

**Healthcare Providers Perspectives of Cognitive Rehabilitation in the Central East
Local Health Integration Network (LHIN)**

by

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ABSTRACT

Aim: Explore healthcare practitioners' capacity within the Central East LHIN to implement cognitive rehabilitation programs to those with dementia.

Methods: This study is designed as a multi-stage qualitative interpretive study utilizing thematic analysis with a maximum variation sampling design.

Results: Five integrated themes were developed over the course of the qualitative data. These themes included: 1. overcoming system challenges in cognitive rehabilitation, 2. debate between standardization and individualization, 3. paradigm shift from treatment to primary prevention, 4. raising awareness through accessible education and services, and 5. continuity and care coordination.

Conclusion: Healthcare providers do not have the capacity to implement cognitive rehabilitation across the Central East LHIN. This study adds to the growing knowledge base of cognitive rehabilitation and will allow for improved dementia capacity planning utilizing healthcare workers unique perspectives and insights.

Keywords: Cognitive rehabilitation; dementia; capacity planning; healthcare providers

AUTHOR'S DECLARATION

I hereby declare that this thesis consists of original work of which I have authored. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners.

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The research work in this thesis that was performed in compliance with the regulations of Ontario Tech's Research Ethics Board/Animal Care Committee under **REB Certificate number 15009.**

Meagan Quesnelle

STATEMENT OF CONTRIBUTIONS

I hereby certify that I am the sole author of this thesis and that no part of this thesis has been published or submitted for publication. I have used standard referencing practices to acknowledge ideas, research techniques, or other materials that belong to others. Furthermore, I hereby certify that I am the sole source of the creative works and/or inventive knowledge described in this thesis.

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LIST OF ABBREVIATIONS AND SYMBOLS

| | |
|------|--|
| AD | Alzheimer's Disease |
| ADL | Activity of Daily Living |
| ADP | Adult Day Program |
| BADL | Basic Activity of Daily Living |
| BPSD | Behavioural and Psychological Symptoms of Dementia |
| BSO | Behavioural Supports Ontario |
| CBT | Cognitive Behavioural Therapy |
| CDR | Clinical Dementia Rating Scale |
| CPG | Clinical Practice Guidelines |
| CST | Cognitive Stimulation Therapy |
| fMRI | Functional Magnetic Resonance Imaging |
| GAIN | Geriatric Assessment and Intervention Network |
| GDS | Global Deterioration Scale for Assessment of Primary Degenerative Dementia |
| HCP | Healthcare Providers |
| IADL | Instrumental Activity of Daily Living |
| LHIN | Local Health Integration Network |
| LTC | Long Term Care |
| MMSE | Mini Mental State Examination |
| OT | Occupational Therapist |
| PSW | Personal Support Worker |
| RN | Registered Nurse |
| SVI | Severe Mental Illness |
| TBI | Traumatic Brain Injury |

Chapter 1. Introduction

Background

Our Canadian society is rapidly aging, and for the first time ever census data reveal that more of Canada's total population are now over the age of 65 compared to youth [1]. By 2031, one in four Canadians will be over the age of sixty-five. The current and upcoming aging population brings an enormous challenge to the Canadian healthcare system not only in terms of volume, but complexity of disease processes that are present in older age [1]. Cardiovascular disease, cancer and neurodegenerative diseases all identify age as a risk factor, which subsequently rank first, second and seventh in the top ten causes of death in Canada [2].

Though neurodegenerative diseases rank as the seventh most common cause of death in Canada, neurodegenerative diseases are one of the leading causes of disability in Canada [1]. Neurodegenerative diseases are classified as diseases that progressively affects the function of neurons, which include Parkinson's disease, Alzheimer's disease and Huntington's disease [1]. Canadians diagnosed with a neurodegenerative disease face both short- and long-term healthcare challenges such as complex comorbidities, challenges with medication adherence and difficulties in accessing appropriate services and support [3]. Challenges such as these require care from inter-professional, interdisciplinary teams coordinating across multiple health platforms and the work of informal caregivers in order to provide the most comprehensive care to clients, which many healthcare providers (HCP) find challenging [3].

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Alzheimer's disease is one of the most common neurodegenerative diseases affecting Canadians [1]. Alzheimer's disease is characterized by irreversible and progressive neuron loss in the brain that impairs memory and other cognitive abilities and in its more progressive stages, limits an individual's ability to complete activities of daily living (ADLs). Alzheimer's Disease is the most common type of dementia, with estimates currently exceeding 600,000 cases and increases expected as high as 950,000 cases in the next 15 years in Canada alone [1]. With Alzheimer's Disease being one of many forms of dementia, it is important to clarify that dementia is an overarching term for a syndrome characterized by difficulties with cognitive function and progressive deficits in memory that interfere with an individual's ability to complete activities of daily living. There are many types of dementia, including frontotemporal dementia, vascular dementia and Alzheimer's disease among others [4]. Alzheimer's disease and other types of dementia will prove to be one of the most important upcoming health challenges Canada will face [4].

Throughout the many types of dementia including Alzheimer's disease, an individual may experience some mild forms of cognitive impairment before progressing through similar, sequential stages of the disease as dementia varies in severity and operates along a continuum from mild to severe. Individual presentations may vary slightly, though most clients diagnosed with dementia experience the following: memory loss, loss of behavioural functioning such as motor function, an inability to execute object discrimination, and language difficulties among other cognitive, behavioural and social symptoms. These symptoms may interfere with the individual's ability to perform activities of daily living and may hinder occupational or social functioning. A key

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component of a dementia diagnosis is that the symptoms clients experience is not due to alterations in consciousness or awareness such as interference from medication [5], which can cause drug interactions producing similar symptoms.

Many recommendations have been put forward by relevant stakeholders to help prepare Canada for the impending dementia crisis. Canada has developed a National Dementia Strategy as of June 22nd, 2019 to present dementia as a national priority with a focus on measurable outcomes, comprehensive targeted training for healthcare professionals and sharing of best practises between interdisciplinary healthcare teams [1]. Canada's National Dementia Strategy has three main objectives, which are to prevent dementia, advance therapies and to improve quality of life [1]. Various community-based organizations such as the local Alzheimer's Society chapters have also indicated a commitment to awareness, education, and research aimed at improving the lives of those diagnosed with dementia [4].

This awareness, education and research involves many important partners in the dementia care continuum. For instance, in the 2010 Rising Tides Report from the Alzheimer's Society of Canada [4], improving quality of life throughout the stages of dementia require comprehensive team-based care from a series of community partners, healthcare professionals and family caregivers. The disease management stage in particular requires a concentrated and comprehensive care plan that includes multidisciplinary healthcare workers collaborating to provide evidence informed treatments to manage the cognitive and behavioural symptoms of dementia [1].

As an example, throughout the disease management stage of dementia an attempt is made by physicians and other healthcare providers to manage the cognitive and

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behavioural symptoms of dementia by prescribing medications such as cholinesterase inhibitors [5] and supplementing acute care with community-based services that are offered through local Alzheimer's Societies, memory clinics and interdisciplinary healthcare teams such as Geriatric Assessment and Intervention Network (GAIN) teams, which provide services in the Central East LHIN and surrounding areas. These services provide education, treatment and support to dementia clients and their families. However, once community aids cannot continue to provide adequate care and dementia symptoms continue to progress, many individuals may need to leave their homes and communities and move into long term care (LTC) facilities. Severe cognitive decline is one of the main predicting factors in entry to long term care [4]. Communication and collaboration between these important stakeholders from the prescribing physician to the occupational therapist in LTC is crucial to ensure the most positive client outcomes in the dementia care continuum.

Within LTC facilities, individuals with dementia comprise nearly 70% of all occupants [6], and can inhabit various residence types such as nursing homes, dementia-specific housing, and private or public care institutions. According to the Canadian Nursing Association, Canada will likely experience a shortage of nearly 200,000 long term care beds by 2038 [6]. Given the upwards projection in estimates of dementia across Canada and the shortage of care facilities for these individuals, it becomes increasingly important not only to find a cure for dementia, but to develop and implement rehabilitation programs that may slow the disease process and/or improve clients quality of life with particular emphasis on cognition given its role in predicting entry into LTC [7].

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Advocates for dementia clients and caregivers suggest viewing dementia from a social disability lens, where it becomes evident that there is an opportunity to highlight programs that alter both the social and structural environments surrounding dementia to lessen the experience of disability. An example of these programs can include cognitive rehabilitation programs, which although new, have begun to suggest possible positive benefits for individuals with dementia and may lessen the behavioural, psychological and cognitive symptoms and improve quality of life for clients. Including cognitive rehabilitation and other social and structural adjustments for those with dementia will begin to allow for mitigating this negative experience of disability and enhancing quality of life, aligning with the goals and aims of Canada's National Dementia Strategy [4].

Currently, few of our treatment options are aligned with the social disability lens for dementia, and even fewer at rehabilitating persons with dementia from a cognitive perspective. The priority in dementia care currently has been on controlling acute presentations of behavioural or physiological symptoms only [8]. Moreover, of the cognitive recommendations that are currently being prescribed, few if any are informed by healthcare providers and take into consideration their perspectives and needs. This leads to what is known commonly as the "know-do" gap, which is the bridge between what is known in the empirical research and what is truly implemented in clinical practice [8]. In order for any recommended treatment to be provided successfully and improve quality of life, the challenges of the "know-do" gap must be understood and addressed to ensure the highest level of care and the most current treatments are actually available for the clients from a comprehensive, lived experience perspective [9].

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1.14 Rationale for Study

Alarming, there is a wide gap between empirical research evidence and its applied practice for cognitive rehabilitation therapies for those with dementia. Given the relative novelty of cognitive rehabilitation practices in this population, implementation has been slow and unable to inform health policy due to both unheeded change by healthcare workers and socio-organizational restraints such as lack of time or funding [81]. Given that there is not yet a cure for dementia, cognitive rehabilitation strategies in particular are instrumental treatment options that should be recommended in tandem with other interventions both pharmacological and non-pharmacological to support the process of reducing the levels of disability in this population and improving quality of life. Though cognitive rehabilitation programs are supported as beneficial in these aforementioned domains, little is known about their availability and use within Canada and healthcare providers capacity to implement this type of programming.

1.15 Study Purpose

The purpose of this study is to understand the capacity for cognitive rehabilitation programs in the Central East LHIN from the healthcare workers perspective., This study aims to determine what is necessary to address barriers to clinical implementation and how current dementia health care workers experience and recommend cognitive rehabilitation for clients with dementia in order to close the “know-do” gap and increase capacity.

This study will use a qualitative methodology to explore the recommendations, use and accessibility of cognitive rehabilitation programs throughout the Central East LHIN from the healthcare workers perspective. The choice to use qualitative

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methodology comes in part from the fact that cognitive rehabilitation is not well defined. Due to its complex nature, quantifying cognitive rehabilitation may not describe the complexity and subtleties of how it is used and offered to individuals with dementia. Using a qualitative methodology also allows for cognitive rehabilitation to be put into the local community context, which will be helpful in examining the strengths and gaps in the programs and services at the community level

The Central East LHIN was chosen as the location to investigate due to the fact that its seven sub-regions provide a good geographical basis for analyzing cognitive rehabilitation care opportunities local to our communities. The LHIN works with primary care providers and health service providers who can provide valuable insight to the use and capacity of cognitive rehabilitation services in this area. In addition, as of 2013 it has been identified that nearly 13,000 residents throughout the Central East LHIN are currently diagnosed with dementia. This is an increase of 60% since 2007, higher than the standard predicted growth rate [82] and shows the growing need for accessible cognitive rehabilitation programs in this area [83].

1.16 Research Questions

The central question for this thesis is to explore the complex set of factors surrounding capacity and implementation of rehabilitation programs for persons with dementia and present the varied perspectives that healthcare providers hold. We aim to learn to what extent and in what ways does the qualitative data on cognitive rehabilitation serve to contribute to a more comprehensive and nuanced understanding of why or why not healthcare practitioners in the Central East LHIN feel as though they have the capacity to implement cognitive rehabilitation programs at their respective institutions.

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Primary Research Question

1. How do healthcare practitioners perceive their capacity in providing cognitive rehabilitation to persons with dementia within the Central East LHIN?

Secondary Research Questions

2. What cognitive rehabilitation services (recommendations or programs) currently exist and are being offered to clients with dementia within the Central East LHIN?
3. Do current dementia healthcare practitioners feel as though they have the capacity to fulfill the current and upcoming needs of the dementia population?
4. What is the most influential perceived barrier in both providing and accessing cognitive rehabilitation programs from the healthcare workers perspective?
5. Do dementia healthcare workers believe they are competent in providing cognitive rehabilitation services, and do their organizations support them in growing their competencies to provide this type of program with their clients?

1.1 Literature Review

A literature review was conducted to identify the provision of cognitive rehabilitative services for those with dementia and healthcare workers experiences delivering these services. The literature search was conducted using ProQuest, Medline, and PubMed. The search was completed with varying keywords including dementia, Alzheimer's disease, service use, cognitive rehabilitation, cognitive remediation, brain training, cognitive therapy, healthcare workers, service providers, nurses, occupational therapists, and rehabilitation. Searches were conducted with these key terms in single use

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and in combination and were logged in order to not duplicate results. Literature is mainly concentrated in the last ten years, from 2007-2019 although earlier articles were included if deemed relevant. Additional articles were found by using referenced material within each article. Articles were refined by English language peer reviewed articles only.

1.2 Understanding Cognitive Decline in Dementia

Before addressing how to target and improve cognition in dementia clients, it is important to understand how degeneration affects dementia clients in order to recognise how cognitive rehabilitation may provide benefits for this population. Many rating scales for understanding cognitive decline in dementia are used in the literature and by healthcare professionals, including the Global Deterioration Scale for Assessment of Primary Degenerative Dementia (GDS), the Functional Assessment Staging (FAST) tool and the Clinical Dementia Rating Scale (CDR) [10]. Though they each differ in the number of stages present throughout the dementia progression, each recognizes that those with dementia will begin as a functioning adult, with no cognitive decline. In the subsequent stages, mild cognitive decline can be seen but is not yet advanced enough to be classified as dementia. In the mild cognitive decline stage, forgetfulness becomes more common, and retrieval of words and spatial information becomes slower. The mild cognitive decline stage continues to develop in some individuals to early stage dementia. This includes symptoms such as decreased concentration, short term recall difficulties and difficulties in complex daily activities such as finances. Following mild cognitive decline, mid-stage dementia presents with additional, compounding symptoms including difficulties with ADLs such as dressing and bathing and in some, a decline in the individual's ability to speak. The last stage of dementia, sometimes referred to as "Stage

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7” or severe or late stage results in persons with dementia requiring assistance with most activities and their progressive limitations in communication, with most clients averaging around 6 words and progressive deterioration in understanding time and place orientation [11].

As the disease process unfolds across the stages above, different memory systems are affected. Episodic and semantic memory abilities are generally the first to decline in those with dementia, followed by instrumental functions and executive functions. However, procedural memory and prospective priming are generally not grossly affected [12]. These large-scale changes in memory are precipitated by smaller changes at the neuronal level of the brain. Though the outward expression of decline may vary between individuals, the underlying biological changes are similar across all varieties of dementia including Alzheimer’s disease (AD). AD has some characteristic neuropathological changes including plaques (made of β -amyloid protein) and neurofibrillary tangles made from tau. The β -amyloid protein accumulation begins to cause brain alterations in neurons and corresponding synapses, which contributes to cognitive decline. These include declines in working and episodic memory attributed in part to brain cell death and loss in synaptic connectivity, which can be seen in fMRI studies presenting as reduced brain activation [13]. The loss in synapses accounts for nearly 90% of the variance in cognition in those diagnosed with AD [14]. Given that this cognitive decline seen in dementia is progressive, there are optimal periods of time within the disease process in which persons with dementia still have some intact memory functioning, such as procedural memory. Targeting these periods of time is the key focus of cognitive

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rehabilitation strategies, where it becomes possible to capitalize on the neuroplasticity of existing networks in order to compensate for failing memory sub-systems [15].

1.3 Cognitive Decline Mediated by Neuroplasticity

Neuroplasticity is the most common theoretical approach underlying the success of cognitive rehabilitation strategies for persons with dementia. It includes the brains dendrites, axons and synapses ability to adjust and react when the brain experiences cell death, whether it be due to attrition or injury. For example, when neurons die or fail, the brain attempts to compensate by increasing the number of dendrite branches within healthy neurons in order to accommodate [16]. This compensatory activity is what is thought to allow cognitive rehabilitation to show some improvements in dementia populations. Cognitive rehabilitation promotes brain plasticity by engaging neuro-modulatory systems through cognitive, psychomotor and/or sensory activities [17] specified by each type of cognitive program, whether that be training, rehabilitation or stimulation. Outcomes of the cognitive rehabilitation subtypes are measured not only in delaying or reversing cognitive deficits where possible, but to also allow the client with dementia to learn and practice individual skills to lessen cognitive demand [17].

1.4 What is Rehabilitation in a Dementia Context?

This section will explore what rehabilitation means and how it must be understood in the context of dementia care. Rehabilitation can be defined as “a process aiming to restore personal autonomy in those aspects of daily living considered most relevant by patients, service users, their family carers and healthcare workers. Rehabilitation is about enabling people who are disabled by injury or disease to achieve their optimum physical, social and vocational well-being” [19].

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Clare and colleagues [20] have recommended that the current model of care for dementia clients is failing, and in order to achieve more optimal outcomes a redistribution of available resources must be implemented. This redistribution includes a strong emphasis on introducing a rehabilitation focused model into current service offerings for clients with dementia. This rehabilitation model is already being suggested in current clinical practice guidelines for dementia, which suggests care in this manner needs to be provided in the community with a strong aim to improve quality of life, maintain and optimize functioning and achieve high levels of engagement in social and personal relationships, all offered by trained and evidence-informed staff [21]. Recent clinical practice guidelines for dementia also suggest these rehabilitation services must be provided from a person centered, identity-based perspective and must ensure that training, knowledge, and dissemination are available to staff who are both willing and able to implement rehabilitation care [20]. This lies in stark contrast to a particular area of concern which is repeated throughout the literature by healthcare professionals: the over reliance on an outdated biomedical model of care, which provides little opportunity for staff training and identification of dementia signs and symptoms particularly in long term and community care settings [22]. Clients with cognitive impairment specifically are often inadequately assessed in these facilities; especially those with symptoms of early onset dementia. This is an unfortunate circumstance, due to the fact that clients with cognitive decline in the early stages of the disease are at the most opportune time to implement pharmacological and non-pharmacological interventions such as cognitive rehabilitation [23].

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1.5 Cognitive Rehabilitation Programs

This section will explore what cognitive rehabilitation means, the subtypes of cognitive rehabilitation and their importance in the care of those with dementia and seeks to provide a nuanced understanding of the differences between the three main subdivisions of cognitive rehabilitation programs which are cognitive training, cognitive rehabilitation and cognitive stimulation. Additionally, this section aims to provide a brief overview of recent literature suggesting cognitive programs may provide some benefits to PWD as a non-pharmacological intervention to consider implementing across the Central East LHIN.

There is a general consensus within the research literature that there are three subtypes of cognitive rehabilitation programs for those with dementia: cognitive training, which is offered to those experiencing mild cognitive decline or mild dementia, cognitive rehabilitation which is offered to those experiencing moderate dementia and cognitive stimulation, offered to those experiencing severe cognitive decline [12]. These three domains of cognitive programming are crucially important to dementia care, given that cognitive decline is the most prominent clinical feature of the disease. Cognitive rehabilitation methods can be defined as a type of rehabilitation that “aims to enable clients or patients, and their families, to live with, manage, bypass, reduce or come to terms with deficits precipitated by injury to the brain” [12]. To best understand how rehabilitation fits with the dementia population, it can be viewed from the previously described social disability lens. When dementia is viewed as a social disability, symptoms can be seen affecting behaviour and memory which in turn affect factors such as confidence and inclusivity [24]. This lived experience of social disability demands a

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“right to rehabilitation” for the dementia population, just as those experiencing other types of disability have a right to treatments of their own [25]. Rehabilitation is so often understood in the context of physical manifestations of injury, but is equally important for those suffering from cognitive rather than physical ailments which includes those suffering from dementia. Cognitive rehabilitation in the dementia population must be understood in the context of the disease itself.

1.5.1 Exploring the Subtypes of Cognitive Rehabilitation

Cognitive rehabilitation programs in a dementia context have many aims and have evolved as both a concept and a framework throughout the empirical literature. From the broadest level of understanding, cognitive rehabilitation is a goal-oriented framework that attempts to improve functional disability in those experiencing dementia. This many include improvements in activities of daily living, reductions in behavioural and psychological symptoms of dementia, and improvements in language and social interaction [25]. When focusing on the cognitive component specifically, rehabilitation targets can include specific memory functions such as recall, time and space orientation, and executive functioning. Cognitive rehabilitation aims to use various learning, re-learning and compensation strategies to improve the brain functioning of those with dementia to create and achieve meaningful, personally relevant goals [25]. There are many reasons why alternative models of care such as cognitive rehabilitation may be offered to persons with dementia, including a failure in the client to respond to traditional therapies, or at the request of the client themselves or the client’s family or due to evidence that alternative models of care may be beneficial [12]. Clinicians may also have expertise in particular alternative models of care such as cognitive rehabilitation, or it

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may be necessitated due to the rate of cognitive decline in the person with dementia and the resources available [12]. For instance, cognitive strategies will differ for someone experiencing only mild decline who may simply wish to grocery shop alone or remember how keep in contact with friends and family through the use of a computer. For someone experiencing moderate or severe decline, cognitive rehabilitation strategies may be used to assist the individuals to continue to dress themselves or participate in a hobby. As the cognitive profiles of the individual change throughout the disease process, different severity levels will require an adapted level of rehabilitation [26]. This has led to the development of three main subtypes of cognitive programs for persons with dementia: cognitive training, rehabilitation and stimulation. A succinct definition of each subtype is provided in the figure below, and each will be expanded on in more detail in the following sections.

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Table 1. Subtypes of Cognitive Programs

| Cognitive Remediation Subtype | Definition | Target Population | Example |
|-------------------------------|--|--|--|
| Cognitive Training | Cognitive training uses repeated practice of specific cognitive tasks applied to everyday activities in a group or individual setting. Cognitive tasks usually advance with difficulty as the training continues. The main features are: repeated practice, use of standardized tasks, theoretically motivated strategies, range of activities (adaptive). The aim is to improve an isolated cognitive domain with the possibility of generalizing to an untrained task [16]. | Mild Cognitive Impairment, Mild Dementia | Training in memory strategies involves the instruction and practice of techniques to minimize memory impairment and enhance performance, and involves learning and practicing strategies such as the method of loci, mnemonics, and visual imagery [78]. |
| Cognitive Rehabilitation | Cognitive rehabilitation is highly individualized, more so than cognitive training. Strategies are developed to address personally relevant, functional and social goals. It may be targeted at specific cognitive domains however it does so using a restorative approach, building on the abilities of the client with dementia that are retrained. The main features are: the use of a restorative approach, individualized goals, aims to improve ADLs [16]. | Mild to Moderate Dementia | Build individual strategies to support functioning in specific situations, for example join the conversation at the family dinner table, or re-engage in a previously enjoyed activity. Compensate for known difficulties and challenges, for example develop strategies to avoid being distracted and lose concentration when preparing meals, modify tasks or the environment, or introduce assistive technology [79]. |
| Cognitive Stimulation | Cognitive stimulation is an individual or group session that aims to stimulate and engage those with dementia in a person-centered manner. The use of reality orientation techniques (using calendars, journals, videos and pictures) is common. The goal is to preserve social and cognitive skills for as long as possible. The main features of cognitive stimulation are: wide range of activities, group format, and significant emphasis on social interaction, use of reality orientation or reminiscence therapy [16]. | Moderate to Severe Dementia | Group CST treatment involves 14 or more sessions of themed activities, which typically run twice weekly. Longer-term, or 'maintenance CST', is outlined in a published treatment manual. Sessions aim to actively stimulate and engage people with dementia, whilst providing an optimal learning environment and the social benefits of a group [80]. |

1.5.2 Cognitive Training

To target those with only mild decline, healthcare practitioners may use the first subtype of cognitive rehabilitation programming, known as cognitive training. Cognitive training works in a scaffolding manner with advancing difficulty of tasks paced by the client themselves or the instructor. In cognitive training, a strong focus lies in repeated

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practice and rehearsal of specific impaired cognitive tasks alongside training of intact cognitive skills [27]. Cognitive training requires high levels of effort from the client and practitioner. As such, individuals who participate in this type of rehabilitation generally still have the capacity to be guided by an instructor such as a neuropsychologist, therapist or online based computer program. Specific cognitive tasks that can be targeted during training include divided attention, memory (spatial, episodic, visual, verbal, working), object discrimination, executive function, language, logical reasoning, speed of information processing, orientation (time, spatial), recognition, association tasks, categorization, and clustering among many others. These domains are often applied to everyday activities in group or individual settings [17]. Cognitive training also employs the use of meta-memory and/or metacognitive strategies to encourage individuals to think about their learning and understand how it occurs. Compensatory approaches are sometimes used in this type of rehabilitation, with approaches such as mnemonic strategies and visual imagery [17]. In sum, cognitive training is approached as the repeated practise on a set of standardized tasks to increase a particular cognitive function, meant to support accomplishment of activity of daily living.

1.5.3 Cognitive Rehabilitation

Cognitive rehabilitation is the second form of rehabilitation for persons with dementia. In contrast to cognitive training, cognitive rehabilitation is best suited to individuals with mild to moderate decline. Cognitive rehabilitation works within a highly individualized framework, even more so than cognitive training. Rather than targeting particular theoretical cognitive domains such as executive function, speed of processing or others that cognitive training supports, cognitive rehabilitation attempts to treat

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cognitive decline from a more macro-level of functional, behavioural, and social disability [17]. Improvements in cognition are not seen as improvements in specific domains alone but also in the improvements in interaction between the client and their environment. In such, memory aids are often employed to allow clients to adapt to cognitive deficits and there is a strong focus on active adaptation to cognitive decline. Many of the strategies employed within cognitive rehabilitation look to build on retained abilities rather than restore declining cognitive domains, though some literature does suggest that training in specific individual cognitive deficits still occurs under the umbrella of cognitive rehabilitation with the use of errorless learning techniques being most common [17]. Many of the strategies used in cognitive rehabilitation are developed to engage the client in attaining personally relevant, social, functional and meaningful rehabilitation goals. Cognitive rehabilitation makes use of a restorative approach which allows for implementation of prompting techniques and adaptation in order to promote independence in accomplishing activities of daily living. Cognitive rehabilitation programs attempt to target training in real world tasks that are adapted to each individual client's current level of functioning [26]. In sum, cognitive rehabilitation is a goal focused cognitive program that attempts to engage clients in individualized, personally relevant rehabilitation goals with less emphasis on particular cognitive domains that characterize cognitive training.

1.5.4 Cognitive Stimulation

The final subtype of cognitive rehabilitation that is best suited to individuals with moderate to severe decline is cognitive stimulation. Cognitive stimulation can be offered in an individual or group session and aims to stimulate and engage persons with dementia

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in a person-centred manner. This treatment type is oriented towards the “personhood” of the individual living with dementia and often employs reality orientation techniques (using reality orientation boards, calendars, journals, videos, pictures of family members) to stimulate mental activity [17]. This type of rehabilitation attempts to connect information using themes, such as past experiences of the client, food or other sensorimotor activities. Reminiscence strategies are used to attempt continuity between previous experience and the individual’s current environment [17]. Cognitive stimulation makes use of strategies that are based in implicit learning, and the range of activities is designed to enhance general cognitive and social functioning [28]. Similarly to cognitive rehabilitation, there is a focus on preservation of cognitive skills that are intact for as long as possible and activities are aimed at strengthening these cognitive abilities and forming social relationships. Examples include physical games, sounds (music) and food, being creative, categorizing objects, orientation, and number and word games [29]. In sum, cognitive stimulation attempts to focus on engaging broad cognitive and social domains in order to stimulate mental and social activity for clients with moderate to severe dementia [29].

Though specific subtypes may be altered to best suit the individual’s level of decline, all rehabilitation programs for individuals with dementia should focus on five main domains: (i) memory enhancement, (ii) social communication, (iii) self care skills, (iv) arrangement of physical environments for optimal functioning and (v) increasing physical activity [30]. Memory enhancement (domain 1) is especially important since there are currently no treatments to reverse the neurodegenerative effects of dementia. Rehabilitation should focus on enhancing memory through behavioural strategies and

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include the use of external memory aids, spaced retrieval and errorless learning methods. The second rehabilitation domain surrounds social communication due to the fact that many individuals with dementia experience aphasia (the inability to speak or comprehend language) as the disease progresses, though individuals may vary in severity. An important goal for rehabilitation then is to ensure that individuals have the opportunity for social interaction and use of language for as long as possible. When this is no longer possible, ensuring the environment has effective communication between individual and caregiver is important as it helps lessen overall dependency [17]. The third rehabilitation domain is to promote self-care skills, which include promoting independence in activities of daily living. Modelling and reinforcement from practitioners and caregivers have been shown to improve these abilities in persons with dementia, and in such a large goal of rehabilitation is to promote independent execution of such activities in order to foster a sense of autonomy and self-efficacy [17]. The fourth rehabilitation domain is to optimize the physical environment. Any restructuring of the environment that lessens the burden of disability and maximizes the current functioning of the individual is important for rehabilitation in this population. Suggestions include enhancing safety, increasing socialization and directing attention and improving orientation towards manageable tasks [30]. Lastly, rehabilitation should promote participation in physical activity for those with dementia. Increasing participation in physical activity has been linked to increased cognitive function, and although persons with dementia may experience functional limitations in performing physical activities, participation can increase independence by increasing strength and balance. Research suggests the implementing physical activity for persons with dementia is both feasible and beneficial [30].

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1.6 The Role of Informal Caregivers in Providing and Supporting Cognitive Rehabilitation

Successful cognitive rehabilitation necessitates a certain level of collaboration between healthcare teams and PWD caregivers. Caregivers are often required to either attend the rehabilitation sessions with their loved ones and/or follow up with cognitive rehabilitation strategies at home to improve retention and increase practice and familiarity with the tasks. For example, the use of external memory aids is common during cognitive rehabilitation and caregivers often use this strategy at home. These environmental modifications may include medication reminders, checklists and calendars. Learning how to use these aids and implementing them at home is an important part in successful cognitive rehabilitation implementation [31]. Caregivers are sometimes instructed to participate in rehabilitation interventions with their loved ones after being given verbal instructions and demonstrations during group sessions with healthcare providers. For example, caregivers who attend group sessions are almost always instructed to repeat some exercises at home and in between group sessions at least three times a week [32] in order to maximize the benefits. If a client is receiving one hour per day of cognitive stimulation administered by healthcare teams, the expectation is that this training will be facilitated by the family caregiver in the home as well as much as possible. Caregivers are often also responsible for tracking neuropsychological and behavioural symptoms using journals in order to report back to healthcare teams [33].

Caregivers who participate in cognitive rehabilitation interventions with their loved ones may experience benefits from their participation, including improved social

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relationships with their loved ones as compared to those caregivers who do not participate [34]. Moreover, participation in cognitive rehabilitation interventions by caregivers did not negatively impact perceived burden or depressive symptoms of caregivers. In sum, active participation from the caregiver in cognitive rehabilitation is important in contributing to the overall success of the program and seems to have minimal impact on the level of burden or depressive symptoms of caregivers [35]. With the collaborative work of healthcare providers and informal caregivers, clients with dementia may increase their access to and benefits from participating in cognitive rehabilitation programs across the Central East LHIN.

1.7 Quality of Life Improvements from Cognitive Rehabilitation

This section seeks to provide some empirical evidence for the improvements in quality of life that cognitive rehabilitation subtypes provide. Previously, cognitive programs had been used to help alleviate deficits in other clinical populations such as schizophrenia, traumatic brain injury and stroke patients [30]. Therefore, it is a reasonable next step to begin to apply its techniques to the dementia population. The various sub-types of cognitive rehabilitation programs have been explored by researchers concentrated in the previous ten years. The benefits these programs in improving quality of life has shown some initial positive support for its usefulness as a non-pharmacological intervention for persons with dementia. A review of some of these studies are presented below.

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1.7.1 Cognitive Training

This section seeks to provide recent empirical literature providing support for some initial benefits of cognitive training for improving quality of life for individuals with dementia. Seven uniquely conducted studies with a variety of implementation methods for cognitive training are presented below. To begin, Tsantali and Economidis [12] conducted a combined cognitive rehabilitation and cognitive training program that was provided as a case study to an individual suffering from mild Alzheimer's disease. The main purpose of this case study was to understand the long-term effects of the intervention and if the training program would delay entry into institutional care living. The training program targeted specific cognitive abilities including naming, recall and coding. Training was delivered over 4 months, 5 times a week for 90-minute sessions with a cognitive neuropsychologist. Strategies included both errorless learning and extended rehearsal, and the use of the neuropsychologist was slowly diminished as the client progressed. After training, the participant showed no declining scores in any of the memory tests given suggesting no cognitive deterioration. Recall, verbal fluency, and performance in activities of daily living all showed improved scores at follow up of 5 years. This case study is important because though acetylcholine targeted drugs may have limited effectiveness after 1-2 years of administration, whereas longitudinal cognitive training may provide compensatory cognitive skills for at least 5 years, perhaps delaying entry to long term care facilities, allowing the client to live in the comfort of their home subsequently improving their quality of life [12].

Changes due to cognitive training can also be seen through the use of functional magnetic resonance imaging (fMRI). 15 individuals with early stage AD received 8-

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weekly 1-hour individualized cognitive training interventions which included learning strategies for elaboration and rehearsal of new information. After the training, brain activation changes were recorded during a face-name learning task. Increased activation was seen in the left frontal cortex during a recognition task in the experimental group, whereas the control group showed declines in activation; indicating support for the cognitive treatment. In addition to this finding, those in the experimental group rated their performance and satisfaction on ADL's was higher than the control group. This study offers a unique view of brain plasticity that surpasses behavioural outcomes alone and provides support for the improvement of quality of life utilizing cognitive training interventions for those with early stage AD [36].

In the dementia client's home, 15 mild AD participants were each given a cognitive intervention to relearn an ADL using the same techniques of errorless and spaced retrieval learning. In the home setting, the training program was tolerated well and reduced dementia symptoms (lowered behavioural and psychological symptoms (BPSD) such as decreased delusions, increased motor movements). The importance of this study is that it shows that more than cognitive outcomes should be measured in order to consider the range of benefits cognitive training may have for persons with dementia (PWD) [37]. Thus, not all cognitive training must be delivered in a clinic or experimental setting in order to provide benefits in improving quality of life [38].

Though the previous three studies have been conducted with face to face training, training over the phone, commonly known as "telehealth" interventions have also been used to deliver cognitive training especially due to its unique opportunity to meet the needs of those living in rural communities [39]. In addition to this, receiving care at home

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is shown to be more beneficial than in a clinic for post-stroke patients resulting in less dependency and lower mortality, and it has been hypothesized that telehealth interventions may be generalizable to the dementia population. An early stage dementia sample ($n = 6$, average age of 71) were provided cognitive training via telephone and a control group was provided the same training but face to face. This training targeted specific cognitive domains including verbal processing, recognition and context identification using 2 weekly sessions, 1 hour long for 3 months. Researchers concluded that the Mini Mental State Examination (MMSE) scores of both groups improved compared to baseline, in addition to increased language abilities, stabilized verbal memory and recall [39].

Berhamaschi [23] has also suggested that single rounds of cognitive training may not be as beneficial as providing continuous cognitive training. For example, 5 months of cognitive training focused on time and space orientation, reasoning and recall exercises was administered to 32 individuals with mild dementia in a randomized control trial. After 5 months, half of the participants stopped the training and the other half continued with weekly training until 1 year where both groups were then compared. Scores on various neuropsychological tests have indicated that for those in the continuous training group, verbal fluency scores and clock drawing performance improved as compared to controls [26].

Combination cognitive programs have also been conducted, such as combination therapy with galantamine and ambulatory cognitive training, meeting one of the main domains of rehabilitation which is to include a physical activity component. This type of cognitive training includes a physical, occupational and speech component that lasted 1-2

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hours, 1-2 times per week. After the training was conducted, a follow up at 3 months showed improved Mini Mental State Examination and Frontal Assessment Battery improvements. In addition, apathy scores in the training group were also shown to improve, suggesting that cognitive training also benefits those with dementia emotionally and in such contribute to an improved quality of life [40].

Cognitive training can also focus on improving specific cognitive skills associated with ADL's in persons with dementia. For instance, 20 participants with mild AD were trained on an ADL using errorless and spaced retrieval learning strategies in a 6-month randomized cross over control study. Individuals who received the twice per week in-home training maintained increases in global cognitive functioning on their ADL at a follow up of three months [41]. Being able to participate in activities of daily living has a positive correlation with quality of life [42], providing an optimistic outlook for cognitive training.

1.7.2 Cognitive Rehabilitation

This section aims to present recent literature on cognitive rehabilitation studies being conducted with dementia populations that provide support for the potential improvements in quality of life from this treatment, and to assist with the distinction between the various subtypes of cognitive rehabilitation and its unique goals and outcomes. In a study conducted by Bahar, Fuchs, Clare and Woods [34] cognitive rehabilitation has been directly compared to reminiscence therapy, cognitive training and care as usual in those with mild AD. This population of AD participants were randomly assigned to a cognitive rehabilitation program, in which training targeted specific domains of attention and executive function. Rehabilitation was individually tailored to

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an activity of daily living using errorless learning strategies. Each intervention was delivered for 3 months, with maintenance or continued training being delivered for 21 months depending on randomization of groups. Rehabilitation proved more beneficial than reminiscence therapy, with participants having lowered rates of functional decline and lowered behavioural symptoms of dementia. In addition to effects on the person with dementia themselves, caregiver burden was also reported as lower in these two groups improving quality of life for caregivers [34]. Moreover, institutionalization was delayed by an average of six months in those who received cognitive rehabilitation programs, allowing clients to live more comfortably in their own homes [43].

1.7.3 Cognitive Stimulation

In cases where an individual has progressed to a moderate or advanced stage of dementia, cognitive stimulation may be more beneficial. Though this has been supported for those in the early stages of AD, it is very rarely used in this stage of dementia [44]. Cognitive stimulation most often applies to an advanced dementia population. For instance, cognitive stimulation has been applied to those living in residential care. In a recent study, those with advanced stage dementia were given Spector's Cognitive Stimulation Activities in a single blind randomized control trial, and found that scores on the Alzheimer's Disease Assessment Scale and MMSE were improved compared to controls [17].

Those living in nursing facilities have also been shown to benefit from a form of cognitive stimulation known as Saïdo learning. This includes stimulation of working memory, reading and writing for 5 days a week. However, in this case the cognitive stimulation was delivered by staff and community volunteers rather than a trained

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neuropsychologist. In comparison to the control group, the experimental group showed improved MMSE scores. In addition, this study found transfer effects, which meant that even specific cognitive domains that were not directly trained by the cognitive stimulation improved [45].

Moreover, qualitative case studies of the clients receiving care speak to large improvements in quality of life and mood improvements for persons with dementia [45]. Only recently has there been interest in investigating cognitive stimulation in both residential populations and community dwelling service users. 236 persons with dementia were randomly divided into a stimulation and maintenance therapy group or a stimulation alone group by Robinson and colleagues [46]. The group that received maintenance cognitive stimulation had increased performance on ADL in addition to scoring higher on the MMSE. Unfortunately, this study mixed with those using community services and those living in residential care, so no conclusions can be made about the benefits of these programs on these populations independently [47]. In summary, cognitive stimulation with varying lengths and intensity seems to be beneficial for more advanced dementia populations not only in enhancing cognition, but also in its effects on improving quality of life, enhancing communication and lessening caregiver burden [48].

1.8 The Importance of the Healthcare Workers Perspective

Understanding the needs of the healthcare workers will underlie the feasibility of implementing cognitive rehabilitation in our local communities. Research suggests that empirical evidence uptake requires both personal, professional and organizational contextual factors [49]. As mentioned previously, adherence to clinical practice guidelines (CPG's) for dementia has been low. To increase the implementation of these

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CPG's, healthcare providers can be viewed as stakeholders whose ideas, needs and expectations should be incorporated into the development of these guidelines. By engaging the stakeholders who are to implement these guidelines, awareness and uptake should logically increase, leading to improved quality of care for those with dementia and other neurological conditions [50]. Treatments for dementia and its associated declines in cognition are interdisciplinary and multifaceted. Due to their complex nature, understanding and evaluating these interventions is a necessary component to improve the health of this population.

Knowledge of the capacity for healthcare workers to implement cognitive rehabilitation and their experiences and beliefs surrounding this particular treatment are required to avoid the risk of the intervention being inadequately implemented. In some fields such as traumatic brain injury and schizophrenia, implementation science is being used to understand how rehabilitation goals are being addressed with clients from a healthcare workers perspective. Qualitative studies have been done with healthcare staff to address why implementation of various treatments is low, similarly to what is being experienced with dementia. For example, despite national guidelines suggesting cognitive behavioural therapy (CBT) for those with schizophrenia, implementation levels are low. A qualitative analysis was done to measure the capacity of healthcare workers in delivering CBT to their clients. Though the healthcare workers had positive attitudes overall to the CPG's in theory, specific barriers such as workload and unavailable staff members hindered implementation. In order to improve accessibility to these services these barriers must be addressed [51]. Similar barriers have been seen in studies addressing traumatic brain injuries and rehabilitation. Therapists were asked their

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opinions regarding community-based rehabilitation, and found barriers with collaboration with other staff members, lack of education and behavioural difficulties [52, 53]. Studies have been completed with stroke rehabilitation, addressing the “practice change” literature, a related term to the “know-do” gap. Staff workload and attitudes again arise as main barriers to implementation [53]. Suggestions were made to improve the rehabilitation implementation in this population based on qualitative interviews which is something we hope to replicate with our clinical populations’ unique challenges and contexts.

1.9 Interest for and Cost of Cognitive Rehabilitation

Health care workers themselves show an interest in improving their level of training and knowledge in providing alternative care methods such as cognitive rehabilitation (66% of primary care workers). Though there may be a small percentage of those who disagree with the implementation of complementary or alternative medicine in primary care (6% of primary care workers), the overwhelming majority believe there is the potential for the integration of these therapies to help save costs (70% of primary care workers) [54]. The cost effectiveness of implementing cognitive rehabilitation programs for persons with dementia have been supported in the literature. Knapp and colleagues [55] provided cognitive stimulation to those individuals with dementia and found that improvements in individual client’s quality of life and cognition improved without increasing the costs associated with care as usual [55]. Other community implemented therapies such as occupational therapy have also been studied and are seen to decrease care costs and improve independence [56]. Though initially costly, the cost of implementing rehabilitative care for persons with dementia may be offset by savings in

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long term care entries, prevention of excess disability and management of behavioural and psychological symptoms such as depression [57] .

A study investigating the experiences of service providers implementing Cognitive Stimulation Therapy (CST) has been conducted in England [58]. Their respondents included support workers, nurses, occupational therapists and clinical psychologists. Current healthcare workers interviewed believed that delivering cognitive stimulation therapy to clients with dementia fit well in current models of care and was in line with the goals of their services. Participants acknowledged the importance of training in order to translate CST into practice. Access to resources and tools was an important facilitator from the health care workers perspectives in administering CST to dementia clients. The authors of this article noted an urgent need for research to investigate the views of other service providers and service commissioners as to why cost effective non-pharmacological methods such as CST are not being made available to the dementia population [58]. A recurring theme throughout cognitive rehabilitation literature suggests that healthcare workers and clients with dementia experience many barriers to accessing alternative methods of care such as cognitive rehabilitation, one of which is a lack of confidence from healthcare providers [59].

1.10 Capacity Barriers in Cognitive Rehabilitation

There are many existing factors that promote and inhibit the implementation of complex interventions such as cognitive rehabilitation. Both cognitive rehabilitation and traditionally recommended pharmacological therapies have limitations and barriers to their implementation. Although traditional pharmacological treatments have been routinely prescribed for person with dementia, an important barrier in their benefits lies in

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the fact that pharmacological treatments for persons with dementia may be difficult due to client's ability to adhere to medication routines. Given the population expected to take this medication are experiencing cognitive decline it becomes less likely that they can take medication reliably, which could negate the potential benefits of medications . For example, community living elderly individuals who were divided in groups of low cognitive function or high cognitive function were asked to take 2 vitamin C tablets per day. Individuals with low cognitive functioning had a relative risk of 4.1 of non-adherence compared to those who were cognitively high functioning [60]. In addition, side effects of medication can act as a deterrent to adherence.

Given this possibility, cognitive rehabilitation in combination with pharmacological treatments may provide limited benefits such as slowing of disease symptoms or progression and improving quality of life. Combination therapies such as concurrent drug and behavioural methods have been evidenced to provide better outcomes for persons with dementia than medications alone and show promising results [17]. Given the increasing evidence that supports cognitive training, rehabilitation and stimulation in those with AD, the 2011 World Alzheimer's Report stated that cognitive rehabilitation interventions and stimulation programs should be 'routinely offered' [47]. Unfortunately, little is known about if this recommended program is being implemented in both community and residential facilities. A possible explanation as to why rehabilitation in this population may be thwarted is that many persons with dementia may face barriers in accessing care. Barriers to treatment may include a lack of capacity (lack of knowledge, funds, availability and/or time), sociodemographic barriers and stigma towards those with dementia.

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1.10.1 Lack of Capacity Barriers

Lack of capacity can be seen as the consistency and availability of cognitive rehabilitation therapies in dementia care which is often poor [48] and differing not only in their location, but also in their goals and eligibility. This makes quantitatively understanding an already inconsistent therapy even more challenging [61]. A common belief is that the lack of participation in cognitive activities by persons with dementia is because they lack the motivation or capacity to complete them [20]. Many individuals with dementia and their caregivers may feel hopeless in regaining cognitive abilities and in such feel that cognitive rehabilitation is too labour intensive and subsequently become apathetic. However, adherence to cognitive rehabilitation regimes is possible with this population if they engage and remain involved and motivated. Strategies have been developed to maximize on these facilitating factors in the various fields of psychology, occupational therapy and nursing [17].

In addition, where an individual with dementia's lives may undermine their capacity to participate in a cognitive rehabilitation program. Though this has not been investigated with cognitive rehabilitation specifically, living in rural locations has been shown to hinder participation in cardiac rehabilitation programs, as participants living in rural areas attended significantly less sessions than those living in urban area [62]. Of the studies being conducted on elderly populations, similar patterns hold true. Those who live in rural areas may face even more unfavourable circumstances as in Ontario, Canada urban or rural living accounts for 9-20% of variance in service use for the elderly [61]. As such, investigating geographical differences in urban and rural differences is important.

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1.10.2 Socio-Demographic Barriers

Socio-demographic factors can also present a challenge in accessing rehabilitation services. For instance, it is robustly supported that socioeconomic status, particularly income and education, have a large impact on health. As socioeconomic status of the population increases, health generally increases [63]. In fact, 87- 92% of the variability in health status of populations can be explained by their socioeconomic status, with two of the strongest contributors being education and income.

As such, income plays an important role in understanding dementia risk. Recent studies have shown that dementia rates vary in a reliable manner based on socioeconomic status, particularly with those in low income brackets being diagnosed with dementia at higher rates [64]. The relationship that income has with dementia is particularly interesting because Canada implements a national Medicare plan. Yet, income remains a significant factor that affects the health status of the dementia population. Income is an important factor when considering accessibility and affordability of treatment, respite and caregiving programs. Rehabilitation services can often pose a high expense for both the costs of enrolling in the treatment and transportation to the clinic or community center providing the treatment. Though few studies have been done with dementia populations, conditions such as traumatic brain injury (TBI) and cardiac rehabilitation have been studied to understand their link with income. With the TBI population, income has been shown to be a predictive factor who successfully re-integrates TBI patients back into the community after injury [65]. Low employment status, self reported income adequacy and occupational class have also been found to contribute to rehabilitation participation restriction in those over 50 living in the community in those with TBI [66].

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Education also plays a role in understanding dementia risk. Individuals who obtain lower education levels have been shown to have lower participation rates in rehabilitation programs [67]. In cardiac rehabilitation, those who had low participation rates in rehabilitation sessions were likely to be unemployed, have lower levels of education and lower income than those who had high participation rates [68]. When systemic barriers to rehabilitation such as those presented in sociodemographic measures are combined with the participation restriction that already occurs due to cognitive impairment, the access, affordability, and awareness of cognitive rehabilitation are all important variables to consider. Therefore, understanding income and education's role not only on the outcomes of dementia rehabilitation but also in access, affordability and awareness of these treatments in the community level is important.

1.10.3 Additional Barriers for Healthcare Providers

Even if practitioners believe in the benefits of an intervention, they may face barriers to implementing it. For instance, nearly 85% of nurses asked in a convenience sample agreed that music therapy (used often in cognitive stimulation programs) would be beneficial for persons with dementia. However, only 30% reported that they implemented this treatment in practice. This was due to the fact that the nurses lacked knowledge, resources and time to do so effectively [69]. Lack of access and fragmentation of resources for the persons with dementia population has been reported by other physicians [70] which only further contributes to difficulties in care. When fragmented community resources and staff lacking the resources, time and/or training is combined with declining participation in cognitively stimulating activities by persons

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with dementia who are over 65 years of age, poor outcomes for these individuals are likely to occur.

No research has been done to date on barriers of implementing cognitive rehabilitation to PWD from the healthcare providers perspective, however there is plentiful research of common barriers healthcare providers experience when trying to implement other various evidence-based therapy models to clients with dementia. For example, evidence-based occupation therapy interventions for PWD are often poorly translated to clinical practice due to lack of confidence and competency, difficulties in finding time for more complex and intense interventions and inconsistencies in eligibility criteria for implementing this program with clients. Additional barriers included the lack of knowledge surrounding occupational therapy interventions and lack of available trained occupational therapists [71].

An additional barrier to cognitive rehabilitation for persons with dementia may come from a lack of support from health care providers themselves. In combination with poor expectations from families and the person with dementia themselves [72], lack of complete support from a healthcare team may make cognitive rehabilitation hard to access. Healthcare practitioners' beliefs may have an especially prominent effect on cognitive therapy accessibility for those who are living in LTC. If the practitioners do not support cognitive therapy for those with dementia, it is likely that these beliefs are represented in the care of those they supervise. For example, those who live in nursing or residential care homes can benefit from cognitive stimulation but their participation is generally hindered [73]. This may be due to the fact that some staff may hold unjustified

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beliefs in which persons with dementia are unable to benefit from any type of interaction or treatment provided by them, and in such it is not offered [74].

1.11 Clinical Practice Guidelines and Cognitive Rehabilitation

The Canadian Medical Association presents Clinical Practice Guidelines (CPG's) for many neurological conditions such as traumatic brain injuries, Parkinson's disease and dementia. Clinicians who follow and use the recommendations suggested in CPG's consistently deliver more positive outcomes to their clients [75]. Current CPG's for dementia combines all the various subtypes of dementia into one, and their purpose as guidelines are to provide clinicians with suggestions and tips for the management of dementia. CPG's are meant to optimize patient care, improve quality of life and are informed by the current empirical literature. The CPG's for dementia suggests the importance of management through primary care, however acknowledges that there may be times that community-based agencies can provide support in addition to primary care [58]. These community-based agencies play a fundamental role in maintaining optimal levels of functioning in persons with dementia through non-pharmacological interventions such as cognitive programs. In fact, current CPG's suggest that pharmacological treatment alone will provide limited value to the client with dementia, and make specific recommendations for cognitive programming activities to help manage behavioural and psychological symptoms in clients and to improve quality of life [58]. These include suggestions such as participating in "healthy brain activities, such as regular exercise, word games and socialization" [58]. Other non-pharmacological methods are recommended in the CPG's for dementia [76], including music therapy, sensory interventions (common in cognitive stimulation, a subtype of cognitive

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remediation programming) and increasing involvement in enjoyable activities (a main component in all subtypes of cognitive remediation). Many of these recommendations suggested in recent CPG's are key components of the various subtypes of cognitive remediation programs described in the following section.

However, adherence and awareness of CPG's in clinical practice has been found to be low for neurological conditions such as dementia and traumatic brain injury [75]. Recent literature suggests that healthcare workers are experiencing barriers to implementing CPG's, including a lack of awareness and disagreement with the content. Clinicians must also feel that they have the required competencies to complete the CPG's [75] and if these conditions are not met, uptake of CPG's will be limited. In order to overcome healthcare provider implementation barriers, a study must be conducted to explore the practical barriers that HCP stakeholders are experiencing in their own contexts and places of work. Without a comprehensive understanding of these barriers, strategies to implementing successful cognitive rehabilitation may never be reached. The present study will help inform which barriers are pertinent to dementia healthcare workers trying to administer cognitive rehabilitation programs in order to facilitate CPG uptake and provide cognitive rehabilitation to clients who may experience benefits to their quality of life.

1.12 Capacity Building in Cognitive Rehabilitation

Many of the barriers surrounding the lack of capacity from both the healthcare provider and the client with dementia themselves addressed above will continue to contribute to the slow uptake of cognitive rehabilitation CPG's and may stall progress that the national Dementia Strategy aims to achieve in our communities. As reviewed

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above, healthcare providers already understand the need for additional access to resources, tools, training and knowledge that is necessary for improving care of their clients. Thus, capacity building among healthcare practitioners must be addressed and understood in the context of cognitive rehabilitation. Capacity can be defined as “the development of knowledge, skills, commitment, structures, systems and leadership to enable effective health promotion programming” [77]. Capacity building among healthcare practitioners has many aims, including improving knowledge and skills, expanding support and infrastructure and developing partnerships in communities to advocate for and implement health promotion programming [77]. Capacity building interventions aim to improve HCP’s individual and organizational practices to provide increasingly relevant, sustainable and empirically informed care to the clients in their local communities. The main components of capacity building are continuous training and knowledge development, confidence and self-efficacy, access to resources, interdisciplinary collaboration and organizational support as well as system readiness [78].

Knowing what is required in order to achieve successful capacity building necessitates an understanding of which areas healthcare providers have or do not have capacity across the Central East LHIN when it comes to providing cognitive rehabilitation to dementia clients. Understanding which areas our healthcare providers do or do not have capacity will assist in implementing the aims and goals of capacity building for this population. Moreover, increasing demands on HCPs and their organizations in meeting the upcoming dementia crisis will make evident possible areas of insufficient preparation. When HCP’s are asked to self-assess their current level of

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public health competency, results suggest they understand the large gap that exists between their own level of mastery and the level of mastery required for effective public health practice implementation [79]. This gap is commonly referred to as the “know-do gap”, which is discussed below.

1.13 The Know-Do Gap in Dementia

Complex medical problems such as the various types of dementia often require complex levels of care provided across many disciplines and teams. A challenge across various domains of healthcare is the challenge of the “know-do” gap, which provides a bridge between what is known in the empirical research and what is truly implemented in clinical practice. On average, it takes nearly two decades for less than a quarter of research to be translated into clinical practice [80]. Simply because research is published does not automatically confer its use in clinical practice, as healthcare workers actions in clinical practice are largely derived from know-how of routines. This delay negatively impacts the community’s needs for effective solutions and treatments for various medical conditions [80]. Various barriers must be considered that impede the know-do gap. For example, clinicians and their colleagues may lack the knowledge in implementing rehabilitation strategies with their client populations especially when faced with institutional and organizational barriers presented above. Some implementation science suggests that the phrase “know-do gap” also encapsulates the idea of a “know-how” gap. Professional factors such as those suggested in the know-how gap are also important to rehabilitation implementation. It provides little value to have CPG’s discuss the importance of non-pharmacological interventions such as cognitive programs if those guidelines are poorly understood by HCP’s. Cognitive rehabilitation programs are

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inherently multi-professional, and in such require collaborative professional interactions in order to be implemented successfully [80]. By addressing some of these “know-do” gap features in the present study, we will contribute significantly to closing the know-do gap in cognitive rehabilitation for those with dementia.

1.17 Significance of the Research

The literature review provides a broad rationale for the importance of cognitive rehabilitation for individuals living with dementia. However, to my knowledge, no research has been conducted in Canada that has investigated how cognitive rehabilitative services are offered to those with dementia in the community, barriers to accessing care, and healthcare practitioner’s experiences and perceptions surrounding their capacity to provide cognitive rehabilitation. If implemented, cognitive rehabilitation allows the individual to experience increased self-esteem, resilience and improved morale and could potentially avoid unnecessary admission into the long-term care facilities and improve overall quality of life [36]. Future research needs to understand how these rehabilitative services are being offered and recommended by healthcare providers if at all in order to successfully implement cognitive rehabilitation interventions. The healthcare workers viewpoint provides an embedded sense of insight and perspective that will ensure recommendations made are congruent with the current community needs. This will allow recommendations and policies to be tailored to their individual work environments to more successfully implement these programs and appreciate the benefits in providing cognitive rehabilitation to persons with dementia [84].

In order to successfully implement these services, researchers must a) understand if these services are being offered in the community, b) understand the accessibility or

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barriers to these services, and c) understand the current and upcoming capacity of these institutions and their healthcare workers in providing cognitive rehabilitation to persons with dementia. Until we understand the current scope of cognitive rehabilitation in Ontario, it will remain unknown what must be improved in order to offer effective and accessible rehabilitative services to these populations, and to promote the use of these services for those who are or will be diagnosed in order to delay institutionalization, improve quality of life and slow the progression of dementia. The findings from this study may help inform more successful rehabilitation program implementation and assist in lessening the disease burden on persons with dementia and their caregivers. Though cognitive rehabilitation has many benefits for patients, the next step is to ensure it is properly implemented on a wide scale [81]. This proposed study aims to address the “know-do” gap that exists between effective healthcare interventions and actual implementation in practice. Once implementation barriers and facilitators are understood, the methods that can promote change and dissemination of empirical research evidence can be used in healthcare systems. As stated by the Alzheimer’s Society of Canada [4], “improved care at every stage of dementia is an achievable goal”. As such, this study aims to address and contribute to a series of long and short term goals.

Short term goals:

1. Understand healthcare workers current understandings of capacity in providing cognitive rehabilitation to clients with dementia.
2. Understand the healthcare workers perspectives on barriers to implementation of cognitive rehabilitation with pertinent examples of contributory and impeding factors to success

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Long term goals:

1. Contribute to Canada's national dementia strategy which includes as one of its goals the delay of institutionalization by alleviating cognitive decline in any capacity, reducing the shortage in LTC beds across Canada.
2. Use what is learned from the qualitative analysis to inform current and upcoming clinical practice guidelines that is sensitive and congruent to the needs of the healthcare practitioners.
3. Close the know-do gap so that research on cognitive rehabilitation can be implemented into clinical practice and clients with dementia have access to the services that may be beneficial in a timely manner.

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Chapter 2. Methodology

2.1 Research Design and Procedure

To achieve the purpose of this study, a qualitative methodology with thematic analysis was utilized. The philosophical paradigm for this qualitative interpretive study was interpretivism, due to the fact that assumptions were made that participants' views of reality are socially constructed and because it was well suited for the naturalistic data collection strategy in this study [85].

The choice to use the thematic analysis approach was due to the fact that a review of the literature in this field has shown that most research to date on this topic had been experimental in nature. This thematic method has not to my knowledge been used to investigate health care workers capacity for providing cognitive rehabilitation programs and to investigate the state of the field of cognitive rehabilitation in a particular region. This choice of method allowed for a better understanding of the topic by beginning to understand why and how cognitive rehabilitation is or is not being offered in the LHIN.

Moreover, cognitive rehabilitation is a new term and there continues to be a lack of consensus surrounding delivery, methods and training in health care providers who deliver these services [86]. As such, investigating health care workers use and knowledge of these concepts will provide assistance to the research community as we continue to attempt to explore deeper into the topics such as cognitive rehabilitation with participants. Using the thematic analysis framework in investigating cognitive rehabilitation as a first step can provide a foundation for the future exploration of this study phenomenon. The study population included a wide range of healthcare providers working within the Central East LHIN (e.g. Registered Nurses, Occupational Therapists, and Recreation

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Therapists) who oversee or deliver cognitive rehabilitation services in their respective places of employment. A multi-stage sampling approach was used to collect data across two data collection points, entitled “Phase One” and “Phase Two”. Phase One was an initial qualitative questionnaire conducted with a total of 43 participants, and Phase Two consisted of a follow up one-on-one interview with 6 key informant stakeholders. The sampling frame included individuals working across the Central East LHIN who provided or oversaw cognitive rehabilitation services in their respective institutions.

Phase One of the multi-stage sampling approach involved the participants who completed an open-ended qualitative questionnaire. The purpose of the qualitative questionnaire was to invite participants to answer a series of open-ended questions in order to provide a description of some of the current attitudes and beliefs of healthcare practitioners in the Central East LHIN regarding their capacity for cognitive rehabilitation. An open-ended questionnaire method was chosen due to its economic and time advantages for the purposes of data collection [87]. The questionnaire was conducted cross-sectionally as it aimed to draw a sample of health care providers in the Central East LHIN at one time period and attempted to describe characteristics of this group of individuals and to gather preliminary information on the conceptualization of cognitive rehabilitation in an overall context [88].

Phase Two of the multi-stage approach involved a qualitative interview that served to clarify questionnaire responses and provide additional information with respect to cognitive rehabilitation. To recruit participants for this phase of the study, a maximum variation sampling approach was used from the pool of participants who completed the questionnaire in Phase One. Maximum variation sampling consists of a conscious effort

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in recruiting a diversity of stakeholders/key informants for the one-on-one interviews, which allowed for a more in depth understanding of the phenomenon at hand. This approach allowed me to sample research participants that could answer our targeted research questions from varying informed perspectives. The open-ended responses through qualitative interviews were used to explain and elaborate participant's original survey responses and offer insight into the convergent and divergent results. The purpose of the two-stage sequential data collection approach is to complement the survey responses with the data collected from the follow up interview to achieve a better understanding of the study phenomenon.

2.2 Phase One: Questionnaire Administration

The online questionnaire was completed within a three-wave administration procedure to ensure a high response rate [87]. First, an invitation email (See Appendix A) was sent to participants by our community organizations coordinator. This letter served as an advance notice that the questionnaire would be administered in the specified timeframe and an informed consent sheet was attached for their review (See Appendix B). One week later, the actual questionnaire was administered via email, with a link to complete online using Survey Monkey (See Appendix C and D). The third communication with participants included a follow up notice 2 weeks after the questionnaire had been sent for those who had not yet completed the questionnaire (See Appendix E).

2.3 Phase Two: Key Stakeholder Interviews

To address any potential gaps in the questionnaire responses, 6 key informants were recruited using maximum variation sampling from the questionnaire respondents

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and were invited to complete an in person interview. Participants were contacted via email or phone (See Appendix F) inviting them to participate once the questionnaire results had been obtained. Participants met the researcher in a location that was convenient for both members. The participant was given an informed consent form (See Appendix G) to sign which provided an overview of the purpose and scope of the interview. Once the informed consent form was signed by the study participant, the interview was administered by the researcher using an interview guide. (See Appendix H). The interview guide included a series of questions with a focus on cognitive rehabilitation. The interviews were approximately 1 hour long and were audio recorded with participants' permission. The main objectives of the interview were to understand the current capacity regarding the practice of cognitive rehabilitation within the Central East LHIN, to understand the levels of compliance and perceived barriers to these services, to establish eligibility and program evaluation outcomes for these services and to understand the inter-professional nature of cognitive rehabilitation. After completing the interviews, the audio recordings were transcribed verbatim and used for subsequent data analysis.

2.4 Study Sites

In this study the online questionnaire targeted the current capacity of cognitive rehabilitation practices within 20 sites across the Central East LHIN, including Alzheimer's Societies (3 Sites), Primary Care Memory Clinics (5 Sites) and Geriatric Assessment and Intervention Networks (12 Teams). These sites were chosen in collaboration with experts in the field and were seen as the main sites throughout the Central East LHIN providing community dementia care.

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The choice to sample from multiple sites was due to the fact that health professional participants have reported in the literature that caring for a person with dementia involves overlapping roles of the various health care providers, each with their own professional perspectives [66]. As such, it was important to capture these varying perspectives in the current study using multiple data collection sites. This mixture of recruitment sites was chosen to ensure that the most commonly used facilities and/or services implementing cognitive rehabilitation in the community were captured in the study. Moreover, the sites were chosen to recruit participants from all seven sub-regions throughout the Central East LHIN as to not cluster the study findings from one particular sub-region. Within each recruitment site, our community organizations coordinator forwarded the Phase One invitation letters and links to the respective program directors who then passed these along to the individuals in their institutions who were responsible for administering rehabilitation services to the persons with dementia, whether they were nurse practitioners, occupational therapists or other healthcare providers. Participants were recruited through snowball sampling where email invitations were distributed through their institutions. Study respondents were individual(s) who were responsible in administering in full or part of the cognitive rehabilitation programs in their organization.

2.5 Study Materials

Informed consent forms were developed for the purpose of this study (See Appendix B and G) and were distributed to all participants prior to beginning the research study. These informed consent forms contained information regarding the design of the study, benefits and possible risks in completing the study, voluntary participation and information regarding how to contact the research team for results of research. Additional

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materials for Phase One included an open-ended questionnaire instrument designed for assessing the capacity and understanding of cognitive rehabilitation (See Appendix C). The questionnaire consisted of 24 questions that asked respondents to discuss any cognitive rehabilitation practices that were being recommended in their institutions including how often these were recommended and the amount of time clients spend participating in these activities or on a waiting list for these activities. The questionnaire also targeted the nature of cognitive rehabilitation services being offered, including asking respondents to report on the follow up procedure in implementing these programs, and specific strategies that are used within these programs. Lastly, the questionnaire attempted to investigate the health care providers' capacity to fulfill the needs of the current and upcoming dementia population.

For Phase two of the study, a detailed interview guide was developed (See Appendix H) in order to elaborate on answers provided in the questionnaire. Topics included barriers to rehabilitation services, definitions of cognitive rehabilitation and future directions and challenges. Participants in this phase of the study were asked to sign an informed consent form prior to completing the interview, just as they would have when participating in the online survey.

2.6 Phase Two Additions Post Questionnaire

Although fairly comprehensive, the initial Phase One questionnaire responses did provide a valuable perspective on additional research insights, there were perspectives and items that were added to the interview guide which had not been initially addressed in Phase One. This missing data from the survey lent itself to additions to the Phase Two interview questions in order to ensure additional perspectives that were missing from the

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Phase One questionnaire were captured in the stakeholder interviews. For instance, interview questions 3, 4, 5 and 6 were developed from initial survey responses that gave me a new perspective on important factors for cognitive rehabilitation implementation utilizing our healthcare workers unique perspectives. These questions addressed the availability of standardized assessment tools, organizational level competency promotion, educational training avenues and examples of challenging cases respectively.

2.7 Ethical Consideration

The overall goal of the study was to come to develop and understand a deeper, more precise and richer understanding of cognitive rehabilitation as it is experienced by healthcare providers in the Central East LHIN. A benefit to the research at hand is the possibility of obtaining a personalized understanding of HCP's capacity for cognitive rehabilitation from the service providers' perspective that those participating may not even have come to realize themselves. The proposed study aimed to surpass a natural attitude towards cognitive rehabilitation and bring about insightful knowledge surrounding cognitive rehabilitation as experienced by service providers in the Central East LHIN. The participants themselves may find benefit in having an outlet to discuss the challenges and successes of implementing or practising cognitive rehabilitation in their respective institutions, and may feel as they are contributing to the implementation of evidence-informed practices for dementia clients in their communities. From an ethical perspective, the use of a thematic analysis approach to data analysis is preferred due to the fact that it requires no participant deception [89]. Though interview and questionnaire research are subject to alterations in participants' memory whether due to decay, response or social desirability errors, self-reported behaviour can still provide an effective

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approach for understanding cognitive rehabilitation throughout the Central East LHIN. There were no unforeseen risks to participating in this study. The use of a community organizations coordinator to reach out to Program Directors in the various sites is twofold; firstly, it assisted us as researchers in making initial contact with various team members and secondly, since the coordinator does not have any employee relations with the participants, they have a lesser chance of feeling coercion to participate in the study.

2.8 Data Analysis and Interpretation

I carried out a thematic analytical approach to address both the questionnaire and interview data combined. This technique is commonly referred to as the “triangulation technique” and allows for the mixing of both data sets (questionnaire and interview) into generating overall themes.

The benefit of using a thematic analytical approach to analyze the study data is that this method is very flexible and provides a thorough and complex account of the data collected. It allowed for the identification of themes within and across my particular data sets from Phase One and Two. A theme for this type of analysis was defined as capturing “something important about the data in relation to the research question, and represents a level of patterned response” [90]. The aim in this type of methodology was to provide a rich account of the entire data set rather than focusing on one particular area of interest, and was conducted with an inductive or “bottom up” manner. This means that the themes that were identified are rooted in the data collected from participants and involved an in depth reading of the data, which is a main component of the six phases of thematic analytic approach.

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2.9 Reflexivity

It is important to note that I came to this research topic with some prior knowledge and analytic thoughts and interests. During my undergraduate thesis, I extensively studied cognitive enhancing drugs in undergraduate populations and thus I have always been interested in the possibility to enhance or modify cognitive abilities. Informing my initial readings included some assumptions that cognitive rehabilitation programs, though beneficial, may rarely be offered due to a general novelty of the concept in the literature and practice guidelines. Additionally, some initial thoughts about barriers to service offerings had been informed by the literature and can be seen as prompts in the questionnaire. From a broader perspective, I must also reflect on how my social background might have affected my research practice. As a woman, I identify greatly with the caregivers because I provide care to many individuals in my immediate family and have seen first hand the time and investment needed to adequately care for loved ones. I believe that my background helped motivate me to study how individuals who suffer from neurodegenerative diseases can receive optimal care to reduce caregiver burden. These reflections helped me become more aware of my own assumptions that contributed to the research process and the importance of practicing reflexivity throughout the research journey.

2.10 Integrated Analysis of Phase One and Two Data

During the data collection process, responses to the questionnaire and interview were actively read and a high level of immersion in the data was facilitated. As responses were submitted, I re-read them individually and subsequently considered them in the context of other responses in order to increase my familiarity with the data. A sustained

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effort was made to notice patterns if they were occurring in the data, and these patterns were recorded in an initial field notes document alongside any interesting responses in the answers. Outlier responses were also recorded in the field notes document to reflect on non-congruent response occurrences in order to further examine them. Any interesting thoughts, reflections or questions I had were also recorded in this document in order to ensure all my field notes were kept organized. Once the target number of responses was reached ($n=43$ questionnaire, $n=6$ for the interviews), data analysis began by reading through the data set in full and reviewing the field notes word document. As I moved through the questionnaire data set, I organized the whole data set into one of the three categories: Level 1 (complete data set), Level 2 (partial data set) and Level 3 (no useable responses – more than 95% blank) and categorized participant responses within these categories. Due to the amount of incomplete responses (Level 3, $n=13$) these questionnaire responses were omitted. All the interview responses once transcribed were used in the thematic analysis.

There was a total of 30 questionnaire responses and 6 interview transcriptions in which a recursive process of reading and re-reading the data as well as jotting down ideas of potential coding schemes was conducted as needed. After an additional round of active reading within the data set and the field notes document, I summarized participant responses by describing the key characteristics of their responses and highlighted recurring findings. This process allowed for identification of possible patterns across the data set that was shaped through reading and summarizing approaches as outlined in Step one of thematic analysis by Braun and Clarke [13].

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Step two of Braun and Clarke included the thematic analysis which outlined a more formal coding process. After the data familiarization process and development of an initial list of ideas about the data, initial codes from the data were produced in order to meaningfully organize data into groups. The codes that were developed refer to the “most basic segment, or element, of the raw data or information that can be assessed in a meaningful way regarding the phenomenon” [13]. Coding was conducted using a data-driven approach, and the entire data set was coded manually by the researcher. The data set was systematically reviewed, and the interesting aspects of the data alongside any initial patterns that were apparent were recorded. The highlighter method was used to identify potential patterns, and after they were identified initially, they were matched up with additional data extracts that supported the particular code. Step three of thematic analysis involved the search for overarching themes; which were considered throughout the coding process. Once the data was coded, the codes were sorted into a series of themes where connections or relationships between the codes and themes were beginning to emerge. Step four included a review of these themes, combining or collapsing them as needed. Step five included defining and naming the themes, which identified the “essence” of what each theme captures and lastly step six was producing the final report with the completed write up of the thematic analysis, which included the five major themes emerged from the integrated findings of both the questionnaires and interviews [68].

2.11 Rigor in Interpretive Qualitative Analysis

To ensure the rigor of this analysis process, Lincoln and Guba [91] provide criteria that can be used to make a judgement about the quality of the qualitative data

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collected. These include dependability and credibility. To address dependability, interpretive research is dependable if the researcher sees a similar phenomenon at different points in time of the data collection or analysis and comes to the same conclusion. This concept is closely related to reliability in quantitative research. In order to ensure that the data collected was dependable, the context surrounding the objects under investigation remained embedded, due to the use of a “bottom up” methodology as mentioned previously.

In order for the data to be credible, the inferences made from the data must be valid. This was done by organizing the study using a multi-stage method, using both the questionnaire and the qualitative interview data. The transcriptions were reviewed two times in full to ensure quality of the transcriptions were accurate. Notes on the reflexivity process and on methodological considerations were kept meticulously in the field notes document, in order for the data collection to be auditable. In addition, following the six phases of thematic analysis as presented by Braun and Clarke [13] ensured the methodological approach was clear, concise and replicable. Lastly, this research is not meant to be widely generalizable. The purpose of this research is truly about understanding the lived experiences of health care providers who are delivering cognitive rehabilitation programs and their understanding of the level of capacity to do so. The research is framed within this particular context and in such, must be understood and used this way. Although some of the responses may be applicable to other service providers, it is not the main purpose of this study to be widely generalizable as it is to provide a rich contextual understanding of capacity for cognitive rehabilitation from the perspectives of health care providers within the Central East LHIN.

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Chapter 2. Results

The purpose of this research study was to explore dementia health care providers' capacity for cognitive rehabilitation programs in the Central East LHIN. Our findings will aid in improving dementia capacity planning in order to create and maintain sustainable, relevant and empirically informed cognitive rehabilitation practices for those with dementia and their families.

Data were collected using a two-phase methodology. Phase one included a comprehensive open-ended survey detailing a number of aspects surrounding cognitive rehabilitation, including if it was offered by the healthcare provider or their place of employment, their strategies in implementing this type of care, their capacity for this type of care and barriers to clients receiving this type of care. The survey target was forty respondents which exceeded the minimum target number.

The second phase of data collection was a face to face interview that followed a comprehensive interview guide developed early in the study design phase. Within this interview, study participants described their outlook and experiences with cognitive rehabilitation practices including their personal perceptions and place of employment's capacity to offer these services throughout the Central East LHIN. Participants provided recommendations for cognitive rehabilitation in current dementia care as well as opportunities and areas for growth in the future of dementia research and care. The research findings presented below are based on the integrated analysis of the open ended qualitative questionnaire results (Phase One), as well as the semi-structured interview data (Phase Two).

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3.1 Characteristics of Study Participants

The participants of this study included 43 healthcare providers' responses from the Phase One questionnaire, spanning across multiple service sites through the Central East LHIN. Of those with complete data sets, the participants were strongly clustered within the local Geriatric Assessment and Intervention Teams, although multiple other service providers participated (Table 1). Catchment areas across the Central East LHIN sub-regions were evenly distributed, as noted in Table 2. Nurses and Occupational Therapists made up the majority of professional designations for the Phase One respondents (Table 3). Our participants suggested the use or recommended all three subtypes of cognitive remediation/rehabilitation programs with a strong emphasis on cognitive stimulation, as outlined in Table 4. Our participants had been working on average for 7.07 years with their current employers, and each reported they were working directly with clients with dementia ranging from 12 to 1000+ clients per month with an average of 227 clients per respondent.

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Table 2

Characteristics of Participants

| Employment Area | <i>n</i> |
|--|----------|
| Geriatric Assessment Intervention Network Team | 17 |
| Acute Geriatric Care | 1 |
| Hospital or Emergency Department | 6 |
| Alzheimer's Society | 1 |
| Community Health Centers | 4 |
| Adult Day Program | 1 |
| Total 30 | |

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Table 3

Catchment Area: Sub-Regions of the Central East LHIN

| Sub Region | <i>n</i> |
|--|----------|
| Durham North East & Durham West | 7 |
| Haliburton County and City of Kawartha Lakes | 5 |
| Northumberland County | 4 |
| Peterborough City and County | 7 |
| Scarborough North and Scarborough South | 7 |
| | Total 30 |

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Table 4

Professional Designations

| Current Role | <i>n</i> |
|-------------------------|----------|
| Registered Nurse | 6 |
| Management | 5 |
| Nurse Practitioner | 4 |
| Occupational Therapist | 9 |
| GEM Nurse | 1 |
| Social Worker | 2 |
| Personal Support Worker | 1 |
| Pharmacist | 1 |
| Undisclosed | 1 |
| Total 30 | |

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Table 5

Cognitive Remediation Services Provided or Recommended

| Subtype | <i>n</i> |
|--|----------|
| Cognitive Training | 4 |
| Cognitive Rehabilitation | 5 |
| Cognitive Stimulation | 7 |
| Offered Services Using Alternative Terms | 14 |
| Total 30 | |

Each participant in Phase Two who interviewed were self-identified as an individual responsible for administering or overseeing cognitive rehabilitation at their respective place of employment. For reporting purposes and to protect participant consent and anonymity, pseudonyms were created for each interview participant. Interview and questionnaire data all contributed to the 5 overarching themes presented below. Though some participants spoke at length about one or two themes in particular, other participants spoke broadly about all themes and in such, all participants' views are represented across the thematic analysis. While the themes are represented categorically, they necessarily overlap in some respects which highlighted the interconnected nature of all five themes. The coded data points from each participant was categorized where they fit most appropriately to ensure the participant's perspectives were described and presented in a meaningful and coherent way.

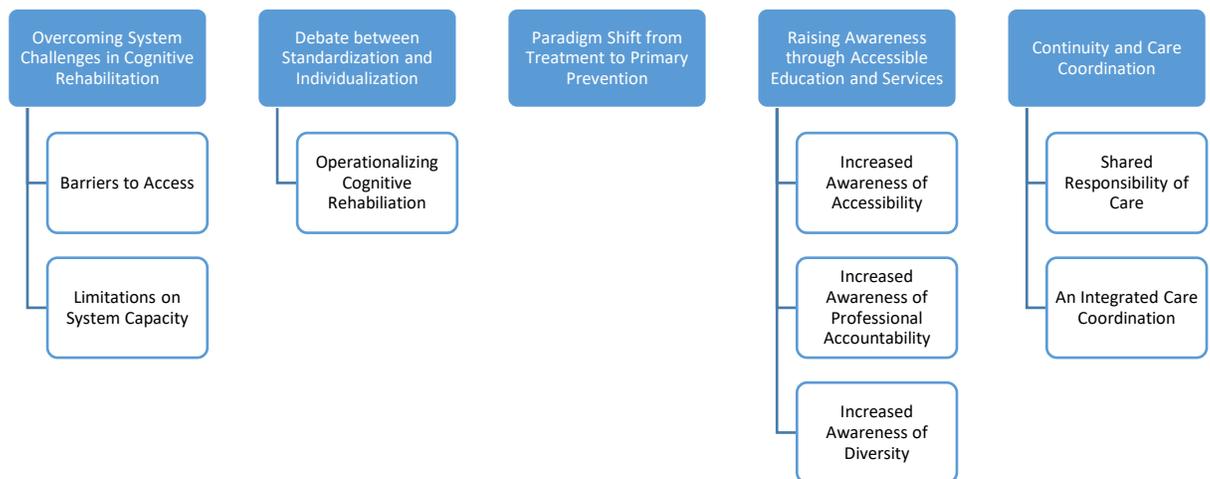
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3.2 Study Findings

Five main themes were represented in the data and are displayed graphically in Figure 3.

1. Overcoming System Challenges in Cognitive Rehabilitation
2. Debate between Standardization and Individualization
3. Paradigm Shift from Treatment to Primary Prevention
4. Raising Awareness through Accessible Education and Services
5. Continuity and Care Coordination

Figure 1. Themes and Associated Subthemes



3.3 Theme One: Overcoming System Challenges

Providing cognitive rehabilitation services comes with many challenges, most of which are shared across healthcare providers in the Central East LHIN. These barriers to

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access are provided from the perspectives of the healthcare provider as to why clients and potential clients are not receiving equitable access to cognitive rehabilitation services.

Healthcare providers also struggle to offer continuous, reliable services due to systemic concerns about capacity, which encompasses time limitations, funding limitations and a lack of resources needed to support cognitive rehabilitation practices. Subsequently, this overarching theme of overcoming system challenges in cognitive rehabilitation encapsulates two subthemes: (1) barriers to access and (2) limitations on system capacity.

3.3.1 Subtheme One: Barriers to Access

Healthcare providers were quick to list their main concerns about accessibility of their programs for their clients. Many revealed precisely the areas of concern which were consistently echoed across all interview participants. Both physical and psychological barriers existed for clients attempting to receive cognitive rehabilitation services. Physical barriers included: the time-consuming nature of the rehabilitation, difficulties with leaving the home including responsive behaviors from the client and transportation concerns, a lack of financial ability to afford program fees, and the web-based platform of rehabilitative services being inaccessible to clients and their caregivers. Psychological barriers included client and caregivers lack of understanding about the need of cognitive rehabilitation, perceived stigma associated with program participation and a sense of learned helplessness.

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Table 6

Barriers to Access for Clients

| Barriers to Access | Illustrative Quote |
|--|--|
| <p data-bbox="298 401 667 432">Subtheme: Physical Barriers</p> <p data-bbox="298 541 841 573">Transportation and Responsive Behaviors</p> <p data-bbox="407 982 732 1014">Lack of Financial Ability</p> <p data-bbox="354 1423 789 1455">Inaccessible Web Based Platform</p> | <p data-bbox="870 468 1401 793">“Transportation is a barrier – getting clients ready in the morning before going to the program is also a challenge to caregivers, especially if the clients have responsive behaviors”.</p> <p data-bbox="870 909 1409 1234">“We have heard many reasons for clients not going to cognitive programs, most are related to cost. Our program is not 100% funded, thus, there is a program fee which is the biggest barrier.”</p> <p data-bbox="870 1350 1414 1749">“I think we put everything online now, and I think that’s awesome. But if I’m a caregiver, I’m not sure that’s completely awesome for the caregivers currently, because they weren’t brought up in an age of computers”</p> |

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| | |
|----------------------|--|
| Learned Helplessness | “There’s a learned helplessness, if they can do it, I try to get them to do it. They don’t have the capacity if you give them a bunch of options, but we want them to have that independence”. |
|----------------------|--|

3.3.2 Subtheme Two: Limitations on System Capacity

Healthcare providers themselves also experienced structural system barriers that limited their capacity to provide cognitive rehabilitation to their clients. System capacity encompasses time, funding and resources needed to support cognitive rehabilitation. Throughout the data collection process, participants revealed high levels of pressure associated with the demands related to the focus on quantity rather than quality of services. Multiple stakeholder interviews and questionnaire responses focused on their lack of capacity to provide rehabilitation services to their clients in need, with a focus in the following areas: funding and resources, staffing shortages, feeling limited by current workloads and available time, as well as clients slipping through structural or referral “cracks” in the system. Additionally, healthcare providers are desperately requesting that their services be allowed to operate more days per week, and increasing their available program seats. Healthcare providers feel there is a growing need to change the regulations surrounding how many times per week clients are allowed to utilize cognitive rehabilitation services and other therapy and respite services, and they believe the broader healthcare system placed constraints over the current program capacity.

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| | |
|--|---|
| <p>Limited by Workloads and Available Time</p> | <p>“There is not enough time to develop appropriate programming. There is no time to administer cognitive training.”</p> <p>“I’d love to be able to have that little bit more time or ability to be able to have more one on one assessments and training once they’re here.”</p> <p>“Unfortunately, there is so much that we are expected to do as an employee, and I just don’t have time. That’s why I sometimes work at home putting programming together.”</p> |
| <p>Clients Slip Through Cracks</p> | <p>“I find those [with dementia] who are lower functioning, they slip through the cracks. We can only hire so many people.</p> <p>“Front line or intake do not always recognize dementia and therefore, our</p> |

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| | |
|--|--|
| <p>Lack of Available Seats/Days per Week</p> | <p>patients may not be found eligible for services.”</p> <p>“It’s three days a week, so could it not be five days a week? There is probably a need for that. I would say that we could be full.”</p> <p>“When you tell caregivers it’s only one day a week... then there’s an entirely different conversation there. What am I supposed to do?”</p> <p>“We have so many people come from the LHIN that need help and we are limited. We’re only allowed to offer one day a week. After four weeks, we can offer two. There’s so many people that have their children looking after them that they need somebody Monday to Friday. We are not allowed.”</p> |
|--|--|

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3.4 Theme Two: Debate Between Standardization and Individualization

Cognitive Rehabilitation is a relatively novel term, and many healthcare providers suggested that a first step in improving their capacity for cognitive rehabilitation would need to begin with operationalizing and standardizing cognitive rehabilitation terms. Many of our healthcare providers agreed that they did offer or recommend cognitive rehabilitation services, but indicated they were not familiar with the multiple terms or alternative terms used for this type of therapy.

Standardization was seen by healthcare providers as a way to help improve the quality of patient care and achieve a more universal approach to cognitive rehabilitation. However, other healthcare providers put emphasis on the fact that this type of care is so often individualized and flexibility is necessary in their practices, in such making standardization difficult. Overall, healthcare provider's goals were to implement a level of standardization alongside personalized care that would be complementary to each another.

Table 8

Lack of Standardization

| Lack of Standardization | Illustrative Quote |
|-------------------------|--|
| Lack of Standardization | “We don’t have a standardized method or expectation of offering cognitive training... I don’t think we are capturing |

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| | |
|--|---|
| | <p>all the opportunities to offer effective treatment.”</p> <p>“This type of care needs to be operationalized as part of the work we do, like a pathway. This is not happening now.”</p> <p>“We need standardized packages to implement – it’s like we are trying to put a black and white spin on something very grey. It’s messy. We need inclusion of accessible and standardized materials.”</p> <p>“I find that we will pull all the standardized things and I’m just like, this isn’t appropriate for them because they are past this level. Some people just like that word, standardized, I would tend to say I’m not sure if that’s the best thing.”</p> |
|--|---|

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3.5 Theme Three: Paradigm Shift from Treatment to Primary Prevention

Healthcare providers increasingly recognize dementia as a target for primary prevention. Many stakeholders suggested that participating in cognitive rehabilitation alongside other physical and social activities can provide positive benefits to clients' cognition, however not all healthcare providers were capable in providing preventative care to their clients. The current scope of cognitive rehabilitation can be seen on a spectrum, with some healthcare providers implementing rehabilitation in a preventative manner, while others using it as an evidence-based treatment to help stabilize or slow the disease progression. Healthcare providers realized the importance of this type of care in the aging population, and the importance of its implementation in earlier stages, particularly for those experiencing mild cognitive deficits. Healthcare providers also proposed a link between client's early detection and the success of cognitive rehabilitation in delaying entry into long term care and improving cognition.

Table 9

Shift from Treatment to Primary Prevention

| Shift from Treatment to Prevention | Illustrative Quote |
|------------------------------------|---|
| | “Family members don't really comprehend the importance of receiving education while the client is still in the early stages of dementia. Some families are not even |

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| | |
|------------------------|--|
| <p>Early Detection</p> | <p>told their loved one has dementia by their family doctors.”</p> <p>“We actively do cognitive rehab and cognitive stimulation and refer to outside agencies (Alzheimer Society and adult day program) for cognitive training or give educational material "train the brain" to those with milder stages.”</p> <p>“They don’t know about [cognitive rehabilitation]. I say to families, how could I get this message to you sooner? I don’t know. Word of mouth, it’s the best. Did you know you can stop your mom's dementia from progressing as fast as it is?”</p> |
| <p>Prevention</p> | <p>“Because the earlier you get it the more prevention strategies you can implement and you have more time. We are seeing a trend in our programs lately that people</p> |

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| | |
|--|---|
| <p>Results of Prevention Delaying Entry to LTC</p> | <p>are coming to us later than they used to.</p> <p>I've been here 23 years, so the clients are coming later. The families are going "Help! I need help! What do we do?"</p> <p>"We tend to focus on the frailest, more advanced dementia, risk of ED visits/crisis. It would be ideal to have more time for prevention (anticipating the next health crisis and planning for that)."</p> <p>"But, I still have people who live alone and probably I would bet you if I asked their caregivers if they didn't have the program- would they be living alone? My guess is most would say no."</p> <p>"If they have access to memory services, we can delay their entry into the care facilities. We are short on beds and running out of room already."</p> |
|--|---|

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| | |
|-----------|---|
| Treatment | “Our hope is that things remain stable/change minimally and the caregiver is coping/has information and support.” “Cognitive stimulation is very effective for people with moderate to severe dementia. Often these are provided in the form of adult day programs or private help.” “We will usually look at compensatory methods but I don’t think we are capturing all the opportunities to offer effective treatment” |
|-----------|---|

3.6 Theme Four: Raising Awareness through Accessible Education and Services

Education was one of the most prominent themes that spanned throughout the Phase One and Two’s study findings. Educational interventions encompassed reading journal articles and other material at home, and participating in short courses or large group setting learning initiatives such as national and international conferences.

Healthcare providers indicated multiple reasons for participating in continuing education initiatives, including personal learning interests and developing increased competency to care for their clients. However, of most importance to healthcare providers was the need

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for accessible education initiatives supported by their place of work, as illustrated in Subtheme One. Nearly all of Phase Two respondents indicated a need for improvement in education surrounding cognitive rehabilitation and underscored improvements in this area would help them adopt new practice methodologies that would be beneficial to the care of persons with dementia.

Moreover, education was intrinsically linked with professional development and many healthcare providers felt it was their professional obligation to stay informed with evidence-based methodologies related to cognitive rehabilitation. However, some healthcare providers indicated that there may be some resistance to change when they feel comfortable with the status quo. This concept of professional accountability is demonstrated within Subtheme Two. Lastly, healthcare workers highlighted the importance of diversity in cognitive rehabilitation care, promoting the idea of culturally diverse programming and a sensitivity to different values in dementia care, as illustrated in Subtheme Three. Additionally, themes of diversity were also discussed in providing equitable and fair treatment to those with various levels of cognitive decline.

Table 10

Raising Awareness through Increased Education

| Raising Awareness Through Increased Education | Illustrative Quotes |
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| Subtheme One: Increased Awareness of Accessibility | “We can think of things that aren’t going to cost money but can provide education instead of like a conversation on the side here, there and everywhere. Sometimes it |

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| | <p>can be better to have an actual half a day course.”</p> <p>“I know the Alzheimer’s society has webinars but I wish there was a little bit more able time for training”</p> <p>“Scheduling education time, I think would benefit all healthcare providers. Being able to sit down, even if it's just at the office, but you know there’s an hour long webinar, everyone needs to do it”</p> <p>“People are not willing to get on board with it – why? Because it takes time out of their life. I’ve got too much other things to do, why do I bother? Everything’s working fine. And then unfortunately it's depending on how long they’ve been there as well. The more senior they are the harder they are to change. Unfortunately I do have that situation, so, and it takes a lot</p> |
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| | <p>of convincing and understanding to get them to access new information.”</p> |
| <p>Subtheme Two: Increased Awareness of Professional Accountability</p> | <p>“I could learn on my time, or you know I have downtime at work, I can go sit down at a computer, put headphones in and learn or something like that. I find, even if something like it’s a webinar type of idea, sometimes even that booklet because you could be observing. Not having to do it on my own time, on a Saturday or Sunday or at night.”</p> <p>“I will tell you, and my boss is 100% aware, I do a lot of work at home. I put new things together, I research, I to find things but I also have to be thoughtful, think about it, I can’t do too much.”</p> <p>“I’m continuing to learn to better their time here, I am not doing it just because I have no other reason. I find I, not have to fight, but I have to stand up for myself,</p> |

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| | <p>even with the small things that we have been able to get the one time funding for, the courses we have been receiving they're response is why do I have to do this? We're fine. No, we're not. We could be doing better, we could always be doing better. But maybe if I had new information I'd find a new way to do it.”</p> <p>“My inpatient team was like ‘oh you have all this knowledge now’ and they would ask me questions, I would give them an answer and they wouldn’t change their practice or wouldn’t change the way they did things. It’s easier to fall back on what you’re used to instead of trying to change your practice.”</p> <p>“I think we do all get in a rut because it is an endless calendar, we’re constantly plugging and it’s like what am I going to do now, what am I going to do now?”</p> |
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| <p>Subtheme Three: Increased Awareness of Diversity</p> | <p>“We need diverse cultural programs for individuals with dementia in our area.”</p> <p>“A multicultural approach is needed as some cultures are not receptive to western approaches to cognitive rehabilitation.”</p> <p>“You don't have much diversity of programming, there's a lot of barriers like language, second language. For adult day programs most people don't want to send their loved ones there, so if you want to say diversity or visit accessibility or whatever the word of the month is now, that I can't think of. Inclusion? I can't think of the word we're looking for, so I don't think we do well including various cultures and things like that in our services.”</p> <p>“Clients may not say something on a daily basis but every once in a while you get through. So we had to start looking at a</p> |
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| | <p>different perspective to make sure everybody was involved.”</p> <p>“Just since January our programming calendar has changed to make sure we adapt and think about the lower functioning clients that do attend and that has definitely made a difference.”</p> <p>“We know younger people are going into long term care homes- well I think that programming needs to reflect that.”</p> |
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3.7 Theme Five: Continuity and Care Coordination

Traditional health care systems are not well equipped to handle individuals who present with complex health needs, and this ideology was shared by many of the healthcare providers who participated in this study. Many healthcare providers spoke of a “maze of referrals” for their clients and caregivers in order to access cognitive rehabilitation services or even get a diagnosis of dementia in order to be referred to these programs. Patient care was seen as hindered by healthcare workers’ participation working in silos, with a lack of communication between providers. Cognitive rehabilitation

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services were seen as poorly integrated into the current scope of dementia care, leading to a complex maze of services and fragmented care coordination for the client and caregiver. Healthcare providers spoke frequently of the lack of consistency in providing and referring clients to these services, and questioned the feasibility of connecting all the various team players in providing continuity and consistent care. However, healthcare providers commented on the interdisciplinary nature of their teams, their willingness and eagerness to connect the gaps in service and to enhance communication between care providers, including a large emphasis on trust and cooperation within the interdisciplinary team. These ideas are illustrated in Subtheme One: An Integrated Care Coordination.

A foundational underpinning of continuity of care was brought forth during the course of this analysis. Healthcare providers share a range of opinions when it comes to the onus of preventative cognitive rehabilitation and other treatment based cognitive rehabilitation services for those with dementia. This idea of onus is reflected in Subtheme Two as a Shared Responsibility of Care. This care requires the interconnected participation of the individual client, their caregiver, community resources such as adult day programs and support from governing bodies for funding and responsibility. This idea of interconnectedness associated with the shared responsibility of care is visually depicted in Figure 2 below.

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Figure 2. Interconnections of Successful Continuation of Care for Clients with Dementia

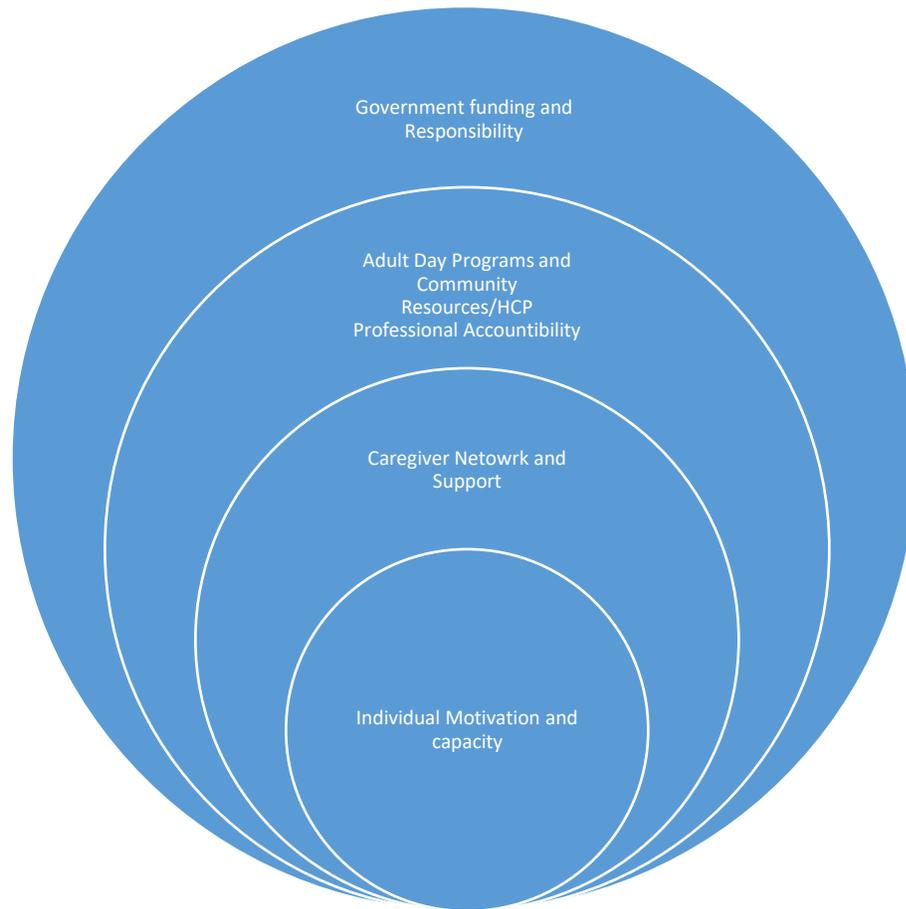


Table 11

Continuity and Care Coordination

| Continuity and Care Coordination | Illustrative Quotes |
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| Subtheme One: Shared Responsibility of Care (Onus) | “We provide resources and the responsibility is on the client and caregiver” |

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| | <p>“Do I want the person who’s the caregiver to do the cognitive rehabilitation program? I wish it wasn’t them. I try to encourage things like day programs, but when people refuse to leave their homes, and they ask, well I can’t keep them busy, he doesn’t want to do anything, and then unfortunately it does fall on them.”</p> <p>“There’s always a caregiver with them and it’s usually an overwhelmed one and the caregiver has to remember so much information they have to remember all their medications and all their answers and they’re overwhelmed with do this, do that and the other, I say get their permission for us to contact them, so they fill out the form and they send it to us. We wait a few days and we’ll contact the caregiver. It just takes the onus off of them.”</p> |
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| | <p>“We need buy-in from care-givers to bring client to cognitive groups or do the individual CST with the client”</p> <p>“One of the biggest things I ask the caregivers for open communication. If your loved one is here, we need the best information to give them the best care while they’re here and you know, if you’re not going to tell us if something happened, it makes it harder for us, for them and us.”</p> <p>“I honestly I don’t think it’s just in regards to the healthcare professionals that need the information, I think it needs to be more accessible to the caregivers because it’s not just here, and the programming and one-on-one, but I think keeping a short list of things a caregiver can do at home, can also help with the rehab.”</p> |
| <p>Subtheme Two: An Integrated Care Coordination</p> | <p>“I think there are many barriers for our clients to be able to follow through on</p> |

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| | <p>recommendations. Lack of an integrated healthcare system currently.”</p> <p>“We lack an integrated health care system (including lack of a common EMR), we have wasted government resources on programs such as health links, and we have untrained and insufficient PSW assistance.”</p> <p>“You have to really trust the team that you’re working with.”</p> <p>“Sometimes we have RPNs students in, that we have had RPNs students in past that look at their placement here and go “why do I need to do this, this is not nursing” and I always tell that my goal for your placement here is for you to understand that we have to work together.”</p> |
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| | <p>“Front line or intake do not always recognize dementia and therefore patient may not be found eligible for services.”</p> <p>“I think it needs to start in family doctors’ offices and I think there needs to be, you know we see about blood pressure, we see about diabetes in the doctor's office but what do we see about dementia.”</p> <p>“Usually I’ll send my recommendations to the family doctor, to then hopefully take those suggestions and implement them, but we’ll often find that when we go for a follow up, that nothings been done.”</p> <p>“There is a strong push for referrals, but also it should be client centered. Is this getting to know the client being lost in translation? It’s a mess logistically to sort out who is even providing these services.”</p> |
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| | <p>“I think that it’s the interdisciplinary team that while we might not know each other- I think it’s so important. It goes even right to the family doctor. The caregiver, the PSW. The whole, everybody, we all need to respect that we all have a part for this person. But if we’re there for the person, that’s just um- you put your own pride of what you do aside, because it’s all for the person.”</p> |
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3.8 Summary of Research Questions Addressed by Thematic Analysis

The primary research question to be addressed was understanding how healthcare providers understood their capacity for cognitive rehabilitation with dementia clients. Capacity is affected by all five themes developed in the course of the thematic analysis. An overwhelming response from our participants alarmingly stated “there is no capacity”, or there was only limited capacity in some way. The capacity for delivering these types of services would necessitate receiving an influx of resources including additional staff and funding (Theme 1), additional training, access and awareness of programming benefits and diversity (Theme 4), and patient care was seen as hindered by healthcare workers’ participation working in silos, with a lack of communication between providers.

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Cognitive rehabilitation services were seen as poorly integrated into the current scope of dementia care diminishing healthcare provider's capacity to provide these programs (Theme 5).

The secondary research questions included what recommendations and services are currently provided to clients with dementia, and are addressed by Theme 2 and 3. Many of our healthcare providers agreed that they did offer or recommend cognitive rehabilitation services, but indicated they were not familiar with the multiple terms or alternative terms used for this type of therapy. Theme three (paradigm shift from treatment to primary prevention) also addresses this secondary research question, as healthcare providers increasingly recognize dementia as a target for primary prevention. Many stakeholders suggested that participating in cognitive rehabilitation alongside other physical and social activities can provide positive benefits to clients' cognition, however not all healthcare providers were capable in providing preventative care to their clients. The composition of strategies used by healthcare providers in recommending or implementing cognitive rehabilitation programs was discussed throughout Theme 2, as the debate between the most useful strategies and how cognitive rehabilitation was understood and operationalized by each healthcare professional varied.

3.9 Mapping Competencies

When addressing healthcare providers' perceived levels of competencies in providing cognitive rehabilitation to their clients, the main competencies required for providing cognitive rehabilitation included a mixture of both hard and soft skills. Soft skills included communication, management skills, flexibility, empathy and creativity. The required hard skills included teachable abilities such as those received through

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formal education including diagnosis, patient management, program development and medication management. Healthcare providers overall were fairly familiar with the cognitive rehabilitation terms and offered them in various programming for their clients, although many did not express confidence in their capabilities to provide this care. They suggested being skilled in their own professional designations (RN, PSW, OT) but did not feel competent in providing this type of care to clients in collaboration with their own services. This finding is not surprising due to the novel nature of cognitive rehabilitation services in dementia care, as well as its lack of standardization and operationalization. Although cognitive rehabilitation may benefit dementia populations, no singular professional designation has sole responsibility for implementing these services. More frequently than not, healthcare providers were taking aspects of cognitive rehabilitation and using it to complement services they already provided to their clients. Due to the high volume of cases required to be managed by healthcare providers, many simply recommended cognitive training exercises to be completed at home and felt little competencies beyond this scope of practice. Although the healthcare providers showed varied competencies in providing cognitive rehabilitation to their clients, providers clearly understood what was necessary to increase their competencies and what their organizations could do to develop them.

As previously discussed, rehabilitation programs for individuals with dementia should focus on five main domains: (i) memory enhancement, (ii) social communication, (iii) self care skills, (iv) arrangement of physical environments for optimal functioning and (v) increasing physical activity [96]. When discussing HCP responses on which core competencies were required to provide cognitive rehabilitation, memory enhancement

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techniques were discussed most frequently. Healthcare providers suggested a variety of tools and programming used with their clients, including music stimulation, external memory aids to be used at home with clients (labelling drawers, cabinets, areas of the home etc.) as well as the level of creativity involved in developing and implementing these types of memory enhancement tools. Healthcare providers suggested that program development whether done at home individually or collaboratively through teamwork were essential in developing programming that works for their clients, with a specific focus on trying to enhance memory using reality orientation techniques and reminiscence therapy that was sensitive to client's cultural backgrounds. For instance, reminiscence therapy in adult day programs often had "themes" that were personally related to the client, including videos, music and games that clients would have played, heard or observed during their lifetimes. This was seen especially in urban areas where multicultural clients were clustered most often. Cognitive rehabilitation programs for clients also place a large emphasis on social communication, which HCP tried to integrate with clients whenever possible. HCP recommended group stimulation sessions often, where mild to moderate dementia clients would participate in cognitively stimulating activities in groups with other PWD, or in collaboration with their caregivers and healthcare teams. Though offered less frequently in the more severe stages of decline due to diminishing language abilities, healthcare providers suggested a main competency in the social communication domain as strong communication abilities and skills between HCP and client and HCP and other team members.

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Domain three in offering successful cognitive rehabilitation surrounds self-care skills. A strong emphasis on developing mutual goals for completing meaningful activities of daily living and improving client's self-efficacy was promoted by HCP. HCP suggested they tried to promote independence in their clients however possible, allowing them to "choose their own activities", "respecting their choices" and "providing clients options when possible". Healthcare providers talked repeatedly about the level of empathy that was necessary to work in dementia care, and related often to what they would want, and the choices they would make if they "were in their shoes".

The fourth rehabilitation domain surrounds optimizing the physical environment, including enhancing safety and promoting independence through environmental modifications. Healthcare providers spoke about the management skills and education required to make or suggest these changes to clients and caregivers. They frequently referred clients to occupational therapists, BSOs and other healthcare services that may promote physical changes in order to adapt the client's environment to remove any excess barriers that would hinder participants participation in cognitive rehabilitation and overall quality of life. These modifications included small changes, such as using telephones with larger buttons in order to make communication easier, as well as instructing caregivers about common hazards in the home to be aware of. None of our HCP participants mentioned physical activity, the last domain of rehabilitation programs for PWD.

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3.10 Convergent and Divergent Results from Phase One and Two

All five themes were present in both the phase one and phase two responses in various levels of detail. Healthcare providers addressed the main system limitations they were experiencing in implementing cognitive rehabilitation from an individual perspective in the questionnaire responses, from an “on the ground” lived experience perspective. Respondents spoke briefly about the main constraints they experienced in the questionnaire, with an emphasis on the lack of time available for implementing complex cognitive rehabilitation interventions and the lack of resources and training required for maximizing their available time. Healthcare providers spoke mainly of the lack of education they had available to them about cognitive rehabilitation, yet however spoke in great detail about their own professional perspectives on cognitive rehabilitation and how their professional designations prepared them for dealing with PWD. Participants mainly commented on their own personal examples and case studies of working with cognitive rehabilitation in their respective institutions.

When responses from the interviews are compared to questionnaire responses, there are some meaningful differences. Besides participants responses being more detailed, many interview participants moved from an individual level approach and perspective to a more structural/macro level approach. The one on one personal nature of the interview allowed participants to feel more comfortable divulging details that were more in depth than explained in the questionnaire, and focused on mechanisms of change that would be required for successfully implementing cognitive rehabilitation. HCP participants responded with more negative comments surrounding capacity for cognitive rehabilitation than were mentioned initially in the questionnaire, divulging that they

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lacked the confidence and competencies that would be necessary more often than was seen in the questionnaire responses. Moreover, HCP respondents in the interviews spoke in more detail about the interpersonal challenges they faced within their healthcare teams as well as more negative attitudes surrounding the implementation of healthcare systems across the Central East LHIN in general, including “wasted resources”, “lack of communication between healthcare teams”, “untrained and insufficient staff” as well as “working with staff who wouldn’t change their practice methodologies” and “fell back into what they were use to rather than changing their practice” when confronted with new knowledge. Many healthcare providers did not mention the importance of the informal caregivers’ role for successful cognitive rehabilitation during the questionnaire, however when prompted during the interviews spoke at length about challenges with working one on one with clients and caregivers. Healthcare providers suggested there are certain challenges when working with caregivers during the interviews. For example, when screening for eligibility of the program, one HCP responded that PWD who need two or more individuals to help with transportation, bathroom/sanitary needs or behavioural concerns would most likely be ineligible for their programming.

Obtaining this information from caregivers can be difficult, and open communication between caregivers and HCP regarding eligibility according to our participant was sometimes dishonest. Our HCP respondent stated that sometimes “the need for services, respite and relief for the caregiver means they don’t divulge all the information you need – that client shows up and they don’t meet the eligibility criteria, they need assistance with using the restrooms or other services and you don’t find this out until they are at the program because the caregiver is so desperate to implement

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programming for them.” Empathy for the caregivers in this position and anger surrounding the lack of services available to PWD is also something that was unique to the interview respondents. HCP understood the burden caring for a loved one with dementia took, and their responses indicated their level of frustration with the lack of services they could provide to these individuals, including only offering a limited number of seats for the programming, feeling constrained due to only offering programming on 2-3 weekdays rather than week-long programs, and feelings of leaving caregivers “with no other options”.

3.1.1 Geographical Differences in Needs and Access

Although many of our respondents across the catchment areas in the Central East LHIN faced similar capacity challenges in implementing cognitive rehabilitation, differences due to living in an urban versus rural location did provide some unique perspectives. For the purposes of this separation, Durham North East and West and Scarborough North and South were considered urban, and Haliburton/Kawartha Lakes, Northumberland and Peterborough were considered rural locations. Broadly, our HCP participants in the urban locations suggested they were dealing with considerably larger volumes of individuals with Alzheimer’s and Dementia in comparison to the burden that rural locations were experiencing.

However, respondents also suggested that this burden may “be due to our lack of staffing, we just don’t have enough people”. HCP in rural areas discussed access to dementia care services including cognitive rehabilitation as more limited than those in urban areas, citing a “lack of transportation”, “lack of trained healthcare professionals”, and “lack of support programs” for individuals with dementia in their areas. Interview

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respondents who mentioned there was a current “know how” of routines that is used for dementia programming, and respondents who questioned other colleagues and staff being “happy with the status quo and resistant to change” also came only from rural respondents. However, participants living rurally also had staff who worked at their current institutions anywhere from 1-9 years longer than those who worked in urban locations which may help explain their commitment to organizational routine and structure. Overall, both urban and rural participants saw the need for enhanced communication between healthcare teams, increased access to funding, training and education as well as the importance of and duty to the best practices for caring with PWD.

3.12 Summary of Results

In summary, five main themes were developed over the course of the questionnaire and interview data, and contributed to the understanding of healthcare provider’s capacity for providing cognitive rehabilitation to their clients with dementia. System challenges were shared by healthcare providers which encompassed time and funding limitations and a lack of resources. Healthcare providers also debated between the usefulness of standardized tools and methodology in cognitive rehabilitation, with some suggesting that standardized and operationalized terminology would help optimize their practices, while others suggesting that these types of services require individualized care. Flexibility was a key competency that was highlighted in this debate, with healthcare providers focusing on implementing a level of standardization alongside personalized care.

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In accordance with the empirical literature, many healthcare providers also recognize the opportunity for cognitive rehabilitation as both a preventative and treatment measure. Although the services offered usually focused on treatment, more healthcare providers are understanding cognitive rehabilitation as a preventative measure for clients with mild stage dementias. In order to improve healthcare provider's capacity for cognitive rehabilitation, a strong emphasis was put on raising awareness through accessible education. Education was mentioned by nearly all participants in both phases of the study, and showed a need for accessible education in an easy to understand format for healthcare workers to stay up to date during their daily practice, rather than by attending yearly conferences or leaving for additional formal training off-site.

Lastly, continuity of care was essential in promoting cognitive rehabilitation, particularly for clients with high levels of needs and complexity. Healthcare providers agreed that working in silos is non-therapeutic and could be disruptive for their clients as this could result in clients being lost in a "maze of referrals". There was a clear connection between the participation of the client themselves, the caregivers involved, the healthcare teams and the larger organizational and governmental structure in collaboratively providing effective and consistent cognitive rehabilitation care to persons with dementia.

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Chapter 4. Discussion

The primary aim of this research study was to understand current healthcare providers' capacity for offering cognitive rehabilitation programs throughout the Central East LHIN. Although research is beginning to suggest cognitive rehabilitation may increase quality of life and provide cognitive benefits for a dementia population, little research has been conducted pertaining to capacity for its implementation.

Regulations for long term care institutions outline those in LTC must receive “care and services to maintain their highest practicable mental well-being” [92]. Although this is the case, research suggests that some clients with dementia may be disqualified for rehabilitation services based on their diagnosis, or face barriers from healthcare providers who believe rehabilitation services are not useful for those diagnosed with dementia [92]. Fortunately, our research suggests that the majority of clients were receiving their cognitive rehabilitation services through adult day program participation, and that this service is “very successful for many clients”. For the clients who were receiving programming through adult day programs or other public services, the average duration of rehabilitation was approximately 39 minutes per session. Clients ranged from receiving these services only one day per week to 5-7 times per week. The average waiting time to access these services were 2-3 months, with 0-25 clients on waiting list, depending on the LHIN catchment area.

If clients were not receiving this type of care through publically funded services, they were purchasing additional services privately or receiving no formal cognitive rehabilitation care at all. In addition, healthcare providers also relied heavily on Behavioural Support Clinicians (BSO's) and their interventions. Referrals are made for

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PSW's to complete resources with clients at home, depending on their cognitive level and nearly all clients seen with dementia were referred to their local Alzheimer's Societies for additional services. When discussing each subtype of cognitive remediation separately, cognitive training was recommended least often. This particular finding is not surprising due to the fact that cognitive training is offered at the earliest level of decline, and our study suggests that the early stages of dementia often gets missed, and clients are seen as ineligible for services. This is echoed in the empirical literature, where diagnosis of dementia is delayed or missed due to brief interactions between health care provider and client, educational deficits and system constraints [93]. When cognitive training is provided, healthcare practitioners suggest their most used services are one on one coaching with clients and families on specific tasks targeting specific cognitive deficits. Cognitive training activities are often recommended at initial assessments, and if attention is needed to specific areas, referrals to occupational therapists, BSO's or PSWs are provided as appropriate. Many healthcare practitioners also recommended "train the brain" material for this subtype of cognitive therapy, which they found particularly useful for clients with milder stages of dementia.

Cognitive rehabilitation was provided by various healthcare practitioners and included brain stimulation techniques, brain games and compensatory strategies. These included using calendars to track the date, written cues and notes as well as reminders for medications and other daily tasks. Healthcare practitioner's main concerns with cognitive rehabilitation was to address the clients Instrumental Activities of Daily Living (IADL's) and Basic Activities of Daily Living (BADL's) and ensure the client had a series of personally relevant functional and social goals successfully met. These were often

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incorporated with occupational therapy goals and treatment, and included recommendations to BSO's when appropriate.

Cognitive Stimulation was unsurprisingly offered most frequently to clients with dementia, given that this therapy subtype is heavily concentrated on as an effective therapeutic technique in the literature, more so than cognitive training or rehabilitation. Healthcare providers indicated they were most comfortable with this type of service offering and used it as frequently as possible with their dementia clients. Therapeutic techniques ranged from providing music therapy to decrease anxiety, various intellectual activities such as group sensory stimulation and coloring. Many healthcare providers spoke specifically on reminiscing therapy strategies, such as the use of memory books and orientation techniques and their contribution to improving quality of life.

More generally, healthcare providers suggested there was some flexibility in their service offerings, with many of their services not distinctly offering one subtype of cognitive therapy over another, rather just a combination of the three subtypes. In addition, some healthcare providers suggested that recommendations are made for some, but not all clients. Healthcare providers took responsibility in referring individuals to these programs based on their client's interest and level of cognitive decline. The caregiver's ability to arrange transportation and payment for these programs considerably affected a client's eligibility.

Research question three aimed to understand if current dementia healthcare practitioners feel as though they have the capacity to fulfill the current and upcoming needs of the dementia population. The overall consensus from healthcare providers to implement cognitive rehabilitation within their institutions varied considerably. Although

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some healthcare providers suggested they may have available potential staff and clients, and they felt confident in their knowledge and skill base (Theme 4), many providers suggested they have limited or no capacity to address the needs of the current and upcoming dementia population. Healthcare providers suggested their outlook was poor, with limited services, time and funding (Theme 1). The third research question addressed the healthcare providers' beliefs in their level of capacity to fulfill the current and upcoming needs of the dementia population. The overall consensus from healthcare providers to implement cognitive rehabilitation within their institutions varied considerably. Although some healthcare providers suggested they may have available potential staff and clients, and they felt confident in their knowledge and skill base, the majority of service providers suggested they have limited or no capacity to address the needs of the current and upcoming dementia population. Healthcare providers suggested their outlook was poor, with limited services, time and funding. Additionally, they stated that they were "more or less working at capacity" and acknowledged the need for additional structural and staffing changes that would be required to offer individualized or group based cognitive rehabilitation services. Others suggested they were unsure if they had the capacity to meet upcoming demands and felt as though the impending dementia crisis would overwhelm and exhaust current staff. Research suggests that their concerns are not unwarranted, as the growing dementia prevalence projects we will need more than double our long-term care beds [94]. This is even the case as the proportion of adults in long term care has been declining over the past two decades as more and more individuals with dementia are staying in their communities, putting additional stress on community resources and home care services [95]. Our participants also provided

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valuable insights into increasing their personal and professional capacity for cognitive rehabilitation, which included increasing the level of professional awareness surrounding these programs, receiving a standardized package to implement with their clients, having ready-made educational materials to give to clients, additional training on incorporating cognitive rehabilitation techniques into clients daily lives and help with marketing and advertising these programs both within their organization and shared across organizations.

The most influential perceived barrier in both providing and accessing cognitive rehabilitation programs from the healthcare workers perspective varied, although support from the caregiver and caregiver buy-in to the importance of the program was mentioned frequently (Theme 5), as well as concerns with transportation, financial constraints and eligibility concerns (Theme 4, Subtheme 1).

Lastly, various competencies are required in providing cognitive rehabilitation services to clients with dementia, including soft skills included communication, management skills, flexibility, empathy and creativity. The required hard skills included teachable abilities such as those received through formal education including diagnosis, patient management, and program development and medication management (Theme 4). Healthcare providers overall did not express confidence in their capabilities to provide this type of care and believed further education (Theme 4) and multidisciplinary care teams (Theme 5) would be required in order cognitive rehabilitation to become a successful reality for those suffering with dementia.

Moreover, no research has been conducted on how to successfully translate the empirical knowledge about cognitive rehabilitation into actual clinical practice. The need

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for dementia care will continue to increase across Canada and globally as the population continues to age. By 2031, nine million Canadians will be over the age of 65 and dementia prevalence will continue to rise [97]. To my knowledge, this study is the first to examine capacity for cognitive rehabilitation from the perspectives of the front-line healthcare workers throughout the Central East LHIN.

This study did not begin with a pre-determined hypothesis, although our initial research thoughts were that those with dementia were not receiving cognitive rehabilitation services to the extent the research suggests they should be, and part of this would be due to constraints perceived by the healthcare providers. In addressing the primary research question of healthcare provider's capacity for cognitive rehabilitation for those with dementia, the outlook was viewed as poor. An overwhelming response from our participants alarmingly stated "there is no capacity", or there was only limited capacity in some way. The capacity for delivering these types of services would necessitate receiving additional training, an influx of resources including additional staff and more funding. This is seen across healthcare fields, where quality improvement implementation initiatives are achieved less than 50% of the time, with organizational changes being cited as the main contributing factor [98]. The barriers discussed by HCP's in this study are also well recognized as contributing to constrained use of other community resource services, such as utilization of domestic violence services, childhood obesity services and stroke rehabilitation [99]. Although healthcare workers believed overall, they were competent in providing cognitive rehabilitation, particularly in their abilities to be communicative, flexible and empathetic, they did not believe they were supported by their organizations. Many healthcare providers stressed the importance of

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education in improving their capacity to deliver cognitive rehabilitation services to their clients. Healthcare providers feel as though they have a professional obligation to stay up to date on novel therapeutic techniques and practice standards, and looked for opportunities for personal and professional development within their workplaces. This idea of a “learning organization” stresses the importance of an adaptive and flexible team as crucial to the organizational success. Similar studies on healthcare implementation have shown a commitment to a learning environment allowed employees to improve leadership expertise and infrastructure [100] and without it, HCP’s experienced a decrease in role satisfaction [101]. Having successful adoption of cognitive rehabilitation will require both professional and organizational level growth, and a focus on learning within an organization should be a main priority if we wish to enhance quality of life and patient centred care for individuals with dementia.

Education is also necessary for the general public and for dementia clients themselves as stigma still exists surrounding dementia care including receiving cognitive remediation and therapy. This aligns with recent research by Phillipson [102] suggesting dementia care is still inaccessible to clients due to stigma surrounding aging and degenerative diseases. However, education can help reduce stigma of health conditions and make access to healthcare less challenging [103]. In fact, when individuals are presented with factual information regarding severe mental illness (SMI), stigmatization reduces [104]. This could easily be transferable to cognitive rehabilitation approaches with dementia clients now that there is an understanding of stigma as a barrier in accessing care.

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With the present understanding of what barriers exist for healthcare providers, we will be able to begin to fill the know-do gap that exists between empirical literature and patient care. The know-do gap exists in cognitive rehabilitation care because ultimately, there is a lack of a facilitating framework for its implementation. Understanding the barriers that exist in implementing cognitive rehabilitation can be viewed fundamentally as needs assessment; working with senior healthcare leaders in this area can both identify barriers and contribute ideas to overcome them. This will directly affect how the program is implemented and the type of assistance necessary to ensure the intervention is successful [105].

The final research question asked healthcare providers to comment on what the most influential perceived barrier is for their clients to access cognitive rehabilitation services. Highly interrelated challenges specifically for clients to access services were concentrated in the following areas: transportation, communication and language barriers, payment or financial constraints, being found ineligible for services and a lack of supportive or available caregiver. Transportation barriers are often cited in the healthcare literature [106] and are particularly important for those with low income who cannot afford driving services such as taxis or are not capable of travelling alone due to concerns regarding memory. Our healthcare providers specifically identified Durham Region Transit's regulations surrounding those with dementia in accessing public transportation as a barrier. Healthcare providers have cited that those who have dementia and are trying to travel using public transportation are turned away due to a lack of care partner able to travel with them. Without a reliable vehicle driven by a caregiver, access to public transportation or the financial means to purchase driving services, clients with dementia

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will have difficulties attending cognitive rehabilitation programs, and this will lead to the hidden costs to the healthcare system such as missed or delayed appointments [107]. Transportation has been identified as a main concern by the Durham Region, where an Age Friendly Durham Strategy and Action Plan has been developed. Within this action plan, expanding transit opportunities in rural areas as well as increasing the frequency and coverage of transportation methods has been identified as developing area of strength within the Durham Region. This action plan identifies various areas of opportunity for development, including specialized transportation availabilities as well as decreasing the fees for public transit for older adults [108].

Barriers also surrounded communication and other language issues, with healthcare providers suggesting that limited verbal ability and poor communications with staff would make accessing services difficult. It seems this relationship is bi-directional, as not only does poor communication hinder accessible services, but healthcare providers continually cite that client's communication ability is a large contributing factor in whether or not they wish to work with dementia clients [109] and there is a continual push for the acquisition of better communication between healthcare staff and senior and/or dementia patients [110].

Healthcare providers also cited payment and financial obligations as a deterrent to service use. As reported in 2018 from the C.A.R.E study, caregivers spend on average nearly 275 dollars per month on dementia related expenses, with many caregivers having to "reduce their own living expenses to pay for caregiving costs" [111]. Healthcare providers have heard on numerous occasions from their clients' caregivers that cognitive rehabilitation and broader dementia services are unaffordable, and keep clients from

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accessing quality care. Different levels of help are required alongside publicly funded programs, such as PSW's, occupational therapists and other private services, and are usually purchased out of pocket by the caregiver in order to provide adequate supervision, care and respite. This is synergistic with the fact that healthcare providers believe there are only a limited number of community programs available for clients with dementia, and many clients are not found eligible for services due to missed diagnoses, behavioural concerns or limited buy-in from the caregiver.

Healthcare providers are asking for a strong development of curriculum and further education in order to implement cognitive rehabilitation into their practices. Continuing education has been discussed widely in the knowledge translation literature as the number one facilitating factor to implementation of novel clinical practice guidelines by healthcare providers [112]. Importantly, my research not only obtained the need for continuing education by healthcare providers but also how they would like to access their information. Structuring time in the work day for improving empirical foundations was important to staff, and, there was a large consensus surrounding implementing dedicated time for professional development and learning within the current workplace structure. Although education was seen as important in implementing new therapeutic techniques, healthcare providers discussed their lack of time and supervisors' lack of interest in changing from the status quo as barriers to this request. Moreover, healthcare providers also suggested a series of examples that would make receiving information more accessible, such as standardized practices, additional conferences or presentations as well as access to online resources. Understanding how healthcare providers want to access their continuing education material will be important in completing the knowledge

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translation process and bridging the 7-year gap that exists between published literature being executed into clinical practice. This research study begins to fill the gap in understanding health care providers' implementation of cognitive rehabilitation and provides suggestions of how to successfully overcome the long waiting period in knowledge translation. Moreover, it provides areas of improvement for increasing the feasibility and capacity of cognitive rehabilitation programs by addressing problem areas of concern as well as continuing to allow healthcare providers the space and flexibility within their workplaces to implement this type of care.

4.1 Healthcare Provider Capacity Building

Two main approaches or methodologies in capacity building are known as the “bottom-up organizational approach”, which includes as an example, provision of skills to staff. The other, a “top down organizational approach” includes effective organizational infrastructure. Both of these capacity building methodologies highlight areas for improvement in capacity building for cognitive rehabilitation HCP which they themselves have addressed within the data. Capacity building is difficult to develop without external assistance, which was echoed by our healthcare providers in their call for a more efficient patient management system, funding from the government and a recognized national priority for cognitive rehabilitation implementation. Capacity building also requires building on available problem-solving abilities and other strengths in staff. HCP suggested the main competencies they have are creativity, flexibility and empathy, which may contribute to effective problem solving.

It has been suggested that effective capacity building interventions involve a commitment to continuous training and learning rather than staff being sent to external

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training or consultants presenting within the workplace [115]. HCP who participated in this study mirrored this same sentiment, and hoped for their organizations to support them in continuing to grow their knowledge, skill and competency base by making time for learning in the workplace and seeing continuing education as part of their professional role and obligations.

HCP also talked about the importance of system readiness and access to resources within their workplaces. For instance, additional resources other than staffing, including the call for more standardized training packages to implement with clients and an overall restructuring of the organization including adding cognitive rehabilitation program seats, and communicating more effectively with other team partners and community stakeholders. This increased level of partnership between and across communities tied into HCP calls for continuity of care. A main component of capacity building is high levels of cooperation and trust [116], and HCP recognized the need for partnerships across organizations and healthcare teams. This increased level of communication and knowledge flow will positively impact HCP at both professional organizations and may help contribute to increased capacity for the community at large. Having an understanding of the obstacles that are inhibiting HCP from implementing cognitive rehabilitation, and mapping them on to areas of improvement in capacity building will begin to assist HCP in overcoming these challenges and making cognitive rehabilitation implementation quicker and easier, with a trained healthcare workforce who have the knowledge, skills, infrastructure and communication necessary to work in a sustainable and collaborative manner . In sum, capacity building will change and challenge the HCP and their organizations ability to effectively manage and address health concerns for their

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clients through improved system structures, a wide range of new approaches and staff training. In particular, increasing HCP expertise that is developed through the bottom up organizational approach and ensuring system readiness through top down organizational approaches will be essential in providing proficient planning, implementation and evaluation of cognitive rehabilitation techniques for PWD.

4.1 Implications for Future Research and Practice

For individuals suffering from dementia, rehabilitation services are essential in providing evidence informed care and may improve both functional and cognitive concerns and improve quality of life, providing relief for both client and caregiver. This qualitative interpretive study has examined health care professional's experiences and perceptions surrounding the capacity for cognitive rehabilitation throughout the Central East LHIN. This study adds to the growing knowledge base of cognitive rehabilitation and will allow for improved dementia capacity planning in order to create and maintain sustainable, relevant and empirically informed cognitive rehabilitation practises for those with dementia and their families. As the dementia population continues to grow at an alarming rate, healthcare providers have insisted they do not have the capacity to fulfill the upcoming needs. Many healthcare providers indicated that they were not familiar with cognitive rehabilitation terms and suggested they may utilize some, but not all subtypes of cognitive training services. Moreover, various barriers exist in successfully implementing cognitive rehabilitation care as discussed above.

Some of the issues that were identified by healthcare providers have been seen previously in the literature, and some were novel. For instance, continuity of care has not only been a topic of concern more generally across several health conditions, but has

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been explored as an indicator for poor health outcomes in those with dementia [113]. Healthcare providers in our study agreed that the fragmented system is difficult for clients and caregivers to manage, but also provided new insights into how to overcome discipline-based silos and enhance communication between dementia healthcare providers across specialties. Given the repeated call to improve continuity of care for those accessing dementia services, and new insights into how and why this is important, improving in this regard may help lower the burden of dementia throughout the Central East LHIN. In such, when designing healthcare systems these recommendations should remain in mind. My study highlights the barriers to access for clients trying to receive cognitive rehabilitation and focuses not only on physical barriers such as transportation, but also psychological barriers to receiving care. There is an overwhelming need to address both the physical barriers of transportation, cost and human resourcing constraints, but also to be mindful of the stigma that still surrounds dementia care and move forward with the understanding that this will necessarily permeate cognitive rehabilitation services within this population.

Lastly, education and knowledge translation continue to play an important role in advancing dementia care and informing healthcare providers who are the front-line service providers for cognitive rehabilitation. Future studies should take into account our findings about accessible continuing education initiatives for healthcare staff, and their call for more standardized training packages to both learn from and provide to their clients. Continuing education practices can both improve the health of patients first and foremost, but also provide a consistent improvement among healthcare staffing professional practise and can give healthcare providers the opportunities to practice new

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skills. Future research should take into consideration the best practices in continuing education for healthcare professionals across a variety of settings including conferences, interactive online workshops and formal training with an emphasis on the particular strategies outlined by our participants in order to ensure accessible and consistent educational attainments by increasingly busy, overburdened healthcare staff. In addition, healthcare providers would benefit from decision support tools to assist them in implementing the cognitive rehabilitation subtypes to the clients that would most benefit from them. For instance, it is understood in the literature that cognitive training is most beneficial for individuals experiencing mild decline, cognitive rehabilitation for those who are experiencing mild to moderate decline and cognitive stimulation for those who are experiencing severe levels of decline due to dementia. However, at present no decision support tools are available to help those with dementia receive the subtype of cognitive rehabilitation that is most successful to each level of decline. Further delineation of these levels of decline as well as the targeted cognitive rehabilitation subtypes best suited to each would assist HCP in improving their capacity to make evidence informed decisions about what type of cognitive rehabilitation their clients need. These decision support tools may improve cognitive rehabilitation practises and standards of care for healthcare teams. This will allow for specific tailoring of treatment according to level of decline or risk level, and will help improve the overall consistency of healthcare delivery and avoid therapeutic interventions to clients with dementia who might not receive the maximum benefit available to them [114]. Future research should also investigate HCP perspectives surrounding their acceptance and utilization of these tools in improving their healthcare practices.

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4.3 Recommendations for Accessible Education

In order to successfully implement cognitive rehabilitation, HCP suggest they need an increase in access to educational tools as well as education being promoted as a priority within their workplaces. HCP in this study suggested that implementing mandatory or recommended training times that work cohesively with their schedule, and ensuring continuing education initiatives occur “on the clock” during working hours is extremely important in enhancing education among healthcare practitioners. Although many HCP in this study did suggest they felt a sense of professional obligation or duty to stay informed with new therapeutic techniques for clients with dementia, they often faced resistance from management and senior staffing leadership styles that made accessing, participating, and implementing new techniques with clients difficult, leading to a “rut in programming”.

At present, most continuing education for health care staff is a series of informal conversations and discussions between healthcare staff and using internet sources to gain new information and program development techniques. However, approximately half of the HCP who participated in this study suggested they wanted more formal implementation of continuing education initiatives. Some recommendations made by HCP included half day in-person courses where they could watch demonstrations and practice hands on cognitive rehabilitation techniques, webinars to participate in if in person training was not available, and additional reading material including booklets and informational websites. For those HCP who were interested in informal learning strategies, it was important to participants that the learning they participated in was self-directed, due to the many demands on their time. Informal strategies that worked for HCP

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included journal reading, informal discussions, reading textbooks, calling other healthcare providers or community members and other independent learning methods.

4.4 Future Cognitive Rehabilitation Recommendations

Lastly, my research study also posed a final question to participants to address their beliefs surrounding their recommendations for cognitive rehabilitation in the future. Their collective responses can be summarized in the following statements:

1. Provide more education and evidence of cognitive rehabilitation benefits to clients, and share this information with healthcare providers in an accessible format
2. Make cognitive rehabilitation more accessible in a community setting, including offering rehabilitation services in all areas, , and provide training to staff who are already working in these areas.
3. Incorporate cognitive rehabilitation into programs that are guided with trained staff such as those working within Adult Day Programs or other programs in our community.
4. Provide more resources to increase capacity and awareness of cognitive rehabilitation among healthcare providers.
5. Get a corporate initiative that supports this work at all levels and improve funding for non-profit agencies for staff training and hiring in order to provide both individual and group interventions at a reasonable cost to the caregiver.
6. Develop a stronger focus on cognitive rehabilitation in our healthcare system.

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4.5 Study Strengths and Limitations

This qualitative interpretative study utilized thematic analysis using a multi-stage study design with maximum variation sampling technique to examine the capacity for providing cognitive rehabilitation to persons with dementia from the healthcare providers' perspectives. The use of multiple data sets collected from a diversified sample of healthcare providers across the Central East LHIN in multiple service provider settings is a primary strength of this research study. This pragmatic approach is complementary in order to provide a more complete picture of the research phenomenon.

A primary disadvantage of using a qualitative methodology is that it cannot be used to draw any definite causal relationship due to the fact that it was not experimental in nature. As such, much of the study findings that were generated is exploratory and descriptive in nature. By following Braun and Clarke's thematic analysis approach and the use of reflexivity, interpretation of study data was investigated to ensure the findings were generated from the participants' perspectives and not misconstrued by the researcher. The purpose of this research was not meant to achieve generalizability, but rather it is about achieving a deeper understanding about the lived experiences of the health care providers who provide cognitive rehabilitation.

Phase One of the study included a cross-sectional questionnaire which was considered to be the most appropriate way to reach a large target audience as well as being efficient and cost effective. This questionnaire allowed us to obtain an initial descriptive overview of the cognitive rehabilitation which was used to help develop the interview guide and probing questions for Phase Two of the study. Trends and patterns could be identified to determine why and how healthcare providers offered these services,

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their initial thoughts surrounding their capacity to offer this type of care as well as the particular barriers they faced, strategies they used and limitations and facilitating factors they encountered. Web-based questionnaires were distributed using the snowball technique, where we achieved the ability of recruiting key informants who can provide insight into our research questions. Web based questionnaires also have an advantage as they are typically quicker to complete and more accurate than face to face or telephone questionnaires [117]. Since the terminology of cognitive rehabilitation are generally novel, associated definitions were available within the questionnaire itself, to allow for consistency of understanding of questionnaire items by the respondents. Additionally, the face to face interviews conducted in Phase Two of the study offered various strengths. These interviews allowed for an increased depth and breadth of data collection and a more nuanced level of understanding of the responses due to the ability of the researcher to interact with the participants in real time. Additional opportunities exist to probe for explanations and more details can be obtained during the duration of the interviews. Another strength of the study is the auditability of study findings. Meticulous field notes were taken throughout the data collection and analysis process with illustrative quotes provided to generate the five overarching themes in context. This audit trail ensures that the conclusions drawn from both phases provided integrated findings that are driven from the data themselves.

Although the methodology had a series of strengths, limitations exist within this research. In the Phase One questionnaire, many respondents skipped questions or did not complete the questionnaire in full. Respondents lacked the opportunities to ask for clarification of questions, leading to missing data that may have affected the validity of

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responses. There were also limitations in the questionnaire. Since the questionnaire is newly developed, reliability testing has not been previously performed, however this qualitative questionnaire has been developed in consultation with the content experts in the field to ensure its content validity. Another limitation in the proposed study is the potential for selection bias from the individuals we are recruiting to complete the questionnaire. We are attempting to overcome this selection bias through maximum variation sampling technique to help minimize the potential of selection bias by promoting the diversity and inclusiveness of our study sample to obtain the most comprehensive view of the phenomenon of interest. Although we attempted to maintain a representative sample, it must be noted that the largest group of respondents were from the employment category of Registered Nurse or Practical Nurse (37% of total sample). Another limitation included the possibility of response biases in the questionnaires and interviews, including recall biases related to accurate recollection of events and social desirability biases associated with reflecting a good image of their workplace.

Additionally, I was restricted to the Central East Region of Ontario as the recruitment site, and this may present a potential bias in the study sample compared with other LHIN locations due to cultural and geographical differences. Additionally, no data was collected regarding the experiences of the individuals receiving cognitive rehabilitation. The focus of our research was to explore the utilization of cognitive rehabilitation from the perspective of the healthcare workers and not on the clients utilizing these services. Understanding care recipient's perspectives should be an important future direction of research in the field of cognitive rehabilitation. Lastly, the

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data transcriptions were performed solely by the researcher where, having peer debriefing to review the transcriptions to ensure its accuracy would have been beneficial.

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APPENDICES

Appendix A.

A1. Initial Invitation Email

Dear <First Name, Inputted by our Community Organizations Coordinator Kelly Kay>:

I am writing to request your institutions participation in a *Health Care Providers Capacity for Cognitive Rehabilitation in Dementia* Questionnaire.

The purpose of the Questionnaire is to engage healthcare providers to provide insight and knowledge as unique stakeholders to the current practices and capacity for cognitive rehabilitation for individuals with Dementia throughout the Central East LHIN. The questionnaire is being completed under the supervision of Dr. Emma Bartfay and Meagan Quesnelle, affiliated with Ontario Tech University.

The information from the questionnaire will be used to understand both the current capacity and perceived upcoming barriers of assisting the increasing Dementia population in Canada. Your participation in this questionnaire is completely voluntary, and you may opt out of any question. All of your responses will be kept confidential and will only be used for quantitative statistical purposes. If used for qualitative purposes, written non-numerical responses will be reported without your identifying information attached. The questionnaire will take approximately 10 minutes to complete.

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The questionnaire will be administered to this email address in the upcoming week.

As the Program Director/Executive director, please pass this information along to the individuals in your respective institutions who are responsible for administering services to your clients with dementia or cognitive impairment, if any, whether they be nurse practitioners, occupational therapists, volunteers etc. Multiple individuals from your institution can complete this upcoming survey.

This is an initial invitation letter only. To complete the survey, please follow the survey link that will be provided in the *upcoming* email. An informed consent form has been attached for your review. If you have any questions about this upcoming survey, please contact Meagan Quesnelle or Dr. Emma Bartfay at:

Meagan Quesnelle: meagan.quesnelle@uoit.net, or 289-675-6642

Dr. Emma Bartfay: emma.bartfay@uoit.ca, or 905-721-8668 x2950

Thank you in advance for providing this important feedback.

Sincerely,

Kelly Kay Signature Line Here

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Appendix B.

B1. Questionnaire Informed Consent Form

Health Care Providers Capacity for Cognitive Rehabilitation in Dementia

You are invited to participate in a research study entitled Health Care Providers Capacity for Cognitive Rehabilitation in Dementia. This study has been reviewed the University of Ontario Institute of Technology Research Ethics Board [15009] and originally approved on February 22nd, 2019. Please read this consent form carefully, and feel free to ask the Researcher any questions that you might have about the study. If you have any questions about your rights as a participant in this study, please contact the Research Ethics Coordinator at 905 721 8668 ext. 3693 or researchethics@uoit.ca.

Researcher(s): Dr. Emma Bartfay, Meagan Quesnelle

Principal Investigator, Faculty Supervisor, Students, etc.: Dr. Emma Bartfay, Meagan Quesnelle

Departmental and institutional affiliation(s): Faculty of Health Sciences

Contact number(s)/email: emma.bartfay@uoit.ca ; Phone: 905.721.8668 ext. 2950 or Meagan.quesnelle@uoit.ca

External Funder/Sponsor: N/A

Purpose and Procedure:

The purpose of the questionnaire is to understand the state of the field related to cognitive rehabilitation for persons with dementia. It serves to answer the question: How

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do existing dementia service providers support the use of cognitive rehabilitation strategies among persons with dementia?

Participants will be asked to contribute to an online questionnaire delivered to them via email. This questionnaire should take no more than 10 minutes in total to complete. The participant will be responsible for answering questions about their current employment institution to ascertain if cognitive rehabilitation practises are being prescribed or recommended within their institution and to what extent these practises fall within the cognitive rehabilitation scope. The participants will be provided with this consent form via email before beginning the questionnaire.

Potential Benefits:

By completing the questionnaire, participants may gain knowledge in the field of cognitive rehabilitation techniques for persons with dementia and will be helping the researchers gain a better understanding of the current scope of cognitive rehabilitation for persons with dementia in the Central East LHIN.

The results of the questionnaire will help inform policy and advance knowledge in the field of cognitive rehabilitation for persons with dementia and to ensure that the Central East LHIN is providing dementia clients with the most comprehensive and evidence informed practice possible.

Potential Risk or Discomforts:

There are no reasonable foreseeable risks (physical, psychological or social) for the participants that complete the questionnaire. Participants are not required to answer any questions they do not wish to and can withdraw from the study at any time.

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Participants will be provided contact information for the research ethics coordinator should they have any questions about their participation.

Storage of Data:

Email addresses from respondents will be directly attached to the responses that are provided to the questions since the questionnaire will be administered via email. However, once data collection is complete the responses will be unlinked from the email addresses for the purposes of data analysis. Email addresses will only be saved temporarily on a password secured computer until all data collection is complete. Participant responses will be saved temporarily on a password secured computer for purposes of analysis. This information will only be shared with the student investigator and the primary investigator (i.e., the research team). All electronic data from this study will be destroyed seven years after publication of the research.

Confidentiality:

Information that will be collected about participants include the name of the institution in which they are currently employed, their professional designation at the institution and the sub-regional location of this institution. The purpose of collecting this information is to enable the research team to identify which stratum of dementia care the responses come from, whether it is a Geriatric Assessment and Intervention Network, a Primary Memory Clinic or an Alzheimer Society. The only individuals who will have access to the identity of the participants are the research team.

All responses are stored on a password protected computer to safeguard the confidentiality of participants. Your privacy shall be respected. No information about

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your identity will be shared or published without your permission, unless required by law. Confidentiality will be provided to the fullest extent possible by law, professional practice, and ethical codes of conduct. Please note that confidentiality cannot be guaranteed while data are in transit over the Internet.

Right to Withdraw:

Your participation is voluntary, and you can answer only those questions that you are comfortable with. The information that is shared will be held in strict confidence and discussed only with the research team.

You have the right to withdraw from the study at any time, without loss of relevant entitlements, for example withdrawing from this study will not affect your employment. There are no consequences to participants who withdraw. However, after completion of the Questionnaire and Interview, the data will be anonymized. Since we are selecting those we interview based on their questionnaire responses, we cannot anonymize until the interviews are completed. However, after the interviews are complete, we will anonymize both the interview and the survey data by using participant number ID's instead of identifiable names. As such, participants will only be able to withdraw their data until the interview process is complete (Approximately two weeks after your interview).

Removal from Study:

If you wish to be removed from the study, you need not offer any reason for making this request. Please contact the research team to inform us of your withdrawal, and close and delete the email with the survey link. No additional steps are required.

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Conflict of Interest:

The researchers do not have any conflicts of interest to declare for this study, and there will be no commercialization from the results of this study.

Compensation:

Compensation is not applicable for this study.

Debriefing and Dissemination of Results:

After the data have been collected and analyzed, participants can request to be informed of the results of the study by contacting the research team in April 2019. If the results of this study will be published, participants are invited to contact the researcher about the results via email or telephone.

Participant Concerns and Reporting:

If you have any questions concerning the research study or experience any discomfort related to the study, please contact the researcher Dr. Emma Bartfay at emma.bartfay@uoit.ca or by phone: 905.721.8668 ext. 2950.

Any questions regarding your rights as a participant, complaints or adverse events may be addressed to Research Ethics Board through the Research Ethics Coordinator – researchethics@uoit.ca or 905.721.8668 x. 3693. By consenting, you do not waive any rights to legal recourse in the event of research-related harm.

Online Consent to Participate:

1. I have read the consent form and understand the study being described.

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2. I have had an opportunity to ask questions and my questions have been answered. I am free to ask questions about the study in the future.
3. I freely consent to participate in the research study, understanding that I may discontinue participation at any time without penalty. A copy of this Consent Form has been made available to me.

I Agree

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Appendix C.

C1. Questionnaire (Survey Monkey)

Health Care Providers Capacity for Cognitive Rehabilitation in Dementia Survey

Study Number 15009

The following 24 questions ask you about: (1) General questions about you, (2) cognitive rehabilitation recommendations (3) follow up and specific cognitive strategies used with clients and (4) rehabilitation effectiveness. Some of the questions will provide examples for you to consider, and will ask you to provide a short answer. There are no right or wrong answers.

Section 1: Description of Cognitive Rehabilitation and questions about your experiences:

Please review the following definitions prior to completing the survey:

Cognitive Rehabilitation is an umbrella term used to capture the many different forms of cognitive therapy programs in helping to rehabilitate the brain. For someone with dementia, cognitive rehabilitation encompasses any program, activity or stimulation that attempts to activate the brain in those with dementia. Generally, cognitive rehabilitation is split into three main types:

1. Cognitive Training:

Cognitive training uses repeated practice of specific cognitive tasks applied to everyday activities in a group or individual setting. Cognitive tasks usually advance with difficulty as the training continues (may range in difficulty, or use self-paced

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levels of difficulty; example: the client themselves paces the cognitive activity to their preferred levels of difficulty). The main features of cognitive training are: repeated guided practice (example: repeatedly attempting to remember word lists, repetition in performing attention sustaining tasks, repeatedly attempting to strengthen working memory through holding items in short term memory), use of standardized tasks, theoretically motivated strategies, range of activities (adaptive) and the aim is to improve an isolated cognitive domain with the possibility of generalizing to a task that was not trained (example: practicing recall to assist with face recognition, but may generalize to remembering names or association such as “sister” as well). Cognitive training is most commonly offered to those with mild cognitive impairment or mild dementia.

2. Cognitive Rehabilitation:

Cognitive rehabilitation is highly individualized, more so than cognitive training. Strategies are developed to address personally relevant, functional and social goals, empowering people with dementia. Like cognitive training, it may be targeted at improving specific individual cognitive deficits, however it focuses on a restorative approach, building on the abilities of the client with dementia that are retained. The main features of cognitive rehabilitation are: individualized goals, aims to improve everyday function/ADL (example: after naming articles of clothing, client would indicate which season each item of clothing is associated with) and the use of a compensatory approach (use of post it notes, digital voice recorder, white board, labelling drawers or dressers). Cognitive rehabilitation is most commonly offered to those with mild to moderate dementia.

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3. Cognitive Stimulation:

Cognitive stimulation is an individual or group session that aims to stimulate and engage those with dementia in a person-centered manner. The use of reality orientation techniques (using calendars, journals, videos, pictures of family) is common. The goal is to preserve social and cognitive skills for as long as possible. The main features of cognitive stimulation are: wide range of activities, group format, and significant emphasis on social interaction, not adaptive, use of reality orientation or reminiscence therapy. The aim is for general improvement in cognitive function.

Section 1.1: Demographics

1. Please indicate the type of institution you belong to (example: Alzheimer Society, Geriatric Assessment and Intervention Network Member, Primary Care Memory Clinic Member etc.)

2. What is the target area or catchment area that your institution aims to serve? As a reminder, the 7 “Sub-Regions” of the Central East LHIN are: Durham North East, Durham West, Haliburton County and City of Kawartha Lakes, Northumberland County, Peterborough City and County, Scarborough North and Scarborough South

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3. What is your designation at the institution in which you are currently employed?

Some examples include: Nurse, Occupational Therapist, Personal Support Worker, Volunteer etc.

4. How long have you been employed/working with your current institution? Please be sure to indicate if you are referring to months/years

5. How many clients is your institution seeing **monthly**?

6. Of these, how many are dealing with cognitive impairments (e.g.: Mild Cognitive Impairment, Dementias)

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7. What type of clients do you serve most frequently at your place of work? Examples may include: Clients with Alzheimer's disease, clients with other types of dementia, clients with mild cognitive impairment, dealing only with caregivers, clients with no memory impairments etc.

Section 2: Is Cognitive Rehabilitation being recommended?

1. Previous to the completion of this questionnaire, were you familiar with any of the above definitions of cognitive therapy or rehabilitation for clients with dementia? Please indicate yes or no as well as specifying which definitions you were or were not familiar with.

2. Using the definitions that were presented at the beginning of this questionnaire, does your institution offer any programs or recommendations to your clients with dementia that fit this above definition? If "No", does your institution use alternative terms? If so, please specify. If "Yes", Please explain the program(s) or recommendation(s):

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3. If you have a cognitive rehabilitation program(s) or make recommendations that you consider cognitively beneficial, how many clients **are you providing these programs or recommendations to** per month?

4. If you have a cognitive rehabilitation program or make recommendations that you consider cognitively beneficial, **how many times per week** are the clients involved in cognitive training?

5. If you have a cognitive rehabilitation program(s) or make recommendations that you consider cognitively beneficial, **how long per session** are the clients involved in the cognitive therapy program?

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6. If you have a cognitive rehabilitation program(s) or make recommendations that you consider cognitively beneficial, how many clients are **on the waiting list (if any)** for these services per month?

7. If you do have clients on a waiting list, how long they have they been on the waiting list?

Section 3: The Nature of Cognitive Rehabilitation Recommendations

1. If you have a cognitive rehabilitation program(s) or make recommendations that you consider cognitively beneficial, what type of follow up is provided to the client?

Some examples include:

Provide documentation such as educational material to the family, Reschedule client for additional visit, Telephone follow up, Follow up is Not Completed etc.

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2. If you have a cognitive rehabilitation program(s) or make recommendations that you consider cognitively beneficial and follow up is provided, **how often** are clients followed up with?

3. Using the definitions presented to you at the beginning of this survey (cognitive training, cognitive rehabilitation or cognitive stimulation) which one(s) most accurately represent the cognitive program(s) you offer or recommend to your clients with dementia?

4. Can you provide examples of your experience with the effectiveness of Cognitive Rehabilitation Programs for seniors with Dementia?

5. Can you provide examples of effective ways to develop increased capacity to meet the needs of dementia population using the services you currently offer?

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6. What are your perspectives of the level of capacity that you possess to address the future needs of dementia population using the services you currently offer?

7. What are some facilitating factors that help your program(s) or recommendation(s) succeed with a dementia population? Some examples may include: Support from Caregivers, Patient Engagement/Motivation, Mutual Goal Agreement between Staff and Client etc.

8. Do you believe the follow up that you or your institution offer are helpful? If “Yes”, how so? If “No”, Why Not?

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9. From the perspective of a service provider, do you believe there are barriers for clients with dementia to access your services or follow through with your recommendations? Some examples may include: Not enough funding, not enough staff, not enough time to provide program etc.

10. What are your recommendations about cognitive rehabilitation for the future?

We appreciate you taking the time to provide us with your suggestions and feedback!

Thank you!

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Appendix D.

D1. Email Invitation with Survey Link Script

Dear <First Name, Inputted by our Community Organizations Coordinator Kelly Kay>:

I am writing to request your institutions participation in a *Health Care Providers Capacity for Cognitive Rehabilitation in Dementia* Questionnaire. The purpose of the Questionnaire is to engage healthcare providers to provide insight and knowledge as unique stakeholders to the current practices and capacity for cognitive rehabilitation for individuals with Dementia throughout the Central East LHIN. The questionnaire is being completed under the supervision of Dr. Emma Bartfay and Meagan Quesnelle, affiliated with the University Of Ontario Institute Of Technology.

The information from the questionnaire will be used to understand both the current capacity and perceived upcoming barriers of assisting the increasing Dementia population in Canada. Your participation in this questionnaire is completely voluntary, and you may opt out of any question. All of your responses will be kept confidential and will only be used for quantitative statistical purposes. If used for qualitative purposes, written non-numerical responses will be reported without your identifying information attached. The questionnaire will take approximately 10 minutes to complete.

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To participate, please click on the following link:

<https://www.surveymonkey.com/r/BVTBCPL>

As the Program Director/Executive director, please pass this information along to the individuals in your respective institutions who are responsible for administering services to your clients with dementia or cognitive impairment, if any, whether they be nurse practitioners, occupational therapists, volunteers etc. Multiple individuals from your institution can complete this upcoming survey.

If you have any questions about this survey, or difficulty in accessing the site or completing the survey, please contact Meagan Quesnelle or Dr. Emma Bartfay at:

Meagan Quesnelle: meagan.quesnelle@uoit.net, or 289-675-6642

Dr. Emma Bartfay: emma.bartfay@uoit.ca, or 905-721-8668 x2950

Thank you in advance for providing this important feedback.

Sincerely,

Kelly Kay Signature Line Here

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Appendix E.

E1. Follow Up Script for Questionnaire Non-Respondents

You were recently invited to participate in an online questionnaire regarding Cognitive Rehabilitation from your Program Director/Executive Director. This questionnaire is still available so that you may provide feedback. If you have not already completed the survey, we encourage you to take a few minutes to do so before August 1st, 2019. Please take a few minutes to complete the survey, as your feedback as healthcare stakeholders will inform our research study immensely. You have the right to refuse to answer any question. Your responses are confidential.

Access the questionnaire at: <https://www.surveymonkey.com/r/BVTBCPL>

PLEASE NOTE: Surveys will CLOSE on August 1st at 5:00PM.

Thank you in advance for your participation

If you have any questions concerning the research study or experience any discomfort related to the study, please contact the researcher Dr. Emma Bartfay at emma.bartfay@uoit.ca or by phone: 905.721.8668 ext. 2950.

Any questions regarding your rights as a participant, complaints or adverse events may be addressed to Research Ethics Board through the Research Ethics Coordinator – researchethics@uoit.ca or 905.721.8668 x. 3693. By consenting, you do not waive any rights to legal recourse in the event of research-related harm.

Sincerely, Kelly Kay

Meagan Quesnelle & Dr. Emma Bartfay

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Appendix F.

F1. Interview Informed Consent

Dear Sir or Madam,

My name is Meagan Quesnelle and I am a Master's student in the Health Sciences Stream at the University of Ontario Institute of Technology (UOIT). I am working on a research project under the supervision of Dr. Emma Bartfay.

I am writing to you today to invite you to participate in a study entitled "Health Care Providers Capacity for Cognitive Rehabilitation in Dementia". You recently completed an online questionnaire and we hope to have you elaborate on your responses in a one time interview.

The purpose of the interview is to explore the capacity of providing cognitive rehabilitation programs in the Central East LHIN from the perspective of key healthcare informant members, and to build on important themes and concepts that were seen in the questionnaire stage to get a more substantial understanding of the scope of cognitive rehabilitation.

This study involves one 60 minute (approximate) interview that will take place in a mutually convenient, safe location. With your consent, interviews will be audio-recorded. Once the recording has been transcribed, the audio-recording will be destroyed.

This interview has no foreseen professional or emotional risks, and care will be taken to protect your identity. You will have the right to end your participation

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in the study at any time, for any reason. If you choose to withdraw, all the information you have provided will be destroyed. All research data, including audio-recordings and any notes will be encrypted. Any hard copies of data (including any handwritten notes or USB keys) will be kept in a locked cabinet at UOIT. Research data will only be accessible by the researcher and the research supervisor. The ethics protocol for this project was reviewed by the UOIT Research Ethics Board, which provided clearance to carry out the research.

If you have any questions concerning the research study or experience any discomfort related to the study, please contact the researcher Dr. Emma Bartfay at emma.bartfay@uoit.ca or by phone: 905.721.8668 ext. 2950. Any questions regarding your rights as a participant, complaints or adverse events may be addressed to Research Ethics Board through the Research Ethics Coordinator – researchethics@uoit.ca or 905.721.8668 x. 3693. By consenting, you do not waive any rights to legal recourse in the event of research-related harm.

Please reply to this email to indicate your interest,

Sincerely,

Meagan Quesnelle & Dr. Emma Bartfay

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Appendix G.

G1. Interview Informed Consent

Health Care Providers Capacity for Cognitive Rehabilitation in Dementia

You are invited to participate in a research study entitled Health Care Providers Capacity for Cognitive Rehabilitation in Dementia. This study has been reviewed the University of Ontario Institute of Technology Research Ethics Board [15009] and originally approved on February 22nd, 2019.

Please read this consent form carefully, and feel free to ask the Researcher any questions that you might have about the study. If you have any questions about your rights as a participant in this study, please contact the Research Ethics Coordinator at 905 721 8668 ext. 3693 or researchethics@uoit.ca.

Researcher(s): Dr. Emma Bartfay, Meagan Quesnelle

Principal Investigator, Faculty Supervisor, Students, etc.: Dr. Emma Bartfay, Meagan Quesnelle

Departmental and institutional affiliation(s): Faculty of Health Sciences

Contact number(s)/email: emma.bartfay@uoit.ca ; Phone: 905.721.8668 ext. 2950 or Meagan.quesnelle@uoit.ca

External Funder/Sponsor: N/A

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Purpose and Procedure:

The purpose of the interview is to explore the capacity of providing cognitive rehabilitation programs in the Central East LHIN from the perspective of key informant members, and to build on important themes and concepts that were seen in the questionnaire stage to get a more substantial understanding of the scope of cognitive rehabilitation. Participants will be asked to answer a series of open ended questions conducted in a quiet space, preferably in their own place of employment or a room in the researchers' institutions. This interview should take no more than 1 hour in total to complete. The participant will be responsible for answering questions about the range of strategies being used in their cognitive rehabilitation practice, their capacity to meet population needs, compliance and barriers, and eligibility and program outcomes. The participants will be provided with this consent form before beginning the interview.

Potential Benefits:

By completing the interview, participants may gain knowledge in the field of cognitive rehabilitation techniques for persons with dementia and will be helping the researchers gain a better understanding of the current scope of cognitive rehabilitation for persons with dementia in the Central East LHIN. The results of the questionnaire will help inform policy and advance knowledge in the field of cognitive rehabilitation for persons with dementia and to ensure that the Central East LHIN is providing dementia clients with the most comprehensive and evidence informed practice possible.

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Potential Risk or Discomforts:

There are no reasonable foreseeable risks (physical, psychological or social) for the participants that complete the questionnaire. Participants are not required to answer any questions they do not wish to and can withdraw from the study at any time.

Participants will be provided contact information for the research ethics coordinator should they have any questions about their participation.

Storage of Data:

Once data collection is complete the responses will be unlinked from the respondents name for the purposes of data analysis. Participant responses will be saved temporarily on a password secured computer for purposes of transcription and analysis. This information will only be shared with the student investigator and the primary investigator (i.e., the research team). All electronic data from this study will be destroyed seven years after publication of the research.

Confidentiality:

Information that will be collected about participants include the name of the institution in which they are currently employed, their professional designation at the institution and the location of this institution. The purpose of collecting this information is to enable the research team to identify which stratum of dementia care the responses come from, whether it is a Geriatric Assessment and Intervention Network, a Primary Memory Clinic or an Alzheimer Society. The only individuals who will have access to the identity of the participants are the research team.

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All responses are stored on a password protected computer to safeguard the confidentiality and anonymity of participants. Your privacy shall be respected. No information about your identity will be shared or published without your permission, unless required by law. Confidentiality will be provided to the fullest extent possible by law, professional practice, and ethical codes of conduct. Please note that confidentiality cannot be guaranteed while data are in transit over the Internet.

Right to Withdraw:

Your participation is voluntary, and you can answer only those questions that you are comfortable with. The information that is shared will be held in strict confidence and discussed only with the research team.

You have the right to withdraw from the study at any time, without loss of relevant entitlements, for example withdrawing from this study will not affect your employment. There are no consequences to participants who withdraw. However, after completion of the Questionnaire and Interview, the data will be anonymized. Since we are selecting those we interview based on their questionnaire responses, we cannot anonymize until the interviews are completed. However, after the interviews are complete, we will anonymize both the interview and the survey data by using participant number ID's instead of identifiable names. As such, participants will only be able to withdraw their data until the interview process is complete (Approximately two weeks after your interview).

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Removal from Study:

If you wish to be removed from the study, you need not offer any reason for making this request. Please contact the research team to inform us of your withdrawal, and close and delete the email with the survey link. No additional steps are required.

Conflict of Interest:

The researchers do not have any conflicts of interest to declare for this study, and there will be no commercialization from the results of this study.

Compensation:

Compensation is not applicable for this study.

Debriefing and Dissemination of Results:

After the data have been collected and analyzed, participants can request to be informed of the results of the study by contacting the research team at any time. If the results of this study will be published, participants are invited to contact the researcher about the results.

Participant Concerns and Reporting:

If you have any questions concerning the research study or experience any discomfort related to the study, please contact the researcher Dr. Emma Bartfay at emma.bartfay@uoit.ca or by phone: 905.721.8668 ext. 2950.

THEMATIC ANALYSIS OF COGNITIVE REHABILITATION

Any questions regarding your rights as a participant, complaints or adverse events may be addressed to Research Ethics Board through the Research Ethics Coordinator – researchethics@uoit.ca or 905.721.8668 x. 3693. By consenting, you do not waive any rights to legal recourse in the event of research-related harm.

Consent to Participate:

1. I have read the consent form and understand the study being described.
2. I have had an opportunity to ask questions and my questions have been answered. I am free to ask questions about the study in the future.
3. I freely consent to participate in the research study, understanding that I may discontinue participation at any time without penalty. A copy of this Consent Form has been made available to me.

Please provide your signature below if you agree to the Consent Form

I Agree,

Appendix H.

H1. Interview Guide

Health Care Providers Capacity for Cognitive Rehabilitation in Dementia

INTERVIEW GUIDE DEVELOPMENT

Overall project goal

To explore dementia health care providers capacity of providing cognitive rehabilitation programs in the Central East LHIN, and to understand the current scope of cognitive rehabilitation practice in this area. This will allow for improved dementia capacity planning in order to create and maintain sustainable, relevant and empirically informed cognitive rehabilitation practises for those with dementia and their families.

Research questions

1. What is the current scope of practise regarding cognitive rehabilitation programs for clients with Dementia in the Central East LHIN?
2. What are the barriers and enablers/ facilitating factors to participating in and accessing these services?
3. Are services being delivered to the client with dementia appropriately based on their severity?
4. Does the Central East LHIN have the capacity to address the needs of clients with dementia?
5. How do service providers understand, implement and experience cognitive rehabilitation in their working environments with clients with dementia?

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6. What interprofessional networks are being used within cognitive rehabilitation practise in the Central East LHIN

Specific objectives

To use a semi-structured interview with key informant members that provide or oversee cognitive rehabilitation services to persons with dementia throughout the Central East LHIN to explore and identify:

- 1) The range of strategies being used in cognitive rehabilitation practice
- 2) How individuals are assessed for eligibility in these programs and how outcomes are evaluated
- 3) What are the levels of compliance and the perceived barriers to cognitive rehabilitation programmes

Potential Participants and Eligibility Criteria

The potential participants for the key informant interviews will include health care professionals such as nurses, occupational therapists and others that either implement or oversee (in the case of directors or executive directors, volunteers) cognitive rehabilitation programs for seniors with dementia throughout the sub-regions of the Central East LHIN. Additionally, perspectives from a caregiver point of view would enhance the cognitive rehabilitation discussion and in such, a caregiver that participates with, or is familiar with a cognitive rehabilitation program delivered in the LHIN could provide valuable insight.

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Interview guide development process

1. Develop interview guides for the key informants to be interviewed [5-7 total].

NOTE: Information obtained from the key informants will be from their views as a service provider and their comments cannot be generalized to equate with program participants thoughts and opinions.

1. Cross check questions with resources used for semi-structured interview guides with rehabilitation professionals, particularly those who deal with persons with cognitive impairments owing to dementia.
2. Guides reviewed by research team and updates made accordingly
3. Guides piloted with one key informant member, and amended as needed prior to any additional interviews

Interview procedures (reminder)

- Interviews will be approximately 1 hour long
- Audio-recorded with the participants' permission
- Conducted in a quiet space, preferably in their own place of employment or a room in the researchers' institutions.
- If participants are associated with each other, they will be interviewed separately

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Terms and definitions used

| | |
|--------------------------|--|
| Dementia | Dementia is not a specific disease. It's an overall term that describes a group of symptoms associated with a decline in memory or other thinking skills severe enough to reduce a person's ability to perform everyday activities. (Alzheimer's Association, 2018) |
| Cognitive Rehabilitation | Cognitive rehabilitation is highly individualized, more so than cognitive training. Strategies are developed to address personally relevant, functional and social goals, empowering people with dementia. Like cognitive training, it may be targeted at improving specific individual cognitive deficits, however it focuses on a restorative approach, building on the abilities of the client with dementia that are retained. The main features of cognitive rehabilitation are: individualized goals, aims to improve everyday function/ADL and the use of a compensatory approach. Cognitive rehabilitation is most commonly offered to those with mild to moderate dementia. |
| Cognitive Training | Cognitive training uses repeated practice of specific cognitive tasks applied to everyday activities in a group or individual setting. Cognitive tasks usually advance with difficulty as the training continues. The main features of cognitive training are: repeated guided practice, use of standardized tasks, theoretically motivated strategies, range of activities (adaptive) and the aim is to improve a isolated cognitive domain with the possibility of generalizing to a task that was not trained. Cognitive training is most commonly offered to those with mild cognitive impairment or mild dementia. |
| Cognitive Stimulation | Cognitive stimulation is an individual or group session that aims to stimulate and engage those with dementia in a person-centred manner. The use of reality orientation techniques (using calendars, journals, videos, pictures of family) is common. The goal is to preserve social and cognitive skills for as long as possible. The main features of cognitive stimulation are: wide range of activities, group format, significant emphasis on social interaction, not adaptive, use of reality orientation or reminiscence therapy. The aim is for general improvement in cognitive function. |

Interview guide content [1 set]

Demographics

Participant group (Alzheimer Society, GAIN, PCMC, Other)

Catchment Area the services are targeted to

Professional Designation at Place of Employment

Length of Employment

Number of clients seen monthly

What types of Clients seen (Mild/Moderate/Severe Dementia, No Dementia, Mild Cognitive Impairment)

Experience working with dementia

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Objective 1

What is the current scope of practise regarding cognitive rehabilitation programs for clients with Dementia in the Central East LHIN

Please explain the program and the strategies you use in this program to improve cognitive functioning in your clients?

How do you choose the most appropriate cognitive training for your clients to address the needs to that particular client at the stage of their illness?

Probes

How do you assess is what we are trying to get at, what standardized assessment tools do you use to assess the eligibility of the clients for a particular cognitive program?

What are some of the main competencies required to implement cognitive rehabilitation programs? Do you feel as though you have the necessary competencies?

What are these competencies – is it knowing how to respond to responsive behaviours, is it the escalating challenging behaviours, dealing with family members

How can your organization help you to continue growing these competencies?

What type of educational training would be most useful to support you to develop these competencies?

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Objective 2

What are the levels of compliance and the perceived barriers to cognitive rehabilitation programmes?

Probes

Do you feel as though you have the capacity to fill the needs of the pop. with what you offer?

What areas of your program do you believe are working well, and why do you believe they are working?

Do you believe any areas in your program are not working well, and why do you believe they are not working well?

Are persons with dementia usually compliant with the program? How do you overcome these issues with compliance – what strategies do you use to overcome non-adherence?

What are issues with compliance or adherence to the treatment plan?

Can you give me an example of a challenging case? Why was it challenging and how did you overcome this challenging case/issues? (This could be more than just a compliance)

What are some facilitating factors that help your program(s) or recommendation(s) succeed with a dementia population?

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Objective 3

Eligibility and Program Evaluation

What are the program outcomes and how do we evaluate these outcomes?

What are examples of positive outcomes or negative outcomes and how do we promote positive outcomes and mitigate negative outcomes?

How do you determine if an individual is eligible for a cognitive rehabilitation program?

How do you know Mr. X is eligible to participate? Referrals? Any testing?

How do we know when we can discharge them? Based on what assessment and criteria – what do you recommend when they are discharged?

What type of follow up do you provide to your clients with dementia and their family members (if any)?

What type of educational material do you provide? Pamphlet, Poster, Booklet?

Objective 4

Understanding the interprofessional nature of cognitive rehabilitation programmes

Probes

What are the roles of the caregiver in cognitive rehabilitation programmes and what is and their level of involvement in this type of program?

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Who are the healthcare professionals who are involved in this? Who are the interprofessional healthcare teams?

Who are the key team players?

What type of expertise do these key team players contribute to the success of the program?

Nurses, doctors, OT, PT.... Does an OT do it differently than a PT, than a nurse, or a doctor...

What are your recommendations about cognitive rehabilitation for the future?

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Appendix I.

II. Ethics Approval

J1. *Date:* February 22, 2019

To: Emma Bartfay

From: Ruth Milman, REB Chair

File # & Title: 15009 - Health Care Providers Capacity for Cognitive Rehabilitation in Dementia

Status: **APPROVED**

Current Expiry: February 01, 2020

Notwithstanding this approval, you are required to obtain/submit, to UOIT's Research Ethics Board, any relevant approvals/permissions required, prior to commencement of this project.

The University of Ontario, Institute of Technology (UOIT) Research Ethics Board (REB) has reviewed and approved the research study named above to ensure compliance with the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2 2014), the UOIT Research Ethics Policy and Procedures and associated regulations. As the Principal Investigator (PI), you are required to adhere to the research protocol described in the REB application as last reviewed and approved by the REB. In addition, you are responsible for obtaining any further approvals that might be required to complete your project.

Under the Tri-Council Policy Statement 2, the PI is responsible for complying with the continuing research ethics reviews requirements listed below:

Renewal Request Form: All approved projects are subject to an annual renewal process. Projects must be renewed or closed by the expiry date indicated above ("Current Expiry"). Projects not renewed 30 days post expiry date will be automatically suspended by the REB; projects not renewed 60 days post expiry date will be automatically closed by the REB. Once your file has been formally closed, a new submission will be required to open a new file.

Change Request Form: If the research plan, methods, and/or recruitment methods should change, please submit a change request application to the REB for review and approval prior to implementing the changes.

Adverse or Unexpected Events Form: Events must be reported to the REB within 72 hours after the event occurred with an indication of how these events affect (in the view of the Principal Investigator) the safety of the participants and the continuation of the protocol (i.e. un-anticipated or un-mitigated physical, social or psychological harm to a participant).

Research Project Completion Form: This form must be completed when the research study is concluded.

Thank you for your explanation of the requirement to use SurveyMonkey. We will accept the use of

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SurveyMonkey for this study. In the future, prior to commencing preparation of a study, please contact the Research Ethics Officer to see if there are any alternatives which are included our list of standard online survey tools.

Always quote your REB file number (**15009**) on future correspondence. We wish you success with your study.

Sincerely,

Dr. Ruth Milman
REB Chair
ruth.milman@uoit.ca

Emma Markoff
Research Ethics Assistant
researchethics@uoit.ca

NOTE: If you are a student researcher, your supervisor has been copied on this message.