COGNITIVE REHABILITATION AND TELEHEALTH VIDEOCONFERENCING:

DEVELOPING AN ACCESSIBLE INTERVENTION

FOR SUBJECTIVE COGNITIVE IMPAIRMENT,

MILD COGNITIVE IMPAIRMENT,

AND DEMENTIA

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ABSTRACT

This dissertation contributes to the growing body of research needed to make cognitive rehabilitation for individuals with dementia more accessible to rural families. Our population is aging, and with age comes both normal and abnormal cognitive aging. In Canada, the proportion of older adults is increasing at a greater rate in rural compared to urban areas, which suggests a high need for dementia care that is accessible to rural families. Teleheath videoconferencing is one way to make treatment more accessible. Over the course of three studies, this dissertation developed goal-oriented cognitive rehabilitation as an intervention for individuals with subjective cognitive impairment (SCI), mild cognitive impairment (MCI), and dementia due to AD, and adapted treatment to be delivered through telehealth videoconferencing.

Study 1 reported a strong preference for telehealth delivered treatment over in-person treatment, and initial treatment goals focused on memory, household activities, other cognitive domains, recreation, and higher order tasks. Responders were similar to non-responders in severity, depression, and caregiver burden, but results suggested differences in awareness and neuropsychiatric symptoms. Cognitive rehabilitation targets functional goals, and Study 2 worked to inform treatment development by focusing on the cognitive correlates of function. Hierarchical regression analyses suggested that immediate memory, executive functions, apathy, and depression accounted for unique variance in instrumental activities of daily living in the clinical sample of individuals diagnosed with no cognitive impairment, MCI, dementia due to AD, and non-AD dementia.

The objective of Study 3 was to explore delivering cognitive rehabilitation through telehealth videoconferencing, and to compare in-person delivery to videoconferencing delivery. Using a combined between-subjects, multiple baseline single case experimental design cognitive rehabilitation was delivered to six participants with either SCI, MCI, or early stage dementia due to AD. Participants were randomly assigned to receive treatment in-person or through videoconferencing. Modifying treatment for telehealth required greater reliance on verbal description, but between-group outcomes were similar with good completion rates and high levels of improved goal performance. Overall, this body of work contributes to developing cognitive rehabilitation for individuals with SCI, MCI, and early stage AD. There is a need to continue to adapt this intervention to telehealth videoconferencing and it is feasible to do so.

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1. General Introduction

This research began with the objective of using telehealth videoconferencing to make a promising, non-pharmacological treatment for early stage dementia due to Alzheimer's disease (AD) more accessible to families who live in rural or remote parts of Canada. This document has been prepared as a manuscript style dissertation, and each of the three studies were written as independent manuscripts. Study 1 has been published as Burton, O'Connell, and Morgan (2016) in the journal *NeuroRehabilitation*, and Studies 2 and 3 are unpublished manuscripts. Over the course of the three manuscripts that are included here you will read about the treatment goals of individuals with mild cognitive impairment (MCI) or dementia (Study 1), theoretical considerations for developing cognitive interventions for this population (Study 2), and our successes and challenges in adapting cognitive rehabilitation to new technology (Study 3). The general introduction is intended to provide the broader historical and research context within which each manuscript is situated and provide a rationale for the research that was carried out.

I argue that non-pharmacological interventions are needed not just for dementia due to AD, but also for individuals with MCI, and subjective cognitive impairment (SCI). You will read that the research to date in this area suggests that goal-oriented cognitive rehabilitation is a promising avenue to pursue (Bahar-Fuchs, Clare, & Woods, 2013; Clare et al., 2010), but the theoretical basis for this intervention needs to be further developed (Giebel, Challis, & Montaldi, 2015). Finally, I argue that it is essential for specialized treatments to be accessible to all Canadians, whether they live in an urban center where services are more readily available, or rural and remote communities. Telehealth videoconferencing has emerged as a feasible and acceptable approach to increasing the accessibility of healthcare services (Dal Bello-Haas, O'Connell, & Crossley, 2014; Greene et al., 2010; Morgan et al., 2009; Morgan et al., 2011; O'Connell et al., 2014; O'Reilly et al., 2007) and it offers the possibility of making cognitive rehabilitation more accessible.

1.1 Introduction to Cognitive Aging

Around the globe, and here in Canada, our population is aging (Statistics Canada, 2010). With age, people change biologically, socially, and psychologically. Age-related cognitive

change is one aspect of aging (Glisky, 2007). Not every individual will experience the same age-related changes and the changes are not the same in each cognitive domain. One approach to organizing cognitive aging is to differentiate developmentally normal age-related changes from abnormal changes in cognition in behaviour (Smith & Bondi, 2013). Broadly, abnormal (sometimes referred to as malignant) cognitive aging is organized across a continuum with no cognitive impairment at one end and dementia at the other (i.e., Jack et al., 2010; Peterson et al., 2004). Across this continuum an array of terms and criteria have been proposed with the goal of identifying prodromal or pre-clinical stages of dementia (i.e., late life forgetfulness, questionable dementia, aging associated cognitive decline, cognitive impairment no dementia, mild cognitive impairment; Smith & Bondi, 2013). The objective of this line of research has been to reliably identify individuals who will go on to develop dementia due to AD as early in the disease course as possible. In the studies presented here, I refer to SCI, MCI, and dementia as descriptors of cognition and behaviour. Within these broad categories any underlying pathology can be due to a number of underlying etiologies (i.e., dementia may be due to Alzheimer's disease, Parkinson's disease, frontotemporal degeneration).

      1.1.1 Subjective cognitive impairment. SCI, which is also sometimes referred to as subjective memory complaints, refers to individuals who believe they have a cognitive problem but are cognitively normal (i.e., no evidence of objective cognitive impairment when neuropsychological tests are administered; Reisberg & Gauthier, 2008). SCI is common among older adults. Community-based studies estimate that among adults age 65 and above the prevalence of SCI is between 25 and 56% (Reisberg & Gauthier, 2008). While the research continues to develop, SCI may be the earliest recognizable impairment that ultimately eventuates in AD or another dementia (Reisberg & Gauthier, 2008). For example, in their widely cited study, Geerlings and colleagues (1999) reported that compared to same age individuals without memory complaints for individuals with complaints the risk of developing AD over an average period of 3.2 years was three times greater. In this study, the question, "Do you have complaints about your memory?" assessed memory complaints (Geerlings et al., 1999). A recent meta-analysis of 28 studies examining the trajectory of individuals with SCI (Mitchell, Beaumont, Ferguson, Yadegarfar, & Stubbs, 2014) concluded older individuals with SCI were twice as likely to develop dementia as individuals without SCI. It appears worry about cognitive change, and not just complaints, is an important factor. For example, Jessen and colleagues (2010)

reported that the risk of dementia for SCI individuals with worry was double that of SCI individuals without worry. If individuals with SCI are the earliest identifiable group along the continuum of abnormal cognitive-aging, then this is where the earliest interventions will need to be developed (Reisberg & Gauthier, 2008; Mitchell et al., 2014). For this reason, in Study 3 where you will read about an intervention for cognitive decline, individuals with SCI were included as participants.

        1.1.2 Mild cognitive impairment. MCI has emerged as the most commonly used and most widely studied diagnostic category referring to individuals within the boundary of normal cognitive aging and dementia (Smith & Bondi, 2013). The diagnostic criteria have evolved since the term was conceived by Petersen and colleagues (1999), and the 2011 American Psychiatric Association and NIA-Alzheimer's Association task force criteria require: (1) concern regarding a change in cognition; (2) impairment in one or more cognitive domains; (3) preservation of independence in functional activities; (4) not meeting the criteria for dementia (Albert et al., 2011). Here in Canada, at the 4th Canadian Consensus Conference on the Diagnosis and Treatment of Dementia, these guidelines were endorsed, however in contrast to the Albert and colleagues' guidelines (2011) Gauthier and colleagues (2012) concluded that the term 'MCI due to AD' be used only in rare circumstances at speciality clinics using detailed neuroimaging. This underscores the uncertainty surrounding the underlying pathology and prognosis of an MCI diagnosis.

        Population studies such as the Cardiovascular Health Study (Lopez et al., 2002) and the Mayo Clinic Study of Aging (Petersen et al., 2010) estimated the prevalence of MCI to be in the 15 – 20% range for adults without dementia who are 65 years old or older. Heterogeneity has been a challenge in the development of the MCI construct. Both prevalence estimates and the longitudinal trajectory of MCI vary depending on the population sampled (i.e., community based or clinical), diagnostic criteria and how they are operationalized, as well as the assessment process (i.e., number of neuropsychological tests administered; Smith & Bondi, 2013). In terms of course, in their meta-analysis, Mitchell and Shiri-Feshki (2009) reported an adjusted annual conversion rate of 5-10 % from MCI to dementia due to AD or vascular dementia. However, MCI is a diagnosis of uncertainty and heterogeneity (Tuokko & Hultsch, 2006) because some individuals with MCI will go on to meet the criteria for dementia, some will remain stable, and some will improve.

Ultimately, the purpose of developing and refining MCI as a construct is to identify individuals who will go on to develop dementia early in the disease course, so that safe and effective interventions that will prevent or reduce the burden of these disorders can be provided (Petersen & Morris, 2005). Currently, there are no pharmacological interventions that improve outcomes in MCI. Reviews and meta-analyses of the pharmacological literature have concluded that medications approved for AD (e.g., cholinesterase inhibitors, memantine) have not been associated with any delay in disease progression for individuals with MCI (O'Brien & Burns, 2011; Russ & Morling, 2012). Furthermore, cholinesterase inhibitors in particular are associated with increased risk of adverse events, particularly gastrointestinal (Russ & Morling, 2012). In contrast, there are a number of promising non-pharmacological interventions for MCI (see Rodakowski, Saghafi, & Butters, 2015 for a scoping review) including cognitive interventions (see Chandler, Parks, Marsiske, Rotblatt, & Smith, 2016; Hong, Jang, Hwang, Roh, & Lee, 2015; Jean, Bergeron, Thiverge, & Simard, 2010 for reviews and meta-analyses). Cognitive interventions for MCI need to be further studied and developing cognitive rehabilitation, a promising but understudied approach to cognitive intervention, is the objective of the research presented here.

1.1.3 Dementia. Dementia is a clinical syndrome characterized by an acquired decline in cognitive functioning in multiple cognitive domains that interferes with social and occupational functioning (Rockwood, Bouchard, Comiciuli, & Leger, 2007). The most recent diagnostic guidelines from the National Institute on Aging-Alzheimer's Association (NIA/AA) working group, which were endorsed at the 4th Canadian Consensus Conference on the Diagnosis and Treatment of Dementia, state that a diagnosis of dementia requires cognitive or behavioural symptoms that interfere with functional activities, a decline from previous functioning, and cognitive or behavioural impairment in at least two domains (Gauthier et al., 2012; McKahn et al., 2011). The presence of cognitive impairment can be detected based on an interview with a knowledgeable informant and a mental status examination or neuropsychological testing (McKahn et al., 2011). Learning and memory, reasoning, visuospatial abilities, language, and personality or comportment are the domains in which cognitive or behavioural impairment may occur. These are the core clinical criteria for dementia, and there are many different causes of dementia. Causes of dementia include AD, VaD, frontotemporal dementia (FTD), diffuse Lewy body disease (DLBD), Parkinson's Disease (PD) and Huntington's Disease (HD). Across the

world, the prevalence of dementia and the proportion of type of dementias differ, but dementia due to AD or VaD are the most prevalent forms of dementia in Europe, North America and Asian countries (Reitz, Brayne, & Mayeux, 2011). Dementia due to AD and mixed AD/VaD are the focus of the research presented here.

Dementia due to Alzheimer's disease. In Europe and North America, AD is the most common type of dementia and accounts for approximately 70% of all dementia cases (Reitz et al., 2011). AD is a progressive, degenerative, and fatal disease. Typically, the earliest deficits are in memory and individuals have difficulty retaining new information as efficiently as they once did (Morris, 2008). Individuals diagnosed with dementia due to AD will meet the core clinical criteria for dementia outlined by the NIA/AA (McKahn et al., 2011). Further, a diagnosis of dementia due to AD requires an insidious onset of symptoms and clear history of worsening cognition (McKahn et al., 2011). The most prominent early cognitive deficits are related to learning and memory, language, visuospatial abilities, or executive functions (McKahn et al., 2011). Amnestic presentations of AD are the most common and AD is characterized by an early impairment in episodic memory (McKahn et al., 2011). Episodic memory refers to information that is learned by an individual and is context-dependent is or linked to a particular time and location (Evans, 2013). In contrast, semantic memory refers to an individual's store of factual knowledge. For example, recalling what one did last weekend is an episodic memory, and recalling that the Edmonton is the capital of Alberta is a semantic memory (Evans, 2013). Generally, as AD progresses, an individual's episodic memory impairment becomes more severe, and impairments in attention, executive functions, semantic memory, language, perception and praxis develop (Evans, 2013).

The neuropathological changes that occur in AD have been described, but the aetiology of this disease is still unknown (Morris, 2008). In regards to neuropathology, AD is characterized by widespread cerebral atrophy in the parietal and temporal lobes in particular (Morris, 2008). Structures in the medial temporal lobes, such as the hippocampus and parahippocampal gyrus, are particularly impacted early in the course of the disease (Morris, 2008). As will be discussed, the neuropathology of AD does not correspond perfectly to the cognitive and functional changes experienced by individuals, however, the early deterioration of the medial temporal lobes relates to the early episodic memory deterioration as these areas are critical for remembering episodes or events (Evans, 2013; Snowdon, 2003). In AD, the integrity of the medial temporal lobes is

impacted by a build-up of amyloid plaques, sometimes referred to as senile plaques, and neurofibrillary tangles (Morris, 2008).

      Mixed Alzheimer's disease and vascular dementia. Broadly, dementia due to vascular disease, or VaD, is a decline in cognitive function due to the negative effects of vascular disease on the brain. There is a great deal of debate and discussion about how to define VaD, how to diagnose VaD and even what to call VaD (Kling, Trohanowski, Wolk, Lee, & Arnold, 2013). Given this lack of clarity it is perhaps not surprising that estimates of the prevalence of VaD in autopsy series varied wildly from 0.03% to 58% of cases (Jellinger, 2007; Kling et al., 2013). Despite this confusion, it has become increasingly apparent that VaD and AD frequently co-occur (Kling et al., 2013).

      The 4th Canadian Consensus Conference on the Diagnosis and Treatment of Dementia recommended that the recommendations from the American Heart Association/American Stroke Association (ASA/AHA) be applied to the diagnosis of the vascular contributions to cognitive impairment and dementia (Gauthier et al., 2012; Gorelick et al., 2011). As with a diagnosis of dementia due to AD, an individual dementia of vascular will meet the core clinical criteria for dementia described above. The ASA/AHA recommended that probable VaD be diagnosed when cognitive impairment and imaging evidence of cerebrovascular disease are present, and there is a clear temporal relationship between the onset of cognitive deficits or the pattern of cognitive impairment, and a vascular event (e.g., clinical stroke) or diffuse, subcortical cerebrovascular disease pathology (Gorelick et al., 2011). Due to the frequent co-occurrence of VaD and AD, individuals with mixed AD and VaD will be included in the studies reported here.

1.2 Conceptual Frameworks for Understanding Dementia due to AD or mixed AD/VaD

      Since AD was discovered to have a neurological basis the conceptual understanding of dementia has focused on dementia as a disease of the brain, and a medical or disease model has dominated the assessment, formulation and treatment of dementia (Spector & Orrell, 2010; Clare, 2008). Research from this perspective has emphasized causal links from pathological changes in the brain to observed features of dementia (Clare, 2008). While this conceptualization of dementia has made valuable contributions, there is reason to believe a broader focus is needed.

      In regards to the limitations of the biomedical model of dementia, brain pathology post-mortem does not always coincide with the cognitive symptoms an individual displayed while

living (Snowdon, 2003). For example, in the Nun Study, a longitudinal study of 678 Catholic sisters, Snowdon (2003) found that 8% of sisters with severe AD neuropathology did not have any memory impairment. Further, just as individuals can have neuropathology without experiencing disability, individuals with dementia can experience disability over and above that arising from purely neurological impairment (Spector & Orrell, 2010). Essentially, an individual experiences more functional impairment than one would anticipate given their neuropathology. This is sometimes referred to as 'excess disability,' which Brody, Kleban, Lawton and Silverman (1971) explain occurs when an individual's functional incapacity is greater than what is warranted by the actual impairment. In short, neuropathology and functional impairment do not always correspond.

The function of individuals with dementia is impacted by psychosocial factors such as the experience of life events, social environment, coping strategies, depression, and anxiety (Spector & Orrell, 2010). For example, Orrell and Bebbington (1998) found that life events such as the death of a loved one or moving into a long-term care facility increase the risk of individuals with dementia being admitted to a hospital. In a longitudinal community-based cohort study, individuals living alone and individuals without any social ties had a greater risk of developing dementia (Fratiglioni, Wang, Ericsson, Maytan, & Winbald, 2000). Further, as long as social contact was experienced as satisfying individuals with infrequent social interactions were not at greater risk for developing dementia (Fratiglioni et al., 2000). In regards to depression and anxiety, Ballard, Bannister, Solis, Oyebod, and Wilcok (1996) estimated that depression has a 20% prevalence rate in clinical samples of individuals with dementia and anxiety has a 30% prevalence rate in these samples. Both depression and anxiety can exacerbate cognitive impairments and reduce quality of life, and depression has further been linked with the decision to admit persons with dementia into a nursing home (Sury, Burn, & Brodaty, 2013). In sum, psychosocial factors play important roles in the function and trajectory of individuals with dementia.

To account for psychosocial factors other models of dementia have been proposed as alternatives, or extensions, to the biomedical model of dementia (e.g., Sabat, 1994; Kitwood & Bredin, 1992; Spector & Orrell, 2010). In contrast to the medical model of dementia, Kitwood and Bredin (1992) proposed a dialectical model of dementia where neurological impairment, the self and social context interact with each other. In keeping with this framework Clare (2008)

refers to the World Health Organization's disability model of dementia, which includes social context and restrictions on social participation. She suggests that dementia due to AD may be best characterized by the biopsychosocial model of medicine originally developed by Engel (1977).

In the context of dementia care and treatment there has been an increasing focus on concepts of personhood and person-centred care, and a developing emphasis on living with and managing dementia. The perspective of the person with dementia and their family members and caregivers has come to be explored and valued (Sabat, 2002). Biopsychosocial models of dementia argue for the importance taking into account the whole person. This includes biological changes, cognitive changes (memory, attention) personality, emotional changes, behavioural changes, social support, and social interaction (Clare, 2008).

Recently, Spector and Orrell (2010) amalgamated existing models of dementia (both biomedical and psychosocial) in a pragmatic biopsychosocial model of dementia. This model, which has not yet been empirically tested, presents dementia as a process beginning with aging and ending in death (Spector & Orrell, 2010). The model describes an individual's current functioning and imagines where he or she could be optimally be functioning, and the difference between these two states represents excess disability. The model conceptualizes an individual's trajectory as being affected by both biological and psychosocial factors, which are categorized as tractable or fixed. Tractable factors are amenable to change and fixed factors relate to history or risk factors and are not amenable to change (Spector & Orrell, 2010). For example, age, health prior to dementia, and genetic factors are biological fixed factors, and physical health and sensory impairment are biological tractable factors. Similarly, education and personality traits are psychosocial fixed factors, and mental stimulation, mood and reaction to life events are psychosocial tractable factors. Biological and psychosocial interventions are included in the model and address tractable factors. The model was designed to help understand and conceptualize what impacts individuals with dementia and how to intervene appropriately (Spector & Orrell, 2010). As will be described, cognitive rehabilitation, which is the focus of the proposed research, fits within a person-centred, biopsychosocial model.

1.3 Cognitive Rehabilitation

The term 'rehabilitation' has been defined in many different ways. As Wilson (1997) explained, dictionary definitions imply that the objective of rehabilitation is to restore function to

a previous level. These definitions are misleading because it is often not possible to restore individuals with a brain injury or neurodegenerative disease "to their former selves" (Wilson, 1997; Clare, 2008). Instead, Wilson (1997) suggests that a more appropriate definition of rehabilitation was the definition written by the World Health Organization (WHO) in 1986. This definition stated:

> Rehabilitation implies the restoration of patients to the highest level of physical, psychological and social adaptation attainable. It includes all measures aimed at reducing the impact of disabling and handicapping conditions and at enabling disabled people to achieve optimum social integration (p.1).

Wilson (1997) further noted that the role of the person engaging in rehabilitation is missing from this definition. The role of the individual is clearly emphasized in McLellan's (1991) definition where he wrote: "Rehabilitation is a process whereby people who are disabled by injury or disease work together with professional staff, relatives and members of the wider community to achieve their optimum physical, psychological, social and vocational wellbeing" (p. 785). This definition of rehabilitation is consistent with a biopsychosocial perspective.

Moving from rehabilitation in general to cognitive rehabilitation in particular Wilson (1997) built on the WHO and McLellan definitions of rehabilitation to develop a definition of cognitive rehabilitation. She wrote that cognitive rehabilitation is "an intervention strategy or technique that intends to enable clients or patients, and their families to live with, manage, by-pass, reduce or come to terms with deficits precipitated by brain injury" (Wilson, 1997, p. 488). The term 'cognitive rehabilitation' seems to imply that the focus of treatment is solely on remediating or compensating for decreased cognitive abilities (Sohlberg & Mateer, 2001). This is not the case and, as Solhberg & Mateer (2001) suggested, a more appropriate term might be *'the rehabilitation of individuals with cognitive impairments.'* While cognitive impairments are certainly an important focus of treatment, social and emotional factors are incorporated into treatment plans and goals (Clare, 2008; Mateer, Sira, & O'Connell, 2006; Sohlberg & Mateer, 2001).

1.3.1 The history of cognitive rehabilitation. The history of cognitive rehabilitation begins with the history of neuropsychology. In fact, Boake (2003) suggests that neuropsychological rehabilitation is as old as the field of neuropsychology itself. Cognitive rehabilitation can be traced back 2,500 to 3,000 years to an Egyptian document about treating

brain injury, and current rehabilitation techniques were foreshadowed by Itard's work with Victor, the Wild Boy of Aveyron in the 18th century (Wilson, 1997). Boake (2003) notes that much of the pioneering work in neuropsychological rehabilitation occurred in the context of aphasia. Howard and Hatfield's (1987) historical review of aphasia therapy includes work that took place as early as the 1600s. Later, in 1865, Broca described a rehabilitation program for an individual who was unable to read words aloud (Berker, Berker, & Smith, 1986).

      The recent history of neuropsychological rehabilitation coincides with major world conflicts, and war casualties stimulated the growth of the field. Wilson (1997) writes that cognitive rehabilitation that would be recognized by todays' practitioners began in Germany following the First World War. At that time brain rehabilitation centres were developed and these centres, clustered in Germany and Austria, provided medical care and rehabilitation to soldiers with brain injuries (Boake, 2003). Typically, these centres consisted of a residential program, a psychological evaluation unit and a specialized workshop. Treatment focused on helping individuals with an acquired brain injury use preserved skills to substitute, or compensate, for lost skills (Boake, 2003).

      In the Soviet Union, during and following the Second World War, Luria and his colleagues treated over 800 soldiers with brain injuries and developed interventions for motor planning, visual perception, and executive functions based on Luria's theory of functional systems (Wilson, 1997; Boake, 2003). In the United Kingdom, it was proposed that neuropsychological rehabilitation could be approached in one of three ways: compensation, substitution, and direct retraining (Wilson, 1997). Similar to the centres in the Soviet Union, brain injury centres in the United States provided specialized rehabilitation services to wounded soldiers. Following the end of the Second World War the professions of occupational therapy, physical therapy, psychology and vocational rehabilitation counselling all expanded to meet the treatment needs of veterans (Boake, 2003).

      In Israel, following the Yom Kipur War in 1973, Ben-Yishay developed a day treatment program where veterans with brain injuries completed a program that included cognitive exercises, psychotherapy, and therapeutic community activities (Ben-Yishay, 1996). Treatment took place over the course of several months, and other countries adopted the day treatment model (Boacke, 2003). In the 1970s and 1980s new models of rehabilitation were developed including residential programs, and programs operated outside of a centre and provided

treatment in the community (Boake, 2003). Interventions for specific cognitive deficits, many using computer programs to drill exercises, were also developed at this time and in the 1980s debate surrounding whether therapies should aim to directly retrain cognitive abilities or to address specific goals took place (Boake, 2003; Sohlberg & Mateer, 2001).

Cognitive rehabilitation has become a practice standard for treatment for individuals who have sustained a traumatic brain injury or a stroke (Cicerone et al., 2005, 2011). In comparison to acquired brain injury, cognitive rehabilitation for MCI and dementia due to AD is a recent development in the broader field of neuropsychological rehabilitation. Cognitive interventions for these populations have not been studied as extensively (Hampstead, Gillis, & Stringer, 2014).

1.3.2 Theoretical foundations of cognitive rehabilitation. The field of cognitive rehabilitation has been criticised as lacking theory. Some have suggested that theory needs to be further developed and integrated into rehabilitation practices, and closer links need to be forged between cognitive science and rehabilitation (e.g., Wilson, 2003; Sohlberg & Mateer, 2001). Others have questioned whether theories of cognitive neuropsychology have lived up to the promise of informing rehabilitation and question the usefulness of theory for cognitive rehabilitation (Coltheart, Bates, & Castles, 1994). Further, as Wilson (2003) tells us, the literature is filled with examples of individuals who state their interventions are theoretically grounded when they are not, and she described models of cognitive rehabilitation as "hard to come by" (Wilson, 2003).

Although models of cognitive rehabilitation may be underdeveloped they have the potential to guide practice in multiple ways. Coltheart and colleagues (1994) explain that a model of cognitive rehabilitation can provide a basis for assessment techniques, define what the focus of treatment should be, and provide ideas for treatment methods (Coltheart et al., 1994). In essence, it has been argued that successful outcomes depend on specific interventions and a disorder must be understood before it can be treated (Stuss, Winocur, & Robertson, 1999).

Any theory of cognitive rehabilitation draws on research from multiple fields. For example, Sohlberg and Mateer (2001) state that rehabilitation specialists need to draw on behavioural, sociological, psychological, and neuropsychological traditions in order to manage cognitive disorders. Further, these professionals need to apply current knowledge form cognitive psychology and the neurosciences (Sohlberg & Mateer, 2001). Similarly, Stuss and colleagues (1999) consider cognitive rehabilitation to be "a truly integrative discipline" that brings together

biology, motivation and social context as well as cognitive psychology (p. 1). These authors believe basic science is the foundation of cognitive rehabilitation and argue that building close links between basic cognitive research and program development leads to programs that are empirically and theoretically based, and address patient's needs (Stuss et al., 1999). Further developing the theoretical basis for cognitive rehabilitation for abnormal cognitive aging is the objective of Study 2.

Compensation or restoration. Within the discussions of theoretically driven cognitive rehabilitation, there has been a great deal of debate surrounding whether it is better to focus on training specific skills or processes, or whether to focus on functional abilities (Sohlberg & Mateer, 2001). This is sometimes framed as a conflict between restoring underlying cognitive abilities (e.g., episodic memory) and using external aids (e.g., consulting a calendar).

Lillie and Mateer's constraint-based model. Lilie and Mateer (2006) proposed constraint-based therapies as a model for cognitive rehabilitation. In this model, there is a conflict between the use of external compensatory methods and the recovery of underlying cognitive functions. Using compensatory aids is seen as a potential threat to the recovery of underlying cognition, which is consistent with data from constraint induced movement therapy. Constraint induced movement therapy is used following a limb injury, and in this approach an individual's functional limb is restrained in order to encourage the use of the affected limb (Lillie & Mateer, 2006). This approach, based on animal studies, is guided by the theory that when an individual injures a limb he or she tends to avoid using the affected limb, but will initially spontaneously use the affected limb. Over time, spontaneous use of the affected limb decreases because use of the unaffected limb is reinforced (e.g., successful feeding) and use on the affected limb is punished (e.g., failed attempts; Lillie & Mateer, 2006). This is referred to as learned non-use and is counteracted by restraining the unaffected limb.

The theory behind constraint-induced movement therapy has been extrapolated to treating individuals with aphasia by creating a game where certain verbal responses are required, which constrains compensatory communication strategies such as gestures (Lillie & Mateer, 2006). Moving from language to cognitive abilities such as memory and attention it becomes more challenging to restrain an intact ability in order to force an impaired ability to be used. Jennings and Jacoby (2003), following a model where memory is divided into the processes of familiarity and recollection, have developed a procedure to restrain familiarity in order to train recollection

in older adults. Constraint-based approaches assume that constraining intact abilities allows the impaired abilities to operate through spontaneous recovery. Importantly, there is no current consensus on the use of constraint models in cognitive training (in part because we are not yet able to constrain recruitment of non-affected neural networks to adequately encourage recovery), and not all in the field agree that use of compensatory aids results in attenuated recovery. Given the relative infancy of this field, with few data suggesting success I do not advocate this approach in cognitive rehabilitation with individuals with dementia. Foremost, I argue that in a degenerative disorder such as AD there is no reason to anticipate the spontaneous recovery of episodic memory and this cognitive ability is deteriorating. Moreover, I argue that restricting a functioning system might facilitate decline rather than recovery. Clearly more theoretical and applied work on constrain-induced cognitive rehabilitation needs to be completed before being applied to dementia.

　　Dixon and Bäckman's model of compensation. Dixon and Bäckman (1999) have developed a theoretical model of compensation that has been applied to cognitive rehabilitation. Dixon and Bäckman (1999) explain that a need for compensation arises when the demands of the environment are greater than the skills an individual possess. These authors define compensation as "a process of overcoming losses or deficits through one of several recognizable mechanisms" and they list remediation, substitution with a latent process, substitution with novel process, (d) accommodation, and assimilation as compensatory mechanisms (Dixon & Bäckman, 1999).

　　Wilson's holistic model. Wilson (1997) describes four approaches to cognitive rehabilitation, and advocates for a holistic approach that goes beyond a detailed understanding of a specific cognitive impairment, beyond training specific abilities, and beyond an integration of learning theory, cognitive psychology and neuropsychology. The holistic approach that Wilson (1997) argues is needed considers the individual's emotional needs, awareness of cognitive deficits, and social context. Wilson's (1997) discussion focuses on treating individuals with acquired brain injuries, but her approach is consistent with the spirit of biopsychosocial models of dementia.

　　There is an emerging consensus that functional changes are the goal of treatment (Hampstead et al., 2014), but in some contexts there continues to be work that strives to train specific skills in the hope that they will generalize. Sohlberg and Mateer (2001) write that cognitive rehabilitation targets functional changes, but does not claim to reduce or cure

underlying impairments. Rather, the aim of cognitive rehabilitation is to maximize function in daily life. Consistent with this view, the goal-oriented approach to cognitive rehabilitation that was further developed in the studies presented here focused on goals that are important to the patient or client, and their family member or caregiver.

1.3.4 Distinguishing cognitive rehabilitation from closely related interventions. Cognitive rehabilitation is one of a number of non-pharmacological cognition focused interventions that have been applied to cognitive impairments in late life including dementia due to AD. To avoid confusion, Clare and Woods' (2004) broad differentiation of cognitive rehabilitation from cognitive training and cognitive stimulation has been adopted here. Cognitive stimulation and reality orientation approaches engage individuals with dementia in group based activities and discussions that aim to enhance cognitive and social functioning (Clare & Woods, 2004). Cognitive stimulation aims to provide global stimulation and is based on the theoretical argument that cognitive functions are not used in isolation but in combination (Clare & Woods, 2004). For example, the broad domain of memory operates with processes related to attention, language, problem solving and others (Clare & Woods, 2004). In contrast, cognitive training involves guided practice on a particular set of standardized tasks that are designed to target specific cognitive functions (Clare & Woods, 2004). Here, the underlying assumption is that practice can improve or maintain function in the given domain (Clare & Woods, 2004). It is further assumed that the effects of practice will generalize to contexts other than the training environment (Clare & Woods, 2004).

In contrast, cognitive rehabilitation is an individualized approach where functional personally relevant goals are identified and addressed collaboratively (Clare, 2008; Clare & Woods, 2004). The focus is on improving everyday functioning rather than improving performance on specific tasks or tests. To summarize, the key feature that distinguishes cognitive rehabilitation from closely related interventions such as cognitive stimulation or cognitive training is the collaborative identification of goals that are personally important to the individual with dementia and the emphasis on improving everyday functioning.

These broad distinctions between cognitive stimulation, cognitive training, and cognitive rehabilitation are clear in theory, but not surprisingly some approaches appear to fall somewhere between these categories and many studies use multiple approaches (Hampstead et al., 2014). At times, authors describe approaches to cognitive rehabilitation that are similar to, but not entirely

consistent with Clare and Woods' (2004) descriptions. For example, Loewenstein, Acevedo, Czaja, and Duara (2004) had individuals complete a cognitive rehabilitation program where each participant completed individual training sessions on the same areas (face-name associations, orientation, procedural memory, sustained attention, visuomotor processing, making change, balancing a checkbook). Here the approach generally targeted everyday functioning rather than broad cognitive domains, which is consistent with cognitive rehabilitation, but focuses on a set of standard training tasks rather than reaching individual goals, which is consistent with cognitive training. Therefore, when describing past research the methods of the intervention are summarized as terminology in the field of psychosocial interventions for dementia are not used consistently.

   1.3.5 A goal-oriented approach to cognitive rehabilitation. The approach to cognitive rehabilitation for individuals with dementia that is the focus of the research presented here is based on Clare's (2008) model. Her approach is consistent with biopsychosocial models of dementia and Wilson's (1997) call for holistic cognitive rehabilitation. As detailed in *Neuropsychological Rehabilitation and People with Dementia* this approach focuses on individuals in the early stages of AD but as Clare (2008) explains, could be applied to individuals in other stages of dementia due to AD or with other types of dementia. Consistent with the biopsychosocial models of dementia described previously, Clare (2008) emphasized that cognitive rehabilitation with individuals diagnosed with dementia takes place within a person centred framework. Therefore the goals of treatment, treatment approaches, and specific techniques are individually tailored. Clare (2008) explained that the model of cognitive rehabilitation she developed for people with early stage dementia integrates evidence and practice from dementia care with evidence and practice from the field of cognitive rehabilitation with individuals who have brain injuries. In her own words:

   "Cognitive rehabilitation involves individually designed interventions aimed at

   addressing specific practical difficulties identified by the person with dementia and/or

   family caregiver that are relevant to everyday life and are related in some way to

   cognitive impairment. The aim is to support aspects of everyday functioning and well-

   being rather than to improve performance on cognitive tests per se. This approach has

   primarily been used with people who have early-stage dementia, but could be applied to

difficulties arising at all stages from mild impairment to severe dementia" (Clare, 2008, p. 66).

Cognitive rehabilitation with people with dementia begins with a thorough assessment, next rehabilitation goals are set, a strategy for addressing these goals is devised and integrated into a broad intervention plan that considers well-being and emotional responses (Clare, 2008). The assessment phase can be based on a dementia diagnostic assessment or can be tailored specifically for planning cognitive rehabilitation. The central objective of an assessment for cognitive rehabilitation is to conceptualize the individual's cognitive difficulties and their relationship to other psychological and social factors (Clare, 2008). Clare's (2008) approach to assessment for cognitive rehabilitation includes a neuropsychological assessment, an assessment of everyday functioning, an assessment of coping style, an assessment of awareness, and an assessment of the family caregiver.

1.3.6 Techniques for cognitive rehabilitation for dementia. The specific techniques used in cognitive rehabilitation can be divided into three broad categories: behavioural approaches, restorative approaches, and metacognitive approaches (Raskin, 2010). Behavioural approaches aim to facilitate change and the level of behaviour and focus on compensating for functional loss (Raskin, 2010). Also referred to as compensatory approaches, behavioural rehabilitation teaches individuals to use compensatory aids to complete tasks. For example, learning to make lists of to be remembered items rather than relying on memory is a behavioural approach. In contrast, restorative approaches aim to improve lost function and change is targeted at the level of restitution (Raskin, 2010). For example, completing a series of drills designed to improve attention by re-establishing injured pathways is a restorative approach. Thirdly, metacognitive approaches aim to train people to use strategies that allow them to self-monitor (Raskin, 2010). Importantly, these approaches are often used in combination.

In her text on text on cognitive rehabilitation and people with dementia Clare (2008) presents methods of memory rehabilitation. The emphasis on memory follows from the focus on individuals with dementia due to AD. Following Clare (2008) methods for memory rehabilitation are emphasized here, however, individuals with AD set a wide range of goals for rehabilitation such as improving concentration and these areas are touched on as well (Clare et al., 2011). Further, in a holistic model of cognitive rehabilitation, areas of functioning outside of the cognitive domain, importantly emotional functioning, are also addressed.

1.3.7 Principles for supporting episodic memory functioning in AD. Episodic memory is memory for events that occurred in a specific spatial or temporal context (Glisky, 2004). There are a number of principles and specific techniques that can guide attempts to promote remaining episodic memory functioning (Clare, 2008). Principles that have been suggested for guiding learning for people with dementia include dual cognitive support (Bäckman, 1992, 1996), errorless learning (Clare, Wilson, Breen, & Hodges, 1999), and effortful processing (Clare & Wilson, 2004). Dual cognitive support refers to using strategies that provide support for the individual with AD both when learning or encoding the material and when retrieving the material. For example, organizing material during study and providing retrieval cues (Bäckman, 1992, 1996). Errorless learning is the general principle of reducing the number of errors during the learning phase (Clare, 2008). Effortful processing suggests that techniques requiring more active processing are more beneficial (Clare, 2008). Specific strategies for rehabilitation such as spaced retrieval, cueing, mnemonics, sematic elaboration and processing and subject-performed tasks are guided by these principles.

Spaced retrieval. Spaced retrieval is a memory intervention where information is recalled successfully at gradually increasing intervals of time (Camp, Foss, O'Hanlon, & Stevens, 1996; Camp & Stevens, 1990; Camp, 2001). For example, immediate recall, recall after a 10 second interval, recall after a 20 second interval, and then intervals of 30s, 1min, 2min, 4min and so on (Camp, 2001). If the individual does not recall the material on a trial then the correct response is provided and he or she is asked to immediately recall the material. Then, the next interval of time is the last trial where the material was successfully recalled. This approach is well studied with participants who have AD and its efficacy has been demonstrated (Camp, 2001). Spaced retrieval has further been applied to the clinical goals of speech language pathologists such as remembering rooms numbers, remembering a daily routine, remembering to have a sip of liquid after a bite of food (Camp, 2001).

Cueing and fading. In cuing, or the method of vanishing cues, a relevant cue becomes less and less detailed as the individual's ability to recall the item improves (Glisky, 2004). For example, when learning the name of an individual the participant would first be shown their entire name as the cue and then letters would be removed in subsequent trials. This method was designed to take advantage of preserved implicit memory functioning in individuals with

amnesia (Glisky, 2004) and has since been applied to help individual with AD acquire new information (Clare, 2008).

Mnemonics. Mnemonics are memory strategies, or techniques, that can be used to help recall information. Clare (2008) suggests that simple mnemonics can help people diagnosed with dementia. For example, someone might be taught to use visual imagery to learn the association between a name and a photograph. Mnemonics are generally used in combination with other techniques such as spaced retrieval. In fact, learning techniques are routinely combined to support episodic memory in cognitive rehabilitation (Clare, 2008), and some research has found that there is no difference in the efficiency of methods including spaced retrieval, cueing and fading, errorless learning, and trial and error approaches (Bier et al., 2008).

1.3.8 Reviewing the evidence for cognitive rehabilitation for MCI and dementia due to AD or VaD. Cognitive rehabilitation for MCI and dementia due to AD looks to improve the lives of people with cognitive impairments and their loved ones. Focusing first on dementia due to AD and then moving down the spectrum of cognitive impairment to MCI, the evidence for cognitive rehabilitation for these populations is summarized. In 2013, Bahar-Fuchs and colleagues updated their Cochrane review of cognitive rehabilitation and cognitive training for individuals with mild to moderate dementia due to AD or VaD. They identified a single RCT of cognitive rehabilitation for this population, and this study (Clare et al., 2010), reported improved patient and caregiver outcomes. In contrast, 11 cognitive training trials were identified and the meta-analysis found no differences between cognitive training and control group (Bahar-Fuchs et al., 2013). At least four other reviews of non-pharmacological interventions for early stage dementia with less stringent inclusion criteria have included cognitive rehabilitation trials in their analyses (Huntley, Gould, Liu, Smith, & Howard, 2014; Kurz et al., 2011; Stizer et al., 2006; Radowski et al., 2015). Compared to cognitive stimulation and cognitive training, cognitive rehabilitation has been understudied (Huntley et al., 2014), which makes it challenging to draw final conclusions about its effectiveness. Kurz and colleagues (2011), in a systematic review of cognition-focused interventions (including cognitive stimulation, cognitive training, and cognitive rehabilitation), concluded that with the exception of Clare and colleagues (2010) and Tsolaki and colleagues (2011; who studied cognitive rehabilitation for MCI) cognitive training and cognitive rehabilitation have little impact on individuals' everyday functioning and ability to manage challenges. Since that publication at least three other randomized trials of goal-oriented

cognitive rehabilitation for individuals with early stage AD have reported significant improvement on personally meaningful goals set by individuals with early stage AD (Kim, 2015; Thiverge, Jean, & Simard, 2014), or functional disability and delayed institutionalization (Amieva et al., 2015).

In addition to the randomized trials summarized above, cognitive rehabilitation for dementia due to AD has been examined in multiple case studies and single case experimental designs (e.g., Bird, 2001; Clare et al., 1999; Clare, Wilson, Carter, Breen, Gosses, & Hodges, 2000; Clare, Wilson, Carter, & Hodges, 2003; Provencher, Bier, Audet, & Gagnon, 2008; Thivierge, Simard, Jean, & Grandmaison, 2008). Two case studies, Bird (2001) and Clare and colleagues (2001) are summarized here as examples and to better illustrate what takes place in a cognitive rehabilitation intervention. Bird (2001) describes a case where cognitive rehabilitation was used to help a woman diagnosed with dementia due to AD who had recently moved into a nursing home. Due to cognitive impairments she was unable to recall that she had given away many of her belongings, and she would accuse staff members of stealing her things. When staff members denied this accusation violence frequently erupted. Bird, the patient, and one of her family members developed a large poster that listed where the patient's prized belongings had ended up. Next, using the methods of spaced retrieval and cue fading, the patient was taught to consult the poster whenever she was uncertain about the location of one of her possessions. For example, during training she was provided with fading cues that ranged from "What do you do when you wonder where your things have gone?" to "Isn't there a notice somewhere that looks like this?" (a blank poster is held up; Bird, 2001). Following training, and a collaborative meeting with nursing home staff to teach the cues, she stopped asking about her belongings and became less angry and physically assaultive.

To provide another example, Clare and colleagues (2001) reported a case where an individual, VJ, who was initially diagnosed with early stage AD learned the names of the members of his social club and was followed up over two years. VJ initially learned 11 face-name associations using an errorless learning method incorporating visual imagery, vanishing cues, and expanding rehearsal (Clare et al., 2001). At the time of the initial assessment there were 3 names that VJ knew and were included in the test trials but on which he was not trained. For 9 months following training VJ practiced daily using photographs, and after 9 months he returned the photographs to the researchers and only practiced during his club meetings.

VJ's recall of the face-name associations was tested weekly in cued recall where the photographs were presented one at a time in a random order and he was asked the name of the person in the photograph. No feedback was provided on the weekly recall tests. During year 1 VJ was tested weekly and during year 2 he was tested monthly. In year 1 VJ's recall remained stable for both trained and untrained items and there was a modest decline on both types of items in year 2. At the end of year there was a significant difference in recall between years 1 and 2 for untrained items only, and performance on trained items was significantly greater than baseline (Clare et al., 2001). These results demonstrate that cognitive rehabilitation can lead to improvement in memory for a specific set of items over time.

Moving from case design studies back to RCTs, Clare and colleagues (2010) reported significant improvement on personally relevant functional goals, and Kurz and colleagues (2012) reported no change in activities of daily living. Clare and her colleagues conducted the first RCT for cognitive rehabilitation for early stage AD in North Wales (Clare et al., 2010). The objective of the study was to determine if cognitive rehabilitation would improve performance on selected functional activities (Clare et al., 2010). Participants were diagnosed with probable AD according to the NINCDS-ARDA criteria and had an MMSE score equal to or greater than 18 (Clare et al., 2010). A sample of 69 participants were randomly assigned to received cognitive rehabilitation ($n = 23$), relaxation training ($n = 24$), or no treatment ($n = 22$). Cognitive rehabilitation took place over eight weekly, 1-hour individual sessions in the participants' homes. Caregivers were invited to participate during the last 15 minutes of each session, but having a caregiver participate was not required. The focus of cognitive rehabilitation was addressing individual personally meaningful goals. Clare and colleagues (2010) write that this was done using practical aids and strategies, techniques for learning new information, practice in maintaining attention and concentration, and techniques for stress management.

The primary outcome measure was the Canadian Occupational Performance Measure (COPM), which allowed participants to set personally important goals and provided a standardized group level comparison (Clare et al., 2010). Clare and colleagues (2010) found that persons diagnosed with AD who received cognitive rehabilitation reported improved function on personally relevant goals when compared with those who did not receive this intervention. Further, persons with AD and their caregivers who participated in the intervention were significantly more satisfied with their day-to-day function. Thus, this study provides preliminary

evidence for the efficacy of cognitive rehabilitation for early dementia. Additionally, Clare and colleagues (2010) reported increased brain activity in individuals who received cognitive rehabilitation compared to those who participated in relaxation training or did not receive any treatment, suggesting that cognitive rehabilitation had an effect at the neuronal level.

Kurz and colleagues (2012) conducted a multicenter RCT of cognitive rehabilitation for early AD. This group assessed the feasibility, acceptance, efficacy, and usefulness of cognitive rehabilitation combined with cognitive-behavioural interventions. A sample of 201 participants who fulfilled the criteria for mild dementia in AD based on the ICD-10 research criteria and a MMSE score equal to or greater than 21 were randomly assigned to the intervention ($n = 100$) or the control ($n = 101$) group. The intervention took place in 12 weekly, one hour, individual sessions and was organized into an opening and closing module and four thematic modules (Kurz et al., 2012). After initial treatment goals were identified in the first module particular standardized treatment strategies were chosen within each thematic module. In this way Kurz and colleagues (2012) sought to balance standardization with individualization. Each module included strategies from neurorehabilitation and strategies from psychotherapy (e.g., use of external memory aids, introduction of daily routines, reminiscence; Kurz et al., 2012). The second module focused on external memory aids, the third module focused on establishing behavioural routines, the fourth module stimulated patients to engage in reminiscence, the fifth module worked on day and activity planning and the sixth module was a review of the program and the goals that were achieved (Kurz et al., 2012). The primary outcome measure was change in functional abilities from the baseline to the post intervention assessment as measured by the Bayer Activities of Daily Living scale. There was no significant change in functional ability (Kurz et al., 2012). However, the intervention was feasible as demonstrated by 70% of the intervention as detailed in the manual being implemented, and acceptable as demonstrated by 87% of patient-carer dyads attending 10 or more sessions (Kurz et al., 2012). Further, after the intervention (both post intervention assessment and six month assessment) depressive symptoms in female participants decreased significantly (Kurz et al., 2012). Lastly, caregiver burden increased significantly in the intervention group but not the control group at the post intervention assessment, but this change was no longer significant at the six month follow up (Kurz et al., 2012).

Increasingly, intervention research has shifted to focus on MCI. For example, a recent scoping review (Radowski et al., 2015) identified 20 non-pharmacological RCTs for MCI and eight for early stage AD. Reviews of cognitive interventions (including cognitive rehabilitation) for MCI (Belleville, 2008; Cotelli, Manenti, Zanetti, & Miniussi, 2012; Hong, Jang, Hwang, Roh, & Lee, 2015; Huckans et al., 2013; Jean, Bergeron, Thivierge, & Simard, 2010; Stott & Spector, 2011) and meta-analyses (Chandler, Parks, Marsiske, Rotblatt, & Smith, 2016; Li et al., 2011) are broadly optimistic. This includes improvements on measures of cognitive performance (e.g., Huckans et al., 2013), and improvements on measures of ADL, mood, and metacognition (Chandler et al., 2016). However promising these results are, it is important to note median effect sizes reported are small (e.g., Chandler et al., 2016). Further, as Hampstead and colleagues (2014) pointed out, methodological limitations including diagnostic variability, the use of multiple techniques, an inadequate consideration of dose-response relationship, variability in outcome measures, and a lack of attention to generalization makes it difficult to draw firm conclusions from this literature. The tendency for individual studies to use multiple techniques (e.g., cognitive and physical interventions) and the tendency for reviews to group disparate interventions together under the umbrella of cognitive interventions makes it challenge to sort through what precisely lead to the improved outcomes. The studies presented here contribute to developing an empirically supported approach to goal-oriented cognitive rehabilitation across the continuum of abnormal cognitive change from subjective cognitive impairment to dementia due to Alzheimer's disease or mixed AD/ VaD.

1.4 Evaluation and Research Design

Rehabilitation is challenging to evaluate and a number of approaches to evaluation can be considered. One of the challenges of evaluating neuropsychological rehabilitation is its' individualized nature. Individuals who participate in rehabilitation set a variety of goals, and different methods need to be used to achieve unique goals (Wilson, 2011). Often, RCTs, or systematic reviews and meta-analyses of RCTs, are cited as the standard for evidence-based clinical practice (Perdices & Tate, 2009). RCTs of cognitive rehabilitation are possible, but challenging to carry out. First, it is not possible to run a double-blind trial where neither the person who is receiving the treatment nor the person providing the treatment knows whether rehabilitation or a placebo is being delivered. Andrews (1991) writes that RCTS are appropriate when 1) the design is simple, 2) marked changes are expected, 3) the factors involved are

relatively specific, and 4) the number of additional variables likely to affect the outcome are few and can be balanced out. In the case of cognitive rehabilitation these conditions are not met (Wilson, 2011). However, despite the fact that RCTs may not be well-suited for evaluation cognitive rehabilitation recent reviews of cognitive rehabilitation, particularly cognitive rehabilitation for dementia, call for additional RCTs (i.e., Bahar-Fuchs et al., 2013). Some groups, such as Clare and colleagues (2010) and Kurz and colleagues (2012), have followed this approach and carried out an RCT of cognitive rehabilitation for dementia.

RCTs are not the only design that can be used to investigate the efficacy of an intervention and there are a multitude of single-subject designs including clinical case descriptions, pre/post designs, A-B designs, multi-phase designs, and multiple baseline designs (Perdices & Tate, 2009). Clinical case descriptions or reports are the least sophisticated single-subject methodology and are limited by their inability to attribute outcomes to treatment (Perdices & Tate, 2009). In pre/post designs the dependent variable is measured one or two times before and after treatment (Perdices & Tate, 2009). In A-B designs the dependent variable is observed multiple times during baseline (A) and treatment (B) phases. A-B designs allow the researcher to establish a stable baseline against which the effects of treatment can be evaluated, but change cannot be attributed to the treatment because this design does not control for threats to internal validity (Perdices & Tate, 2009).

Single experiment case designs have five essential features: 1) repeated measurement over time, 2) a well-established baseline, 3) stability in the dependent variable within each phase, especially when the phase changes, 4) replication across behaviours (dependent variables) or individuals to address threats to internal and external validity, and 5) experimental control by changing one variable at a time (Allen, Firman, & Sanger, 1992). Tate and colleagues (2008) developed a measure for evaluating the methodological quality of single-subject designs and n-of-1 trials. Single case experimental designs may be the most appropriate method for evaluating neuropsychological rehabilitation and have the potential to lead to significant developments in the field (Wilson, 1997).

1.5 Need for Rural Treatment

The potential of goal-oriented cognitive rehabilitation for dementia is clear, and Clare's (2010) recent publication gives tangible support to this claim. What is not clear is the generalizability of this treatment. If cognitive rehabilitation is going to have an impact on the

$857 billion economic burden of dementia in Canada it needs to be able to be delivered by professionals who did not develop the treatment, and be accessible to everyone who is impacted by dementia (Alzheimer's Society of Canada, 2010). This project seeks to address both of these needs by replicating Clare and colleagues' (2010) results, and examining how cognitive rehabilitation can be provided to rural Canadians using telehealth videoconferencing.

       1.5.1 Evidence for the use of telehealth videoconferencing. There is emerging evidence indicating technology-facilitated health services can effectively improve the access to services for individuals who live in rural and remote communities (e.g., Morgan et al., 2011; O'Connell et al., 2014). The University of Saskatchewan's Rural and Remote Memory Clinic (RRMC) team, with whom this project is affiliated, pioneered research on telehealth for dementia care (Morgan et al., 2009; Morgan et al., 2011). Most recently, Morgan and colleagues (2011) found that individuals diagnosed with dementia who were attending the RRMC for dementia diagnoses were highly satisfied with pre-clinic assessment and follow-up appointments delivered through telehealth. Further, these telehealth appointments reduced participants' travel by an average of 462 km per round trip and rated telehealth as significantly more convenient than in-person appointments (Morgan et al., 2011). More recently, telehealth has been shown to be a successful medium for a support group intervention (O'Connell et al., 2014) and for a remotely delivered exercise intervention (Dal Bello-Haas et al., 2014).

       1.5.2 Non-inferiority studies. Previous research has established that mental health services provided through telecommunications can be as effective as in-person delivery of health care services (Greene et al., 2010; O'Reilly et al., 2007). Greene and colleagues (2010) explained that specially designed 'noninferiority' studies are the most rigorous way to determine whether a novel treatment or modality is as good as a well-established standard treatment. Since the goal is to show equivalence between groups beyond merely demonstrating statistically non-significant differences between groups, noninferiority studies pose significant methodological and design challenges (Greene, Morland, Durkalski, & Frueh, 2008). The purpose of this specific project is not to establish whether cognitive rehabilitation delivered through telehealth is as effective as in-person delivery (viz., a noninferiority study). Rather, this is foundational research designed to determine whether cognitive rehabilitation designed for in-person delivery is feasible to be translated to remote delivery using telehealth. Moreover, this project aims to establish whether

telehealth delivery of cognitive rehabilitation is acceptable to persons with AD and their caregivers.

1.5.3 Remotely delivered rehabilitation. Rehabilitation that is delivered using videoconferencing has been increasingly studied over the last ten years and, although the field is plagued by inconsistent terminology and comprehensive studies are lacking, the results are promising (Rogante et al., 2010). For example, early research suggests that remotely delivered rehabilitation for individuals who have sustained traumatic brain injuries (TBI) is feasible. Tam and colleagues (2003) reported a series of three case studies where individuals with TBI participated in cognitive rehabilitation using customized online software. This software combined videoconferencing with screen sharing and participants completed computer based activities that targeted word recognition, semantic memory (i.e., memory for factual knowledge) and prospective memory (i.e., memory to perform something in the future).

In other work, Bergquist and colleagues (2008, 2009) opted to use technology to remotely teach participants who had had a severe TBI to use a calendar as a compensatory memory strategy. They adapted Sohlberg and Mateer's (2001) calendar training procedure to an instant messenger format and also taught participants to use a personal diary. Both interventions lead to increased use of compensatory strategies and improved mood (Bergquist et al., 2009). Finally, in an approach that is more similar to the type cognitive rehabilitation studied here Bourgeois, Lenius, Turkstra, and Camp (2007) had participants with chronic TBI identify three everyday memory problems (e.g., forgetting appointments, forgetting day planner at home, losing items) and provided either spaced retrieval, or memory strategy instructions over the telephone. Individuals in the spaced retrieval group made greater gains in their target goals than those given strategy instructions, and both groups improved their everyday memory functioning. These studies suggest that traditional, in-person cognitive rehabilitation strategies can be delivered by videoconferencing, instant messaging or telephone. Although cognitive rehabilitation has been delivered remotely, it has not been provided to individuals with dementia and this is the gap this project seeks to fill.

1.6 Overview of the Studies

In the series of three studies presented here, Study 1 and Study 2 lay the foundation for the intervention that is delivered in-person and through videoconferencing in Study 3. The objective of Study 1 is to better understand the needs of rural individuals with MCI, dementia

due to AD, or mixed AD/VaD. The first purpose of this study is to enquire about whether families are interested in cognitive rehabilitation, and if they would prefer to participate through videoconferencing. This study also explores the goals of patients and caregivers, which informs treatment development. Knowing what functional goals families want to target helps to inform the development of specific techniques. Finally, Study 1 considers differences between those who are interested in cognitive rehabilitation and those who are not.

Study 2 is also concerned with guiding treatment development and providing data to ensure that the types of techniques that are being developed stand the greatest chance of leading to meaningful change in function. Study 2 approached this objective by looking at the cognitive and neuropsychiatric correlates of function. In order to improve performance on meaningful day-to-day activities or instrumental activities of daily living it is important to understand which cognitive and clinical domains account for the most variance in function. As is reviewed in the introduction to Study 2, previous research in this area has provided mixed results.

The objective of Study 3 is to compare cognitive rehabilitation delivered in-person and delivered through telehealth videoconferencing to individuals with SCI, MCI, and dementia due to AD. A single case experimental design is used to compare treatment modalities. The purpose of this study is to replicate previous work where cognitive rehabilitation was delivered in-person and to explore the feasibility and acceptability of videoconferencing delivered treatment.

1.7 Statement on Intellectual Contributions

In order to fulfill the requirements of a Ph.D. dissertation I, Rachel Burton, have been responsible for the literature review, study design, original data collection, data analysis, and manuscript preparation for the three manuscripts presented here. Dr. Megan O'Connell has been my research supervisor. As supervisor, she was consulted throughout the course of the research, has reviewed this document, and is a co-author on all three studies. We agreed that I contributed 90% to the manuscripts presented here. Archival data form the Rural and Remote Memory Clinic (RRMC) was used in Studies 1 and 2. This data was collected by the inter-professional RRMC team lead by Dr. Debra Morgan. Dr. Morgan is a co-author on Studies 1 and 2.

1.8 General Introduction References

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2.1 Study 1 Abstract

Goal-oriented cognitive rehabilitation is a promising intervention for individuals diagnosed with mild cognitive impairment (MCI) or dementia due to Alzheimer Disease (AD). Videoconferencing delivered cognitive rehabilitation is a potential avenue for increasing accessibility for rural patients and their families. First, we were concerned with the accessibility of the treatment for individuals in rural and remote areas. Second, client-centered goal setting was explored by asking this sample about their goals for cognitive rehabilitation. We mailed questions to all active patients with diagnoses of MCI or dementia due to AD of a rural memory clinic and compare features of the responders versus the non-responders. We asked about interest in videoconferencing delivered treatment and about goals for cognitive rehabilitation, which were thematically analyzed. The responders ($N = 25$) were similar to non-responders in severity, depression, and caregiver burden. Of the responders, 80% were interested in videoconferencing developed treatment. A thematic analysis coded 95% of responses as amenable to cognitive rehabilitation. Participants' goals were focused on memory, household activities, other cognitive domains, recreation, and higher order tasks. This work informs the development of both in-person and videoconferencing delivered cognitive rehabilitation for individuals diagnosed with MCI or dementia.

2.2 Exploring interest and goals for videoconferencing delivered cognitive rehabilitation with rural individuals with Mild Cognitive Impairment and Dementia

Cognitive rehabilitation is an individualized approach to helping persons with cognitive impairments including dementia set and attain functional goals (Clare et al., 2010). In the approach to be studied here, individuals with mild cognitive impairment (MCI), early stage dementia due to Alzheimer's Disease (AD), or early stage mixed AD and Vascular Dementia (VaD) and their family caregivers collaborate with health professionals to set personally important goals that are relevant to their everyday functioning (Clare et al., 2010). Goal-oriented cognitive rehabilitation is a promising, non-pharmacological intervention (Clare et al., 2010), and this study was designed to inform the development of cognitive rehabilitation in three ways. First, we aimed to explore interest in videoconferencing delivered cognitive rehabilitation. Second, we aimed to explore the types of goals that are set by individuals with cognitive impairments. Third, we aimed to compare the clinical characteristics of individuals who responded to a questionnaire asking about cognitive rehabilitation to those who did not.

Rationale for exploring videoconferencing

To date, goal-oriented cognitive rehabilitation for individuals with MCI or early stage dementia has always been delivered in-person (i.e., Clare et al., 2010; Kurz et al., 2012; Thivierge et al., 2014). The need for treatment to take place in-person limits the accessibility of cognitive rehabilitation. Specifically, individuals in rural and remote areas face barriers to accessing health care and are often required to travel long distances to major centers in order to access specialized health care services (Bédard, Koivuranta, & Stuckey, 2004; Forbes, Morgan, & Janzen, 2006; Morgan, Semchuk, Stewart & D'Arcy, 2002). This study explored whether individuals with mild cognitive impairment (MCI), early stage dementia due to AD or mixed AD/ Vascular Dementia (VaD) and their family caregivers were interested in videoconferencing delivered cognitive rehabilitation.

For individuals residing in rural and remote areas the accessibility of interventions is an important consideration (Morgan et al., 2009). Simply, participating in a weekly intervention that is located a few kilometers from your home is a much different undertaking than if the same intervention is a few hundred kilometers from your home. Therefore, participants were asked if they were interested in participating in cognitive rehabilitation in Saskatoon, SK (at least 100 km away) and if they would be interested in participating in cognitive rehabilitation delivered using

telehealth videoconferencing at their local hospital. After exploring interest in videoconferencing delivered cognitive rehabilitation, the second part of this study explored goals for cognitive rehabilitation.

Rationale for exploring goals

Goal setting, and the explicit focus on individualized personally relevant functional goals, differentiates cognitive rehabilitation from closely related interventions such as cognitive training (Clare, 2008; Clare & Woods, 2004). It appears that the individualized, goal-oriented nature of cognitive rehabilitation is essential for significant functional improvement (Bird, 2001; Bovend'Eerdt, Bottell, & Wade, 2009; Clare, Wilson, Carter, Hodges, & Adams, 2001; Clare et al., 2011; Kurz et al., 2012). A person-centered approach to setting relevant functional goals for cognitive rehabilitation, the cornerstone of this intervention, is one focus of the proposed study.

When goals for cognitive rehabilitation are set in collaboration, goals related to memory, practical skills and activities, concentration, organization, naming and social interaction are set and addressed in the intervention (Clare et al., 2011). In collaborative goal setting, goals for rehabilitation are determined through a discussion between the person with dementia, the clinician and, in some cases, a family caregiver (Clare, 2008). Since a number of people, with different interests, work together to set goals for cognitive rehabilitation it is unclear how much the final goals that are addressed, and reported in the literature, reflect what individuals with cognitive decline (e.g., MCI or AD) hope to achieve, what family caregivers hope to achieve, and what areas the therapist prefers to target.

The objective related to goal setting in the current study is to explore what individuals who are invited to participate in cognitive rehabilitation hope to get from the intervention before they meet with a therapist to set goals. We were interested in knowing what kinds of objectives individuals have, and how their goals relate to the available, empirically supported interventions that are part of cognitive rehabilitation.

Goal setting can be defined as "the identification of and agreement on a behavioural target which the patient, therapist or team will work towards over a specified period of time" (National Collaborating Centre for Chronic Conditions (Great Britain), & Royal College of Physicians of London, 2008, p. 37). Goal setting is widely considered to be integral to rehabilitation and is an essential skill for rehabilitation professionals (Playford et al., 2009; Scobbie, Wyke, & Dixon, 2009). In the context of neuropsychological rehabilitation goal based

approaches have been used in rehabilitation for aphasia (Hersh, Worrall, Howe, Sherratt, & Davidson, 2012), acquired brain injury (Dalton et al. , 2012), stroke (Albert & Kesselring, 2011) and neurological conditions (Black, Brock, Kennedy, & Mackenzie, 2010). Perhaps surprisingly, outside of person centred cognitive rehabilitation, goal setting is rarely used in providing treatment to individuals with AD or other subtypes of progressive dementia (Clare et al., 2011).

There is some empirical support for goal-based approaches to rehabilitation, but the evidence for goal-based approaches leading to improved functional outcomes or improved quality of life is inconsistent (Levack, Taylor, Seigert, & Dean, 2006). For example, during inpatient neurological rehabilitation there is evidence for the validity of achieving short-term goals, for example 'independent initiation of basic functional words in conversation,' as a measure of progress toward rehabilitation goals for discharge (Black et al., 2010). In other research, Parsons, Rouse, Robinson, Sheridan, and Connolly (2011) found that older adults who were engaged in goal planning, as opposed to a standard needs assessment, experienced a greater change in health related quality of life following homecare services. A recent systematic review of goal planning in rehabilitation concluded goal planning increases an individual's participation in rehabilitation focusing on cognitive and motor tasks, and leads to improved adherence to treatment plans but, overall, due to methodological limitations and a lack of clarity about the purpose of goal-setting interventions, evidence for goal planning leading to improved functional outcomes or quality of life is inconsistent (Levack et al., 2006).

In rehabilitation, there has been an increasing focus on person-centred, collaborative goal setting (Hersh et al., 2012). In person-centred consultations the control of the consultation, decisions about interventions, or management of problems is shared, and the consultation focuses on the patient as a whole person and seeks "an integrated understanding of the patients' world" (Lewin, Skea, Entwistle, Zwarenstein, & Dick, 2001; Playford et al., 2009, p. 341). Professional organizations, rehabilitation professionals and people seeking rehabilitation all promote or seek collaborative goal setting (McClain, 2005; Playford et al., 2009; Rosewilliam, Roskell, & Pandyan, 2011). Despite these recommendations, there is a gap between the intention to involve clients in making decisions about therapy and actual practice where collaborative goal setting is uncommon (Hersh et al., 2012; Rosewilliam et al., 2011).

Hersh and colleagues (2012) summarized research from a patient perspective and explained that at times client's expectations of rehabilitation differ from the expectations of their

therapists, clients have insufficient information about rehabilitation, and client and therapist goals for rehabilitation differ. From the perspective of therapists, at a consensus conference on goal setting, rehabilitation professionals noted that individuals may set goals that are highly ambitious and the therapist's desire to set achievable goals can conflict with or undermine the ideal of a person-centred approach (Playford et al., 2009). Further, therapists may avoid collaborative goal setting to avoid instilling false hopes, and individuals may present goals that undermine their autonomy, self-worth or social participation, which contradicts the objective of enhancing these through rehabilitation (McClain, 2005; Playford et al., 2009). Of particular relevance for the current project, individuals who have cognitive or communication difficulties can be difficult to engage in collaborative goal setting and these individuals are particularly unlikely to be involved in collaborative goal setting (Scobbie et al., 2009; Parry, 2004). Finally, this approach is time consuming and patients may be reluctant to share their goals because they are intimidated in medical situations (McClain, 2005). In short, the practice of collaborative goal setting in rehabilitation is challenging.

Within a person-centered, biopsychosocial model of dementia, cognitive rehabilitation addresses goals that are personally relevant to the individual. In cognitive rehabilitation goal setting follows a thorough assessment (Clare, 2008; Sohlberg & Mateer, 2001). Clare (2008) suggests that for people with dementia the assessment include neuropsychological functioning, everyday functioning, coping style, awareness and an assessment of the family caregiver. Goal setting takes place during and following the assessment, and desired outcomes are identified collaboratively (Clare, 2008). Clare suggests that goals can be identified "straightforwardly through discussion" or a standardized occupational therapy tool such as the Canadian Occupational Performance Measure can be used (Clare, 2008, p. 114; Law, Baptiste, Carswell, McColl, Polatajko, & Pollock, 2005). In her text on cognitive rehabilitation with people diagnosed with dementia Clare (2008) outlines the following steps for selecting cognitive rehabilitation goals:

1. Determine whether the person is able or willing to indicate something that he or she would like to be different
2. Identify the area to focus on – for example, memory problems, family relationships, or participation in activities

3.   Identify the specific issue to focus on – for example, remembering the names of people met during an activity

4.   Establish the baseline level of performance

5.   Identify the goal expressed in clear behavioural terms

6.   Identify the level of performance that will indicate whether the goal is (a) wholly or (b) partially achieved

7.   Plan the intervention to address the goal, using appropriate methods and techniques

8.   Implement the intervention

9.   Monitor progress and adjust the intervention if necessary

10.   Evaluate the outcome of the intervention and decide on any further steps that may be needed

Clare notes that family caregivers and the person diagnosed with dementia may have different goals and suggests "careful and sensitive negotiation is required in order to try to reach a consensus that is acceptable to both parties, acknowledging the different emotional and practical needs of all involved" (Clare, 2008, p. 114). The possibility of the therapist and the person with dementia having different goals is not discussed, but this is particularly relevant for cognitive rehabilitation because there is a limited set of empirically supported techniques through which goals for treatment can be addressed. Cognitive rehabilitation for individuals with dementia has primarily been studied with individuals who have been diagnosed with early stage AD (Clare, 2008). The techniques that have been studied are primarily related to addressing goals related to memory problems (Clare, 2008). Therefore, individuals may set goals that are not readily addressed using techniques that have studied in this population. Further, as reviewed, the literature on goal setting in rehabilitation indicates that, in practice, collaborative goal setting is challenging, under implemented and includes conflicts.

While previous research has reported goals set in collaboration, the objective of this study was to describe the initial goals for cognitive rehabilitation that individuals with MCI, AD or mixed AD/VaD and their family caregivers set without therapist input. It is important to know what individuals with cognitive decline hope to achieve through cognitive rehabilitation in order to plan, implement and evaluate interventions that are focused on collaborative person-centred goals. Additionally, the differences between the initial goals reported in the current study and the

collaborative goals reported in the literature will provide an indication of amount of therapist input and change from personal goals to therapy goals.

Rationale for comparing responders to non-responders

Before even discussing goals for treatment individuals are invited to participate in cognitive rehabilitation, and it appears that a substantial proportion of individuals who may benefit from cognitive rehabilitation opt not to participate in treatment. For example, in Clare and colleagues (2010) randomized control trial (RCT) 212 individuals with early stage AD or mixed AD/VaD were approached to participate, and 60% (127 people) chose not to pursue the intervention. No analyses were done to determine whether there were systematic differences between those who expressed interest in participating and those who did not. In Kurz and colleagues (2012) study 405 individuals were assessed for eligibility and 32 % (128 people) were not interested in participating (76 other people did not meet the study's inclusion criteria). Again, there was no systematic comparison between those who were approached but did not participate and those who did. Differences between individuals interested in cognitive rehabilitation and individuals who are not interested have implications for interpreting research in the area, and for deciding who may benefit from this intervention.

A unique strength of the Rural and Remote Memory Clinic (RRMC) sample used in the current study is that clinical data was available for both families who opted to respond to the questionnaire that was developed as well as families who opted not to respond. Therefore, responders and non-responders were systematically compared. Biopsychosocial models of dementia and the cognitive rehabilitation literature suggest a number of factors that may relate to interest in cognitive rehabilitation. Potentially relevant variables include cognitive function, dementia severity, awareness, education, previous life events, personality traits, age, physical health, mood, coping style, and self-efficacy (Spector & Orrell, 2010; Clare, 2008). The family context, particularly the burden, mood, and coping style of close caregivers are also important considerations as cognitive rehabilitation generally, although not always, requires the support of a caregiver. Further, it is recommended that an assessment for person centred cognitive rehabilitation include an evaluation of neuropsychological function, everyday functioning, coping style, awareness and an assessment of the family caregiver (Clare, 2008).

The choice of variables for the study considered pragmatic as well as theoretical constraints. The participants attended the Rural and Remote Memory Clinic (RRMC) for an

interdisciplinary dementia assessment and have been followed up by the clinic (Morgan et al., 2009). The study had the advantage of drawing on archival data, but the choice of variables was limited by the archival data that has been collected. Based on the recommended components of an assessment for cognitive rehabilitation, and the available archival data, we compared individuals with MCI, AD, or mixed AD/VaD who responded to a questionnaire about cognitive rehabilitation and those who did not respond along the following dimensions: dementia severity, self-perception of cognitive function, depression and neuropsychiatric symptoms. Levels of caregiver burden were compared across caregivers who are interested and caregivers who are not interested in cognitive rehabilitation.

In summary, the purpose of this study was to inform the development of videoconferencing delivered cognitive rehabilitation for individuals diagnosed with MCI, AD or mixed AD/ VaD. Our objectives were to determine whether videoconferencing facilitated treatment was of interest to RRMC families, and to better understand what families and patients would hope to achieve through the intervention. Further, we compared responders to non-responders on a set of theoretically relevant variables in order to better understand how the sample of individuals who opt to participate in cognitive rehabilitation may be different from those who opt not to participate.

2.3 Study 1 Method

Participants

Participants were recruited from a Rural and Remote Memory Clinic (RRMC). The RRMC provides one-day interdisciplinary dementia diagnostic assessments and follow-up assessments to individuals who reside more than 100 km from large urban centres (Morgan et al., 2009).

For the study reported here, participants were individuals who were seen at the RRMC, for either an initial assessment or a follow-up assessment, between November 2011 and June 2014. Participants were invited to participate in two waves. Initially, individuals who were diagnosed with either MCI, vascular cognitive impairment (VCI), AD, VaD, or mixed AD/VaD with an MMSE score equal to or greater than 18 were invited to participants. Due to a low response rate, individuals with a diagnosis of Parkinson's disease, dementia due to Lewy Bodies or cognitive impairment not otherwise specified were invited to participate, and the MMSE cutoff was removed. Clinic patients and family caregivers were both invited to participate.

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Individuals who had previously indicated to the clinic nurse that they were not interested in participating in additional research studies were not invited to participate. A total of sixty-one clinic patients and their family caregivers were invited to participate. Ten patients and 15 family caregivers completed questionnaires for a total response rate of 21%. The diagnoses of the patient participants are reported in Table 1.

Materials and Procedure

Participants completed the Everyday Memory Questionnaire (EMQ), which was developed for the purposes of this study (see Appendix for the EMQ). The EMQ describes cognitive rehabilitation, asks individuals if they would be interested in cognitive rehabilitation, asks whether they would prefer to participate in-person or over through telehealth videoconferencing, and asks participants about what everyday problems they would hope to address through cognitive rehabilitation.

To develop the EQM, an initial list of questions related to interest in cognitive rehabilitation and possible goals for rehabilitation was developed based on goals reported in previously published studies of cognitive rehabilitation for individuals with dementia. Two RRMC patients and three RRMC family caregivers were interviewed over the telephone. Based on their responses an initial pilot questionnaire was developed. This initial questionnaire was piloted in-person with 10 family caregivers who attended the RRMC. Family caregivers completed the questionnaire and discussed its clarity while they waited for the individual they accompanied to the clinic to complete a neuropsychological assessment. The questionnaire was revised based on the feedback from these pilot participants. For example, questions were reworded for clarity. Further, pilot participants requested examples of the kinds of goals or problems that could be addressed in cognitive rehabilitation and examples were added to the EMQ and based on the goals reported by Clare and colleagues (2011).

Participant's responses on the EMQ were related to scores on a series of psychometrically sound measures from the RRMC database (Morgan et al., 2009). The specific measures that have been selected from the database are briefly introduced below.

Dementia severity. The Clinical Dementia Rating (CDR; Berg, 1988) is a clinician's global rating of dementia that takes into account the results of cognitive performance and rating of cognitive behaviour in everyday activities. The CDR is based on a semi-structured interview with the individual being rated and an informed collateral source (Berg, 1988). The interview

covers the domains of memory, orientation, judgment and problem solving, community affairs, home and hobbies, and personal care (Berg, 1988). Summing the scores in each of these "boxes" provides the CDR sum of boxes (CDR-SOB), a more detailed measure of global dementia severity, the CDR-SOB is more sensitive measure than the CDR and will be used here (O'Bryant et al., 2008).

Depression. The Centre for Epidemiologic Studies Depression Scale (CES-D; Radloff, 1977) is a self-report scale developed to identify depression in the general population. The CES-D is a 20 item scale covering the major components of depression identified in the literature and emphasizing affective components including depressed mood, feelings of guilt and worthlessness, feelings of helplessness and hopelessness, psychomotor retardation, loss of appetite and sleep disorders (Radloff, 1977). The CES-D is a widely used and well-studied tool (Ros, Serrano, Latorre, Navarro, Aguilar, & Ricarte, 2011). It has been found to have adequate internal consistency and test-retest reliability with Cronbach's alpha between 0.82 and 0.91, and test-retest reliability ranging from 0.52 to 0.57 depending on the sample and time interval (Lewinsohn, Seeley, Roberts, & Allen, 1997; Radloff, 1977; Ros et al., 2011). There is also strong evidence for the validity of the CES-D including evidence for its use with community dwelling older adults and older adults with cognitive impairment (Lewinsohn et al., 1997; Ros et al., 2011). The items from the scale cluster in four dimensions, and Radloff (1977) recommends using the total score and the total score from the CES-D will be used here.

Caregiver burden. RRMC family caregiver responses will be related to their archived scores on the Zarit Burden Interview (ZBI; Zarit et al., 1985). The ZBI is a self-report measure of caregiver burden. The questionnaire asks family caregivers how they feel about taking care of another person. Here, the short form of the ZBI developed by Bédard, Molloy, Squire, Dubois, Lever, and O'Donnell (2001) will be used as this was the version administered to RRMC family members. The short form of the ZBI has adequate internal consistency (Cronbach's $\alpha = 0.88$ - 0.90), and there is evidence for its predictive validity (Bédard et al., 2001; O'Rourke & Tuokko, 2003).

Self-perception of cognitive function. The Self-Rating of Memory Scale (Squire & Zouzounis, 1988) is a brief self-rating form where individuals describe their perception of their memory functioning. The form asks individuals to think of how their memory was four years ago compared to how it is now and indicate whether their memory is much worse, slightly worse, the

same, slightly better or much better on a number of tasks. The Self-Rating of Memory Scale provides a measure of self-perception of cognitive function.

The Neuropsychiatric Inventory. The Neuropsychiatric Inventory (NPI) is a twelve item semi-structured interview developed and validated to assess behavioural and psychiatric symptoms of individuals diagnosed with dementia (Cummings, 1997; Cummings et al., 1994). The NPI has 12 items: delusions, hallucinations, agitation/aggression, depression/dysphoria, anxiety, euphoria/elation, apathy/indifference, disinhibition, irritability/lability, aberrant motor behaviour, night-time behaviour, and appetite/eating change. Family caregivers rated the frequency and severity of each symptom as described by Cummings and colleagues(1994) where higher scores indicate more frequent and/or severe symptoms. Previous research has reported adequate test-retest reliability of the items ($r = 0.51 - r = 0.98$), and good content and concurrent validity (Cummings, 1997; Cummings et al., 1994).

Questionnaire Administration

The final version of the Everyday Memory Questionnaire was mailed to 61 RRMC patients and caregivers for a total of 122 potential participants. All questionnaire packets contained a letter of invitation, consent forms, the questionnaire and a self-addressed, stamped envelope. Four weeks after the questionnaires were mailed a reminder phone call was made to all individuals who had not returned a questionnaire.

2.4 Study 1 Results

In-person and Videoconferencing Interest in Cognitive Rehabilitation

Twenty-five participants completed and returned the EQM for a total response rate of 20.5% ($N = 25$ of 122 potential participants). Questionnaires were completed by 10 patient/family member dyads, three individual family members, and two individual clinic patients. Of the individuals who completed the EQM, 80% reported they were interested in participating in cognitive rehabilitation. All respondents were interested in participating through telehealth and no participants were interested in participating in-person. One family caregiver noted on his or her questionnaire that it might be feasible to attend an initial session in-person, and then he or she would prefer to complete the remaining sessions through telehealth. In regards to treatment delivery (in-person vs. telehealth), the responses of the 10 clinic patient/family member dyads that both completed the EQM were 100% congruent.

Goals for Cognitive Rehabilitation

Participants' responses on the EMQ were coded using thematic analysis as described by Braun and Clark (2006). After familiarizing ourselves with the data, and generating initial codes using an inductive approach participants' response were broadly sorted into two major categories: goals that were deemed amenable to cognitive rehabilitation and goals that were deemed inconsistent with cognitive rehabilitation. The responses in these two overarching categories were further categorized and organized into themes.

After generating an initial set of codes for responses that were amenable to cognitive rehabilitation the following categories were decided upon: memory, other cognitive domain, recreation, household, higher order management, and basic function. The decision was made to code responses in more than one category if appropriate. For example, the response:

"Remembering the laundry. When to put it in. When to take it out."

was coded as both a 'memory' item and as 'household' item. Broadly, participants responses included statements related to both cognitive domains and daily function, and this is reflected in the category codes that were developed. Two researchers (RB and MO) coded the responses into thematic categories. To organize the responses Table 2 displays all of the participants responses and the themes into which they were categorized. This displays the interrelationships between the themes as well as the number of items that fell into each theme. Figure 1 summarizes the frequency of each category theme.

As noted, a minority of the problems identified in the questionnaires were deemed to be challenging to address in cognitive rehabilitation and, in our opinion were considered inappropriate or unrealistic for cognitive rehabilitation. These problems are indicated in Table 2, and we identified three thematic across these problems: (1) problems related to education needs, (2) overly ambitious goals, or (3) problems outside the scope of clinical psychology. Education needs:

Education required on services homecare provide (Caregiver)

What are the next steps when memory gets worse? (Caregiver)

Outside the scope of clinical psychology:

My balance (especially up and down stairs) (Clinic patient)

Tremor of right arm (Clinic patient)

Meal planning to get proper nutrition (Caregiver)

With his hearing (Clinic patient)

Overly ambitious:

Being able to drive again (Caregiver)

Handling her own finances (Caregiver)

Profile Analysis

The profiles of the responders and non-responders were compared using SPSS MANOVA. This revealed that the two groups' patterns of dementia severity, depression, self-rating of memory, caregiver burden, and neuropsychiatric symptoms were similar (i.e., the null hypothesis for the test of parallelism was not rejected, $F(4, 34) = 1.91$, $p = 0.13$, $\eta^2 = 0.20$). Notably, this is a large effect size (Cohen, 1988) and raises the possibility of a Type II error which would indicate that the groups patterns might differ.

Irrespective of groups, participants' average scores across measures did not differ (i.e., the null hypothesis for the test of flatness was not rejected, $F(4,31) = 0.95$, $p = 0.45$, $\eta^2 = 0.11$). Again, this moderate effect size (Cohen, 1988) raises the possibility of a Type II error.

Finally, there was no evidence that one group, on average, scored higher on the set of measures than the others (i.e., the null hypothesis for the test of levels was not rejected, $F(1, 34) = 3.38$, $p = 0.08$, $\eta^2 = 0.09$). The profiles are displayed in Figure 2.

2.5 Study 1 Discussion

This study had three sets of objectives. First, we wondered whether individuals diagnosed with MCI or dementia due to AD or mixed AD/VaD and their family caregivers who reside in rural areas were interested in accessing cognitive rehabilitation through telehelath videoconferencing. As stated, 80% of respondents in the current study reported they were interested in cognitive rehabilitation, and of those 100% stated that they would prefer to participate through videoconferencing. It is important to acknowledge that the RRMC sample is unique in that all of participants have previous experience with telehealth videoconferencing (Morgan et al., 2009). Individuals with less prior exposure to videoconferencing may be more hesitant to indicate their interest in videoconferencing facilitated treatment.

Next, we were interested in the types of goals individuals with cognitive impairments and their family caregivers are interested in targeting when they are not collaborating with clinicians. Here, we wondered about the degree to which the goals reported in the cognitive rehabilitation literature were influenced by clinician's desires to select treatment goals that are realistic and

attainable. Overall, the goals reported by both family members and individuals with cognitive impairments in our sample were consistent both with goals identified in therapist/ participant collaborations (Clare, 2010) and problems chosen by researchers (Kurz et al., 2012). Importantly, very few goals (5%) were coded as not being amenable to cognitive rehabilitation. Further, memory focused goals, goals related to household activities, and higher order goals were frequently reported and are all well-suited to be addressed through errorless and spaced retrieval which are both approaches that have been well-studied in MCI and dementia samples (Camp, 2001; Thivierge et al., 2014).

As discussed in the procedures section, developing a questionnaire for asking about cognitive rehabilitation was an iterative process. Initially, we began with a semi-structured telephone interview, and open-ended questionnaire. Our objective was to try not to lead respondents, but we found that participants required examples and structured questions. The structured nature of the questionnaire is a limitation, as individuals were certainly influenced by the options provided in the questionnaire. Despite this, we feel that our questionnaire offers a sort of middle ground between an open question and goals arrived at collaboratively in a clinical setting. The goals reported and summarized here could inform researchers developing protocols and approaches for future cognitive rehabilitation studies. For example, in their recent randomized study of cognitive rehabilitation for early stage AD Thivierge and colleagues (2014) chose to focus on instrumental activities of daily living. The goals addressed in their study (i.e., using a television remote control, using email, and origami) capture only a subset of the goals reported by our participants.

Finally, a unique strength of this study and of the RRMC sample is that we were able to compare individuals who responded to the questionnaire to individuals who did not respond. This allows us to comment about the degree to which individuals in our sample who were interested in cognitive rehabilitation are similar to individuals who were not interested in cognitive rehabilitation. A profile analysis was carried out to compare the responders (80% of which were interested in cognitive rehabilitation) to the non-responders. As described in the results section the results of the profile analysis are challenging to interpret. The tests of levels, parallelism and flatness were all non-significant, which means that we failed to reject the null hypotheses in each of these cases. However, the effect sizes were such that a Type II error may be present in the test of parallelism and flatness. Based on the separating error bars visible in

Figure 2 we cautiously submit that individuals with cognitive impairment in the responder group are reporting poorer memory and their caregivers are reporting fewer neuropsychiatric symptoms. It may be the case that responders had greater awareness of their memory deficits and families struggling with greater neuropsychiatric symptoms did not feel that cognitive rehabilitation was appropriate for their needs. We suggest that those who are interested in cognitive rehabilitation and who participate in the trials reported in the literature are a unique subgroup of the larger MCI/early stage dementia population. We hope that this research will be followed up by others has it the potential to help clinicians make decisions about whether their clients are good candidates for cognitive rehabilitation.

Overall, we offer the following conclusions from the study. Rural families are interested in telehealth delivered cognitive rehabilitation, and their goals for treatment are congruent with the available, evidence-based strategies for cognitive rehabilitation in MCI and early stage AD. This study adds to the rationale for developing videoconferencing facilitated cognitive rehabilitation for rural individuals diagnosed with MCI, early stage AD, and mixed AD/VaD.

2.6 Study 1 References

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Table 2.1

Participant diagnoses

Diagnosis	Responders ($n = 15$)	Non-responders ($n = 45$)
MCI	5	15
VCI		2
AD	8	21
VaD	0	1
AD/VaD	2	1
DLB		1
Parkinson's		1
Dementia NOS		3

Table 2.2

Problems reported on the Everyday Memory Questionnaire

Theme & Frequency count	Caregiver	Individual with Cognitive Impairment
Memory 23	Short term memory Mom needs help with very short term memory. She writes everything down now to help remember things. Short term memory To remember the date Recognize friends he hasn't seen recently Remembering names of people Mom has trouble with people's names. Remember names of specific people and personal information People's names Remember name of some people which are visually remembered.	Forgetting!!! Short term memory Memory I have short term memory loss some times I'm told Peoples names and where I met them and what they do Remember names of specific people Remember people name of long ago. But not yesterday, I meet the day before. Sometimes remembering a name Remembering specific people. I still know if I recognize someones face but not the name. Remembering the names of people I've known for years but don't see on a regular basis. When I'm talking to someone, I quite often, cant' find a word or the name I want to say.
memory +	Finding household items such as food,	Being able to find items around the

household 14	dishes. Items around the house. Remember where he put things – needs a bit more routine maybe or more lists. Trying to find things or remembering to do things. Being able to find things around the house Difficulty in remembering where household items are stored and restoring them to where they are normally stored Be able to find items around the house Turning light of during the day Remember to turn lights off when leaving the room Remembering "better" – to turn off lites	house, to remember where I've put them. Remembering the laundry. When to put it in. When to take it out. Remebr to find book I started Learn to use phone.
memory + **higher order** **management** 10	Remembering personal info. Remembering a series of tasks Homecare comes twice a day for meds and she has no memory of them being there. Says she's fired them. Learn simple things such as cooking or warming up food Remembering what is planned for the day – he keeps a calendar To remember where we're going	When my Drs. Appointment is.

	when we go somewhere	
	Remember to take pills	
	Be able to track the meals she's had	
	To remember what somebody tells him	
memory + **personal care** 4	Remember to bathe (2) Remember to change clothing daily Remember that she must wear depends undergarments	
memory + **recreation** 2	Remembering how to play cards Remember to exercise, become active again	
memory + **household +** **higher order** **management** 1	Learn more complicated uses for the phone	
memory + **higher order** **management +** **recreation** 1	I would like mom to learn how to run a computer.	
Other **Cognitive** **Domains** 27	Doesn't concentrate. Listening/ paying attention/ focusing Stay with a conversation so it doesn't have to be repeated Maintain concentration during	Start and finish one project before starting another I do known what to next. But can follow instructions. Trouble with figures

conversations

Being able to concentrate during conversations is a big one, also affects her ability to concentrate during activities.

Can't follow conversation

Maintaining concentration – to remember to finish something started.

Concentration on tasks to complete them

Not get distracted during activities

What day is it?

The date and time definitely.

Know what day it is and *plans for the day.*

Sense of directions when we are driving.

Keep track of current happening

Increased ability to concentrate on written problems.

Improved language skills – naming items

Remembering how to spell simple words.

Reading and understanding written word

Counting backwards

Rember how to spell

I am good at the first of a conversation but by almost through I can't remember.

Maintain concentration, not get distracted during an activity (2)

other cognitive domains + **recreation** 5

Difficulty watching TV programs

Reading – paper, books, spelling.

He reads books but doesn't finish them.

Read books.

Start to read books again

Recreation 13	Visit outside her home – be comfortable outside. Visit or phone friends Visiting More social activity More socializing More time on leasure and social activities. Play cards *Return to old clubs and groups.*	Visit with family. Visit with friends and family More time socializing activities How to downsize my pictures. How to get started, what to keep. Leisure activities like walking.
recreation +household 3	Using the phone Talking on the phone is limited.	Taking some piece of equipment apart and then putting it together
recreation + higher order 1	Using computer for email without <u>me</u> caregiver doing all the steps	
Household 4	Cooking, cleaning Lacks confidence to do laundry or bake bread Laundry	Shopping lists – being able to destroy old lists
household + higher order 14	To put things away and take care of mail and bills when they come in Keep track of bills and deadlines, appointments etc. Keep paperwork organized – not placing in various locations. Some others are buying groceries and	Help in building confidence with everyday chores. i.e., laundry, shopping, moving into a new place. Relearning how to do things like where the garbage goes, mail delivery. With moving learning about new

	realizing what items you need and how some items are not required or excessive amounts of certain items, etc.	surrounding and appliances
		Writing cheques
		Improve use of calendar
	Multiple grocery lists – reported buying	
	Grocery list	
	Maintain appointment dates on calendar	
	Recognizing need for and initiating tasks around house. E.g., Empty garbage, get wood for fireplace	
	Doing when I lay down in the afternoon for a rest.	
Inconsistent with Cognitive Rehabilitation 6	With his hearing.	Tremor of right arm.
	Even being able to drive again.	My balance (especially up and down stairs).
	Relax when driving.	
	Handling her own finances.	
Relationship 1	I would like to know what to do when we disagree about something	
General well-being 1		I tire faster than I used to

Note. Goals written in italics were underlined examples on the EQM. Numbers in brackets indicate that the same goal was written more than once by different participants.
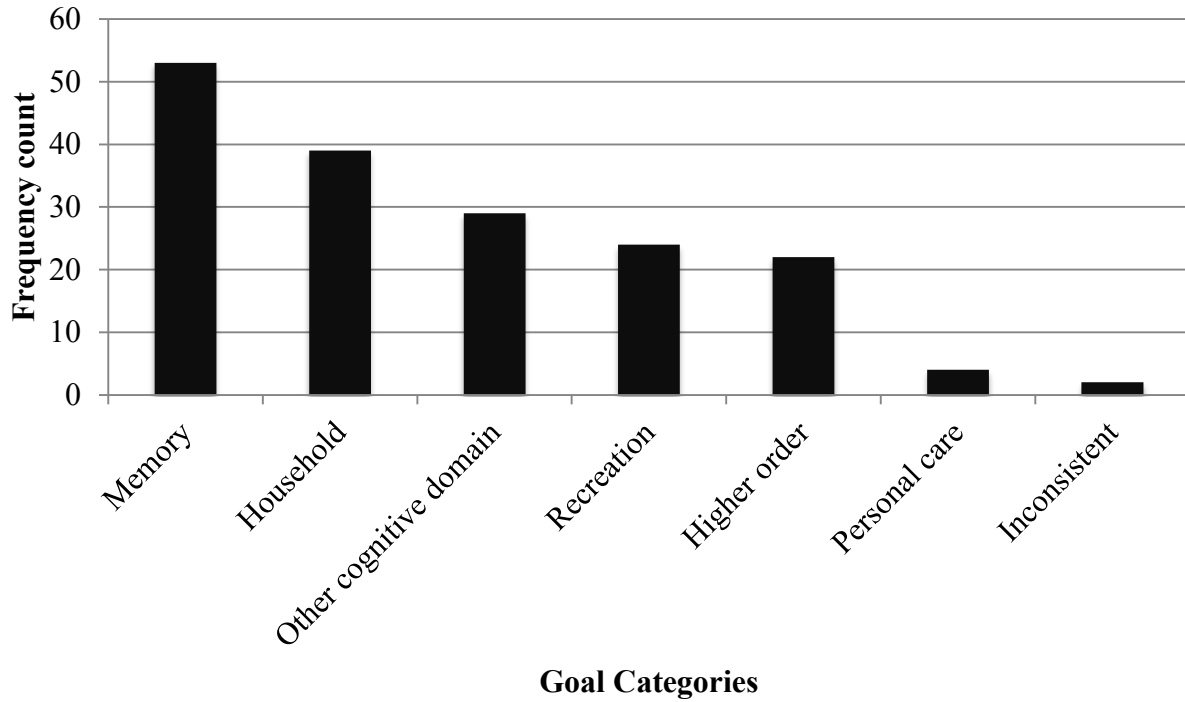
Figure 2.1. Frequency of goals categories reported on the Everyday Memory Questionnaire. Participant responses could be coded in multiple categories.
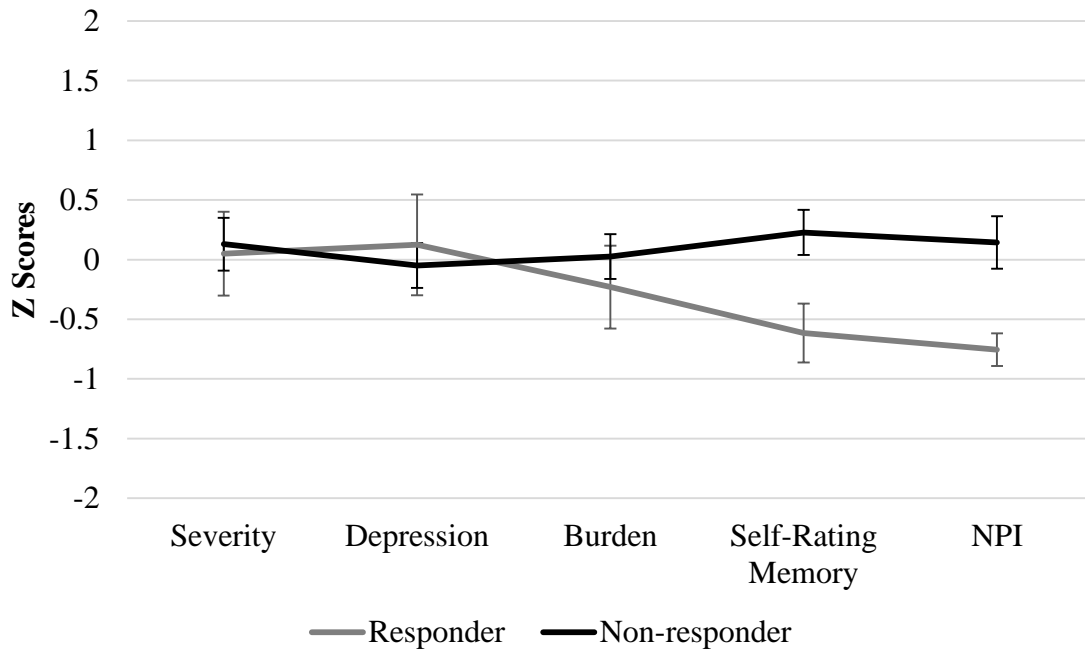
Figure 2.2. Profile plot of participants who responded to the EQM and participants who did not respond to the EQM. The figure plots severity as measured by the CDR-SOB, depression as measured by the CESD, caregiver burden as measured by the Zarit Burden Inventory, and the neuropsychiatric symptoms as measured by the NPI. Standard errors are represented by the error bars.

3. Link from Study 1 to Study 2

Both Study 1 and Study 2 are concerned with planning goal-oriented cognitive rehabilitation for individuals diagnosed with MCI, dementia due to AD, or mixed AD/VaD. Both studies seek to gather information to guide researchers about the interventions that will need to be implemented during cognitive rehabilitation sessions. Study 1 did this by asking participants (both patients and family members) about the types of goals that they would be interested in setting if they were to participate in cognitive rehabilitation. Study 2 approaches treatment planning from a different perspective. As discussed in Study 1 and in the General Introduction, cognitive rehabilitation aims to target functionally relevant goals. As you will read, Study 2 is concerned with the cognitive and neuropsychiatric correlates of the functional goals participants will set in cognitive rehabilitation. As much as it is important to understand what domains participants hope to target it is important to understand what variables are likely to underlie deficits in performing instrumental activities of daily living (IADL), so that the techniques that are applied can target the appropriate area of difficulty. In this way, Study 2 also works to contribute to our theoretical understanding of cognitive rehabilitation for individuals diagnosed with MCI, AD, or mixed AD/VaD.

4.1 Study 2 Abstract

The ability to carry out instrumental activities (IADL) of daily living allows older adults to continue to live independently. Previous research suggested IADL were supported by multiple cognitive and neuropsychiatric factors. The primary goal of this study was to investigate whether immediate memory, executive functions, depression, and apathy, predicted unique variance in IADL over and above demographic variables (age and education) and general cognitive screening (Mini-Mental State Exam). Participants ($N = 403$) were recruited from the Rural and Remote Memory Clinic (75 cognitively normal; 75 mild cognitive impairment; 139 dementia due to Alzheimer's disease; 114 non-Alzheimer's dementia). Results of hierarchical regression analyses suggested immediate memory, executive functions, apathy, and depression each accounted for unique variance in IADL in the overall sample, but as a predictor only apathy predicted variance in IADLs above demographics and general cognitive status. Further analysis of the diagnostic subgroups suggested different variables were more strongly associated with IADL from group to group (apathy and depression for normal participants, apathy for MCI participants and for participants with dementia due to AD, but not for those with non-AD dementia). The implications for developing cognitive rehabilitation interventions are discussed.

4.2 Cognitive and Neuropsychiatric Correlates of Functional Impairment Across the Continuum

of No Cognitive Impairment to Dementia

Instrumental activities of daily living (IADL) are the day-to-day functional activities that allow an individual to live independently. They include tasks such as cooking, shopping, financial management, travelling, and medication management (Sikkes, de Lange-de Klerk, Pijnenburg, Scheltens, & Uitdehaag, 2009). IADL are more complex than basic activities of daily living (BADL), which are focused on personal care and self-maintenance skills such as bathing, toileting, and eating (Sikkes et al., 2009). As adults age and move from middle age to old age changes in independence and function take on considerable importance for individuals, for families, and for communities. Older adults often hope to continue to live in their own home environments and expect to age in place (e.g., Robinson & Moen, 2000). In the context of health, and neurodegenerative disease in particular, changes in functional status have significant diagnostic implications; decline in function and impairment at work or other usual activities are core features of a dementia diagnosis (McKhann et al., 2011; Robillard, 2007). When individuals with cognitive concerns participate in cognitive rehabilitation treatment goals are focused on improving function, increasing participation in meaningful activity, and managing day-to-day problems (Clare et al., 2010; Giebel & Challis, 2015; Kurz et al., 2012). This study aimed to inform the development of these interventions by furthering our understanding of the cognitive and neuropsychiatric correlates of IADL.

Research on the trajectory of impairment in late life and in dementia has tended to focus on cognition rather than instrumental activities of daily living (IADL; Farias et al., 2013), but increasingly the focus of interventions, particularly cognitive rehabilitation is on function and personally relevant goals (Clare, 2008; Kurz, Leucht, & Lautenschlager, 2011). The gap in understanding the variables that underlie decreased function leads to the criticism that interventions are delivered without a strong theoretical framework (Giebel & Challis, 2015). In 2007, Royall, Lauterbach, Kaufer, Malloy, Coburn, and Black noted that the extensive literature on cognitive assessment had yet to be integrated with the literature on functional status. Since that meta-analysis, research in this area has continued to develop (see Giebel, Challis, & Montaldi, 2015; Lindbergh, Dishman, & Miller, 2016; McAlister, Schmitter-Edgecombe, & Lamb, 2016; Overdorp, Kessels, Claassen, & Oosterman, 2016 for more recent reviews and meta-analyses), but additional research is needed to clarify the relationship between functional

impairment, cognitive deficits, and neuropsychiatric symptoms across the continuum of healthy aging, mild cognitive impairment (MCI), and dementia.

A handful of meta-analyses and systematic reviews have worked to integrate the literature on the cognitive correlates of IADL in older adults, including studies that analyzed data from a broad range of clinically relevant populations (Royall et al., 2007; Overdorp et al., 2016) and analyses focused on the MCI literature (McAlister et al., 2016; Lindbergh et al., 2016). These meta-analyses have consistently reported a great deal of heterogeneity in the literature (Royall et al., 2007; Lindbergh et al., 2016). For example, in Royall and colleague's (2007) meta-analysis the total variance in function accounted for by cognitive variables in the 68 studies included in the analysis ranged from 0% to 78.0%. The population sampled, (e.g., clinical, community based), effects of clinical condition (e.g., healthy older adults, MCI, dementia due to AD, non-AD dementia), approach to IADL assessment (e.g. self-report questionnaire, informant questionnaire, performance based), cognitive and neuropsychological tests selected, and approach to prediction models all contribute to the variability in the literature examining neuropsychological function and IADL (see Gold, 2012 for a narrative review and discussion).

Despite the study-to-study variability some consistent findings are emerging. Globally, cognition seems to account for a relatively small proportion of the total variance in IADL (e.g., McAlister et al., 2016; Royall et al., 2007). Royall and colleagues (2007), who included studies from the neuropsychiatric, geriatric and rehabilitation literature, reported that cognition explained an average of 21% of the total variance in function. Similarly, McAlister and colleagues (2016) who included only MCI samples, reported cognition accounted for an average of 23% of the variance in function. It has consistently been the case that broad, non-specific screening tests such as the Mini Mental State Exam (MMSE; Folstein, Folstein, & McHugh, 1975) are strongly associated with function (e.g., Gold, 2012; Royall et al., 2016). For example, Royall et al. (2007) were surprised to find that general screening tests were the category of cognitive predictor that explained the most variance in functional outcome (i.e., general tests explained more variance than tests in the visual spatial, attention, executive, memory, or verbal domains; Royall et al., 2007).

Many authors have worked to identify the relationship between specific cognitive domains and IADL in late life (e.g., Bangen et al., 2010; Burton, Strauss, Hultsch, & Hunter, 2006; Chaytor, et al., 2015; Farias et al., 2009; Makizako et al., 2015; Marshall et al., 2011; Rog

et al., 2014; Schmitter-Edgecombe & Parsey, 2014; Tuokko, Morris, & Ebert, 2005; Woods, Weinborn, Velnoweth, Rooney, & Bucks, 2012). Despite substantial heterogeneity from individual to study to individual study, trends have emerged in recently published meta-analyses. Overdorp and colleagues (2016), who included a broad range of clinical conditions but only studies that examined both neuropsychological test performance and morphological brain changes, concluded memory, and executive functions independently predict IADL. Similarly, in their meta-analysis of cognition and function in MCI, McAlister and colleagues (2016) concluded executive functions (particularly switching and particularly as measured by the Trail Making Test B), delayed memory (particularly short delay), visual memory, attention, and working memory were the strongest correlates of function in that order.

Executive functions in particular have been a focus of the research on IADL and cognitive function (e.g., Gold, 2012; Vaughan & Giovanello, 2010). In dementia due to AD, Martyr and Clare (2012) carried out a meta-analysis of the correlation between executive functions and activities of daily living in individuals with dementia due to AD. They reported a consistent moderate relationship between executive functions and activities of daily living (Martyr & Clare, 2012). Importantly, the term 'executive functions' does not refer to a single cognitive or neurophysiological process, but to a broad range of different cognitive processes that are sensitive to, but not specific to, impairment in circuits of the prefrontal cortex (Alvarez & Emory, 2006). Executive functions are top-down, effortful mental processes (Diamond, 2013). The core executive functions include inhibition and interference control, working memory, and cognitive flexibility (e.g., Diamond, 2013; Miyake et al., 2000). Rather than selecting a single neuropsychological test measuring executive functions, in the investigation of IADL and cognition presented here we included three tests of executive functions in our analyses: the Trail Making Test B (Reitan, 1992), the Stroop test (Trennery, Crosson, DeBoe, & Leber, 1989), and COWAT verbal fluency (Spreen & Benton, 1977). In this way, we hope to better understand the heterogeneity in the results of studies examining the relationship between executive functions and IADL.

Cognitive rehabilitation endeavours to take a holistic, biopsychosocial approach to intervention (Clare, 2008), which includes working to address goals related to emotional well-being. Therefore, we wanted to consider variables outside the domain of cognition in this study. Depression and apathy are particularly relevant clinical variables when considering the

determinants of decreased function across the continuum from normal aging to dementia (Rog et al., 2014; Okura et al., 2010). Definitions of apathy focus on impairment in goal-directed behaviour and, depending on the author, conceptualize apathy as a disorder of motivation, interest, action, initiation and/or emotional reactivity (see Mortby, Maercker, & Forstmeier, 2012 for a critical review). Depression is characterized by depressed mood (feelings of sadness, emptiness, hopelessness) and/or anhedonia (loss of interest or pleasure in activity; American Psychiatric Association, 2013). Apathy and depression are overlapping constructs, and anhedonia and apathy in particular are closely tied conceptually. Nonetheless, the constructs can be differentiated and this distinction is particularly relevant for older adults (Mortby et al., 2012). For example, previous research found high apathy scores were not associated with elevated depression in individuals diagnosed with AD and in individuals with right hemisphere stroke (Marin, Firinciogullari, Biedrzycki, 1994).

Depressive symptoms were associated with functional impairment and disability in community samples of older adults (Beekman, Deeg, Braam, Smit, & Van Tilburg, 1997; Patrick, Johnson, Goins, & Brown, 2004; Vanoh, Shahar, Yahya, & Hamid, 2016), a clinical sample of older adults with coronary heart disease (Sin, Yaffe, & Whooley, 2015), and mixed community/ institutional samples of individuals with and without dementia (Forsell & Winbald, 1998). Apathy, which is generally found to be more common in dementia compared to MCI or cognitively normal samples (Okura et al., 2010), has also been associated with decreased function (Clarke et al., 2011; Lechowski et al., 2009). When depression and apathy are considered concurrently, which is important because of their conceptual overlap, findings have been mixed. For example, Lam, Tam, Chiu, and Liu (2007) found that both depression and apathy predicted function in their MCI subsample, but only apathy predicted function in their dementia subsample. Rog and colleagues (2014) built on this work by including neuropsychological predictors of function in a sample of individuals across the cognitive continuum from normal aging to dementia. In their overall sample they found that memory, executive functions, depression and apathy each made independent contributions to everyday function. In a secondary analysis, they suggested that the relationships between depression, apathy, cognition, and function varied by diagnostic category. Specifically, for cognitively normal participants' episodic memory, executive functions, and depression were all significantly correlated with function. For individuals with MCI only depression and apathy were correlated

with function, and in the dementia sub-sample only episodic memory and executive function were correlated function. The study presented here builds on this work.

The purpose of this study is to extend previous research that has examined the relationship between IADL, demographic/clinical variables, and cognitive variables including executive function. Despite substantial heterogeneity, executive function, immediate memory, depression, and apathy have consistently been associated with functional abilities, but because they have rarely been examined concurrently (see Rog et al., 2014 for an exception) it is unclear how much unique variance in IADL each account for. We hypothesized that adding these neuropsychological variables (immediate memory, executive functions) and neuropsychiatric variables (depression, apathy) in the second step of a hierarchical regression would account for significantly more variance than a model that included only age, education, and MMSE independent variables. We anticipated that immediate memory, depression, and apathy would each significantly predict unique variance in IADL. Regarding executive functions, based on McAlister et al. (2016) we hypothesized that Trails B would a strong predictor of IADL. A second purpose of this study was to explore whether diagnostic category (e.g., cognitively normal, MCI, AD, non-AD dementia) influenced the strength of the relationship between each of the independent variables (executive functions, immediate memory, depression, apathy) and IADL.

This study has three strengths. First, the sample is clinical and closely related to the individuals with cognitive concerns who may be referred for cognitive rehabilitation. Second, we chose to consider three measures of executive functions (Trail Making Test B, COWAT, and Stroop) separately. Third, cognition and mood are considered concurrently, and we have worked to differentiate low mood from apathy. The goal of this work is to inform the development of cognitive rehabilitation strategies for individuals across the continuum of normal aging, MCI and dementia. We believe better understanding the relationship between the strongest correlates of IADLs in this population will strengthen the theoretical basis for cognitive rehabilitation interventions.

4.3 Study 2 Method

Participants

Participants were 403 consecutive referrals to an interdisciplinary memory clinic, the Rural and Remote Memory Clinic (RRMC; Data Release 6), who were found to have no

cognitive impairment (n = 75), MCI (n = 75), dementia due to Alzheimer's disease (n = 139), or non-AD dementia (n = 114). The non-AD dementia subgroup included individuals who met the diagnostic criteria for dementia due to frontotemporal lobar degeneration, vascular dementia, mixed dementia, or Lewy body disease. See Morgan and colleagues 2009 for a complete description of the procedures at the RRMC. Diagnoses were based on consensus between the clinic's neurologist and neuropsychologist, and were consistent with the guidelines provided from the Third Canadian Consensus Conference on the Diagnosis and Treatment of Dementia (CCCDTD3; Robillard, 2007). The assessment included a clinical interview with the participants and a knowledgeable informant, a neuropsychological assessment, a neurological assessment, a physical therapy assessment, a CT head scan, and recent blood work. Table 1 provides descriptive statistics for the sample broken down by diagnostic category. Informal caregivers accompanied patients to their assessment appointment provided the collateral information and completed questionnaires. Most commonly caregivers were family members: 30% were wives, 18% were husbands, 24% were daughters, 8% were sons, and 10% had another relationship with the patient including nieces, nephews, grandchildren, or friends.

Measures

The complete list of measures administered to RRMC participants at the time of their initial assessment is described in Morgan et al., 2009. Here, the following measures were used to address the study's hypotheses.

Measure of IADL. The Functional Activities Questionnaire (FAQ; Pfeffer, Kurosaki, Harrah, Chace, & Filo, 1982) was used as the measure of function and IADL. The FAQ is an informant-completed measure that asks caregivers to rate the patient's ability to perform daily activities (e.g., pay bills, shop, work on a hobby, prepare a meal) from 'normal' to 'dependent'. Scores range from 0 to 30 and higher scores indicate greater dependence. The FAQ discriminated between dementia and non-dementia samples (Juva et al., 1997), and between MCI and AD samples (Kaur, Belchior, Gelinas, & Bier, 2016; Teng, Becker, Woo, Cummings, & Lu, 2010).

MMSE. The Mini Mental State Exam (MMSE; Folstein et al., 1975) is a widely used cognitive screening measure. The items on the MMSE were designed to capture orientation, immediate and delayed recall, calculation, and language (Strauss, Sherman, & Spreen, 2006). The internal consistency of the MMSE ranges from .31 to .96, the test retest reliability is

adequate ranging between .80 and .95, and the inter-rater reliability is marginal .65 (Strauss, Sherman, and Spreen, 2006). Regarding evidence for validity, the MMSE is moderately to highly correlated with other screening tools (e.g., the Dementia Rating Scale), and has been found to be sensitive to moderate to severe dementia, but generally does not differentiate individuals with less pronounced cognitive changes (e.g., MCI; Strauss, Sherman, and Spreen, 2006).

Immediate Memory. Memory was measured using the immediate memory index from the Repeatable Battery for the Assessment of Neuropsychological Status (RBANS; Randolph, Tierney, Mohr, & Chase, 1998). The immediate memory index is comprised of two subtests: list learning, and story memory. The immediate memory index ($M = 100$, $SD = 15$) is based on the sum of the age-scaled subtest scores. Strauss and colleagues (2006) summarized the evidence for the reliability and validity of the RBANS subscales. The split half reliability coefficients for the subtests of the RBANS were in the .80s, and test-retest reliability coefficients ranged from .55 to .78. There is evidence to support the use of the RBANS to differentiate individuals with a dementia diagnosis from healthy individuals, and individuals with dementia due to a cortical etiology from individuals with dementia due to a subcortical etiology (Strauss et al., 2006).

Measures of executive functions. Three measures of executive function were used in the analyses reported below: the Trail Making Test B (TMT-B; Reitan, 1992), the Controlled Oral Word Association Test (COWAT; Spreen & Benton, 1977), and the Stroop Neuropsychological Screening Test (Trennery, Crosson, DeBoe, & Leber, 1989). For each of these measures standard age-corrected scores (i.e., z-scores) are always reported.

The TMT-B (Reitan, 1992) was administered as a measure of divided attention. In healthy adults and older adults, the reliability coefficients for TMT-B have been found to be adequate and range from $0.67 - 0.89$ (Strauss et al., 2006). In clinical samples the results have not been as consistent, and although reliability can be high in clinical populations this has not uniformly been the case. Related to the population studied here, in sample of older adults with diffuse cerebrovascular disease reliability was on the TMT-B was 0.67 (Strauss et al., 2006).

The Controlled Oral Word Association Test (COWAT; Spreen & Benton, 1977) was used as a measure of verbal fluency. Verbal fluency evaluates the spontaneous production of words under restricted conditions (Strauss et al., 2006). In healthy adults test-rest reliability coefficients have consistently been reported to be above 0.70, and small but reliable practice effects have been found (Strauss et al., 2006).

The Stroop Neuropsychological Screening Test (Trennery et al.,1989) was administered as a measure of executive function. As summarized by Strauss and colleagues (2006) the reliability of the Stroop Test has been shown to be adequate with test-retest reliability coefficients ranging between 0.73 and 0.91. Here, we used the colour-word interference scores only, which is a measure of the ability to inhibit an automatic response (Trennery et al., 1989).

Depression. Depression was measured by the Centre for Epidemiologic Studies Depression Scale (CES-D; Radloff, 1977), which is a self-report scale developed to identify depression in the general population. The CES-D has been found to have adequate internal consistency and test-retest reliability (Cronbach's alpha between 0.82 and 0.91, and test-retest reliability ranging from 0.52 to 0.57 depending on the sample and time interval; Lewinsohn, Seeley, Roberts, & Allen, 1997; Radloff, 1977; Ros et al., 2011). There is evidence for the validity of the CES-D in samples of community dwelling older adults and older adults with cognitive impairment (Lewinsohn et al., 1997; Ros et al., 2011).

Apathy. The Neuropsychiatric Inventory (NPI; Cummings et al., 1994; Cummings, 1997), which was designed specifically to assess psychopathology in individuals diagnosed with dementia, provided a measure of apathy. The NPI is a caregiver completed measure of patient behaviours associated with caregiver distress. The frequency and severity of twelve symptoms (delusions, hallucinations, agitation, dysphoria, anxiety, apathy, irritability, euphoria, disinhibition, aberrant motor behaviour, night-time behviour disturbances, and appetite and eating abnormalities) are rated and caregiver distress related to each symptom is measured (Cummings, 1997). In the standardization sample of individuals diagnosed with dementia test-retest reliability was 0.79 overall. In the analyses below, the apathy severity score, which was rated from 0 to 3 by caregivers (if apathy was absent, this was rated 0) was used in all analyses.

4.4 Study 2 Results

All analyses were carried out using IBM SPSS 24. Prior to analysis, the assumptions of multiple regression were checked following the procedures outlined by Tabachnick and Fidell (2013). FAQ, MMSE, RBANS index scores (Immediate Memory, Visuospatial, Language, Attention, and Delayed Memory), Trails B, Stroop, COWAT, CES-D, and NPI apathy scores were examined for missing values, and the fit between their distributions and the assumptions of multivariate analysis. Specifically, the assumptions of normality, homoscedasticity, and multicollinearity were reviewed.

No univariate outliers were identified. Mahalanobis distance was used to examine multivariate outliers and no cases with $p < 0.001$ were identified. The distributions of FAQ ($Z = 3.62$), MMSE ($Z = -4.5$), and CES-D ($Z = 3.64$) were all significantly skewed. Delayed Memory had significant kurtosis ($Z = 3.04$). When a square root transformation was applied, FAQ, MMSE and CES-D scores were no longer significantly skewed. Significant skewness remained for the Delayed Memory scores. The regression analyses reported below were run with and without transformation, and the results were not substantially different. This is consistent with Tabachnick and Fidell's (2013) assertion that statistically significant skewness does not make a substantial difference in regression analyses when sample sizes include more than 100 cases. For ease of interpretation, non-transformed variables and results are reported here.

The assumptions of linearity homoscedasticity were examined using bivariate scatterplots, and no clear deviations from either of these assumptions were observed. Finally, the correlation matrix revealed no correlations greater than 0.90, indicating that multicollinearity was not problematic. The correlation between Immediate Memory and Delayed Memory from the RBANS, $r = .767$, $p < .0001$, was high enough that we considered including both measures of memory redundant, and only Immediate Memory was included in subsequent analyses. This decision was based on the recommendations of Tabachnick and Fidell (2013), the skewed distribution of Delayed Memory, and previous research demonstrating the stronger relationship between immediate memory and function vs delayed memory and function (e.g., Martyr et al., 2014).

Hierarchical regression (also known as sequential regression) was used to determine if executive function, immediate memory, depression and apathy improve prediction of IADLS beyond differences in age, education, and global cognitive function as screened by the MMSE. Given the complexities and challenges surrounding measures of executive functions reviewed in the introduction the decision to use three separate measures of executive functions was made, and the hierarchical regression was run three separate times using the Stroop test, COWAT, and TMT-B as measures of executive function. Due to multiple comparisons, p was set to 0.01, nevertheless the focus for interpretation remained on variance accounted for rather than mere p-value.

Hierarchical regression results with the Stroop test as the measure of executive functions. Table 2 displays the unstandardized regression coefficients (*B)*, the standardized

regression coefficients (β), the t values, and the squared semipartial correlations (si^2), after each step of the analysis. R was significantly different from zero at the end of each step. In step 1, age, education and MMSE were entered into the equation, $R^2 = 0.17$, F_{inc} (3, 178) = 12.40, $p < .001$, 95% CI [.08, .27]. In step 2, immediate memory, COWAT, NPI apathy, and CESD were entered, $R^2 = .36$, $\Delta R^2 = .19$, F_{inc} (4, 178) = 12.77, $p < 0.001$, 95% CI [.25, .47]. The addition of Stroop, immediate memory, depression and apathy lead to a significant increase in R^2, and an additional 19% of the variance in FAQ was accounted for. With all IVs included in the equation, the adjusted R^2 value of .36 indicates the complete model accounts for approximately one third of the variability in FAQ. The demographic/screening variables accounted for one tenth of the variance in FAQ, and executive functions (measured by the Stroop test in this case), immediate memory, depression, and apathy accounted for an additional fifth of the variability in predicting FAQ scores.

Hierarchical regression results with Trails B as the measure of executive functions. Table 3 displays the unstandardized regression coefficients (B), the standardized regression coefficients (β), the t values, and the squared semipartial correlations (si^2), after each step of the analysis. As in the previous analyses R was significantly different from zero after each step in the analysis. In step 1, age, education and MMSE were entered into the equation, $R^2 = 0.23$, F_{inc} (3, 184) = 18.80, $p < .001$, 95% CI [.12, .32]. In step 2, immediate memory, Trails B, depression and apathy added to the prediction of FAQ, $R^2 = 0.36$, $\Delta R^2 = .14$, F_{inc} (4, 184) = 9.71, $p < .001$ 95% CI [.26, .47]. The addition of Trails B, immediate memory, depression and apathy lead to a significant increment in R^2, and an additional 14% of variance accounted for in FAQ. With all IVs included in the equation, the adjusted R^2 value of .34 indicates over a third of the variability in FAQ is accounted for by the demographic, cognitive, and neuropsychiatric variables. These results are consisted with the pattern of the hierarchical regressions reported above. Again, when added to the model, executive functions, depression, and apathy predict additional variability in FAQ.

Hierarchical regression results with COWAT as the measure of executive functions. The unstandardized regression coefficients (B), the standardized regression coefficients (β), t values, and the squared semipartial correlations (si^2) after each step of the analysis are shown in Table 4. R was significantly different from zero after each step. In step 1, age, education and MMSE were entered into the equation, $R^2 = .25$, F_{inc} (3, 247) = 24.47, $p < .001$, 95% CI [.17, .35].

In step 2, immediate memory, COWAT, depression, and apathy added to the prediction of IADL, $R^2 = .35$, $\Delta R^2 = .11$, F_{inc} (4, 247) = 10.13, $p < .001$, 95% CI [.26, .45]. The addition of COWAT, immediate memory, depression, and apathy lead to a significant increment in R^2, and an additional 11% of variance accounted for in FAQ. With all IVs included in the equation, the adjusted R^2 value of .35 indicates more than a third of the variability in FAQ is accounted for by the demographic, cognitive, and neuropsychiatric variables selected here. This pattern of results suggests that a quarter of the variability in FAQ is accounted for by demographic variables (age, education) and general cognitive function (MMSE). Consistent with the previous regression analyses, executive functions as measured by COWAT, immediate memory, depression, and apathy account for additional variability in predicting FAQ over and above these demographic/screening variables.

Correlations with function by diagnostic subgroup. The Pearson product-moment correlations between the independent variables of interest (MMSE, immediate memory, COWAT, Stroop, Trails B, depression, and apathy) and function as measured by the FAQ were examined within each diagnostic group (no CI, MCI, dementia due to AD, non-AD dementia). These correlations are provided in Table 5. As shown there, for those with no cognitive impairment there was a moderate relationship between apathy and FAQ, and depression and FAQ. In individuals diagnosed with MCI, there was moderate relationship between apathy and FAQ. In individuals diagnosed with dementia due to AD there was a moderate relationship between apathy and FAQ, but no substantial association between apathy and FAQ for non-AD dementia. The association between the general cognitive status screen, MMSE and the FAQ was only moderate for the groups diagnosed with dementia (AD and non-AD dementia).

4.5 Study 2 Discussion

First, we found that for the sample as a whole immediate memory, executive functions, depression, and apathy all accounted for variance in IADL above and beyond the variance accounted for by age, education, and general cognitive function. This was true regardless of the measure of executive functions used. In the hierarchical regression analyses the measures of executive functions (Stroop, Trails B, and COWAT) independently predicted a small proportion of the total variance (squared semipartial correlations ranging from -.13 to -.10). This is consistent with previous researchers such as Marshall et al. (2011) who found executive functions were related to informant reported IADL impairment in cognitively normal older

adults, individuals with MCI and individuals with dementia due to AD. Like the work presented here, this relationship persisted even after accounting for diagnosis, global cognitive impairment, memory performance, depression and apathy. The hierarchical regression analyses are consistent with Gold's (2012) argument about the treatment of executive function in IADL prediction models. Namely, IADL is a multidimensional construct and relies on multiple cognitive systems, which means that the strength of the relationship between IADL and any particular cognitive variable depends on whether or not demographic variables and general cognitive function are included in the prediction model. Consistent with this hypothesis, the models reported here suggest executive functions, as measured by Stroop, Trails B, and COWAT, and immediate memory account for a modest amount of unique variance in function.

This study worked to consider how the correlates of function might vary by diagnostic subgroup across the continuum from no cognitive impairment to dementia. Regarding the cognitive variables, immediate memory was not substantially correlated with function, but general cognitive status was moderately associated with function for both the AD and non-AD subgroups. Memory impairment is the hallmark of dementia due to Alzheimer's disease and cognitive rehabilitation interventions focus on this domain (e.g., Clare, 2008; Kurz et al., 2011); consequently, the lack of association was surprising. In addition, we were surprised by the non-significant correlations between the measures of executive functions and IADL across all three clinical groups. Previous meta-analyses reported a moderate association between IADL and executive functions in AD (Martyr & Clare, 2012) and between Trails B in particular and IADL in MCI (McAlister et al., 2016). For the non-AD subsample, it may be the case that the strongest correlates of function for non-AD dementia were not included here. For example, in dementia due to Lewy Bodies (DLB) motor dysfunction accounted for more variance in IADL than either cognitive changes or behavioural changes (Hamilton et al., 2014). Future studies, reviews, and meta-analyses should continue to divide heterogeneous samples into diagnostic subgroups as there do appear to be clear differences in cognitive correlates of function from MCI to AD to non-AD dementia.

Moving on to consider to consider the relationship between depression, apathy, and function, the hierarchical regression analyses suggested apathy predicted the most unique variance in FAQ with medium squared semipartial correlations (ranging from .29 to .38). In contrast to the predictive strength of apathy, we were surprised to find that depression was not a

substantial predictor of function. These results are in contrast to Okura et al. (2010) who found those with clinically significant depression, but not apathy, had higher odds of IADL limitations. However, our results are consistent with Norton, Malloy, and Salloway (2001) and Senanarong et al. (2005) who both reported apathy, but not depression, was associated with function. Previous researchers (Lam et al., 2007; Rog et al., 2014) have suggested that the relative importance of depression and apathy may depend on the diagnostic subsample. This possibility was explored here, and the relative importance of depression and apathy, did vary from diagnostic subsample to diagnostic subsample.

In the subsample diagnosed with no cognitive impairment, our results suggested that both depression and apathy were moderately associated with IADL. Rog et al. (2014) found depression, but not apathy, correlated with everyday function in their normal subsample. This difference may be because our cognitively normal sample was referred for a specialized dementia assessment whereas Rog et al. (2014) used a community sample. We did not find any association between depression and IADL in our clinical subsamples (MCI, AD, non-AD dementia). A recent meta-analysis (Lindbergh et al., 2016) of function in MCI reported depression was not an effect size moderator, which is consistent with the lack of relationship we found between depression and IADL in this study. Our data suggest for individuals diagnosed with MCI or AD there was a moderate relationship between apathy scores and FAQ scores. In the non-AD subsample, there was no relationship between function and either depression or apathy. Most other researchers have used either a heterogeneous dementia subsample (i.e., AD is not differentiated from other aetiologies of dementia), or an AD only subsample (i.e., individuals diagnosed with non-AD dementia were not included). Norton et al. (2001), in a mixed dementia sample (majority dementia due to AD), found apathy accounted for variance in function, but depression did not. Similarly, Lam et al. (2007) and Senanarong (2005) reported apathy was associated with decreased function in their AD sample. Lam et al. (2007) also included a 'questionable dementia subscale' (similar to MCI) and for this group both depression and apathy were associated with decreased function. Based on the correlational analyses, our results further support concluding that in individuals without cognitive impairment, MCI, and AD apathy, but not depression, are associated with decreased function.

It is important to acknowledge the limitations of this study. First, there has been substantial discussion in the literature about the evidence for the validity of IADL questionnaires (Marcotte,

Scott, Kamat, & Heaton, 2010). At present, there is no agreed upon gold standard for assessing IADL but self-reported questionnaires, informant reported questionnaires, and performance based measures do seem to produce different estimates of function (e.g., Loewenstein & Acevedo, 2009) and are not always strongly correlated with each other (Schmitter-Edgecombe, Parsey, & Cook, 2011; Vaughan & Giovanello, 2010). The FAQ is a widely used measure of IADL and although there is good evidence of its discriminability (Juva et al., 1997; Teng et al., 2010) its other psychometric properties (e.g., test-retest reliability, internal consistency) have been inadequately studied (Kaur et al., 2016).

The FAQ approach to measuring IADLs is problematic because of its reliance on an informant report, as was done in the current study. Informant state of mind, particularly distress and depression can impact their informant ratings of function (Mangone, et al., 1993; Martyr & Clare, 2017; Martyr, Nelis, & Clare, 2014). In fact, in 37 persons with early stage dementia due to AD or mixed vascular/AD (MMSE >18), patient self-report of function was more associated with objectively measured function than was informant reports (Martyr & Clare, 2016). Informant burden and distress are related with informant rated IADLs, but their relation is complicated. Longitudinal studies demonstrate that changes in caregiver burden are related to patient changes such as increasing functional (Berger et al., 2005) and neuropsychiatric symptoms (Berger et al., 2005; Mohamed, Rosenbeck, Lyketsos, & Schneider, 2010; van der Lee, Bakker, Duivenvoorden & Droes, 2017). Moreover, increasing caregiver distress, over time, is related to increasing neuropsychiatric symptoms of persons with dementia (van der Lee et al., 2017). Dementia severity, caregiver distress, and caregiver rated FAQ accounted for a large proportion of variance in caregiver burden (38%), but disinhibition and apathy accounted for an additional 21.8% of the variance in caregiver burden (Branger, Enright, O'Connell, & Morgan, 2017). Although, approaching the limitation of caregiver distress/burden influencing caregiver reported IADL by partialling out the variance due to burden is conceptually problematic, we repeated the hierarchical regressions with burden partialled out and the results did not change: apathy remained the sole robust predictor of IADLs. Nevertheless, there is likely a bidirectional relationship between burden and informant rating of the IADLs of their loved one with dementia that cannot be ignored and is a limitation of these data and their conclusions. Ideally, studies investigating predictors of function would use multiple methods to evaluate function (McAlister et al., 2016).

Another limitation to the current analyses is the restricted sample used for the executive function analyses, particularly for the Stroop and Trails B because a large proportion of the sample with dementia was unable to complete these tests. We have demonstrated that inability to complete the Stroop and Trails B is not necessarily due to impaired executive function per se, but rather impairments in memory, language, visuospatial abilities, and attention (Enright, O'Connell, McKinnon, & Morgan, 2015). Consequently, the EF analyses are restricted only to those whose cognitive abilities were sufficiently strong to allow their completion of the Stroop and the TMTB, which could have restricted the range of possible Stroop and Trails B performance, possibility obfuscating their relation with IADL in persons with dementia.

This study is also limited by the decision to use a single item from the NPI to assess apathy. Again, although is approach has been used in previous research (e.g., Rog et al., 2014) it is not the most robust approach to measurement. Single item measures are problematic because their internal consistency cannot be evaluated (Gardner, Cummings, Dunham, & Pierce, 1998). Apathy emerged as a strong predictor of function in the hierarchical regression analyses reported here, and future studies should continue to examine the relationship between apathy and function. However, apathy is a challenging construct to assess because there is a lack of consensus about the clinical definition of apathy (Rog et al., 2011; Clarke et al., 2011).

A final limitation pertains to the group we have labelled as cognitively normal, which was based on their neuropsychological performance and clinical history. This group sought specialist consultation and agreed to be assessed after waiting a considerable length of time (the clinic's waitlist is typically around 11-12 months). Clearly, they were initially concerned about their cognition, despite their neuropsychological performance within normal limits. Worry about subjective cognitive complaints without evidence for objective cognitive impairments, also referred to as subjective memory impairments or subjective cognitive impairment is a heterogeneous group whose symptoms might be related to mood or anxiety (Burmester, Leathem, & Merrick, 2016). Moreover, epidemiological data prospective over six years suggests those with subjective memory impairment might be at risk for subsequent diagnoses of dementia (Jessen et al., 2014), but part of the heterogeneity in this new area of literature are the methods used to categorize within normal limits on objective testing (Burmester et al., 2016) and more research is required.

Despite these limitations, the results of this study can help inform cognitive rehabilitation in a number of ways. First, these results support efforts to approach cognitive rehabilitation from a holistic perspective (e.g., Clare, 2008). This study added further support to the hypothesis that function is supported by both cognitive and neuropsychiatric variables, and here we found that memory, executive functions, depression, and apathy all predicted variance in IADL performance over and above demographic variables and general cognitive function in the overall sample. Memory based interventions have been the central focus of the majority of cognitive rehabilitation interventions (e.g., Clare, 2008), and the results presented here support that approach particularly for individuals with MCI or dementia due to AD, which is where the majority of the cognitive rehabilitation studies have focused. As clinicians work to expand and develop these interventions the results reported here suggest that symptoms of apathy are an important domain to consider. First, we suggest focusing on working to differentiate apathy from depression during the assessment and treatment-planning phase of interventions. Non-pharmacological treatments for apathy are an active area of study (see Goris, Ansel, & Schutte, 2016 for a systematic review; O'Connell, Mateer, & Kerns, 2003 for a discussion of practical considerations) and some, such as music based interventions and external cuing appear promising. As discussed, apathy needs to be differentiated from depression and our results suggest the subgroup of individuals where depression focused interventions are most likely to support function are those who present for assessment with subjective concerns, but who are cognitively normal. These individuals should be screened for depression and depressive symptoms should be treated in any cognitive rehabilitation interventions that are provided. Finally, although the literature examining predictors of IADL is full of mixed results, due to differences in methodologies and limits in assessment measure, this area has the potential to further develop the theoretical basis upon which interventions are being developed.

4.6 Study 2 References

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Table 4.1

Descriptive statistics for demographic and clinical variables for each of the diagnostic subgroups

	No CI	MCI	AD	Non-AD
	M (SD)	*M (SD)*	*M (SD)*	*M (SD)*
	n	*n*	*n*	*n*
Age	60.79 (12.97)	70.92 (11.25)	75.98 (7.44)	71.95 (10.54)
	75	74	138	113
Gender (% female)	55%	55%	68%	56%
Education	12.49 (3.32)	10.92 (3.40)	10.10 (3.27)	10.88 (3.31)
	59	65	119	93
FAQ	4.74 (5.66)	7.56 (5.71)	15.74 (7.75)	15.20 (8.21)
	66	72	133	107
MMSE	28.41 (1.53)	27.03 (2.12)	21.66 (4.11)	23.04 (4.66)
	59	64	120	91
Memory	95.98 (11.31)	78.78 (14.93)	57.62 (14.07)	64.95 (16.88)
	58	64	109	79
Stroop (*z* score)	-.41 (1.18)	-1.43 (1.23)	-1.90 (1.23)	-2.23 (1.02)
	53	54	61	47
Trails B (*z* Score)	-.61 (1.25)	-1.37 (1.31)	-2.05 (1.28)	-2.35 (1.11)
	56	52	64	49
COWAT (*z* score)	-.72 (1.25)	-1.28 (1.08)	-1.41 (.99)	-1.95 (1.03)
	58	64	107	80
NPI Apathy Severity	.75 (.94)	.55 (.81)	1.02 (.98)	1.17 (1.01)
	65	69	132	103
CESD	18.38 (11.09)	14.64 (9.0)	12.71 (10.0)	13.30 (8.71)
	68	66	79	111

Note. FAQ = Functional Activities Questionnaire; Memory = Immediate Memory index from the Repeatable Battery for the Assessment of Neuropsychological Status; MMSE = Mini-Mental

State Exam; NPI = Neuropsychiatric Inventory; CESD = Center for Epidemiologic Studies – Depression scale.

Table 4.2

Hierarchical Regression Analyses Predicting IADL Function with the Stroop test as the Measure of Executive Function

Variable	B	β	t	sr_i^2
Step 1				
Age	.14	.22	2.90**	.20
Education	.07	.004	0.06	.004
MMSE	-.63	-.27	-3.43**	-.23
Step 2				
Age	.14	.23	3.13**	.19
Education	.10	.04	.64	.04
MMSE	-.40	-.17	-2.04	-.12
Memory	-.02	-.05	-.56	-.03
Stroop	-.83	-.15	-2.09	-.13
NPI apathy	3.04	.39	6.38***	.38
CESD	.001	.002	0.03	.002

Note. Memory = Immediate Memory index from the Repeatable Battery for the Assessment of Neuropsychological Status; MMSE = Mini-Mental State Exam; NPI = Neuropsychiatric Inventory; CESD = Center for Epidemiologic Studies – Depression scale.

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

Table 4.3

Hierarchical Regression Analyses Predicting IADL Function with Trails B as the Measure of Executive Function

Variable	B	β	t	sr_i^2
Step 1				
Age	.12	.19	2.62**	.17
Education	.14	.06	.89	.06
MMSE	-.82	-.37	-4.95***	-.32
Step 2				
Age	.14	.22	3.08*	.18
Education	.13	.06	.86	.05
MMSE	-.51	-.23	-2.69*	-.16
Memory	-.01	-.02	-.17	-.01
Trails B	-.79	-.14	-2.04*	-.12
NPI apathy	2.82	.35	5.81***	.34
CESD	-.02	-.02	-.37	-.02

Note. Memory = Immediate Memory index from the Repeatable Battery for the Assessment of Neuropsychological Status; MMSE = Mini-Mental State Exam; NPI = Neuropsychiatric Inventory; CESD = Center for Epidemiologic Studies – Depression scale.

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

Table 4.4

Hierarchical Regression Analyses Predicting IADL Function with COWAT as the Measure of Executive Function

Variable	B	β	t	sr_i^2
Step 1				
Age	.16	.23	3.83**	.21
Education	.07	.03	.47	.03
MMSE	-.73	-.36	-5.77***	-.32
Step 2				
Age	.19	.28	4.49***	.23
Education	.11	.05	.78	.04
MMSE	-.54	-.27	-3.45**	-.18
Memory	-.02	-.04	-.51**	-.03
COWAT	-.72	-.11	-1.86	-.10
NPI apathy	2.43	.30	5.72***	.29
CESD	.04	.05	.81	.04

Note. Memory = Immediate Memory index from the Repeatable Battery for the Assessment of Neuropsychological Status; MMSE = Mini-Mental State Exam; NPI = Neuropsychiatric Inventory; CESD = Center for Epidemiologic Studies – Depression scale.

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

Table 4.5

Correlations with function (FAQ) for each diagnostic group

	No CI	MCI	AD	Non-AD
	r, n	*r, n*	*r, n*	*r, n*
MMSE	-.07, 55	.04, 61	-.35, 117***	-.33, 88*
Memory	.07, 54	.08, 61	-.10, 108	-.08, 78
Stroop	-.10, 54	-.04, 51	-.09, 60	-.07, 46
Trails B	-.25, 52	.14, 50	-.01, 63	-.05, 49
COWAT	-.10, 54	.02, 61	.09, 105	-.16, 79
NPI Apathy	.47, 65***	.30, 68*	-.37, 131***	.18, 102
CESD	.34, 61**	.05, 64	.12, 110	.10, 79

Note. Memory = Immediate Memory index from the Repeatable Battery for the Assessment of Neuropsychological Status; MMSE = Mini-Mental State Exam; NPI = Neuropsychiatric Inventory; CESD = Center for Epidemiologic Studies – Depression scale.

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

5. Link from Study 2 to Study 3

In the next manuscript, Study 3, cognitive rehabilitation is delivered to individuals with subjective cognitive impairment (SCI), mild cognitive impairment (MCI), and dementia due to Alzheimer's disease (AD). Whereas Study 1 and Study 2 could both be conceptualized as treatment planning studies, in Study 3 the intervention is actually delivered and evaluated both in-person and through telehealth videoconferencing. Studies 1 and 2 asked questions about the need for telehealth videoconferencing, the types of goals participants hope to address, and the cognitive and neuropsychiatric domains where techniques will need to be directed in order to impact these functional goals. In many ways, Study 3 builds on this work by applying the available empirically supported techniques to address the goals of participants. You may recall from the General Introduction that I argued for the need for remotely delivered interventions to improve care for rural families with a family member experiencing abnormal cognitive aging. Study 1 supported that need by demonstrating interest in and preference for telehealth videoconferencing treatment. The goal of Study 3 is to better understand how feasible this is to do by comparing in-person treatment to videoconferencing treatment, and documenting/describing how cognitive rehabilitation can been adapted for remote delivery.

6.1 Study 3 Abstract

Non-pharmacological interventions are needed to support the function of older adults struggling with subjective cognitive impairment (SCI), mild cognitive impairment (MCI), and dementia due to Alzheimer's Disease (AD). Telerehabilitation, which aims to provide rehabilitation at a distance, has emerged as a promising approach to expanding the accessibility of specialized interventions. The aim of this study was to compare goal oriented cognitive rehabilitation delivered in-person to cognitive rehabilitation delivered through telehealth videoconferencing. Using a combined between-subjects, multiple baseline single case experimental design, cognitive rehabilitation was delivered to six participants with SCI ($n = 4$), MCI ($n = 1$), or dementia due to AD ($n = 1$), randomly assigned to in-person or telehealth videoconferencing cognitive rehabilitation. Those assigned to in-person treatment completed 100% of eight planned cognitive rehabilitation session. In the telehealth condition 88% of sessions were completed. When initial and final Canadian Occupational Performance Measure scores were compared performance on 6/6 goals addressed in-person improved and performance on 7/9 goals addressed through telehealth improved. Delivery of cognitive rehabilitation by videoconferencing was feasible, but required modifications such as greater reliance on caregivers/clients for manipulating materials.

6.2 Telerehabilitation: Feasibility of Videoconferenced Cognitive Rehabilitation For

Patients with Memory Concerns

Worldwide populations are aging (World Health Organization, 2015). In Canada, the rural population is older and aging faster than the urban population (Statistics Canada, 2010). The incidence of dementia increases with age, and in rural and remote communities, where the proportion of older adults is the greatest, formal dementia services are the least accessible (Bédard, Koivuranta, & Stuckey, 2004; Statistics Canada, 2010). Long travel distances and transportation difficulties further limit accessibility (Bédard et al., 2004). Telemedicine, or telehealth, is the remote delivery of health care services, where distance is a critical factor, by means of information and communications technology (World Health Organization, 2015). Expanding telehealth services has been suggested to reduce disparities in urban and rural healthcare (Romanow, 2002). Interventions to support the function of older adults with cognitive concerns, including dementia, are needed and it is essential that these interventions are accessible to the families they are intended to reach. Cognitive rehabilitation is a promising, but understudied, non-pharmacological individualized treatment that has been shown to help individuals with mild cognitive impairment (MCI), early stage dementia due to Alzheimer's Disease (AD) and Vascular Dementia VaD set (Burton, O'Connell, & Morgan, 2016) and attain personally important functional goals (Bahar-Fuchs, Clare, & Woods, 2013; Clare et al., 2010; O'Sullivan, Coen, O'Hora, & Shiel, 2015). This study investigated the feasibility and acceptability of delivering cognitive rehabilitation to individuals with subjective cognitive impairment (SCI), MCI, and early stage dementia using telehealth videoconferencing.

Telemedicine and dementia

Research on telemedicine and dementia has primarily focused on diagnosis (e.g., Barton, Morris, Rothlind, & Yaffe, 2011; Martin-Khan et al., 2012), clinical consultation, follow-up appointments (Morgan et al., 2009), and support for family caregivers (Serafini, Damianakis, & Marziali, 2007; Lorig et al., 2012; O'Connell et al., 2014). In comparison, relatively little work has studied interventions for individuals diagnosed with dementia, although research in this area has begun to emerge. For example, Dal Bello-Haas, O'Connell, Crossley, and Morgan (2014) demonstrated that videoconferencing is a feasible method to deliver an exercise intervention for rural individuals with dementia due to AD. This study builds on these examples of remotely

delivered interventions for individuals with dementia, as well as work in tele-rehabilitation more broadly.

Tele-rehabilitation

Tele-rehabilitation is "the set of instruments and protocols aimed at providing rehabilitation at a distance" (Rogante, Grigioni, Cordella, & Giacomozzi, 2010, pp. 287-288). Tele-rehabilitation has been used to provide a range of interventions to individuals diagnosed with a number of different disorders. For example, tele-rehabilitation has been used to treat stroke (Gervasi, Magni, & Zampolini, 2010), spinal cord injury (Pain al., 2007), traumatic brain injury (Man, Soong, Tam, & Hui-Chan, 2006; Bergquist, Gehl, Lepore, Holzworth, & Beaulieu, 2008), multiple sclerosis (Finkelstein, Lapshin, Castro, Cha, & Provance, 2008), and cognitive impairment following intensive care (Jackson et al., 2012). Diverse use of telehealth includes delivering diagnostic assessments, caregiver support groups, individual and group psychotherapy (Greene et al., 2010), home exercise programs, clinical consultations, and cognitive rehabilitation using information and communications technology (Rogante et al., 2010).

Cognitive Rehabilitation for Dementia due to Alzheimer's Disease and Vascular Dementia

Clare and her colleagues have developed a goal focused approach to cognitive rehabilitation for individuals with early stage dementia due to AD, or mixed AD and VaD (Clare, 2008; Clare et al., 2010). In this approach, cognitive rehabilitation begins with an assessment, which is followed by collaborative goal setting (Clare, 2008). Typically, functional goals related to everyday memory problems, practical skills, and activities and concentration are set, and improved function in these areas has been reported in multiple studies (e.g., Bird, 2001; Clare, Evans, Parkinson, Woods, & Linden, 2011; Clare, Wilson, Breen, & Hodges, 1999; Clare, Wilson, Carter, Breen, Gosses, & Hodges, 2000; Clare, Wilson, Carter, & Hodges, 2003; Provencher, Bier, Audet, & Gagnon, 2008; Thivierge, Simard, Jean, & Grandmaison, 2008). Generally these collaborative goals are addressed in weekly one hour sessions using empirically supported techniques such as spaced retrieval, cueing and fading, errorless learning, and external memory aids (Clare, 2008). Although promising, research evaluating cognitive rehabilitation for individuals with early stage dementia is still emerging (Kurz, Leucht, & Lautenschlager, 2011).

Remotely delivered cognitive rehabilitation. The majority of literature on remotely delivered cognitive rehabilitation focuses on interventions with individuals who have a traumatic brain injury (TBI). Early research suggests that remotely delivered rehabilitation for individuals

who have sustained traumatic brain injuries (TBI) is feasible (e.g., Bergquist et al., 2009; Ng, Polatajko, Marziali, Hunt, & Dawson, 2013). For example, Tam and colleagues (2003) reported a series of three case studies where individuals with TBI participated in cognitive rehabilitation using customized online software. This software combined video-conferencing with screen-sharing and participants completed computer based activities that targeted word recognition, semantic memory (i.e., memory for factual knowledge) and prospective memory (i.e., memory to perform something in the future). In other work, Bergquist and colleagues (2009) opted to use technology to remotely teach participants who had had a severe TBI to use a calendar as a compensatory memory strategy. They adapted Sohlberg and Mateer's (2001) calendar training procedure to an instant messenger format and also taught participants to use a personal diary. Both interventions led to increased use of compensatory strategies and improved mood (Bergquist et al., 2009). Finally, in an approach that is more similar to the type of cognitive rehabilitation reported here, where the intervention is tailored to personally important problems identified by the participants, Bourgeois and colleagues (2003) had participants with chronic TBI identify three everyday memory problems (i.e., forgetting appointments, forgetting day planner at home, losing items) and provided either an errorless learning approach, spaced retrieval, or memory strategy instructions over the telephone. Individuals in the spaced retrieval group made greater gains in their target goals than those given strategy instructions, and both groups improved their everyday memory functioning. These studies suggest that traditional, in-person cognitive rehabilitation strategies can be delivered by videoconferencing, instant messaging, or telephone.

Remotely delivered cognitive rehabilitation has also been demonstrated for persons with dementia. Joltin, Camp, and McMahon (2003) used the telephone to train spaced retrieval, a memory intervention, to help three women previously diagnosed with dementia recall target information. The goals addressed using spaced retrieval were set in collaboration with family caregivers, staff at the assisted living facility, and the individual diagnosed with dementia (Joltin et al., 2003). Two participants set the goal to recall what time to take their medications, and one participant set the goals to recall her grandson's names, her room number and the year (Joltin et al., 2003). The first participant (MMSE = 17) did not always answer the telephone when the researchers called to provide spaced retrieval training and after four sessions she was still unable to recall the times to take her medication for longer than two minutes (Joltin et al., 2003). The

second participant (MMSE = 17) was able to pick up a prompt card listing the times she needed to take her medications across a five-minute interval at the conclusion of the intervention. The third participant (MMSE = 13) achieved all three of her goals (grandchildren's names, room number, year) and was able to recall the target information across three sessions (Joltin et al., 2003). The author's concluded that it is feasible to modify spaced retrieval for remote delivery, and this study builds on this work.

Objectives

Tele-rehabilitation is a developing field with the promise of increasing the accessibility of specialized interventions such as cognitive rehabilitation. This research built on previous research examining cognitive rehabilitation delivered in-person to individuals with dementia, remotely delivered interventions for individuals with dementia, as well as remotely delivered cognitive rehabilitation delivered to individuals with TBI. To date, remotely delivered cognitive rehabilitation for persons with dementia has not been systematically studied. Interventions that are included in cognitive rehabilitation, such as spaced retrieval, have been applied in a tele-rehabilitation format, suggesting that this may be an acceptable and feasible approach to increasing the accessibility of cognitive rehabilitation for dementia for persons residing in rural and remote areas. The purpose of this study was to investigate the acceptability and feasibility of delivering cognitive rehabilitation to individuals diagnosed with dementia due to AD or mixed AD and mixed AD and VaD using telehealth videoconferencing.

6.3 Study 3 Method

Experimental Design

This study used a combined single-case and between-subjects design. More specifically, the features of a between-subjects design were combined with the features of a multiple-baseline design. After an initial in-person pilot participant (participant A), five participants were randomly assigned to participate in cognitive rehabilitation either in-person or through telehealth videoconferencing. Multiple baselines were measured within-subjects, and treatment modalities were compared across participants. At the initial assessment participants selected at least two goals for cognitive rehabilitation. After three weeks of baseline assessment, Goal 1 was targeted and baseline assessment for Goal 2 continued. After three weeks of Goal 1 intervention, Goal 2 was targeted. In this way, both the in-person and telehealth groups were observed repeatedly during the baseline and treatment phases. The repeated observations over the baseline and

treatment phases meet the criteria for a multiple-baseline design (across groups) (Kazdin, 2011). In single-case experimental design guidelines, three is the minimum number of data points required to establish a baseline, and the minimum number of data points needed in each phase (Smith, 2012).

Participants

Participants were recruited through community based organizations and a hospital-based geriatric assessment program. Initially we hoped to recruit participants solely from clinical settings, but low enrolment led us to expand our recruitment strategy and inclusion criteria. With the expanded criteria, individuals with subjective cognitive decline and no diagnosis, MCI, early stage dementia due to AD, or mixed AD and VaD, were all invited to contact us if they were interested in participating in the study. Diagnosis was self-reported (i.e., participant's reported that they had received a diagnosis of dementia due to AD from their neurologist, reported no diagnosis), but all self-reported diagnoses were consistent with the clinical interview, neuropsychological tests, and questionnaires administered in the assessment for the study. Prior to enrolling in the study, participants completed a brief clinical interview where cognitive rehabilitation was reviewed, and a Mini-Mental State Exam (MMSE; Folstein, Folstein, & McHugh, 1975) was administered. All individuals were encouraged to participate with a family member, or friend, but this was not mandatory.

Measures

Two sets of measures were used in this study: pre-post and weekly measures. A set of measures was administered to participants at the initial assessment and after the intervention was delivered. Second, weekly observational measures and measures of goal performance and satisfaction, described below, were collected. The measures were selected to be similar to those used by Clare and colleagues in their 2010 randomized control trial.

Initial assessment and post-treatment measures. All participants completed neuropsychological testing and self-report measures of mood, anxiety, and quality of life. Support persons completed measures of quality of life (self and participant), function (participant), and caregiver burden. Each of the measures and their psychometric properties are briefly described below.

Rivermead Behavioural Memory Test III (RBMT-III). The RBMT-III was developed to detect memory impairment and change in memory impairment over time (Wilson, 2003). The

test was specifically designed to detect problems that may interfere with rehabilitation (Strauss, Sherman, & Spreen, 2006). The reliability of RBMT-III was assessed using alternate forms reliability (Wilson et al., 2008). The reliability of the subtests of the RBMT-III ranges from $r =$ 0.58 to $r = 0.68$ in a mixed clinical sample (Wilson et al., 2008). The RBMT-III was developed with a specific focus on ecological validity and there is evidence for the measure's validity. The test differentiates between individuals with and without brain injury (Wilson et al., 2008). Further, the RBMT-III's subtests correlate as anticipated with other cognitive tests, with observations of everyday memory failures and with subjective ratings of memory performance completed by patients and relatives (Wilson et al., 2008).

Delis Kaplan Executive Function System (D-KEFS), verbal fluency subtest. The verbal fluency subtest of the D-KEFS includes letter fluency, category fluency, and category switching (Delis, Kaplan, & Kramer, 2001). The letter fluency condition, where individuals are asked to say words that begin with a particular letter has high (0.80 – 0.89) internal consistency (Strauss et al., 2006). The category fluency condition, where individuals are asked to say words from a particular semantic category (e.g., boy's names) has adequate (0.70 – 0.79) test-retest reliability. The category switching condition, where individuals are asked to alternate between saying words from two different semantic categories (e.g., fruit and furniture) has low (< 0.59) test-retest reliability.

Test of Everyday Attention (TEA). The TEA is a measure of attentional processes, and participants completed elevator counting, and elevator counting with distraction subtests (Ridgeway, Robertson, Ward, & Nimmo-Smith, 1994). These subtests measure sustained attention, and selective attention/working memory respectively (Strauss et al., 2006). There are two forms of the TEA and test-retest reliability was calculated by correlating Version A and B following a one week interval, and therefore this correlation provides information about both test-retest reliability and alternate forms reliability (Strauss et al., 2006). The reliability of the map search, elevator counting and elevator counting with distraction subtests was adequate ($r =$ 0.75 – 0.86). In regards to the measure's validity, the TEA is a theoretically based test of attention, and there is evidence for its ecological validity. Nevertheless, further evidence of its convergent and discriminant validity and its psychometric properties in clinical samples is needed (Strauss et al., 2006).

Quality of Life in Alzheimer's Disease (QoL-AD). The QoL-AD scale is a 13-item questionnaire completed by both the individual diagnosed with and his or her caregiver to generate self and informant ratings (Logsdon, Gibbons, McCurry, & Teri,, 1999). The QoL-AD has adequate internal consistency and test-retest reliability, and there is evidence for its validity as a measure of quality of life in persons with AD (Logsdon et al., 1999). In their recent review of measures of health related quality of life for individuals diagnosed with dementia, Perales, Cosco, Stephan, Haro, and Brayne (2013) reported that there is good evidence for the internal consistency, test-retest reliability, content validity, convergent validity and responsiveness of QoL-AD.

World Health Organization Quality of Life Assessment, short version (WHOQOL-BREF). Caregivers completed the World Health Organization Quality of Life Assessment, short version (Skevington, Lofty, & O'Connell, 2004). The WHOQOL-BREF is a 26-item questionnaire covering the physical, psychological, social, and environmental aspects of quality of life (Skevington et al., 2004). The field trials for the WHOQOL-BREF reported that the measure had good to excellent reliability and there was preliminary evidence for the measure's validity (Skevington et al., 2004). Subsequent research has found similar results and, in regards to older adults specifically, Steinbüchel, Lischetzke, Gurny, and Eid (2006) reported that the psychometric properties of the WHOQOL-BREF items were adequate.

Zarit Burden Inventory (ZBI). The ZBI is a self-report measure of caregiver burden and the short form of the ZBI has adequate internal consistency (Cronbach's $\alpha = 0.88 - 0.90$), and there is evidence for its predictive validity (Bédard et al., 2001; O'Rourke & Tuokko, 2003).

Weekly measures. First, every week during both the baseline and the treatment phase, the participant and therapist completed the Canadian Occupational Performance Measure 4th Edition (COPM; Law, Baptiste, Carswell, McColl, Polatajko, & Pollock, 2005). The COPM begins with a semi-structured interview where clients identify problems related to self-care, productivity, and leisure (Carswell et al., 2004). Clients rate the importance of each activity from 1 to 10 and then problems to be the focus of therapy are identified (Carswell et al., 2004). Here this was done in conjunction with setting goals for cognitive rehabilitation. Following the administration guidelines for the COPM, for each problem clients then rated their current performance and their satisfaction with their performance from 1 ('not able to do it' or 'not satisfied at all') to 10 ('able to do it very well' or 'extremely satisfied') (Carswell et al., 2004).

Performance and satisfaction ratings on the problems that were addressed as goals for cognitive rehabilitation were completed weekly. The COPM was designed to measure change in performance and satisfaction with performance. The measure is responsive to change, and a two-point change has been established as clinically significant (Wressle, Samuelsson, & Henriksson, 2009). The COPM has demonstrated adequate test-retest reliability (.84-.92) and there is evidence for the measure's content, criterion, and construct validity (Law et al., 2005).

During both the baseline and intervention phases, the number of learning trials related to a specific goal were observed and recorded. For example, if an individual set the goal to learn the names of the members of a social group or improve recall of personal information this was addressed using vanishing cues and spaced retrieval in order to reduce errors and be consistent with the principles of errorless learning (Clare, 2008). The observed measure was the proportion of items correctly recalled. Or, if an individual set the goal to keep track of the date and the plans for the day this was addressed using prompting and fading to teach the use of a calendar. Here, the outcome measure was the level of prompting at which the calendar was consulted.

Intervention Phase

Cognitive rehabilitation followed the procedures outlined by Clare (2008) in her manual *Neuropsychological rehabilitation and people with dementia.* This manual emphasizes individualized, person-centered goal setting. One participant set goals related to mood and sleep. Here, cognitive behavioural strategies were used to treat insomnia (Silberman, 2008) and low mood (Beck, 2011; Dobson & Dobson, 2009). All of the interviews, assessments, and interventions were completed by a senior doctoral student in clinical psychology (RB) and supervised by a neuropsychologist (MEO).

Procedure

Assessment. First, all participants participated in an assessment where the pre-treatment testing and an interview were conducted. The assessments were carried out over one or two sessions, based on the scheduling availability of the participants. Following the first pilot participant, participants were then randomly assigned to participate in cognitive rehabilitation in-person, or cognitive rehabilitation through telehealth videoconferencing.

Baseline phase. Following the assessment, goals for cognitive rehabilitation were set collaboratively and baseline performance and satisfaction was measured using the COPM for all goals during three baseline sessions (labeled B1, B2, and B3 on Figures 1-6). Following three

weeks of baseline measurement, each participant's first goal (or set of goals in the case of participant D) was addressed in the subsequent cognitive rehabilitation sessions. Baseline COPM measurement continued for all goals that were not the target of the intervention (i.e., Goal 2 and Goal 3). For each participant, Goal 2 was addressed starting in the fourth week of cognitive rehabilitation (CR 4). Baseline data was collected for Goal 2 (and Goal 3 for participants C and D) during the cognitive rehabilitation sessions that targeted Goal 1 (CR 1, CR2, and CR3 on Figures 1-6). Similarly, for participants with a third goal baseline data for Goal 3 was collected during the first six cognitive rehabilitation sessions and Goal 3 was addressed in the seventh week of the intervention (CR 7).

Intervention phase. The cognitive rehabilitation intervention followed the guidelines provided by Clare (2008) in her text on cognitive rehabilitation for people with dementia. Each participant's first goal(s) were addressed in cognitive rehabilitation on the fourth week, following the baseline phase. A new goal, or set of goals, was introduced every three weeks (i.e., in CR 4, and in CR 7). For all participants, the treatment phase was designed to take place over eight weeks, and this decision was based on the procedure reported in Clare and colleagues (2010). Participants attended the Video Therapy Analysis Lab (ViTAL) on the University of Saskatchewan campus once a week for a one-hour session.

Research journal. RB kept a research journal during this study beginning in the recruitment phase. Entries were made in the journal after each assessment, baseline, and intervention session. Journal entries documented what took place in the sessions, reflections on the experience of delivering the intervention, and emphasized any adaptations that were made in order to make cognitive rehabilitation more amenable to videoconferencing.

Data Evaluation

Evaluation of the quantitative data provided by participants. The data from the study were evaluated using visual inspection and statistics. In single-case research visual inspection is the primary method of data evaluation and, although statistical methods for evaluating single case data are increasingly available, they are not widely used (Kazdin, 2011). Visual inspection is based on exploration of changes in the magnitude of the data and changes in the data across phases (e.g., from the baseline to the intervention phases). There are two characteristics of single case data related to magnitude: changes in means across phases and changes in level across phases (Kazdin, 2011). A change in means refers to a change in the average of a measure in one

phase to another. A change in level refers to shift, jump, or discontinuity in the data from the end of one phase to the beginning of another. There are also two characteristics related to rate of change: changes in trend and latency. A change in trend is a change in the slope of the data from one phase to the next. A change in latency refers to the period of time that elapses from the time the phase changes (i.e., the onset of the intervention) until there is a change in the data.

Visual inspection is a reliable method of data evaluation when the results are strong and changes from one phase to the next are clear (Matyas & Greenwood, 1990). Therefore, visual inspection encourages researchers to study interventions that have potent effects that are readily observable because weak results are generally not visible under visual inspection (Kazdin, 2011). The insensitivity of visual inspection to weak results is often considered to be a strength of this approach rather than a limitation. For example, looking for consistent results that can be easily seen also minimizes the chances of making a Type I error (concluding that the intervention has an effect when the results are due to chance; Kazdin, 2011). In the current multiple-baseline study we were interested in determining whether there is a significant change in performance from the baseline to intervention phase, and changes in level and trend were both of interest.

Evaluation of qualitative data provided in the research journal. The journal documenting the experience of adapting cognitive rehabilitation to telehealth videoconferencing was analyzed thematically. Journal entries were organized into a descriptive summary based on the method of qualitative description detailed in Sandelowski (2000, 2010), and the technique of thematic analysis was as described by Braun and Clark (2006). The thematic analysis took a theoreticl approach (as opposed to an inductive approach) insofar as I specifically coded responses related to ways in which the videoconferencing delivered intervention needed to be modified. This method of qualitative description is a low inference qualitative methodology, and it is intended to generate a comprehensive summary of an event in everyday terms (Sandelowksi, 2000).

6.4 Study 3 Results

Participants

Eight individuals were recruited to participate in this study, two discontinued the study following the initial assessment. In one case, the family member support person reported she and the participant did not have time to participate. In the other case, the family member support person reported that initial assessment had been distressing for the participant, and following a

family discussion it had been decided that participating in the study was likely to be more distressing than helpful. Demographic and descriptive data for the six individuals who participated are presented in Tables 1 and 2.

Goals and completion

Participants each set between one and five goals for cognitive rehabilitation. Goal setting was collaborative. In total, 15 goals were addressed in this study. Table 3 lists the specific goals and the cognitive rehabilitation strategies that were used to address them. The study was designed to deliver eight sessions of cognitive rehabilitation (in the intervention phase that followed the baseline phase). All three participants randomly assigned to complete the intervention *in-person* completed eight sessions. In the *telehealth* group, one individual completed 8 sessions, one individual (Ms. D) completed 7 sessions, and one individual (Ms. F) completed 6 sessions. Ms. D reported that she had decided to go on vacation and therefore we decided to cancel the final training session and complete post-treatment assessment. Ms. F only had one goal for cognitive rehabilitation, and she felt it had been accomplished after six cognitive rehabilitation sessions. Overall, 100% of the intervention sessions were completed for the in-person group and 88% of the intervention sessions were completed for the telehealth group.

Goal performance

The primary outcome measure was goal performance as measured by the COPM. Figures 1 – 6 display the COPM scores across the baseline and intervention phases for each of the six participants.

In-person intervention (participants A, B, and E). Figures 1, 2, and 5 display the session-by-session COPM scores for Ms. A, Mr. B, and Ms. E who were all assigned to participate in cognitive rehabilitation *in person*.

Ms. A (patient; PT) participated in person with her husband (caregiver; CG), and their data are represented in Figure 1. Ms. A's goal was to improve her recollection of personally significant life events. A memory book was compiled by Mr. A and her husband, and this book was trained using spaced retrieval and fading and cueing in two sets of 10 memory book pages (i.e., 2 sets of 10 pages each). Baseline data from all measures was collected. Set 1 was studied in sessions CR 1, 2, and 3 (indicated by the first vertical line in Figure 1). Sets 1 and 2 were both studied in sessions 4, 5, 6, 7, and 8. Visual inspection of Figure 1 suggests Ms. A's (COPM PT)

COPM scores (standardized measure of goal performance based on 1-10 ratings on a visual analog scale) were relatively stable across the cognitive rehabilitation, but her husband's increased with the number of intervention sessions. Moreover, Figure 1 demonstrates a clear effect of the spaced retrieval: recall of both memory book sets was at floor during the baseline, and only recall set 1 improved with the initiation of spaced retrieval (first vertical line in Figure 1) and the untrained set 2 remained at baseline, only improving after initiation of training (second vertical line in Figure 1).

Mr. B set two goals for cognitive rehabilitation. First, he wanted to keep better track of his daily notes and "musings" which were disorganized. Second, he wanted to reduce feelings of frustration when challenged during a task in order to feel more engaged in his daily activities (e.g., attending club meetings, taking his dog for a walk). Figure 2 shows a moderately stable baseline for Goal 1 and robustly stable initial baseline for Goal 2 as measured by the COPM. At the first intervention session (first vertical line in Figure 2) a consolidated notebook strategy was introduced to target Goal 1, and COPM scores for both goals show a change in level and trend. The change in level is maintained throughout the remainder of the sessions. Although Goal 2 was not explicitly targeted until session CR 4 (the second vertical line in Figure 2), when relaxation techniques and cues were introduced, nevertheless Goal 2 scores appeared to have improved with the intervention targeting Goal 1. Introducing the organizational strategy designed to target Goal 1 had a greater impact on Goal 2 scores than the relaxation exercises designed to address Goal 2. If Mr. B's frustration is conceptualized as being a reaction to cognitive lapses that were not mitigated by his previously disorganized memory aide strategy, this 'bleeding' of the organizational intervention from one goal to another goal is expected.

Ms. E set two goals for cognitive rehabilitation. Following three baseline sessions (B1, 2, and 3) we focused on her goal to improve her recall of bridge (a card game) strategies, which she enjoyed studying. This was addressed using the Preview Question Read State Test (PQRST; Moffat, 1984) strategy, a hierarchical strategy for organizing texts, which was trained using spaced retrieval. Ms. E also began to use an external aid (note taking) when reading her bridge books. Visual inspection of Figure 3 shows some variability in the baseline, but consistent and sustained improvement one session after initiation of the intervention aimed at this goal (first vertical line in Figure 3). The baseline sessions for goal 2, keeping track of daily activities, also

show variability, but COPM scores clearly increase after this goal was the focus of cognitive rehabilitation (second vertical line in Figure 3).

Telehealth intervention (participants C, D, F). Figures 4, 5, and 6 display the session-by-session COPM scores for Ms. A, Mr. B, and Ms. F who were all randomly assigned to participate in cognitive rehabilitation through telehealth videoconferencing.

Following three baseline assessment sessions Ms. C's cognitive rehabilitation sessions (CR1, 2, and 3; first vertical line in Figure 4) focused first on strategies for learning and remembering names using cuing and fading of face-name associations and spaced retrieval. Next we targeted her sleep (CR 4, 5, and 6; second vertical line in Figure 4) using strategies from CBT-I, and finally her ability to recall what she read (CR 7, 8; third vertical line in Figure 4) using external aids and PQRST. Visual inspection of Figure 3 suggests name recall and reading improved, with sleep showing variability through its baseline sessions (B1-3, CR 1-3) and training sessions. Reading performance improves starting at CR 3 suggesting treatment carry over from training naming strategies, which makes sense considering that the strategies for learning and remembering names (i.e., face-name associations) require one to slow down, to focus on the information that is being presented, and to work to encode it in a more rich, elaborative manner.

Ms. D reported subjective cognitive impairment and set five goals, which were addressed in three training sets. Cognitive rehabilitation was ended after seven sessions due to a summer vacation for Ms. D. Ms. D had five goals for cognitive rehabilitation and these were addressed in three sets (see Table 3). Goal set 1 focused on keeping track of day to day events and what to bring to club meetings was addressed using external aids. Ms. D was using a number of different systems (cell phone, notebook, day timer), which were consolidated. Visual inspection of Figure 5 suggests that despite some variation in the baseline sessions (B1, 2, and 3), performance on Goal 1 improved by three points on the COPM from the highest baseline rating to the highest intervention rating. This increase begins following the first vertical line and is maintained over the course of the remaining sessions. Similarly, performance on Goal set 2, which was concentration and driving, improved when cognitive rehabilitation targeted this goal starting in CR 4 (second vertical line). Goal 3, reading, was targeted only in CR 7 using PQRST, but performance improved starting in CR 1 and 2, which suggests that the specific training provided during cognitive rehabilitation in CR 7 did not cause the improvements shown in the Figure 5.

Rather, the strategies used starting in CR 1 (external aids) appeared to have supported her goal to recall what she had read. My impression was that Ms. F tended to multi-task, and moved quickly form one partially finished task to the next. Using external aids may have reduced the load on her working memory, which would allow her to devote more of her cognitive resources to reading when she picked up a book or newspaper.

Ms. F only had one goal for cognitive rehabilitation: she described herself as an avid reader and reported struggling to recall the plot of a novel while reading. Her goal was to be able to keep track of significant characters and their relationships when reading, which was addressed using the PQRST strategy taught through spaced retrieval. This was also combined with external aids including using sticky notes in her books to mark important passages and writing down notes about major characters which she could refer back to. Keeping track of appointments was rated weekly using the COPM as a comparison goal, and served as the second baseline, but was never trained. Visual inspection of Figure 6 suggests little variability in this comparison measure, which was, unfortunately likely at ceiling even during the baseline and was therefore never trained. Regarding Ms. F's goal, the baseline phase is stable and substantial improvement in performance is present beginning with cognitive rehabilitation in CR 1 (vertical line in Figure 6).

Secondary outcomes

The pre-treatment and post-treatment scores for the secondary outcome measures are presented in Table 2. To facilitate comparisons reliable change indices (RCI) are provided where they were available in the literature. When RCI were not available, standard error of the difference (SE_D) or minimum clinically important differences (MCID) are provided in the table. There were few changes in the secondary measures that exceeded these estimates of change, and only changes greater than the SE_D, RCI, or MCID are reported below.

In-person intervention (participants A, B, and E). Ms. A was the only individual with a dementia due to AD diagnosis who participated in the study and her scores on the RBMT-III and DKEFS letter fluency declined in the 12 weeks between the initial assessment and post-treatment assessment. This may reflect disease progress or failure to benefit from practice (the DKEFS RCI includes practice effects). Although still minimal she also had an increase (from 0 to 3) on the HADS depression subscale that was greater than the MCID. She reported improved quality of life, but her husband reported decreased quality of life. Mr. B had decreased category fluency as measured by the DKEFS, and decreased anxiety as measured by the HADS. His wife

reported improved quality of life for herself, decreased quality of life for Mr. B, improved function for Mr. B, and increased caregiver burden. Ms. E had decreased divided attention as measured by elevator counting with distraction, decreased depression as measured by the HADS. A support person did not accompany her.

Telehealth intervention (participants C, D, and F). Ms. C had improved category fluency and decreased anxiety as measured by the HADS. Ms. D had improved letter fluency as measured by the DKEFS and decreased depression as measured by the HADS. Her husband reported improved quality of life for himself, and improved function for Ms. D. Ms. F had improved memory as measured by the RBMT-III, decreased anxiety and depression as measured by the HADS. Her husband reported decreased quality of life for himself, and improved function for Ms. F.

Findings from the research journal

The research journal was used to reflect on the process of conducting this study, to document any challenges and successes that may not have been fully captured by the quantitative measures, and to document modifications that were made in order to deliver the intervention to the individuals in the telehealth group. It is important to note that this analysis is intended to summarize the experience delivering cognitive rehabilitation and this is best understood as an individual experience at a particular time. It may be helpful to others who are considering how to adopt interventions to telehealth and is included here for that reason. The codes that were generated were organized into two major themes: 'relationship and therapeutic alliance' and 'method and technique.' Text pertaining to how I felt working with the participant, comments the participant made regarding comfort or how they felt in the session were coded in the 'relationship and therapeutic alliance category'. 'Engagement' (interest in the intervention and attendance), 'connection and enjoyment' (parternship with participants and func during the sessions), and 'responsibility' (my sense of personal accountability) were coded as subthemes. Text pertaining to study design, measurement, or comparisons between in-person and telehealth treatment were coded in the method and technique theme. 'Adjustment to telehelealth' (comparison between conditions where further subthemes of 'different but not worse', 'reliance on verbal description', and were coded) and 'challenges of measurement' were the themes within 'method and technique'. The findings of the thematic analysis are summarized in Table 4 and

characteristic examples of text from the journal are presented in the table. Figure 7 visually illustrates the relationship between the major and minor themes.

Although it is given less attention in the literature, the research journal reflects the importance of building rapport and an alliance in order to carry out the cognitive rehabilitation. Initial codes were organized into the minor themes of 'engagement,' 'enjoyment and connection,' and 'responsibility.' It is notable that these themes were similar irrespective of treatment modality (in-person versus videoconferenced). Figure 7 shows how the method and techniques used in the study to deliver cognitive rehabilitation occur within the context of a strong therapeutic alliance.

The theme of 'method and technique' is comprised of journal entries that comment on the adaptation of cognitive rehabilitation to telehealth videoconferencing, and entries that comment on how sessions were conducted within the context of the demands of the study design. Participants adjusted easily and quickly to working through telehealth videoconferencing. Here, the journal entries were organized into the subtheme of 'different but not worse.' Participants commented that although they might have preferred to meet in-person the videoconferneced sessions ran smoothly. As a clinician, I noted challenges due to not being able to physically interact with materials. For example, I couldn't pick up a day timer and read through what the participant had written. Therefore, I had to cue participants to read out written notes or from worksheets. Initial codes in the research journal were organized into the minor theme 'greater reliance on verbal description.' Lastly, journal entries comment on working to adjust and modify goals and sessions in order to make the intervention measureable and adhere to the multiple baseline design. Initial codes were organized into the subtheme 'measurement challenges.'

6.5 Study 3 Discussion

The results of this study cautiously suggest that cognitive rehabilitation can be adapted to telehealth videoconferencing for older adults with subjective memory impairment. The study also adds to the growing body of literature that suggests goal oriented cognitive rehabilitation delivered in-person is a promising non-pharmacological intervention for older adults with subjective memory impairment, MCI, and early stage dementia due to AD. For participants who completed the initial assessment and baseline sessions, participation was excellent with 100% completion for the in-person group and 88% completion for the telehealth group. Although both groups demonstrated high completion rates, the lower rate for telehealth may suggest that

telehealth delivered treatment is less acceptable to participants or something about this modality of treatment (such as the virtual nature of the interpersonal connection, or added challenge of describing steps and materials verbally rather than physically interacting or handing something in to be read) delivery made completion of the sessions less motivating. Despite this caveat, these are both high completion rates suggesting participating through either delivery modality was acceptable to participants. The themes from the research journal also support this conclusion; although some participants assigned to telehealth were initially apprehensive or even disappointed to be assigned to the telehealth condition, as sessions progressed the theme 'different but not worse' as a description of videoconferencing delivered sessions emerged from the research journal entries.

Importantly, the results suggest participants' goal performance improved across both treatment delivery modalities. Of the 15 goals set in this study, performance on only two goals (Sleep set by Participant C, and Concentration set by Participant D) did not improve by two or more points on the COPM. Participants C and D were both assigned to the telehealth group, so this raises the possibility that telehealth may reduce the efficacy of cognitive rehabilitation for older adults with subjective cognitive impairment. It may also be the case that these goals are less amenable to cognitive rehabilitation. Improved sleep in particular is not a typical goal for cognitive rehabilitation, however, improving sleep and managing daytime sleepiness were both reported as goals set in Clare and colleagues' (2011) study (goal attainment was not reported goal by goal). In the sleep intervention literature more generally, Cognitive Behavioural Therapy for insomnia (CBTi) is an effective treatment, demonstrates efficacy that is similar to pharmacological interventions with better long-term outcomes, and has been recommended as a standard treatment for insomnia (Siebern & Manbern, 2010). Importantly, a full course of CBTi, which is typically between 6-8 sessions was not delivered here (Ms. C participated in 5 sessions that focused on her goal to improve her sleep). Overall, the results of this study suggest that it is worthwhile to pursue adapting cognitive rehabilitation to telehealth videoconferencing. This is consistent with previous research that has explored remotely delivered cognitive rehabilitation (i.e., Bourgeois et al., 2003) as well as remotely delivered psychotherapy (i.e., Greene at al., 2010; O'Connell et al., 2014).

The importance of establishing a strong therapeutic relationship was a major theme that emerged from the research journal. This aspect of cognitive rehabilitation has perhaps not been

emphasized enough in the literature, and clinicians who are providing the intervention (whether or not they have been trained as psychotherapists) may benefit from attending to the research on the common factors of psychotherapy (see Wampold, 2015 for a recent summary of the common factors literature based on meta-analyses). This is not to suggest that the therapeutic relationship has been ignored in the cognitive rehabilitation literature, but to highlight the importance of not emphasizing technique (i.e., errorless learning and spaced retrieval) at the expense of developing an alliance. One imagines that telehealth videoconferencing could impact developing an alliance, however, this was not noted in the research journal and psychotherapy non-inferiority trials (i.e., Greene et al., 2010), and other videoconferenced work (O'Connell et al., 2014) detail how the therapeutic relation can be established and maintained remotely. Future researchers might consider adding a formal measure of alliance to their protocols.

In carrying out this study we learned a number of things that may be helpful for future researchers. First, we were surprised by how challenging it was to recruit research participants with MCI or early-stage AD. Those recruited and retained in the study were highly motivated and engaged, which is a self-selection bias. This recruitment challenge and the way in which participants were randomly assigned to the in-person or telehealth videoconferencing limits the conclusion we can draw about delivering cognitive rehabilitation through videoconferencing to individuals with MCI or dementia due to AD (the three telehealth participants were individuals with subjective memory impairment). We were also surprised to find that the majority of the participants in this study opted to participate without a support person. This was either because no support person was available (Ms. C), because a support person was not interested in participating (Mr. B and Ms. E), or because it was decided that the support person was not needed (Ms. D and Ms. F). Only Ms. A's husband accompanied her to every session. This is noteworthy because Ms. A was the only participant with a diagnosis of dementia due to AD. Previous research (i.e., O'Sullivan et al., 2015) has recommended that a support person always be included in the intervention. The results of this study suggest that for individuals with SCI a support person is not necessary, but for individuals with dementia due to AD or MCI we continue to recommend a support person.

We also came to reconsider our experimental design. The multiple baseline design was chosen in order to be able to infer that any improvements in COPM scores were due to cognitive rehabilitation interventions rather than common therapeutic factors such as establishing a

positive relationship with the researcher delivering the treatment. As the study progressed, it became apparent that skills being taught for one goal carried over to other goals, and in some cases (Participant D in particular), participants spoke explicitly about generalizing strategies from a goal that was being trained to a goal that was not being trained. Of course, this is excellent for that individual, but it does limit the usefulness of within-person multiple baselines for cognitive rehabilitation. Therefore, this type of experimental design is not recommended, at least not for similar goals. Furthermore, in this study we chose to rely on visual inspection to examine our data. This has the advantage of highlighting strong effects, which are more likely to be functionally relevant. The limitation of this approach is that subtle trends such as serial dependency are not readily observable using visual inspection, visual inspection is unreliable when effects are not large, and for these reasons statistical methods of analyzing single-case data have been increasingly studied and used (Matyas & Greenwood, 1990).

The findings presented in this study support developing goal oriented cognitive rehabilitation delivered both in-person, and expanding the accessibility of this intervention by adapting it to videoconferencing. Further research is needed to replicate the results presented here. Additionally, this data does not fully explore the adaptation of cognitive rehabilitation to videoconferencing for individuals with cognitive impairments consistent with MCI or dementia due to AD. Given the increasing prevalence of cognitive impairment in late life in both urban and rural areas, interventions aimed at supporting the personally relevant functional goals of these individuals are clearly needed.

6.6 Study 3 References

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Table 6.1

Participant characteristics

Participant	Treatment delivery	Age	Years of education	Gender	Recruitment source	Diagnosis	Relationship to support person	Involvement of support person
A	In-person	72	18	Female	Support organization	AD	Husband	Attended all sessions
B	In-person	68	14	Male	Support organization	MCI	Wife	Initial interview and questionnaires
C	Telehealth	80	16	Female	Community	SCI	None available	None
D	Telehealth	66	13	Female	Community	SCI	Husband	Initial interview and questionnaires
E	In-person	77	12	Female	Community	SCI	Husband	Questionnaires only
F	Telehealth	68	16	Female	Community	SCI	Husband	Initial interview and questionnaires

Note. AD = dementia due to Alzheimer's disease; MCI = mild cognitive impairment; SCI = subjective cognitive impairment.

Table 6.2

Initial Assessment and Post Cognitive Rehabilitation Assessment Measures for Participants and Support Persons

Measure	max	Participant A		Participant B		Participant C		Participant D		Participant E		Participant F	
		In-person		In-person		Telehealth		Telehealth		In-person		Telehealth	
	SE_D/RCI[a]	Initial	Post	Initial	Post	Initial	Post	Initial	Post	Initial	Post	Initial	Post
MMSE	30	17		27		29		27		29		26	
RBMT-3	194 SS	55	45	101	103	158	151	158	152	152	158	106	144
	100% ile	0.2	0.2	4	4	92	82	93	82	84	92	5	63
	$SE_D=7.6$[b]												
DKEFS	19 SS												
Letter fluency	RCI=2.7[c]	6	2	11	12	8	9	13	16	14	14	15	16
Category fluency	RCI=3.1[c]	3	3	9	5	10	14	18	16	18	18	16	17
Switching ttl correct	RCI=5.8[c]	1	1	8	8	14	13	19	18	17	18	15	14
Switching ttl switch	RCI=5.4[c]	1	1	10	9	15	13	17	14	17	14	15	13
TEA													
Elevator count	7 raw[d]	6	4	6	7	7	-	7	7	7	7	7	7
Elevator distr		dc	dc	5	6	dc	-	11	11	13	9	5	6

Measure													
	$SE_D=.8^d$												
QoL AD	52	25	48	34	34	108	109	106	108	28	who qol	115	118
	$SE_D=3.8^e$												
Bristol	60	0	1	3.5	1	0	0	0	0	0	0		0
	$SE_D=4.0^f$												
HADS anxiety	21	4	4	8	5	6	0	6	7	10	10	4	2
	$MCID^g=1.4^h$												
HADS depression	21	0	3	2	2	1	1	2	0	9	7	2	0
	$MCID=1.6^h$												
Caregiver Measures													
WHOQOL-BREF	130	103	79	86	91	-	-	91	96	-	-	126	110
	$SE_D=1.9^i$												
QoL-AD	52	40	36	30	22	-	-	0	-	-	-	0	0
	$SE_D=3.8^e$												
Bristol	60	18	14.5	7.5	2.5	-	-	6	0	-	-	10	0
	$SE_D=4.0^f$												
ZBI	36	35	-	37	51	-	-	13	-	-	-	6	-
	$SE_D=7.0^j$												

Note. Initial assessment and post-intervention measures for participants randomly assigned to the in-person cognitive rehabilitation group. Participants were all encouraged to participate with a support person, but participants C and E stated that no support person was available to

participate. [a]Standard error of the difference (SE_D) is the SD of the expected test-retest difference score if no change has occurred; accounts for standard error in measurement (SEM) at both time points; $SE_D = \sqrt{2 * (SEM)^2}$. SEM $= SD\sqrt{1 - reliablity}$. Reliable change indices (RCI) incorporate SE_D and expected improvement in performance due to practice effects or expected changes due to standard error in prediction and regression to the mean in addition to practice effects, depending on the RCI formula. [b]No RCIs reported in the literature; Wilson et al., 2008 reported SEM. [c]DKEFS RCIs from Brooks et al., 2011; 90th percentile with average practice effect used. [d]no RCIs reported in the literature, reliability of elevator counting not reported due to ceiling effect, reliability of elevator counting with distraction Strauss et al., 2006 reliability .857; $SD = 1.42$. [e]internal consistency reliability 0.82; $SD = 6.3$ Thorgrimsen et al., 2003. [f]test-retest reliability $= 0.95$; $SD = 12.7$; Bucks et al., 1996. [g]MCID - Minimum Clinically Important Difference. [h]Phuhan et al., 2008 detail changes in HADS scores that were important based on external measures, which is a suggested method for determining MCID. [i]Skevington 2004 did not provide an overall internal consistency reliability, but instead they reported for each subscale: these were averaged (average reliability 0.778; ranging from .82 to .68 for the 4 subscales), and SDs were pooled (ranging from 2.6 to 3.2) based on the sample of 11830 to equal 2.88. [j]internal consistency reliability .90; $SD = 15.64$; Bedard et al., 2000.

Table 6.3

Participants' Goals and Cognitive Rehabilitation Strategies Used to Address These Goals During the Intervention

Participant	Intervention delivery	Goals	Cognitive rehabilitation strategies used to address goals
A	In-person	(1) To remember personally significant life events and accomplishments. (2) To know the names and relationships of important people (e.g., grandchildren, siblings, friends).	These two goals were addressed together using an external aid (memory book), which included photos, newspaper clippings, and documents displaying significant people and events. Twenty pages from the memory book were chosen and these focused on in two sets of ten using spaced retrieval and cuing and fading.
B	In-person	(1) To keep track of date, plans, and activities. (2) To reduce frustration related to memory and organizational difficulties; feel more engage in activity at hand.	An external aid (day timer) was used to address this goal. Use of the day timer was trained using spaced retrieval and cuing and fading. A relaxation exercise and relaxation cues chosen by Mr. B were used to address this goal.
C	Telehealth	(1) To recall the names of group members. (2) To improve sleep.	Face-name association and spaced retrival was used to address this goal. Sleep hygiene, relaxation strategies (e.g., deep breathing), and cognitive behavioural (e.g., developing alternative thoughts for

			cognitive distortions) was used to address this goal.
		(3) To remember what was read in a novel or non-fiction book.	External aids and PQRST were used to address this goal.
D	Telehealth	(1) To remember plans and what to bring to club meetings.	External aids (using a single, large day timer), and habits and routines were used to address these goals.
		(2) To keep track of the date and plans for the day.	
		(3) To feel more confident driving and navigating.	Relaxation strategies (e.g. deep breathing), external aids (e.g., GPS), and habits and routines were used to address this goal.
		(4) To maintain concentration when multi-tasking at home.	Goal management training was used to address this goal.
		(5) To remember what was read in the newspaper or a novel.	PQRST was used to address this goal.
E	In-person	(1) To remember what was read in bridge books and apply it when playing bridge.	External aids and PQRST were used to address this goal.
		(2) To know what was done from day-to-day and be able to tell friends on the phone.	An external aid (daily journal) and routine was used to address this goal.
F	Telehealth	(1) To keep track of plot and characters when reading a novel.	External aids (e.g., notes, sticky tabs, and highlighting) and PQRST were used to address this goal.

Note. PQRST = Preview, Question, Read, Study, Test.

Table 6.4

Themes from the research journal

Major theme	Minor theme	Characteristic examples
Relationship and therapeutic alliance		
	Engagement	*Mr. B's wife explained that she preferred not to attend sessions with her husband because she felt so busy with other commitments. It will be important to have at least one session with her where I show her how we have been using the book.*
		Mr. and Mrs. D are both highly engaged. Megan and I discussed the self-selection that is taking place in my recruitment process.
		Ms. E called me this morning to ask if it would be alright if her husband did not attend. When she arrived she explained the he "doesn't really believe in mental things" and didn't think she needed to participate in the study.
	Connection and enjoyment	*I really enjoyed working with her and found her bright, perceptive, and easily engaged.*
		He seems to enjoy attending our sessions. Specifically, we laugh and joke a little. He always attends.

I am enjoying working with him…some things are a bit challenging/ frustrating. He talks a lot and it can be challenging to interrupt and redirect him to the task at hand.

She is friendly and easy going, and it's highly enjoyable to work with her.

Ms. E commented that participating has been "very interesting and I've enjoyed coming".

	Responsibility	*This is a deeply personally challenging research project. It is so much more difficult than using archival data because of the personal connection and responsibility I feel towards the research participants.*
		I have to manage the expectations and the hopes of the participants.
Method and technique	Adjustment to telehealth	*She noted that she was disappointed to be assigned to the telehealth videoconferencing condition, but would participate.*
	Different but not worse	*The volume was too loud and it hurt Ms. C's ears. She easily turned down the volume using the remote control.*
		I could hear a delay between when I spoke and when my voice played in the testing room which was distracting.

Ms. C said it was fine to see and talk to me through videoconferencing. In fact, it was better than expected.

Ms. D said it [telehealth] *was just fine. Mr. D commented that he preferred when we talked face to face and I was in the same room as them. That being said, he agreed with his wife that it was perfectly feasible to work with me through videoconferencing and the goal setting session had gone well.*

There is a bit of overlap in us speaking. Conversing is not quite as natural. Ms. F compared it to talking on a cell phone, and not being sure when it was her turn to talk.

Greater reliance on verbal description	*I noticed that it was more difficult to see if her chest and abdomen were rising and falling as we practiced diaphragmatic breathing. To compensate, I asked her to describe any spots where she was struggling verbally.*
	I could not see what was written, so she read what was written to me.
Challenge of measurement	*It has been very challenging to balance meeting their goal of developing Ms. A's ability to discuss important autobiographical events with the need to have measureable outcomes.*
	… it starts to feel "like a test and that's never fun".

I have observed marked "spillage" from the intervention items to the baseline items. Ms. A now recalls pieces of information about the photos that she could not previously tell me. It will be very difficult to describe whether improvements in Ms. A's descriptions of the pages of her memory book are due to spaced retrieval and prompting and fading, or whether they are due to reminiscence and increased familiarity with the pages in the book.

I am noticing that it is very challenging to address goals purely and there is contamination between goals.
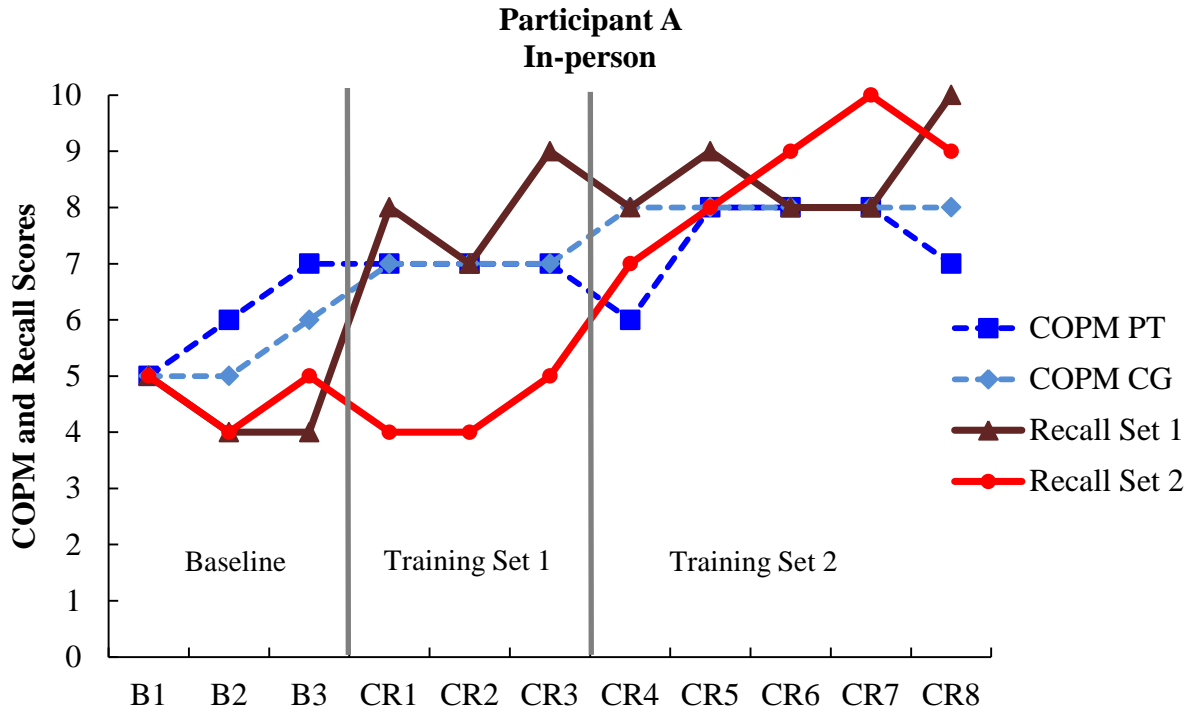
Figure 6.1. Canadian Occupational Performance Measure (COPM) scores and total item recall scores (two sets of 10) for participant A. The first line indicates when training for Recall Set 1 was initiated and the second line indicates when training for Recall Set 2 was initiated.
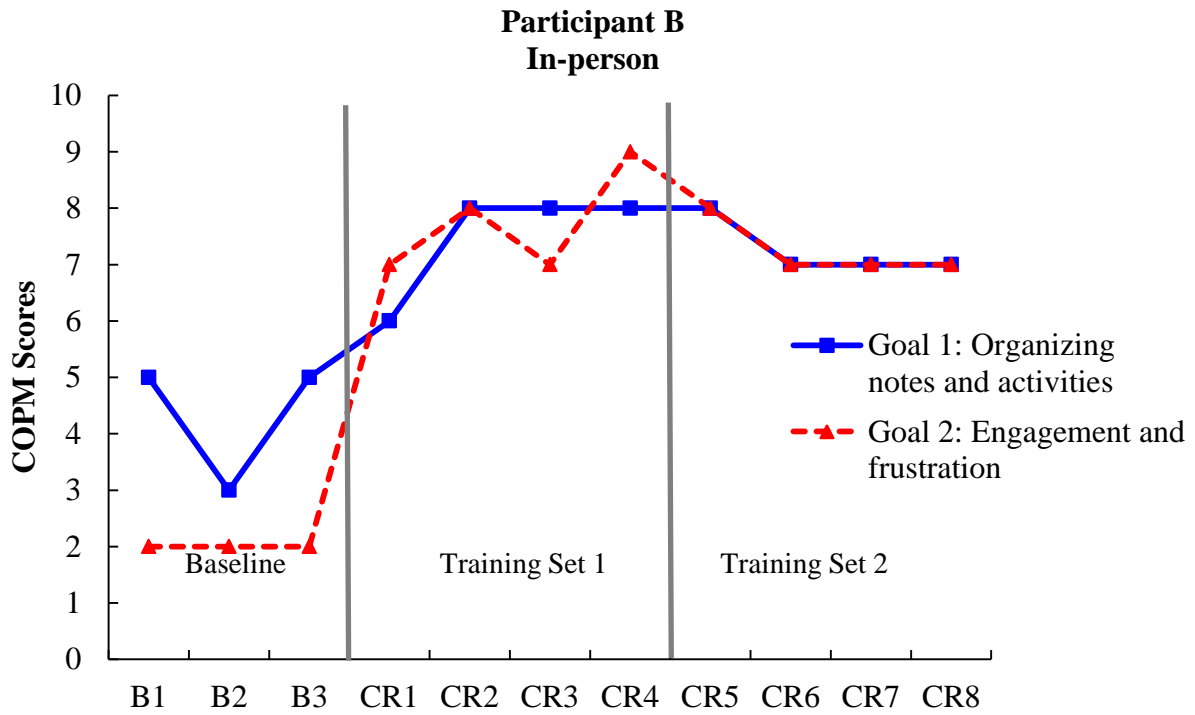
Participant B
In-person

Figure 6.2. Canadian Occupational Performance Measure (COPM) scores for participant B who

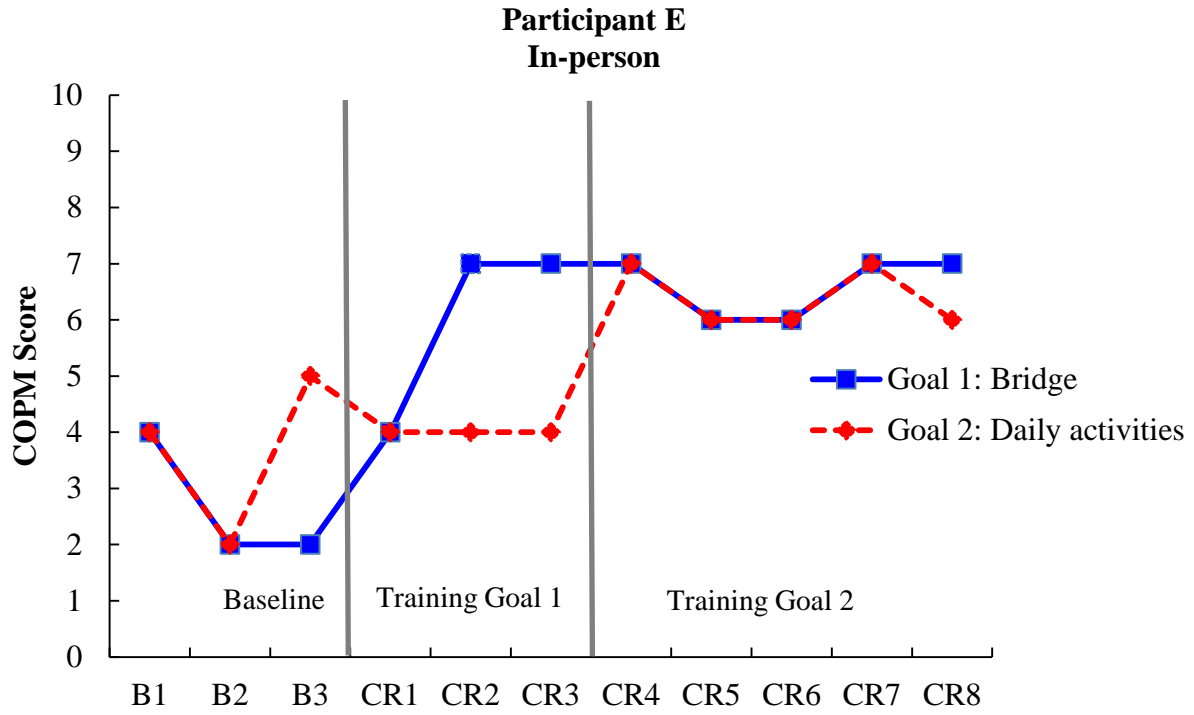attended cognitive rehabilitation sessions in-person.

Figure 6.3. Canadian Occupational Performance Measure (COPM) scores for participant E who attended cognitive rehabilitation sessions through in-person.

Figure 6.4. Canadian Occupational Performance Measure (COPM) scores for participant C who attended cognitive rehabilitation sessions through telehealth videoconferencing.
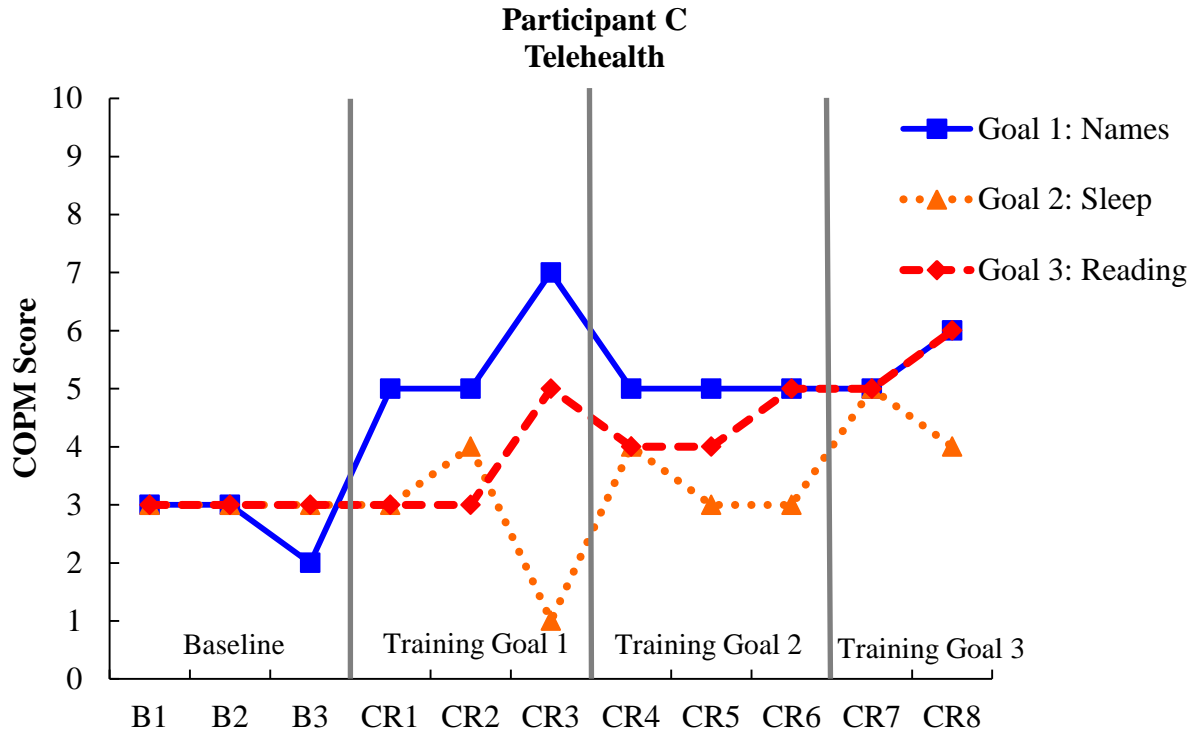
Figure 6.5. Canadian Occupational Performance Measure (COPM) scores for participant D who attended cognitive rehabilitation sessions through telehealth videoconferencing.
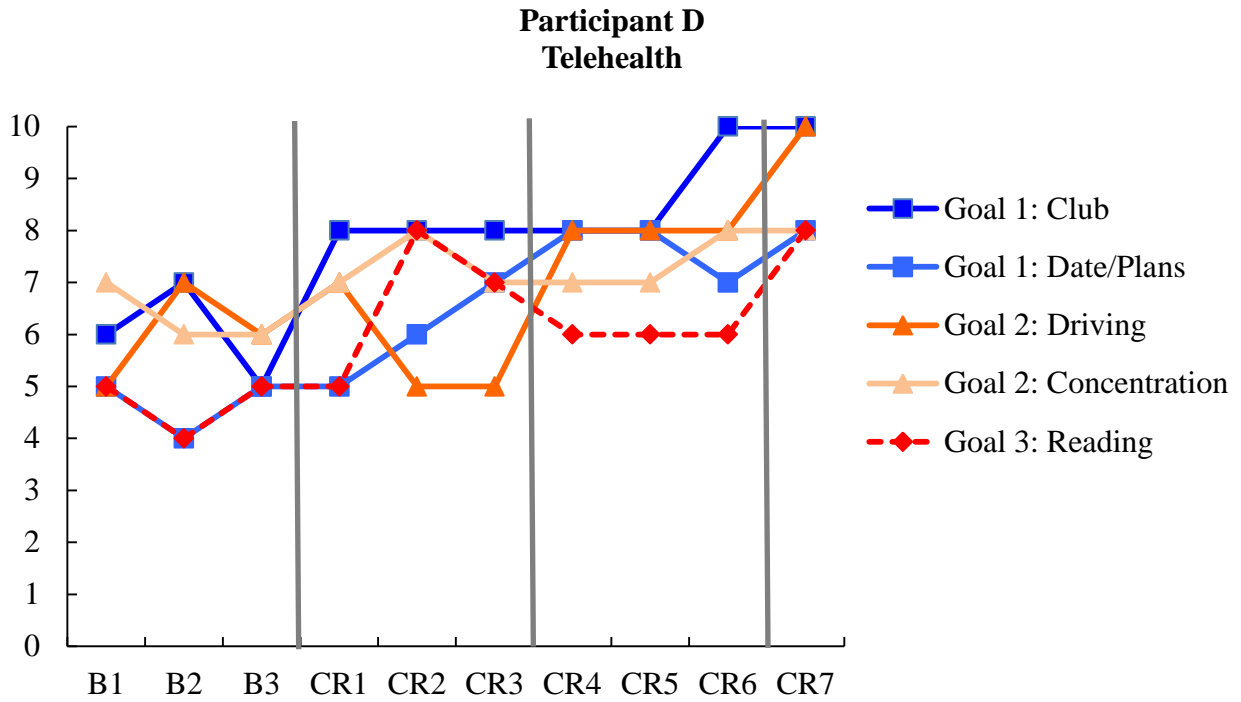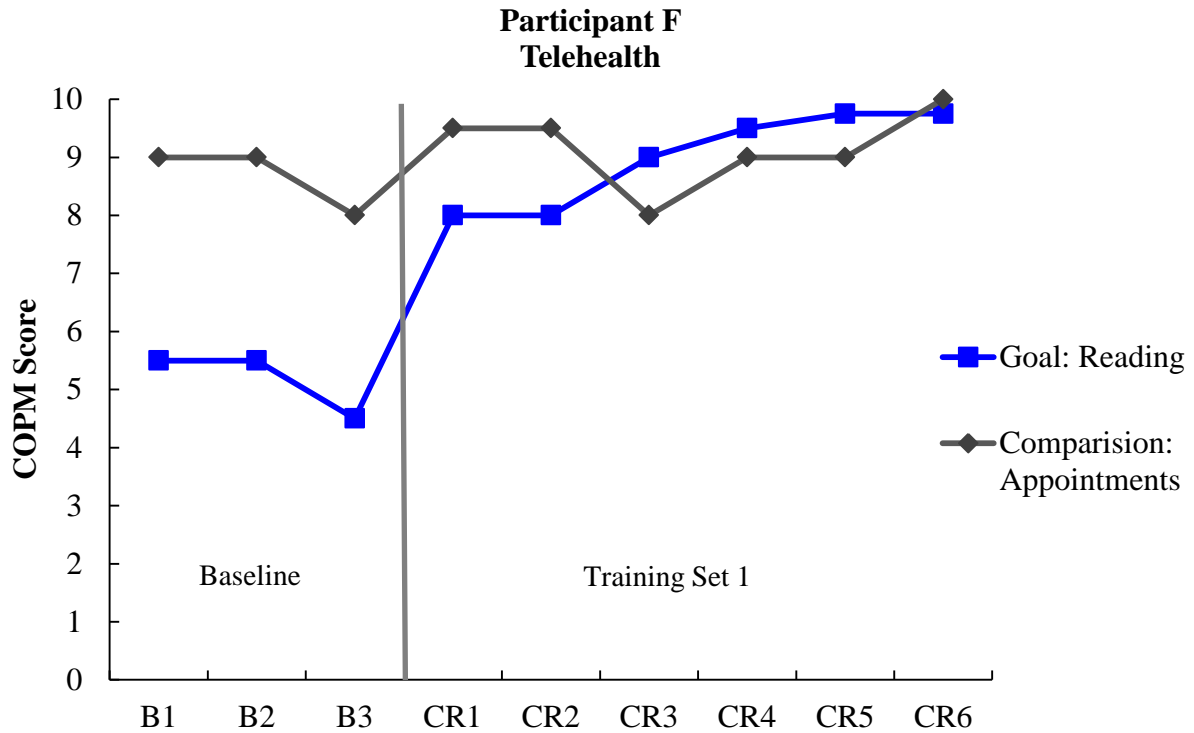
Figure 6.6. Canadian Occupational Performance Measure (COPM) scores for participant F who attended cognitive rehabilitation sessions through telehealth. Here, only one goal was set to improve recollection when reading. Keeping track of appointments was rated weekly as a comparison measure to provide a second baseline.

Relationship and Alliance

- Engagement and connection

- Enjoyment

- Responsibility

Method and Technique

- Challenge of measurement

- **Adjustment to telehealth**

  Different but not worse

  Greater reliance on verbal description
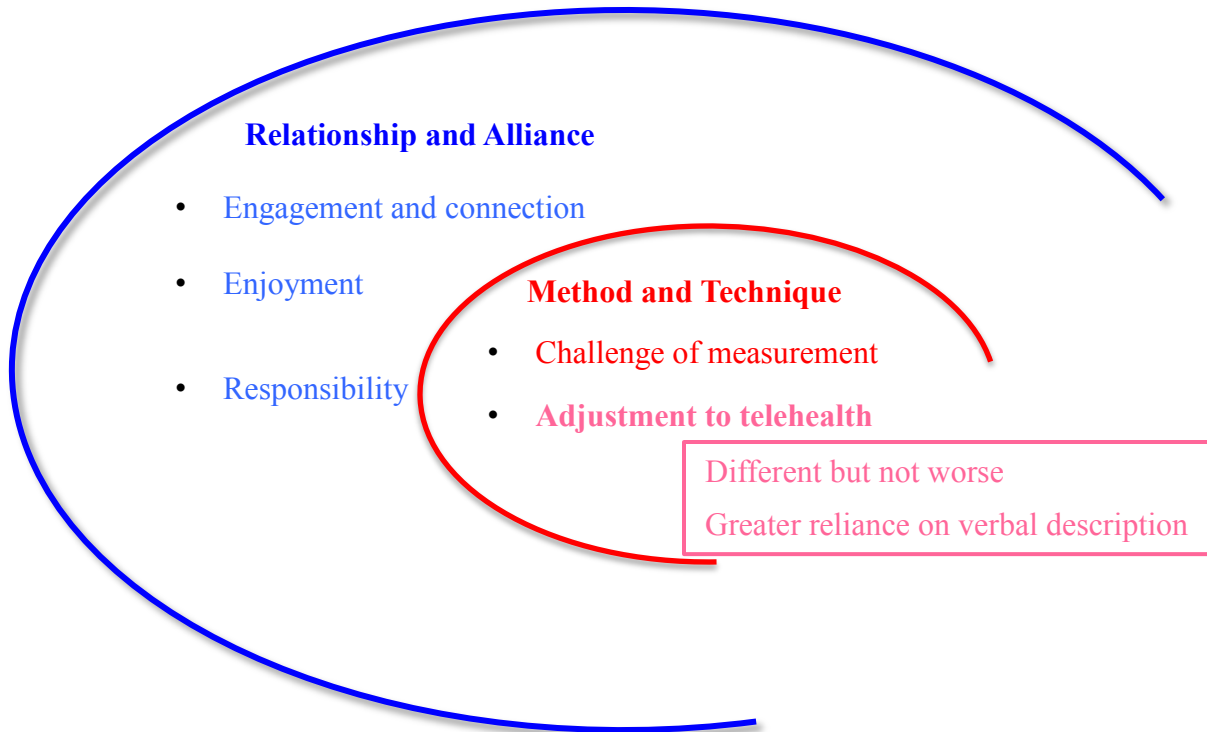
Figure 6.7. Findings from an interpretive description of the research journal, which documented the researcher's experience delivering cognitive rehabilitation in-person and through telehealth. This figure is the final thematic map, showing two major themes (Relationship and Alliance; Method and Technique) and how they are related to each other and their minor themes. Themes were developed from coding and organizing the research journal.

7. General Discussion

There is no doubt that the rising tide of dementia is a major social and economic concern (Alzheimer's Society of Canada, 2010). This is true both in Canada and around the world (Reitz, Brayne, & Mayeux, 2011; Smith & Bondi, 2003). It is reflected in academic articles and in newspaper headlines. The three studies that have been presented here sought to develop cognitive rehabilitation as an intervention to help older adults with cognitive concerns and their families cope with the day-to-day functional challenges associated with cognitive decline. Studies 1 and 2 focused on clinical samples of participants with mild cognitive impairment (MCI), dementia due to Alzheimer's disease (AD), and non-AD dementia. Study 3, a single case experimental design where cognitive rehabilitation was delivered to participants, also included participants with subjective cognitive impairment (SCI) recruited from the community. In addition to developing the intervention to be delivered face-to- face, Studies 1 and 3 explored how cognitive rehabilitation could be more accessible using telehealth videoconferencing. Together, the research presented here contributes to our understanding of who might be most likely to seek cognitive rehabilitation, fills in gaps in our theoretical understanding of this intervention, and better describes how this intervention can be delivered successfully in-person and through telehealth videoconferencing. This research is significant because this is the first time cognitive rehabilitation has been delivered to this population remotely using telehealth videoconferencing.

This general discussion first recalls the original objectives of each of the studies and then highlights each study's most salient findings. The relationships between the studies are considered and discussed, and the ways in which these studies relate to each is further considered. The discussion concludes with reflections on the overall limitations of the research presented here and considerations for future researchers. Ultimately, the work that has been presented here is concerned with improving the function and quality of life of individuals and families across the continuum of normal aging to dementia, and is guided by the value of developing empirically supported treatments that are as accessible as possible.

7.1 Study Highlights, Contributions, and Conclusions from the Studies

The defining feature of cognitive rehabilitation is that it is an intervention that is adjusted to target the functional goals of the individual (Clare & Wilson, 2004). The first study had three objectives. First, I asked whether Rural and Remote Memory Clinic (RRMC) patients with MCI,

dementia due to AD, or mixed AD/VaD and their caregivers were interested in participating in cognitive rehabilitation and whether they would prefer to participate in-person or through telehealth videoconferencing. Next, I asked about the goals participants had and because of the literature describing the challenges of collaborative goal setting (i.e., Playford et al., 2009; Rosewilliam, Roskell, & Pandyan, 2011) I wanted to better understand how initial goals set without therapist input would map onto goals reported in the literature. The third objective of Study 1 was to examine whether and how participants who indicated interest in cognitive rehabilitation differed from those who either did not respond to the questionnaire, or indicated they would not be interested in cognitive rehabilitation. Here, the cognitive profile of the individuals who responded to the questionnaire was compared to the profile of the individuals who did not respond. This study was an important first step because it allowed me to begin to explore whether rural families would be interested in participating in cognitive rehabilitation if it were available. Having a better understand of participants' goals in the context of their cognitive abilities allowed us to better prepare for Study 3, where I was collaborating with participants to deliver cognitive rehabilitation in-person and through telehealth. Future researchers who are preparing to provide cognitive rehabilitation (particularly in a remotely delivered format, but also in-person) will also benefit from a better understanding of the characteristics of those who expresses interest in participating in an intervention, and their initial goals for treatment.

Study 1 concluded that individuals with MCI, dementia due to AD, VaD or mixed AD/VaD and their support people residing in rural or remote areas were interested in participating in cognitive rehabilitation (80%) and had an overwhelming preference for participating in cognitive rehabilitation through videoconferencing (100% of those who were interested in cognitive rehabilitation preferred to participate through videoconferencing). This clearly supports the need to explore the feasibility of videoconferencing delivered treatment, as was done in Study 3. The goals that were reported by participants were coded as amenable to cognitive rehabilitation and consistent with the types of goals that had been reported previously (i.e., Clare et al., 2011; O'Sullivan, Coen, O'Hara, & Shiel, 2014). Memory related goals and household related goals were the most frequent. Based on the literature documenting the challenges of collaborative goal setting in rehabilitation (i.e., Scobbie, Wyke, & Dixon, 2009; Rosewilliam et al., 2011) I had expected to find a greater discrepancy between participants' goals and the goals reported on the literature. In contrast, the results of Study 1 are more encouraging

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than anticipated because they suggested that the intervention techniques that have been the focus of cognitive rehabilitation research were largely consistent with participants' own goals; at least for participants who responded.

It is interesting to note that there were differences between the goals reported by Study 1 participants and the goals that were actually addressed by Study 3 participants. In Study 3, where the intervention was delivered, participants did primarily set goals related to memory, but goals such as reducing frustration, improving sleep, and confidence with driving and navigation were also set. This may be due in part to higher level of cognitive function (i.e., the inclusion of SCI participants) in Study 3 compared to Study 1. Certainly the implications and feasibility of setting a goal related to driving are much different for an individual with SCI compared to an individual with a diagnosis of dementia due to AD. It will be important for future research to better delineate how goals relate to domain and degree of cognitive impairment. Another possibility, is that goals shifted when participants were involved in collaborative goal-setting process with the researcher rather than when they were filling out a semi-structured questionnaire at home.

The response rate in Study 1 was low (21%), and in interpreting those results I made the assumption that those who did not return a questionnaire were unlikely to be interested in participating in cognitive rehabilitation or unlikely to be able to commit to attending cognitive rehabilitation sessions. The low response rate and the results of the profile analysis raised the possibility that those who are most likely to participate in cognitive rehabilitation (referred to as responders) are a unique subgroup of the MCI/early stage dementia population. This was also reflected in Study 3 where, after a challenging recruitment process, the sample there was a self-selection bias in that the participants were notably engaged/motivated. In a profile analysis comparing responders and non-responders in Study 1 the results suggested responders had greater awareness of their memory deficits and families were struggling with fewer neuropsychiatric symptoms. Meanwhile, in Study 2, memory and two neuropsychiatric symptoms (depression and apathy) accounted for meaningful variance in function. This is significant for clinicians wondering about how the populations described in the research map on to the individuals they see in their practices who express interest in a non-pharmacological intervention, and for researchers considering the types of cognitive interventions that need to be studied and developed. Furthermore, this may explain why the goals that participants identified were more consistent with the literature than expected. Those with low awareness or with

primary concerns outside the scope of cognitive rehabilitation would not have seen their needs reflected in the semi-structured questionnaire and may have simply self-selected out of the study. The possible difference in degree of neuropsychiatric symptoms between responders and non-responders is also relevant when reflecting on the results from Study 2 where neuropsychiatric symptoms (particularly apathy) accounted for a significant amount of variance in function.

Reviewing and reflecting on Study 2 reveals this study took a different approach and stepped back from cognitive rehabilitation as an intervention to be planned and delivered and worked to consider cognitive rehabilitation in a broader theoretical context. The general introduction highlighted the fact that cognitive rehabilitation has frequently been criticized as an intervention that lacks a theoretical basis (Wilson, 2003). This is true not only for goal-oriented cognitive rehabilitation for individuals with dementia, the focus of the research presented here, but also for cognitive rehabilitation for individuals with TBI, which is the commonly and thoroughly studied population (Wilson, 2003).

Study 2 focused on the cognitive and neuropsychiatric variables that have most consistently been shown to predict variance in function (see Giebel, Challis, & Montaldi, 2015; Lindbergh, Dishman, & Miller, 2016; Mcalister, Schmitter-Edgecombe, & Lamb, 2016; Overdorp, Kessels, Claassen, & 2016; Royall, Lauterbach, Kaufer, Malloy, Coburn, & Black, 2007 for reviews and meta-analyses). This study asked whether immediate memory, executive functions, depression, and apathy accounted for variance in function over and above the variance explained by demographic variables and general cognitive screening. Using a hierarchical regression the results indicated that, yes, these cognitive and clinical variables do explain unique variance in IADL. This set of results is important for developing cognitive rehabilitation interventions because it suggests that improving performance on functional goals requires addressing multiple domains. Not only does this suggest a need to move beyond memory focused interventions and considering executive functions more explicitly (particularly as measured by Trails B and COWAT), but it also highlights a need to consider domains beyond cognition such as apathy. How this might be done is considered in more detail below where directions for future research are considered.

Moving on to consider Study 2 in more detail, the overall sample was broken down into diagnostic subgroups, which revealed differences in the relationships between the independent and dependent variables. The strongest correlates of IADL were apathy and depression for

cognitively normal participants, apathy for MCI participants, MMSE and apathy for AD participants, and MMSE only for non-AD participants. Huckans and colleagues (2013) presented a theoretical model of cognitive rehabilitation interventions for MCI that is consistent with both the biopsychosocial perspective argued for in the general introduction, and the results of Study 2. In this model, which focused on MCI specifically, MCI is presented as middle state between normal cognitive aging and dementia, and individuals can shift along this continuum by either increasing protective factors (i.e., Mediterranean diet, cognitively stimulating activity) or decreasing risk factors (i.e., smoking, heavy alcohol consumption; Huckans et al., 2013). In other work, Giebel, Challis, and Montaldi (2015) systematically reviewed the literature on function and cognition with the goal of informing cognitive rehabilitation, but focused only on cognition and only on memory (long-term memory, working memory, and prospective memory). Reading this literature shows the scope of the models ranges from explaining the mechanism of a single technique or principle to presenting a person-as-a-whole model. While it is important to understand the efficacy of a particular technique for addressing a particular goal it is also important to build an intervention that is flexible enough to be tailored to unique goals and functional objectives of a particular individual or family. Hampstead, Gillis, and Stringer (2016) propose a model for building an evidence based cognitive rehabilitation. This proposal is primarily focused on RCTs, but single-case experimental designs, such as the one used in Study 3, also offer a way to balance study a particular technique with targeting individualized goals.

In Study 3 cognitive rehabilitation was delivered in-person and through videoconferencing. Study 1 in particular was carried out in order to inform Study 3, and the high preference for participating through telehealth videoconferencing replicated previous research (i.e., Morgan et al., 2011) supporting the need to develop remotely accessible interventions for individuals with MCI, dementia due to AD, or mixed AD/ VaD. The major objectives of Study 3 were to investigate the acceptability and feasibility of delivering cognitive rehabilitation through telehealth videoconferencing, and describe how the intervention needed to be modified in order to be amenable to telehealth.

Recall that in Study 3, the experimental design combined features of between-subjects design and multiple baseline single case design (Kazdin, 2010), and cognitive rehabilitation was delivered to three participants in-person and three participants through videoconferencing. Diagnostically, participants ranged from subjective cognitive impairment to dementia due to

Alzheimer's disease. This diagnostic heterogeneity, which was present in each of the three studies (although Study 3 is the only study that includes subjective memory impairment), is a limitation of the research discussed here (discussed further below), but the single case experimental design format allows the reader to examine the impact of cognitive rehabilitation over a range of impairment level. Very broadly, on the basis on Canadian Occupational Performance Measure (COPM) scores, visual inspection of the session-by-session plots suggested that for most functional goals participant's performance improved from their baseline sessions following cognitive rehabilitation sessions in both the in-person (improvement on 6/6 goals) and telehealth groups (improvement on 7/9 goals). However, the multiple baseline aspect of the study design, which was intended to increase the internal validity of the study, was problematic. A multiple baseline design was chosen because it allows cause and effect relationships to be examined to demonstrate treatment efficacy (Tate et al., 2008). In fact, as Tate and colleagues (2008) note multi-phasic designs are the most robust single case experimental designs. Goal performance was rated during a minimum of three baseline sessions to provide an adequate baseline, and we saw that performance on goals improved before they were specifically trained. In other words, training on an initial set of goals frequently improved performance on both trained and untrained goals. I have so far conceptualized this as a challenge to the internal validity of the experimental design precluding us from concluding that improvements in goal performance were due to the specific interventions (i.e., spaced retrieval, external aids) that were introduced. This could also be understood as generalization from a trained goal to an untrained goal. In fact, in Ng and colleagues (2013) study of telerehabilitation for individuals with TBI designed their study so that generalisation could be examined by measuring performance on untrained goals following training on trained goals.

In designing this study Tate and colleagues (2008) scale for rating the methodological quality of single-subject designs was consulted and the majority (7/11) criteria were met. The areas where the methodological rigor of the study did not meet the criteria recommended related to inter-rater reliability, independence of assessors, statistical analysis, and generalization. I carried out all of the assessment and intervention procedures myself and no additional raters were used. To some degree, concerns about the reliability of measurement are mitigated by choosing a measure with good evidence for its reliability and validity (COPM; Law et al., 2005). No statistical analyses were carried out. Some, such as Matyas and Grennwood (1990) would

argue that this is a major limitation of this study. Others, such as Kazdin (2011) have suggested that visual inspection may actually be superior to statistical analysis because it focuses only on large effects, which are more likely to clinically meaningful. Regardless, this is an area where this study could have been further developed.

An additional limitation of Study 3 is that transfer and spontaneous use of the tools and strategies learned in cognitive rehabilitation were not assessed. Individuals were trained on specific goals of their choice with the objective of bringing about meaningful, functional improvement on these goals in an everyday context. The goals participants selected were trained in the therapy environment and were never assessed in other domains of the individual's life, such as in their homes, which is a limitation. However, the more functionally relevant a goal is the less the need there is to formally assess generalization. Nevertheless, more compelling evidence for the effectiveness of cognitive rehabilitation would be gathered by assessing goal performance in an individual's everyday environment. Given that previous research has found that even when participants are successfully trained to use external aids the transfer of strategies learned in one context to another context, and the spontaneous use of a strategy is challenging and does not always take place (Bier et al., 2008) generalization should be more formally assessed in future research (Hampstead et al., 2016).

7.2 General Limitations

7.2.1 Low response rates and missing data. Limitations that are particular to each of the studies have already been commented on, but there are also several general limitations to the studies presented here. Across the studies that were presented here, collecting adequate data was a challenge. In Study 1 the response rate (21%) was strikingly low, which was addressed by comparing responders to non-responders. This proved to be a useful analysis, however it does raise questions about the degree to which a cognitive rehabilitation intervention is of interest to the general population of patients and caregivers accessing diagnostic and follow-up at a memory clinic.

In Study 2, data was missing particularly for the hierarchical regression analyses where Trails B or the Stroop test were used as the measure of executive functions. Furthermore, more data was missing in diagnostic subgroups with greater cognitive impairment. For example, for Trails B the total sample was reduced from $N = 403$ to $n = 184$. In contrast the COWAT had a higher rate of completion. Here, the completion rate ranged from 70% for the non-AD dementia

group up to 86% for the MCI group. This means (in part) that the COWAT analysis had the most statistical power. The question of how to interpret this missing Stroop test and Trails B data has previously been asked with RRMC data by Enright et al. (2015) who concluded that impairments in domains of cognitive function other than executive functions (i.e., language, immediate memory, attention, and visual-spatial reasoning) predicted completion of the Stroop test and of Trails B. Therefore, the samples used for each of the three hierarchical regression analyses varied, and the Stroop test and Trails B analyses were run with less impaired samples. This further emphasizes the point that all measures of executive functions are not measuring the same construct, and caution is warranted in selecting a measure of executive functions.

Finally, in Study 3, where the focus was on participating in a study rather than on completing a study as was the case in studies 1 and 2, data was missing. Largely this was caregiver data in cases where caregivers did not attend sessions with the individual who was participating in cognitive rehabilitation. In some case however, participant data was also not fully collected. This was most noticeably the case for the Test of Everyday Attention where the Elevator Subtest was used, and the issue here was that some participants were unable to distinguish between the low and high tones. The result was that the cognitive profile of participants was incompletely described. As noted in Study 3, the measures were chosen based on the tests administered by Clare et al., (2010), however in future research I would not choose to administer the Test of Everyday Attention.

7.2.2 Choice of variables and measures. In any study decisions need to be made about what variables to include and how to operationalize them. In the studies presented here I was interested in informing and developing cognitive rehabilitation, which aims to help individuals with cognitive impairments achieve meaningful functional goals. Therefore, logically, the most relevant variables and measures were ones that related directly to functional outcomes. In some instances, such as the decision to use the Canadian Occupational Performance Measure (COPM), which assessed participant-specific goals, a functionally relevant outcome measure was used. In my opinion, this is strength of Study 3. However, the studies presented here also relied heavily on neuropsychological tests and self-report measures of function, which is a limitation insofar as the goal of this research is to inform an intervention that aims to achieve meaningful, functional improvement. Some authors, such as Hampstead et al., 2016, have described the ecological relevance of neuropsychological measures as tenuous, whereas others have reported a moderate

relationship between a comprehensive neuropsychological assessment and functional daily living skills (Farias et al., 2003). In 2003, Ruff reflected on the history and future of the field of neuropsychology and argued that there was a need to develop more ecologically relevant tests. In 2016, Hampstead et al. made a similar argument and emphasized the need for more functionally relevant measures. Clearly, developing and using more ecologically relevant measures continues to be an area for future development.

      7.2.3 Diagnostic heterogeneity. Diagnostic inconsistency adds additional variability to studies in this area (Hampstead et al, 2016), and this was also the case in the studies presented here. This was perhaps most clearly an issue in Study 2 where the subgroups that were used could have been further categorized. The MCI and non-AD dementia subgroups in particular could have been further examined. The MCI construct has been refined to include amnestic and non-amnestic MCI, and single and multi-domain MCI (see Smith & Bondi, 2013 for an overview). Further, as described in the Study 2 the non-AD subgroup included participants with dementia due to Parkinson's disease, Huntington's disease, Lewy bodies, and frontotemporal degeneration. These subgroups of dementia have different presentations, and different underlying pathology. Therefore, one would predict that these subgroups may also show different functional correlates.

      There is a much greater lack of clarity surrounding the most appropriate diagnostic classification of the individuals who participated in Study 3, as we relied on self-reported diagnosis, an abbreviated interview, and abbreviated neuropsychological assessment. Study 3 included individuals with SCI, MCI, and dementia due to AD. The single-case experimental design format made it possible to examine changes in goal performance for individuals in each diagnostic group. Restated, this design meant results were not collapsed across diagnostic categories. However, it is unclear to what degree diagnosis, or degree of cognitive impairment, impacted the outcome of cognitive rehabilitation.

7.3 Next Steps and Future Directions

      Cognitive rehabilitation is a rich area of inquiry, and further developing this area has the potential to dramatically improve the quality of life of those individuals and families struggling with cognitive impairment. The general introduction delineated the history of cognitive rehabilitation, and as noted in that section, the historical roots of cognitive rehabilitation can be traced as far back as 3,000 to Egyptians working to develop means of managing brain injuries

(Boacke, 2003). To conclude, I consider the future of cognitive rehabilitation for people living with SCI, MCI, or dementia due to AD or mixed AD/VaD, and I consider how future researchers might continue to build on the work that has been presented here.

Using telehealth videoconferencing was an important feature of this work and the most novel part of the three studies. To my knowledge, goal-oriented cognitive rehabilitation has not previously been delivered to individuals with SCI, MCI, or dementia through telehealth videoconferencing. This research demonstrated that adapting this intervention to telehealth videoconferencing is feasible and acceptable to participants. Furthermore, while questions about efficacy remain, all participants in the intervention (Study 3) improved their function on at least one personally important, functional goal regardless of treatment modality. At a minimum, this literature would benefit from additional studies investigating the acceptability, feasibility, and efficacy of telehealth delivered videoconferencing for individuals with SCI, MCI, and dementia due to AD. It will be particularly important to better study how cognitive rehabilitation can be adapted to videoconferencing for individuals with MCI and dementia due to AD. In thinking about feasibility and efficacy one area of focus has been on which individuals are most likely to participate in cognitive rehabilitation and most likely to benefit from the intervention. For example, Study 1 commented on how individuals with less awareness may be less likely to express interest, and one limitation of Study 3 is the degree to which level of cognitive impairment impacts participation and treatment gains was not fully delineated. However, it is likely also the case that some goals are more amenable to being delivered through videoconferencing based cognitive rehabilitation than others. This is in contrast to the idea that some individuals are more likely to benefit from cognitive rehabilitation than others. The results of Study 3 raised the possibility that the goals of improved sleep and concentration were less amenable to cognitive rehabilitation delivered through videoconferencing. One way to better understand which goals are more amenable to cognitive rehabilitation would be to match participants on goals and then randomly assign them to either participate in-person or through telehealth videoconferencing. Adjusting the experimental design in this way would be a useful next-step in further evaluating videoconferencing based cognitive rehabilitation for individuals with SCI, MCI, or dementia.

Telehealth videoconferencing also opens up possibilities for improving the accessibility of treatment options for individuals with SCI, MCI, and dementia due to AD more generally. As

Clare (2017) recently explained, it is important to clearly differentiate cognitive rehabilitation interventions from other nonpharmacological interventions that are related to cognitive rehabilitation, but are not actually cognitive rehabilitation. However, other nonpharmacological interventions such as caregiver support groups, psychotherapy for depression, and groups focused on social contact can all be complementary to cognitive rehabilitation (Clare, 2017).

Considering the relationship between psychotherapy and cognitive rehabilitation may be important, and in my mind the line between psychotherapy and cognitive rehabilitation is a blurry one. While cognitive rehabilitation is certainly written about as a holistic, biopsychosocial intervention, the emphasis is largely on applying principles and strategies to work around/compensate for cognitive impairments, or build on remaining cognitive strengths. It is written about more as a specific type of rehabilitation, but could also be conceptualized as a type of psychotherapy. Study 2 highlighted the relationship between neuropsychiatric variables (mood and apathy) and function, and future researchers might consider how interventions such as cognitive behavioural therapy, interpersonal psychotherapy, or emotion focused therapy can be further integrated into cognitive rehabilitation. Furthermore, Study 3 highlighted the importance of a therapeutic alliance in cognitive rehabilitation. Alternatively, one might think about how principles from cognitive rehabilitation (such as spaced retrieval) could be applied within a more traditional psychotherapy framework. For example, a researcher or clinician might use spaced-retrieval to teach an individual a cue that would prompt going for a walk as part of a behavioural activation intervention. The goals reported by participants in Study 1, particularly goals coded as related to household tasks, higher order cognitive function, and recreation, also support the conclusion that cognitive rehabilitation interventions need to be more fully developed outside the domain of memory. Similarly, this is reflected in the goals related to frustration, concentration, and confidence set in Study 3.

Interventions that move beyond the scope of psychological interventions will also be indicated and supportive for many individuals who are participating in cognitive rehabilitation. This is in line with Huckans et al. (2013) who proposed the intervention model based on modifiable risk factors already described above. For example, lifestyle factors such as smoking and heavy alcohol consumption have been associated with an increased risk of cognitive impairment and dementia, and lifestyle factors such Mediterranean diet, physical activity, and cognitively stimulating activity have been associated with a decreased (Huckans et al., 2013).

One example of an integrative/interdisciplinary approach to cognitive rehabilitation is Chew et al.'s (2015) multimodal cognitive and physical rehabilitation program for individuals diagnosed with mild dementia and their caregivers. This program, which included a mixture of individualized goal setting and group-based interventions, was facilitated by a multidisciplinary team of physiotherapists, occupational therapists, and psychologists. Goal attainment scaling was the primary outcome measure in this study and 62% of participants met or exceeded their goals (there was no control group). In my opinion, research in cognitive rehabilitation for individuals with SCI, MCI, and dementia should become increasingly multidisciplinary and multi-component. Telehealth also has the potential to make this line of multidisciplinary interventions more accessible.

Telehealth provides the possibility of making psychological interventions more accessible, but it also raises the possibility of increasing the accessibility of other specialist interventions such as physical therapy, and nutrition (i.e., consultation with a registered dietician). Telehealth eliminates the need for professionals to be co-located and therefore offers the possibility of making a truly 'whole person' approach to cognitive rehabilitation more feasible. This is especially true when considering how to provide services to individuals who reside in rural or remote locations where, as has been emphasized throughout this document, specialist care is less available. Multidisciplinary, telehealth-facilitated care is being evaluated in the context of range of health conditions and populations including paediatric obesity (Slusser et al., 2016), elderly people discharged from the hospital at risk for falls (Giordano et al., 2016), Parkinson's disease (Pretzer-Aboff & Prettyman, 2015), and cardiac rehabilitation (Banner et al., 2015). In one example, Pretzer-Aboff and Prettyman (2015) used telehealth to assemble a multi-disciplinary assessment and treatment team for individuals diagnosed with Parkinson's disease in Delaware where there is no movement disorder specialty clinic. Cognitive rehabilitation for individuals with dementia might also make use of technology in order to develop more comprehensive programs and allow individuals to set goals outside the scope of clinical psychology. In fact, the participants in Study alluded to this idea when they set goals related to improving balancing, reducing a tremor, improving hearing, and meal planning. This adds support to the suggestion of further developing multimodal cognitive rehabilitation.

In thinking about the future of cognitive rehabilitation for individuals with SCI, MCI, and dementia due to AD another area another area that is important to consider that has not yet been

fully discussed here is how group based cognitive rehabilitation might be delivered through telehealth, and how group-based delivery might augment the treatment that was described here. The potential benefits of delivering treatment in a group format are important to consider for clinical reason as well as financial ones. Clinically, groups offer benefits that individual treatment cannot. For example, groups provide the opportunity for their members to experience universality and altruism (Yalom & Lescz, 2005). They also provide opportunities to develop socializing techniques and for interpersonal learning (Yalom & Lescz, 2005). The therapeutic factor of universality refers to the experience of meeting others with similar struggles, a reduced sense of isolation, and a feeling of connection to others. Social isolation and exclusion is frequently part of the experience of individuals diagnosed with dementia and connecting with others with the same condition has been found to be an important source of support for these individuals (Greenwood & Smith, 2016). Regarding altruism, a group approach to cognitive rehabilitation would allow group members to help each other, and the experience of helping others can boost self-esteem (Yalom & Lescz, 2005). This is not something the format of individual cognitive rehabilitation studied here is able to provide. Similarly, a group format would allow participants to learn from each other's examples, and simply to socialize. The challenge of adopting goal-oriented cognitive rehabilitation to a group format would be to ensure that the individualized nature of the goal-oriented cognitive rehabilitation is not lost in a group format. This is essential because ensuring that individual participants have the opportunity to set and attain goals that are meaningful to them is the purpose of cognitive rehabilitation, by its definition (Clare, 2017). One approach might be to have individual pre-group, preparation sessions with participants where goal setting takes place and then use the group setting to work through and practice the specific goals of individual members.

Finally, if one imagines a comprehensive, holistic approach to dementia care a program like this logically would include supports for caregivers. A concern that has been raised is whether cognitive rehabilitation might actually increase caregiver burden. For example, attending cognitive rehabilitation appointments and practicing strategies at home becomes "one more thing" caregivers are asked to take on. Caregiver support groups are a staple of Alzheimer's associations and particularly in the case where cognitive rehabilitation was being implemented in a group format caregivers might meet while their family member is participating in the cognitive rehabilitation portion of the program.

Lastly, in my opinion, both research and health care would be improved by greater collaboration between relevant stakeholders including researcher based in academic institutions, health care centres (i.e., hospitals, mental health centres, primary care centres), individuals and families with SCI, MCI, or dementia, and community organizations such as Alzheimer's societies. In many ways, the program of research that was carried out and reported here was top-down, and researcher lead. In future, I would focus first on building relationships with grassroots organizations with the goal of lending a set of research skills to problems or questions identified by stakeholders living day-to-day with cognitive concerns.

7.4 General Discussion References

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Everyday Memory Questionnaire For Clinic Patients

We are making a program to help people with memory concerns better handle everyday problems. In the program people are taught ways to deal with some daily memory challenges.

The program is not ready yet and we would like to know what kind of problems people with memory concerns might like help with. **Please keep in mind that you are <u>not</u> being asked to participate in the program. We need your help to <u>design</u> the program.**

The program involves learning specific ways to better live with difficulties related to memory changes. The program will not restore memory abilities but provide ways to handle loss.

Example: In the program we are developing someone who is frustrated by not knowing what day it is and the plans for the day might learn to use a detailed diary to check the date, write down plans and review plans that had been completed.

Part 1: In the space below we have outlined some common areas where people have problems. For each area there are examples of problems that people have asked for help with. <u>What everyday challenges would you like to address</u>? Please write down any challenges <u>you</u> would like help with.

Memory problems: _____

_____

_____

_____

Examples	
Remember the names of specific people	Remember personal information
Remember to turn off lights in the house	Be able to find items around the house
Manage medication more independently	Know what day it is and plans for the day

Practical skills and activities: _____

_____

_____

_____

Examples		
Learn to use a phone	Handle money better	Increase time spent doing leisure activities
Take up writing again	Start to read books again	Increase time spent doing a social activity
Return to a club or group	Visit with friends or family	Learn to email friends or family

Concentration: _____

_____

_____

_____

Examples
Keep track of conversations   Maintain concentration and not get distracted during an activity

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Organisation: _____

_____

_____

_____

Examples
Improve use of calendar   Sort and keep track of mail

Part 2: Circle or underline <u>one or two </u>of the problems you wrote down in Part 1 that you <u>most </u>want help with.

Part 3: For the questions below please circle Yes or No. Remember, we are asking for your help to *design* a program and are not asking you to participate.

1. Would you be able to meet with the researcher once a week for eight weeks in Saskatoon?

   Please circle: *Yes* **or** *No*

2. Would you be able to meet with the researcher once a week for eight weeks over telehealth?

   Please circle: *Yes* **or** *No*

3. Who completed this questionnaire?

   Please circle: *Memory Clinic Patient* **or** *Family Member* **or** *Both Together***.**