information that agrees with the TFLS to the same degree regardless of their relationship to the patient or how much time they spend with the patient. This may be able to be extrapolated to these individuals providing equally accurate oral medical

and psychosocial histories to clinicians conducting intake interviews. This finding suggests that information obtained from caregivers via clinical interviews may also be equally accurate regardless of how much time the caregiver spends with the patient. Indeed, it appears that the accuracy of collateral reports received from caregivers and family members is not dependent on the nature of the relationship with the patient or the number of days per week spent together.

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Appendix A: DSRS

DEMENTIA SEVERITY RATING SCALE (DSRS)

PARTICIPANT'S NAME:_____ DATE:_____
PERSON COMPLETING FORM:_____
Please circle the most appropriate answer.
Do you live with the participant? No Yes
How much contact do you have with the participant? Less than 1 day per week 1 day/week 2 days/week 3-4 days/week
5 or more days per week
Relationship to participant
Self Spouse Sibling Child Other Family Friend Other _____
In each section, please circle the number that **most closely applies** to the participant. This is a general form, so no one description may be exactly right -- please circle the answer that seems to apply most of the time.

Please circle only one number per section, and be sure to answer all questions.

MEMORY

0 Normal memory.
1 Occasionally forgets things that they were told recently. Does not cause many problems.
2 Mild consistent forgetfulness. Remembers recent events but often forgets parts.
3 Moderate memory loss. Worse for recent events. May not remember something you just told them. Causes problems with everyday activities.
4 Substantial memory loss. Quickly forgets recent or newly-learned things. Can only remember things that they have known for a long time.
5 Does not remember basic facts like the day of the week, when last meal was eaten or what the next meal will be.
6 Does not remember even the most basic things.

DEMENTIA SEVERITY RATING SCALE (DSRS)

SPEECH AND LANGUAGE

0 Normal ability to talk and to understand others.

1 Sometimes cannot find a word, but able to carry on conversations.

2 Often forgets words. May use the wrong word in its place. Some trouble expressing thoughts and giving answers.

3 Usually answers questions using sentences but rarely starts a conversation.

4 Answers questions, but responses are often hard to understand or don't make sense. Usually able to follow simple instructions.

5 Speech often does not make sense. Can not answer questions or follow instructions.

6 Does not respond most of the time.

RECOGNITION OF FAMILY MEMBERS

0 Normal - recognizes people and generally knows who they are.

1 Usually recognizes grandchildren, cousins or relatives who are **not** seen frequently but may not recall how they are related.

2 Usually does not recognize family members who are not seen frequently. Is often confused about how family members such as grandchildren, nieces, or nephews are related to them.

3 Sometimes does not recognize close family members or others who they see frequently. May not recognize their children, brothers, or sisters who are not seen on a regular basis.

4 Frequently does not recognize spouse or caregiver.

5 No recognition or awareness of the presence of others.

ORIENTATION TO TIME

0 Normal awareness of time of day and day of week.

1 Some confusion about what time it is or what day of the week, but not severe enough to interfere with everyday activities.

2 Frequently confused about time of day.

3 Almost always confused about the time of day.

4 Seems completely unaware of time.

DEMENTIA SEVERITY RATING SCALE (DSRS)

ORIENTATION TO PLACE

0 Normal awareness of where they are even in new places.

1 Sometimes disoriented in new places.

2 Frequently disoriented in new places.

3 Usually disoriented, even in familiar places. May forget that they are already at home.

4 Almost always confused about place.

ABILITY TO MAKE DECISIONS

0 Normal - as able to make decisions as before.

1 Only some difficulty making decisions that arise in day-to-day life.

2 Moderate difficulty. Gets confused when things get complicated or plans change.

3 Rarely makes any important decisions. Gets confused easily.

4 Not able to understand what is happening most of the time.

SOCIAL AND COMMUNITY ACTIVITY

0 Normal - acts the same with people as before

1 Only mild problems that are not really important, but clearly acts differently from previous years.

2 Can still take part in community activities without help. May appear normal to people who don't know them.

3 Often has trouble dealing with people outside the home without help from caregiver. Usually can participate in quiet home activities with friends. The problem is clear to anyone who sees them.

4 No longer takes part in any real way in activities at home involving other people. Can only deal with the primary caregiver.

5 Little or no response even to primary caregiver.

DEMENTIA SEVERITY RATING SCALE (DSRS)

HOME ACTIVITIES AND RESPONSIBILITIES

0 Normal. No decline in ability to do things around the house.

1 Some problems with home activities. May have more trouble with money management (paying bills) and fixing things. Can still go to a store, cook or clean. Still watches TV or reads a newspaper with interest and understanding.

2 Makes mistakes with easy tasks like going to a store, cooking or cleaning. Losing interest in the newspaper, TV or radio. Often can't follow a long conversation on a single topic.

3 Not able to shop, cook or clean without a lot of help. Does not understand the newspaper or the TV. Cannot follow a conversation.

4 No longer does any home-based activities.

PERSONAL CARE - CLEANLINESS

0 Normal. Takes care of self as well as they used to.

1 Sometimes forgets to wash, shave, comb hair, or may dress in wrong type of clothes. Not as neat as they used to be.

2 Requires help with dressing, washing and personal grooming.

3 Totally dependent on help for personal care.

EATING

0 Normal, does not need help in eating food that is served to them.

1 May need help cutting food or have trouble with some foods, but basically able to eat by themselves.

2 Generally able to feed themselves but may require some help. May lose interest during the meal.

3 Needs to be fed. May have trouble swallowing.

DEMENTIA SEVERITY RATING SCALE (DSRS)

CONTROL OF URINATION AND BOWELS

0 Normal - does not have problems controlling urination or bowels except for physical problems.

1 Rarely fails to control urination (generally less than one accident per month).

2 Occasional failure to control urination (about once a week or less).

3 Frequently fails to control urination (more than once a week).

4 Generally fails to control urination and frequently can not control bowels.

ABILITY TO GET FROM PLACE TO PLACE

0 Normal, able to get around on their own. (May have physical problems that require a cane or walker).

1 Sometimes gets confused when driving or taking public transportation, especially in new places. Able to walk places alone.

2 Cannot drive or take public transportation alone, even in familiar places. Can walk alone outside for short distances. Might get lost if walking too far from home.

3 Cannot be left outside alone. Can get around the house without getting lost or confused.

4 Gets confused and needs help finding their way around the house.

5 Almost always in a bed or chair. May be able to walk a few steps with help, but lacks sense of direction.

6 Always in bed. Unable to sit or stand.

INTERPRETATION
Add up the points for all sections.

Score
0-18 --- Mild
19-36 -- Moderate
37-54 -- Severe

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Appendix B: Figures and Tables

Table 1. *Descriptive Statistics of Patient Demographic Information*

	Variable	N	Percent
AD group			
	Gender		
	Female	91	60.3
	Male	60	39.7
	Race and Ethnicity		
	American Indian	1	0.7
	Asian	2	1.3
	Black	13	8.6
	White	133	88.1
	No Response	1	0.7
	Hispanic	7	4.6
	Age		
	60-69	12	7.9
	70-79	52	34.4
	80-89	81	53.6
	90+	6	4.0
	Educational Attainment		
	0 through 11th grade	13	8.6
	High School graduate	57	37.7
	Some college or associate degree	35	23.2
	College graduate or more	46	30.5
MCI group			
	Gender		
	Female	37	57.8
	Male	27	42.2
	Race and Ethnicity		
	American Indian	0	0
	Asian	1	1.6
	Black	4	6.3
	White	59	92.2
	No Response	0	0
	Hispanic	3	4.7
	Age		
	60-69	8	12.5
	70-79	28	43.8
	80-89	25	39.1
	90+	3	4.7
	Educational Attainment		
	0 through 11th grade	0	0
	High School graduate	21	32.8

	Some college or associate degree	18	28.1
	College graduate or more	25	23.4
NC Group			
Gender			
	Female	21	53.8
	Male	18	46.2
Race and Ethnicity			
	American Indian	0	0
	Asian	0	0
	Black	2	5.1
	White	37	94.9
	No Response	0	0
	Hispanic	1	2.6
Age			
	60-69	8	20.5
	70-79	15	38.5
	80-89	16	41.0
	90+	0	0
Educational Attainment			
	0 through 11^{th} grade	5	12.8
	High School graduate	10	25.6
	Some college or associate degree	14	35.9
	College graduate or more	10	25.6

Figure 1. *DSRS score by Diagnostic Group*

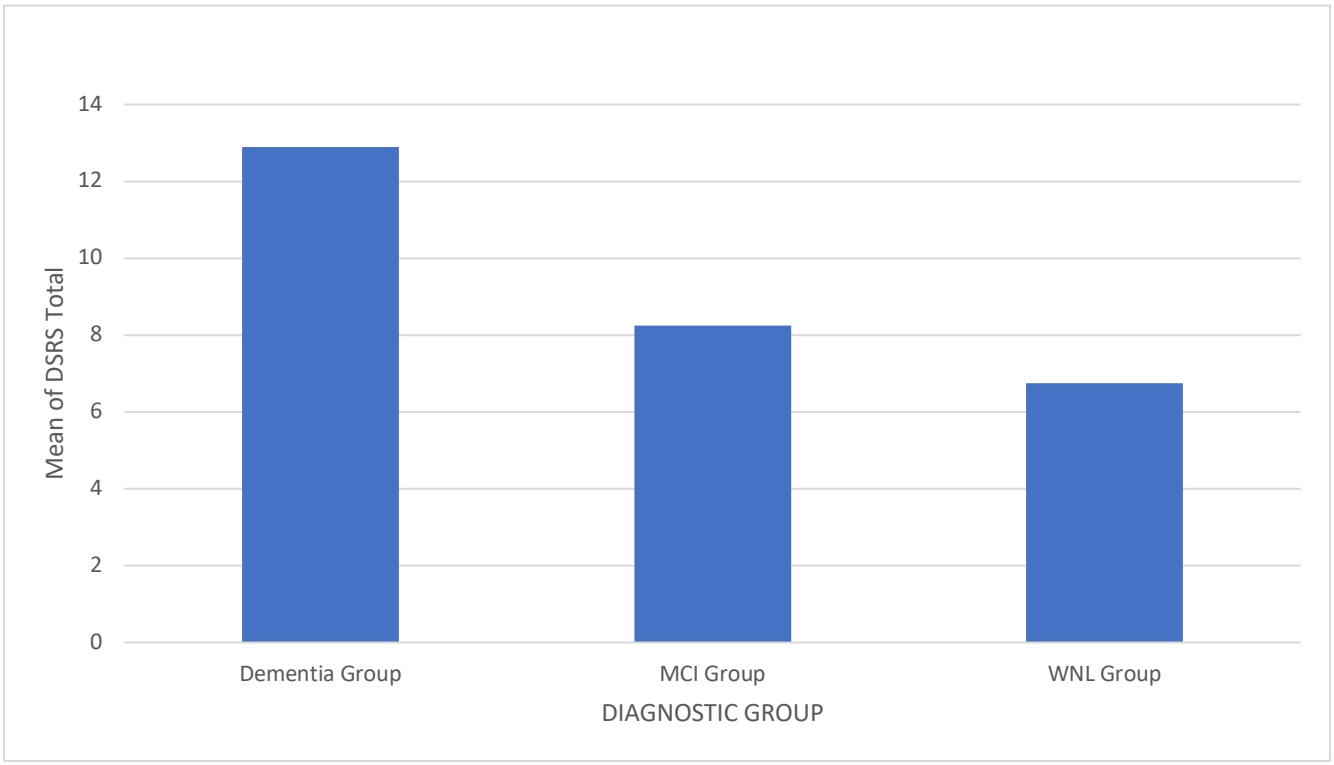

Table 2. *Means and standard deviations of overall DSRS and total TFLS scores by diagnostic group*

	Variable	M	SD
AD group			
	TFLS	33.65	7.62
	DSRS	12.9	5.94
MCI group			
	TFLS	42.83	3.57
	DSRS	8.25	4.51
NC group			
	TFLS	43.85	4.30
	DSRS	6.74	4.75

Table 3. *Means, standard deviations, and correlations of overall DSRS score with neuropsychological tests measuring global cognitive functioning, executive functioning, and adaptive functioning*

Variable	M	SD	r
MoCA	19.31	4.31	-.27**
M-WCST Categories	3.05	1.81	-.25**
M-WCST Perseverative Errors	9.58	8.83	.28**
Stroop Color Word	17.99	10.05	-.22**
Trail Making Test Part B	210.79	89.24	.32**
TFLS Total Score	37.61	7.90	-.32**

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