Physical Activity Participation in Mild Cognitive Impairment and Alzheimer’s Disease.

by

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A thesis submitted in conformity with the requirements for the degree of Master of Rehabilitation Science
Rehabilitation Sciences Institute
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Abstract

This document explores how older adults with cognitive impairment and their caregivers experience and perceive physical activity (PA) and their health beliefs concerning PA. Ten care dyads, consisting of one community-dwelling adult aged 65 years or older diagnosed with Mild Cognitive Impairment (MCI) or mild-to-moderate Alzheimer’s Disease (AD) and one familial caregiver, were selected to participate in this qualitative study. Information on weekly PA levels, apathy, and apathy-associated distress were collected using questionnaires. Semi-structured interviews were used to explore the PA experiences, beliefs, and perceptions of dyad members. Thematic analysis of interview transcripts yielded four emergent themes: (1) PA as a meaningful activity, (2) Feeling is more important than thinking, (3) Participation is possible despite dementia, and (4) Caregivers as enablers. Findings from this thesis address a current gap in the literature concerning the value and use of PA for health promotion by older adults with cognitive impairment.
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Chapter 1

1 Introduction

1.1 Rationale

Propelled by numerous factors leading to increasing life expectancies and declining birth rates, older adult populations around the world are growing at unprecedented rates. The number of adults aged 60 years and older is expected to double from 901 million in 2015 to almost 2.1 billion by 2050 (1). The Canadian population is no exception to this phenomenon. In 2016, the number of “seniors”, adults aged 65 years and older, exceeding the number of children, aged 14 years and younger, for the first time in our country’s history (2). By the late 2050’s, there will be just over 2 working-age Canadians (15 to 64 years) for each senior, compared to a ratio of 4.5 to 1 in 2013 (2).

With this dramatic demographic shift, increases in the prevalence of age-related diseases are also anticipated. Dementia, or a decline in cognitive function leading to social and occupational impairments (3), is one such age-related disease that poses a looming threat. Over the next three decades, the global prevalence of dementia is expected to nearly double every 2 decades, swelling from an estimated 46.8 million cases in 2015 to 131.5 million cases in 2050 (4). A similar trend is expected to unfold in Canada, with dementia prevalence in adults aged 65 years and older expected to nearly double between 2014 (513,953 cases) and 2033 (986,954 cases) (5).

These anticipated changes in global demographics will require changes in health and social services to match the needs of aging populations. In anticipation of these changing demands, research-informed action is urgently needed to reduce the occurrence of age related diseases, many of which are non-communicable and amenable to preventive efforts (6). New approaches to detecting and treating dementia are needed, as well as strategies to maintain wellbeing and function in persons already living with dementia. Alzheimer’s disease (AD) is one of the most common contributing factors to dementia, implicated in over two thirds of all dementia cases (7). AD is rarely the sole pathological feature in dementia, however, and is often comorbid with other pathology in “Mixed Dementia” (8) (9). There is currently no proven
disease-modifying therapy to “cure” dementia. In the absence of a cure, strategies for prevention through risk modification, symptom management, and quality of life improvement are immediately needed.

Physical activity (PA) has the potential to play a role in each of these strategies mentioned above. In the scientific literature, PA is defined as any movement of skeletal muscle resulting in expenditure (10). In more practical terms, PA refers to the activities done as a part of daily life, including occupational, transportation, and athletic activities. Exercise is a type of PA, specifically done for the purpose of improving one’s health or physical fitness (10). Low PA levels are a risk factor for AD, with 13% of the attributable risk of AD associated with insufficient PA levels. An estimated 25% reduction of this risk factor alone could prevent 1 million cases of AD globally (11). PA is associated not only with a reduced likelihood of developing AD, but also of progressing from the pre-dementia diagnosis of Mild Cognitive Impairment (MCI) to AD (12). Even after diagnosis, higher levels of PA are associated with higher levels of global cognitive function in mild to moderate AD (13), as well as higher domain-specific performance in executive function, language, and memory (14) (15) (16) (17). PA is also associated with improvements in depressive symptoms and maintenance of functional abilities in dementia (18) (19).

Despite the benefits of PA for both the prevention and management of dementia, translation of this research into healthy behaviours of older adults (adults aged 65 years and older) is currently lacking. In this age group at increased risk for dementia, Canadians report the lowest PA levels of any age group, with only 43% of older adults reporting any PA in their leisure time in 2014 (20). Age-specific Canadian PA recommendations indicate older adults should achieve a minimum 150 minutes per week of moderate-to-vigorous PA (MVPA), with muscle strengthening activities done twice weekly and balance training exercises if for calls prevention (21). An earlier study indicates that even fewer older adults achieve recommended PA levels on a weekly basis to maintain health, with only 11% of participants meeting or exceeding Canadian PA recommendations in a nationally representative sample (22). Similar PA levels have been reported for older adults with MCI or AD in Canada, with only 16% of one sample from a rural memory clinic fulfilling Canadian PA recommendations (23).
Hence, there is substantial room for improvement when it comes to increasing PA participation of aging adults in Canada. Current models of human behaviour change from the field of implementation science indicate that understanding the beliefs of a population concerning a health behavior is important for designing health behaviour change interventions (24). The use of social and psychological theories of human behaviour to inform development and implementation of interventions allows for researchers to take a systematic, scientifically-grounded approach to enhance the efficacy of interventions rather than going on intuition alone. Current frameworks for understanding behaviour change support the idea that an individual’s experiences and perceptions of target behaviours in relation to their social and environmental context are also important aspects to consider for effecting behaviour change (24). Thus, in considering PA as a health behaviour for dementia prevention and management, successful translation of research showing the benefits of PA in dementia into community-based dementia management strategies will require an understanding of factors influencing participation of persons with AD in PA. A small body of literature suggests persons living with MCI or AD may experience additional barriers to PA participation due to cognitive symptoms (25) and caregiver dynamics (26). Given the economic and clinical benefits of early intervention for AD (27) (28), PA programs will also need to include persons with MCI, but there is currently no research describing PA participation factors in this population. As such, there is currently a knowledge gap in the scientific literature concerning the health beliefs and perceptions of older adults with MCI or AD concerning PA, and the factors that influence their participation in PA. Creation of this knowledge is necessary for developing and implementing evidence-informed health promotion initiatives using PA for the prevention and management of dementia.

1.2 Research Question

The research question addressed in this thesis explores the lived experiences of persons living with MCI and AD and their caregivers concerning PA participation by asking, “What are the perceptions, beliefs, and experiences, of community-dwelling older adults with MCI or AD and their caregivers concerning PA as a health behaviour?”

To explore PA perceptions, care dyads composed of one older adult with MCI or AD and their caregiver were asked to describe how they define PA and exemplar activities they associate with it. To understand how this population perceives PA as a health-promoting behaviour,
participants were asked to indicate what they perceive the “recommended” levels of PA to be for older adults both with and without cognitive impairment.

To explore PA beliefs, participants were asked to describe the potential risks and benefits that they associate with PA, as well as the factors that motivate them to participate in PA.

To explore PA experiences, participants were asked to discuss activities they typically participate in, as well as activities that they have engaged in at various points throughout their life. To understand the influence of aging and cognition on PA participation for this group, participants were asked to describe the factors that influence their ability to engage in PA (i.e. barriers and facilitators to PA). Participants were also asked to elaborate on theirs (or their care partner’s) experiences engaging in PA as an older adult with cognitive impairment and their experiences with PA-promoting programs and services available to them in the community.

1.3 Organization of Thesis

This first introductory chapter provides a broad overview of the need for this thesis and the research questions being investigated to address this need.

Chapter 2 provides the essential background information for understanding the how PA may be of benefit as a strategy to preventing progression of MCI and AD and to manage cognitive and functional declines in these conditions. Chapter 2 takes a practical look at how PA is currently used and perceived by older adults with and without cognitive impairment, and the factors that must be considered if PA is to be effectively used as a strategy to maintain health of older adults with cognitive impairment.

Chapter 3 outlines the guiding theoretical framework for the qualitative research study supporting this thesis and the broad approach taken to exploring PA participation of older adults with MCI and AD in this study.

Chapter 4 outlines how this approach was actualized into specific methods for the conduct of this study.
Chapter 5 details the results of this study, describing the demographic, PA, and motivational characteristics of study participants and the themes that emerged from interviews on PA perceptions, experiences, and beliefs of older adults with MCI or AD.

Chapter 6 provides a critical discussion of these results, limitations of the study that may have influenced the results, and implications of these findings on individual, care network, community, and public policy levels.

Chapter 7 provides a synthesis of prior chapters and conclusions arising from study findings in the context of the existing literature.

Chapter 8 suggests future directions to be taken in scholarly work to increase scientific understanding of PA and health promotion in older adults with MCI or AD, and opportunities to apply the findings of this thesis research to support healthy, active aging in the community.
Chapter 2

2 Review of the Literature

2.1 Preface

To understand the rationale for using PA as a health-promoting behaviour, it is important to first review the specific benefits of PA for older adults with cognitive impairment. To contextualize these benefits, the epidemiology, social impact, and biological underpinnings of AD are reviewed. In relation to preventing the onset and progression of MCI and AD, specific health-related factors that predispose these conditions are summarized, as well as potential opportunities for PA to be used in reducing the impact of these factors in contributing to cognitive impairment. The specific cognitive and functional benefits of PA for older adults both with and without cognitive impairment are reviewed to indicate how PA could be used in strategies beyond prevention to support symptom management.

Following this foundational review, this chapter then juxtaposes the promising findings of literature on the benefits of PA for older adults with cognitive impairment with literature on the more practical aspects of translating this knowledge into health-promoting behaviours. To do so, this chapter draws upon literature from health psychology and implementation science in reviewing behaviors, barriers, and facilitators to PA for older adults with cognitive impairment and the theoretical approaches used to study behaviour change. The culmination of this review is the identification of a literature gap concerning the perceptions, experiences, and beliefs of older adults with MCI or AD concerning PA, and the need for research addressing this gap to translate research on the benefits of PA for brain health into strategies to prevent and manage MCI and AD.

2.2 Alzheimer’s Disease and Mild Cognitive Impairment

Domain-specific cognitive impairment occurs naturally in older adults due to normal age-related processes (29). Cognitive decline caused by AD, however, is not a part of healthy aging. AD is a neurodegenerative disorder that causes a progressive worsening of cognitive function, behavioural symptoms, and eventual loss of independence due to social, occupational, and
functional impairments (30). MCI is a diagnosis of cognitive impairment beyond what is expected given an individual’s age and educational history. The operational definition of MCI is cognitive impairment that is beyond what would be expected as a part of normal cognitive aging given one’s age and education, but not severe enough to interfere with social, occupational, and functional capacities (31). The concept of MCI as an intermediate level of cognitive impairment between healthy aging and dementia only emerged in 1988 (32), and as a diagnostic entity in 1999 (33) (34). The recognition of MCI as a distinct, pre-dementia entity provides an opportunity to identify individuals in early stages of cognitive decline who are at high risk for developing dementia, and the implementation of interventions to attempt to prevent or slow their progression to dementia (34). MCI, however, may or may not naturally progress to dementia, and can have a number of aetiologies other than AD (35). Four distinct subtypes of MCI have been described in the literature, differentiated by the presence or absence of an amnestic component and whether one or multiple cognitive domains are affected (36). MCI with a prominent amnestic component is more likely to progress to dementia caused by AD (35).

2.2.1 Epidemiology

2.2.1.1 Prevalence

2.2.1.1.1 Dementia

In 2013, an estimated 46.8M people were living with dementia globally, which is anticipated to swell to 74.7M by 2030 (4). This massive increase in prevalence is largely attributed to anticipated changes in global population structure, with growth of the 65 years and older demographic outpacing growth in younger age groups (6). Proximal factors driving the rapid aging of global populations include: increased lifespan from improved healthcare and sanitation, decreased maternal and fetal death at childbirth, decreased fecundity, and aging of the Baby Boomer generation into the 65 and older demographic (1). Predictions for dementia prevalence in Canada over the coming decades are no exception to this trend. In 2014, an estimated 514,000 older adults (9% of older adult population) were living with dementia in Canada (5). Dementia prevalence in Canada is expected to almost double by 2033 to affect an estimated 987,000 older adults (10% of older adult population) (5).
The presence of a gender bias in dementia prevalence is contested in the literature. While women constitute a greater proportion of persons diagnosed with dementia at 65% of all cases in Canada (5), studies investigating gender differences in dementia prevalence indicate that age-related prevalence is similar between men and women (37) (38). The higher total prevalence of dementia in women may be an artefact of greater life expectancy for women, as dementia prevalence increases with advancing age (39). One study suggests that age-related declines in AD incidence may occur earlier in men, further magnifying the influence of greater life expectancy for women on age-independent dementia prevalence by gender (40). In Canada, an estimated 2.8% of women aged 65-74 years were living with dementia in 2014, with prevalence rising to 11.6% for women aged 75-84 years and 37.1% for women aged 85 years and older (5). A similar trend exists for men, with dementia prevalence at 1.9% for men aged 65-74 years, 10.4% for men aged 75-84 years, and 28.7% for men aged 85 years or more in 2014 (5).

2.2.1.1.2 Alzheimer's Disease

AD is the most one the most common contributing cause of dementia, estimated to be implicated in two thirds of all dementia cases in Canada (7). The Canadian Study of Health and Aging looked at dementia prevalence in older adults in community and institutional settings using a nationally representative sample and found 63.7% of dementia cases were attributed to AD (41). Comparatively, vascular dementia (VaD), the second most common contributing factor to dementia, was implicated in 19.2% of dementia cases in the Canadian Study of Health and Aging (41). “Pure” AD, however, is thought to occur less frequently in community samples than AD comorbid with vascular or other neurodegenerative pathologies, referred to as “mixed dementia” (8).

2.2.1.1.3 Mild Cognitive Impairment

Prevalence of MCI in older adults (65 years and older) is estimated at 3-19%, with a large range of estimated prevalence due to detection bias in community compared to clinical populations, where the number of people diagnosed with MCI may be higher due to their involvement with a the healthcare system (i.e. a sample chosen from a population that has visited a clinic is more likely to be diagnosed with MCI than a random sample from the community) (31). MCI can be classified by subtype, depending on the nature (amnestic vs. non-amnestic) and number (single-domain vs. multi-domain) of cognitive capacities affected Invalid source
specified.. These subtype classifications provide relevant information for the prognosis of cognitive impairments. Approximately 5-10% of all MCI cases progress to AD with an annual conversion rate of 7% (42), but for the amnestic subtype of MCI where memory impairments are present, the annual conversion rate to AD is higher, indicating increased likelihood of MCI due to AD pathology (35).

2.2.1.2 Economic Impact

The economic impact of dementia is anticipated to rise with the projected increased prevalence of dementia over the coming decades. Globally, the annual total estimated cost of dementia (direct medical costs plus paid and unpaid caregiving costs) was $818B USD in 2015, or approximately 1% of the world’s Gross Domestic Product. By 2018, this is anticipated to surpass $1T USD, and rise to $2T USD by 2030 (4). In Canada, the annual monetary economic burden of dementia was estimated at $9.9BCAD in 2008, and is expected to increase ten-fold to $96.9B by 2031. When the opportunity costs of unpaid caregivers are also factored into this equation, the annual estimated total economic burden in Canada increases to $14.9B in 2008 and is projected to cost $152.6B by 2031 (43).

2.2.2 Symptoms

The appearance of clinical symptoms in AD closely tracks the progression of neuropathological changes in AD as previously described. The manifestation of these neuropathological changes is a progressive worsening of cognitive function and neuropsychiatric symptoms (NPS) that ultimately impair an individual’s occupational and functional abilities (44). Cognitive domains affected by AD include memory, executive functioning, visuospatial orientation and processing, and language (44). Memory impairments may behaviourally present as repetitive questioning, misplacing objects, getting lost in familiar areas, and forgetting names and appointments. Executive function impairments may present as problems with goal-directed behaviour, problem solving, following complex instructions with multiple steps, wayfinding difficulties, and making judgments based on the relative weights of risks and benefits of potential outcomes. Visuospatial orientation and processing symptoms may present as problems recognizing familiar faces or objects or wayfinding difficulties. Language symptoms may present as difficulty finding words that are commonly used, as well as errors in writing, speech, and
reading comprehension tasks. Similar symptoms are present in MCI, but are not so severe as to cause impairments in social and occupational functioning (35).

NPS in AD include agitation, apathy, depression, irritability, sleep disturbances, delusions, anxiety, euphoria, changes in appetite, hallucination, disinhibition, and motor disturbances (30) (45). One population-based study found 51% of MCI patients experience at least one NPS compared to 27% of cognitively-healthy older adults, (46). Another study examining NPS prevalence in dementia based on data from the same population found 80% of participants with dementia experienced at least one NPS since being diagnosed, with 75% of participants with dementia experiencing one or more NPS in the prior month (47).

2.2.3 Diagnostic Criteria

2.2.3.1 Mild Cognitive Impairment

Neuropathological changes caused by AD can begin to occur decades before the onset of symptoms (48). Onset of AD symptoms is insidious, occurring gradually over the span of months to years. Typically, either the individual or a concerned family member or friend may initially report early symptoms as subjective memory complaints or changes in behaviour and cognition relative to one’s previous level of functioning. Cognitive impairments can be in one or multiple domains (e.g. memory, problem solving, language), and are beyond what is expected given an individual’s age and education. Brief tests of global cognitive function like the Montreal Cognitive Assessment (49) can be used to differentiate MCI from normal age-related cognitive decline. MCI is a non-dementia state of cognitive impairment characterized by progressively worsening impairment in one or more cognitive domains, not necessarily including memory, beyond what is expected as a part of normal aging. In MCI, these impairments affect social and occupational functioning in daily life, but people with MCI are still able to live independently with minimal assistance. Further assessments may determine an identifiable cause of MCI not due to AD pathology, such as white matter disease, vitamin deficiencies, infection, or another form of dementia (35) (50).

2.2.3.2 Dementia due to Alzheimer's Disease

If cognitive impairment continues to worsen, a diagnosis of “probable dementia due to AD” may be made based on a clinical judgment supported by any of several sources of
information: serial neuropsychological tests, clinical observations, patient and caregiver reports, imaging and laboratory tests, the patient’s medical history, and a clinical interview. A diagnosis of probable dementia due to AD is given when there has been a documented history of cognitive decline leading to impaired social and occupational functioning, and an inability to complete activities of daily living independently. Initial presence of memory deficits and impairment in at least one other cognitive domain can help differentiate AD from other dementias, but other potential causes must be ruled out prior to diagnosis. Imaging techniques and biomarker tests can support AD diagnosis and are increasingly being used as part of screening for AD in clinical and research settings (51), but do not provide stand-alone diagnostic tests (44). A diagnosis of dementia due to AD can only be confirmed through post-mortem examination of brain tissue that indicates the presence of neuropathological hallmarks of AD.

2.2.4 Current Approaches for Treating Mild Cognitive Impairment and Alzheimer’s Disease

Currently, there are no disease-modifying therapies for MCI or AD. Pharmacotherapies aiming to slow the progression of cognitive symptoms and manage associated NPS have been the mainstay of AD treatment approaches. Experimental and approved therapies for AD and MCI have targeted pathological protein metabolism, neurotransmitter imbalances, inflammation, and oxidative stress associated with AD pathology and symptoms (30) (52) (53). No therapies have proven effective in treating MCI due to AD pathology (50). Two classes of drugs, cholinesterase inhibitors and anti-glutamatergic agents, are approved for use in mild-to-moderate and moderate-to-severe AD, respectively (30) (54) (55) (56) (57), and are the current standard of care for AD. These treatments have a marginal effect on slowing the progression of AD, but have not been shown to halt or reverse disease processes (58). Pharmacotherapy to slow progression from MCI to AD has seen similarly little success. A randomized, controlled, double-blind trial comparing efficacy of cholinesterase and antioxidant therapies to a placebo found no significant change in conversion from MCI to AD over 3 years across the three groups (59).

Other approaches to AD therapy have targeted immune responses, inflammation, and oxidative stress. Immunotherapy in AD uses antibodies and the human body’s adaptive immune system to help clear pathological proteins that aggregate in the brain to cause AD (60). Early studies investigating antibody therapy for AD had significant adverse events (61), and recent phase 3 clinical trials have so far failed to show clinically significant improvements in cognitive
and functional abilities (62) (63). Non-steroidal anti-inflammatory drugs have been associated with reduced risk of developing AD in prospective cohort studies, but results of randomized controlled trials have not found a causative link between non-steroidal anti-inflammatory use and AD prevention (64). Therapies targeting oxidative stress in AD to reduce damage by free-radicals to brain tissue and blood vessels have used antioxidants such as vitamin E (30), but a recent Cochrane Systematic Review found no evidence supporting the therapeutic benefits of vitamin E in AD (65).

Antipsychotic, antidepressant, anticonvulsant, and anxiolytic medications are used for the management of NPS in MCI and AD. The side-effects and risks associated with these treatments often outweigh their benefits, however, and their use must be carefully considered in the context of an individual’s other medications. Due to the marginal benefits of these drugs and the high burden of their side-effects, non-pharmacological interventions to manage NPS, such as environmental interventions, are recommended before using medical management (66).

In summary, there are currently no proven pharmacotherapies for preventing progression of MCI to AD. Currently approved therapies for dementia due to AD fail to prevent or reverse progression, and at best provide modest benefits in managing cognitive symptoms and NPS. At present, there is a need for supplementary strategies to enhance the current pharmacotherapies used to reduce or prevent cognitive decline in MCI and AD.

2.3 The Biological Basis of Alzheimer’s Disease and Cognitive Benefits from Physical Activity

Research indicates that the onset of pathology in AD begins decades before the onset of symptoms (48). There are a number of hallmark pathologies in the brain that occur in AD, reflecting the combined roles of the nervous, immune, and cardiovascular systems in AD disease processes: accumulation of amyloid-β (Aβ) in extracellular plaques, neurofibrillary tangles (NFTs) within neurons characterized by the presence of hyperphosphorylated tau inclusions, decreased synaptic density, neuronal atrophy, overzealous microglial and astrocytic responses, and cerebral amyloid angiopathy (CAA) (67). This brief review of the neuropathology and progression of AD provides a basis for understanding the potential mechanisms of benefits associated with PA for reducing cognitive and functional decline in AD and potential ways that PA may interact with AD disease processes to slow or prevent progression.
2.3.1 Amyloid and Tau Proteins

At the level of the nervous system, AD is characterized by the accumulation of Aβ plaques outside of neurons in the brain, and hyperphosphorylated tau inclusions in neurons called NFTs. Aβ is a normally produced fragment of the larger membrane-bound amyloid precursor protein (APP), which is highly conserved among vertebrates (68). APP is present in the brains of all humans, as well as other tissues throughout the body including the skin (69), skeletal muscle (70), adipose tissue (71), and the intestinal epithelium (72). Aβ is produced by two cleavage events mediated by α-secretase or β-secretase in the extracellular domain and γ-secretase at a transmembrane domain to yield a peptide composed of 38-43 peptides.

The association between Aβ pathology and AD was first discovered in 1984, when Aβ was first isolated from the brains of persons with AD (73). Since then, a confluence of evidence from research investigating the role of mutations in key genes for the production and metabolism of Aβ has implicated pathological clearance of AB as an initiating factor for a cascade of events leading to AD pathology and its disease symptoms, and the Amyloid Cascade Hypothesis of AD has been the historically prevalent hypothesis of AD aetiopathogenesis for almost a quarter century (74). This evidence predominantly comes from: (i.) research on individuals with Down Syndrome due to trisomy 21 who develop AD earlier and more frequently due to an extra copy of the gene coding for APP leading to an extra “dose” of amyloid (75), (ii.) association of mutations in the gene coding for APP around sites for cleavage of Aβ by secretases with familial AD (76), (iii.) association of mutations in the genes coding for subunits of γ-secretase, an enzyme involved in cleavage of APP to produce Aβ, with familial AD (77), and (iv.) association of the Apolipoprotein E4 isoform, a genetic risk factor for earlier onset and great risk of AD, with Aβ deposition (78) (79).

Tau, the other protein implicated in AD pathology, is a naturally-occurring microtubule-associated protein found in human neurons important for stabilizing microtubules that support the cytoskeleton of axonal projections (80). Hyperphosphorylated tau is a major component of NFTs seen in AD has been known for over 30 years (81), and the number and distribution of tau NFTs are significantly associated with disease severity as described in the Braak Staging of AD pathology (82). Tau NFTs are not unique to AD, however, and are also present in other neurodegenerative dementias (83). Rather, Aβ plaques and tau NFTs are present in all older
adults to some extent, regardless of their cognitive status. It is the specific intensity and pattern of Aβ and NFT deposition that differentiates AD pathology from other dementias and normal age-related changes in the brain (84). Tau NFT progression throughout the brain follows a typical course in AD as described by the Braak Staging system for AD, with tau NFTs first appearing in the transentorhinal region of the brain then appearing in the entorhinal cortex, limbic regions, temporal neocortex, association cortices, and finally primary sensory areas (82) (85). The progression of NFTs through the brain also tracks the appearance of clinical symptoms in AD, with the first clinical presentation of AD typically occurring when NFT pathology reaches the limbic structures causing impairments in memory (84). Neuronal loss is associated with NFTs in AD (86), and is better correlated with changes in cognitive function in AD than number of NFTs present (87). Losses in synaptic density follow patterns of neuronal loss in AD (88) and provide a pathological marker that best correlates with cognitive function in AD (89).

According to the Amyloid Hypothesis of AD, Aβ accumulation in the brain precedes the pathological accumulation of tau in brains with AD (79). Injections of Aβ fibrils into the brain accelerate the formation of NFTs in mouse models that express a mutant form of tau prone to forming filaments characteristic of frontotemporal dementia with parkinsonism (90). In mouse models containing genetic mutations affecting both tau filament formation and amyloid production, these double-mutant mice developed more NFTs than mice with single mutations affecting just tau filament formation or amyloid production (91). In another study using tau-knockout mouse models with mutations in genes responsible for amyloid production that cause familial early-onset AD in humans, the absence of tau protected the mice from developing learning and memory deficits typical of AD (92). While Aβ is the instigating factor for tau NFT formation in AD, a separate study found that mice with double mutations associated with early-onset AD in humans that lacked tau also had a reduced number of amyloid plaques, contesting the notion that the effects of tau in AD are only “downstream” of amyloid (93). Rather, aberrant Aβ production and metabolism may instigate a pathological feedback loop between Aβ and tau leading to AD progression.

2.3.2 Innate Immune System

The immune system is also implicated in the development of AD. Pathology caused by Aβ and triggers an immune response in the brain (94). Microglia are cells comprising a regional
component of the innate immune system found only in the central nervous system, responsible for surveying the brain for foreign pathogens and non-specifically engulfing and degrading them via phagocytosis (95). Microglia have long been associated with Aβ plaques in AD (94), and more recently have been shown to play a role in mediating the clearance of Aβ from the brain (96). Receptors located on the cell surface of microglia can bind Aβ (97) (98), and engulf and digest Aβ protein fragments through phagocytosis or trigger the release of enzymes into the extracellular environment to digest Aβ plaques (99). Production of Aβ in AD that outpaces the ability of microglia to clear these pathological proteins has been suggested as a possible role of the innate immune system in AD pathology (100). This is supported by the association of mutations in genes affecting microglial function at the level of cell-surface receptors that detect Aβ in the brain with an autosomal dominant early-onset form of AD (i.e. TREM2) (101) and increased risk of sporadic AD (i.e. CD33) (102).

Astrocytes are glial cells found throughout the central nervous system that perform a variety of vital functions, some of which include: scaffolding the organization of grey matter in the brain (103), maintaining the brain’s homeostatic environment (104), maintaining tight junctions between vascular endothelial cells that form the blood-brain barrier (BBB) (105), regulating blood flow through brain microvasculature to match neuronal activity (106) (107), modulating synaptic transmission (108), and syncing neuronal activity to the brain’s extracellular environment (109). Any form of brain injury leads to a response from astrocytes called “reactive astrogliosis”, in which they try to repair damage caused by the injury or prevent further damage from occurring (110) (111). Evidence from autopsy studies indicates that reactive astrogliosis occurs in response to brain injury caused by AD pathology, with reactive astrocytes associated with Aβ-containing plaques in the brains of people with AD (112). More recently, research indicates this association of reactive astrocytes with neuronal plaques in AD is driven by neuronal damage associated with these plaques rather than the presence of Aβ itself, which drives the microglial response in AD (113).

2.3.3 Cerebrovascular Pathology in Alzheimer’s Disease

Pathological changes in AD can manifest in the form of changes to blood vessels in the brain. Aβ deposits are not only found in the extracellular environment of the brain, but also in the walls of blood vessels in the brain causing cerebral amyloid angiopathy (CAA) (73) (114).
Reports of CAA prevalence in AD range from 82-98% (115). In addition to the deposition of Aβ in the walls of cerebral vasculature, thickening of the basement membrane that lines blood vessels in the brain to provide structural support is characteristic in AD. Thickening of the basement membrane underlying cerebral vasculature causes these vessels to become more rigid and tortuous, which disrupts smooth, laminar flow through blood vessels. Turbulent blood flow through these vessels can interrupt the steady flow of oxygen and glucose needed to supply brain tissue and decrease the efficiency of clearance of metabolic waste products from the brain (116). Pathological changes to brain vasculature in AD thus can create an environment of “injury” in the brain, triggering the activation of astrocytes, which then leads to increased amyloid production (117), initiating a cascade of neuropathological changes to cause AD (118). This model of vascular damage leading to AD pathogenesis constitutes the Vascular Hypothesis of AD (119). More recently, a positive feedback loop between Aβ and cerebrovascular disease (CVD), a category of diseases caused by vascular pathologies in the brain including atherosclerosis, cortical and lacunar infarcts, and small vessel disease, as an initiator and driver in AD progression has been suggested (120). In this loop, impaired Aβ production and metabolism in familial (genetically determined) AD or CVD are the instigating factors in sporadic (non-familial) AD (120).

2.3.4 Proposed Mechanisms of Benefits from Physical Activity in Alzheimer’s Disease

PA is defined in the scientific literature as “any bodily movement produced by skeletal muscles that results in energy expenditure”, whereas exercise is “a subset of PA that is planned, structured, and repetitive and has as a final or an immediate objective the improvement or maintenance of physical fitness” (10). As PA provides a more inclusive definition of activity than exercise, PA has been chosen as the central topic of interest in this research to capture both structured exercise as a form of PA as well as other unstructured forms of PA. As supported by the literature reviewed in this section, research on the relationship between PA the maintenance of cognitive health across the lifespan overwhelmingly supports the position that PA is important for the prevention and management of AD. Mechanisms thought to convey the benefits of PA for the maintenance of cognitive health in older adults hinge upon the interaction between immune, nervous, and cardiovascular processes.
Immunologically, PA is associated with reduced inflammation and oxidative stress in the body, which may help to counteract the contributions of these processes in hastening cognitive aging and AD pathology. As reviewed in Chapter 2.3.2, AD pathology can trigger an innate immune response. A component of this response is inflammation, during which chemical messengers secreted by immune cells increase the movement of other immune cells to a region of injury to promote clearance of a foreign pathogen from that area. While this process typically resolves when the pathogen is cleared, AD, however, is marked by a chronic, widespread, increasing presence of pathological proteins (Aβ, hyperphosphorylated tau) that overwhelms the body’s innate response to injury. As a result, the chronic activation of the immune system leads to a chronic state of inflammation, which can cause significant collateral damage to the tissue surrounding a region of injury as the immune system releases harmful reactive oxygen and nitrogen species to disrupt pathogens’ structure and function. In this way, a natural immunological response to injury can become pathological in AD. Evidence supporting this proposed role of the immune system in AD progression comes from research that has found elevated levels of pro-inflammatory compounds in AD patients relative to healthy older adults (121) (122). Multiple studies have found lower levels of C-reactive protein, a biomarker of systemic inflammation, in persons with AD, but high levels of C-reactive protein have been associated with lower cognitive function and higher mortality in AD (123) (124) (125). PA thus may exert its benefits in part by reducing immunoreactivity that can exacerbate AD pathology through reducing pro-inflammatory factors in the body (126) (127) (128).

Reactive oxygen and nitrogen species released by immune effector cells to attack extracellular pathogens are non-specific, equally disrupting healthy cells and pathogens by interfering with protein, lipid, and carbohydrate structure, leading to disruption of cell membranes and DNA damage. The cumulative effect of these interactions between reactive oxygen and nitrogen species and healthy cells, and the resultant damage, is referred to as “oxidative stress”. In order to counteract the effects of these harmful compounds and reduce the impact of oxidative stress on cellular integrity, cells must process these harmful species by neutralizing them with anti-oxidant species. PA has been shown to reduce levels of oxidative stress through promoting the formation of mitochondria (129), which are the organelles responsible for facilitating this neutralization of reactive oxygen and nitrogen species. Specifically in MCI and AD, increased levels of oxidative stress have been observed (130). As
well, mitochondrial dysfunction has been associated with AD pathology, resulting in insufficient energy levels and processing of harmful oxidative species, which can lead to cell death (131). PA may thus exert benefits in AD by improving the body’s ability to manage oxidative stress, and in doing so, reduce the impact of overzealous immune responses that exacerbate AD on healthy brain tissue.

In regard to the role of the cardiovascular system in AD pathology, PA may exert its benefits through reducing the incidence of vascular risk factors associated with AD (132) and maintaining a steady supply of oxygen and vital nutrients to the brain (133). As reviewed in Chapters 2.3.3, impaired vascular function seems to act as both a cause and consequence of AD. In contributing to AD, numerous vascular risk factors (e.g. obesity, high cholesterol, midlife hypertension) and vascular diseases (e.g. atherosclerosis, small vessel disease, heart failure) have been found to act as predisposing factors for AD. Increased PA levels have also been found to reduce the risk of developing these predisposing conditions like atherosclerosis (134), hypertension (135), and cardiovascular disease (136), and thus may act as a second-hand contributor to reduction of AD risk.

The pathology associated with the nervous system in AD leads to neuronal death in specific brain regions and gross atrophy. PA may additionally be of benefit in AD by counteracting this degenerative process through increasing the creation of new neurons and the secretion of neurotrophic factors. The cortex and medial temporal lobe structures like the hippocampus are brain regions targeted by AD pathology. PA has been associated with preservation of temporal lobe structures in older adults (137) (138) (139) and reduced amounts of cortical thinning (140). While this may be due to increased vascularization caused by increased levels of vascular endothelial growth factor in response to PA (141) (142), not the creation of new brain tissue, evidence from animal studies suggests that the latter may also be occurring in the temporal lobes.

Animal studies have found that increased PA levels are associated with significant increases in levels of brain-derived neurotrophic factor (BDNF), a neuronal growth factor in the brain and the creation of new neurons specifically in the hippocampus (143) (144). Given that this region is targeted by AD pathology leading to catastrophic memory impairment, PA may exert its benefits by counteracting this degenerative process. Similar increases in peripheral BDNF levels in response to exercise have been observed in human older adult populations with and without
cognitive impairment (126) (145) (146) (147), suggesting that a similar process may mediate the brain health benefits of exercise in older adults. Research supporting the effects of exercise on BDNF production have largely focused on aerobic exercise interventions, but resistance training interventions have also shown cognitive benefits in older adults (148) (149) which may be mediated by increased levels of Insulin-Like Growth Factor 1 as opposed to BDNF (150).

In summary, PA has multiple systemic effects on the body, a selection of which have been described here. These specific processes oppose known factors contributing to the generation and progression of AD pathology. In light of this, PA may provide a strategy that works across multiple body systems to prevent or slow progression of AD. The following sections of this chapter outline the benefits of PA for reducing the onset and progression of MCI and AD and the benefits of PA for reducing the impact of cognitive and functional symptoms in MCI and AD.

2.4 The Relationship between Physical Activity and Factors Influencing the Onset and Progression of Mild Cognitive Impairment and Alzheimer’s Disease

Factors influencing the onset and progression of MCI and AD encompass both non-modifiable age and genetic risks, as well as health-related, social, and behavioural factors with modifiable aspects that can be addressed through interventions. This section reviews these factors, and builds upon the prior section reviewing neuropathology and progression of AD in discussing how specific factors play a role in the onset and progression of pathological cognitive decline, and how the beneficial effects of PA can be used to as a potential strategy to reduce or prevent cognitive and functional decline in MCI and AD by counteracting these factors.

2.4.1 Physical Activity for Reducing the Risk of Mild Cognitive Impairment and Alzheimer’s Disease

Physical inactivity has been cited as one of the highest-contributing modifiable risk factors for AD, with an estimated one in every 10 cases of AD in USA, Europe, and the UK attributable to physical inactivity (151). One meta-analysis of AD risk estimates the global
population attributable risk of physical inactivity for AD at 12.7% (95%CI, 3.3-24.0), which represents almost 4.3 million cases of AD reported in 2010 (151). The following section explores in more detail the benefits of addressing physical inactivity as a risk factor for both preventing and managing MCI and AD.

In retrospective analyses, PA levels both at mid-life (152) and late-life (153) (154) have been associated with a reduced risk of cognitive impairment, with the greatest benefits for people who have been physically active throughout their lives and in their teens (155). Prospective cohort studies have also provided evidence for the role of PA in the primary prevention of MCI and AD. The Canadian Study of Health and Aging found that for adults aged 65 years and older, engaging in PA was associated with decreased risks of cognitive impairment (OR=0.58; 95% CI, 0.41-0.83), AD (OR=0.50; 95% CI, 0.28-0.90), and all types of dementia (OR=0.63; 95% CI = 0.40-0.98) compared to those not engaging in PA (156). A recent meta-analysis of 9 prospective studies (n=20,236) on the association between PA and AD found a significant reduction in AD risk for physically active compared to inactive older adults (153). A prospective cohort study of people diagnosed with MCI also found an association between PA and reduced risk of progression to dementia over two and a half years (12).

Results from these observational studies provide evidence supporting the important role of individuals in taking preventive action to maintain their cognitive health across the lifespan. The results of these studies support the existence of a causal effect of PA on prevention in MCI and AD. Randomized controlled trials are necessary to demonstrate the existence of an intervention effect of PA for preventing the onset and progression of AD and MCI using specific PA protocols. In older adults at increased risk for AD, no randomized controlled trials with longitudinal follow-up have been performed to determine the intervention effects of PA on AD prevention, but multiple interventional trials of older adults at increased risk for developing AD have yielded promising results.

The following sections of this thesis detail the nature of specific factors influencing the onset and progression of MCI and AD, and how PA may help to address these factors.

2.4.2 Risk Factors for Mild Cognitive Impairment and Alzheimer's Disease

Although MCI does not always lead to AD or dementia, risk for developing AD is 3-5 times higher in MCI compared to cognitively healthy adults (157). Presence of MCI is a risk
factor for developing dementia and AD (158), and in some cases is a state of cognitive impairment caused by AD pathology preceding dementia (35) (50). Risk factors associated with an increased likelihood progressing from MCI to AD are similar to the risk factors for AD experienced by cognitively health persons: advancing age (159), female sex (159), presence of AD risk genes (160), lower educational attainment (161), metabolic syndrome (162), and diabetes (163). The presence of memory impairments and neuropsychiatric symptoms (NPS) in MCI is associated with increased risk for progressing to AD (35) (164). Presence of vascular risk factors have been associated with increased incidence of MCI (165), and mixed findings have been reported about their influence on risk for converting from MCI to AD (166) (167).

2.4.3 Advancing Age

Advancing age is a primary risk factor for AD, so much so that age at which one is diagnosed is used to aetio logically classify AD. The minority of AD cases (5%) are “early onset”, diagnosed before 65 years old (168), and most are attributed to any of three dominantly-inherited mutations. Early-onset AD is also associated with a more rapid, severe decline in cognitive and functional abilities (169). The majority of AD cases (95%) are classified as late-onset, and diagnosed in persons aged 65 years or older. The likelihood of being diagnosed with AD doubles approximately every 5 years over the age of 65 (170).

While there is no way to stop individuals from aging, PA appears to help halt or reverse some age-related declines in brain health preceding AD. In looking at brain imaging biomarkers (amyloid burden, hippocampal volume, glucose metabolism) and cognition in a group of middle-age adults at risk for AD, one group found a significant interaction between age and PA on presence of age-related changes in imaging biomarkers for AD and cognitive function (171). This study found that being classified as an “active” individual (self-report questionnaire, either meeting or not meeting published PA guidelines) attenuated the relationship between increasing age and the presence of AD imaging biomarkers (increased brain metabolism, reduced amyloid burden, and higher hippocampal volume) and decline in domain-specific cognitive function (immediate recall, visuospatial processing, processing speed and flexibility) relative to inactive individuals.

Various types of PA are also associated with changes in brain volume and connectivity in healthy older adults, which supports the potential use of PA to counteract decreases in brain
volume and connectivity seen in AD. One randomized controlled trial found that participation in an aerobic exercise intervention (details on frequency, intensity, type, and duration not provided) reversed age-related declines in hippocampal volume relative to participants in a stretching control group, and that pre-intervention fitness levels for participants in the stretching control group mitigated some declines in hippocampal volume (172). A separate study found that both aerobic (walking) and non-aerobic (stretching and toning) interventions led to improved connectivity in brain networks that are affected by aging, and that these improvements were associated with improvements in executive function (173). Thus, research indicates that PA may help sustain cognitive health and reduce the progression of age-related changes in brain health preceding cognitive impairment.

2.4.4 Genetic Contributions

Genetic contributions to the onset and progression of AD have been researched extensively, yielding many fundamental insights that inform our current understanding of AD pathogenesis. Mutations at 20 loci in the human genome have been associated with AD susceptibility (174), but for the purposes of this thesis, a brief overview of key genetic contributors to AD will suffice.

Possessing genes with mutations affecting the processing of $\alpha$ can be a causative factor in dominantly-inherited early onset AD (76) (77). Offspring of individuals carrying genetic mutations associated with dominantly-inherited AD have a 50% chance of developing AD. The majority of AD cases are not caused by dominantly inherited mutations, but possessing certain AD risk genes can also predispose an individual to developing sporadic, late-onset AD (175). For late-onset AD, having a first-degree relative with AD is associated with a 24-30% higher lifetime risk of AD, approximately 2.5 times greater than individuals without first-degree relatives diagnosed with AD (176) (177) (178).

In particular, allelic variants of the $APOE$ gene coding for Apolipoprotein E, a protein involved in lipid transport, cholesterol metabolism, and the brain’s response to injury, have been extensively researched in relation to their influence on AD susceptibility. The three $APOE$ alleles found in humans exert distinct effects on AD susceptibility: the “protective” $\epsilon 2$ allele associated with reduced AD risk has a frequency of 8.4% in the general population, the “neutral” $\epsilon 3$ allele conveying no significant risks or protections for AD has a frequency of 77.9%, and the “risk-promoting” $\epsilon 4$ allele associated with a higher likelihood of developing AD has a frequency of
13.7%. By contrast, the frequency of the ε4 allele in the AD population is approximately 40%. Having a single copy of the ε4 allele increases an individual’s risk of developing AD by 2.6 times if the paired with an ε2 allele, or 3.2 times if paired with an ε3 allele, relative to someone with an ε2/ε3 genotype. Individual homozygous for ε4 have a 14.9 times higher AD risk than individuals with no ε4 alleles (179). An individual’s APOE genotype has implications not only for AD susceptibility in both early and late onset AD, but also for age of onset, with the ε4 allele associated with earlier age of onset in cases of late-onset AD (180) (181). Despite their strong influence on AD susceptibility, however, risk genes like APOE are neither necessary nor sufficient for developing AD, and interact with risk factors like sex (182), hypercholesterolemia (183), Type 2 Diabetes (T2D) (184), and history of traumatic brain injury (185) to influence the development of AD.

Studies have also examined the relationship between PA and genetic risk for AD associated with APOE genotype. Population-based studies have found mixed results concerning the relationship between APOE genotype, PA, and AD risk. Findings from data collected in the CAIDE Study examining the relationship between lifestyle factors at midlife on cognitive and cardiovascular health in old age found APOE ε4 carriers who reported engaging in exercise1 for 20-30 minutes at least twice weekly were less likely to have dementia (OR=0.41, 95% CI, 0.15-0.97) and AD (OR=0.24, 95% CI, 0.05-0.67) at follow-up an average of 21 years later (186) relative to inactive APOE ε4 carriers. The data from the CAIDE study, however, also indicate that APOE ε4 non-carriers experience greater preventive benefit from PA than do APOE ε4 carriers (187). Similar findings on the relationship between APOE status, PA, and cognitive decline were reported from data collected in the Seven Countries Study, which found that older adult APOE ε4 carriers getting an average of less than 1 hour of PA2 per day had a greater risk of cognitive decline over 3 years relative to active APOE ε4 carriers (OR=3.7, 95% CI, 1.1-12.6) (188). The German Study on Aging, Cognition, and Dementia in Primary Care (AgeCoDe)

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1 Exercise is defined in the CAIDE Study as engaging in activities causing breathlessness or sweating.
2 PA is defined in the Seven Countries Study as self-reported frequency and durations of walking, bicycling, hobbies, gardening, sports, and occupational activity.
reported similar findings, indicating APOE ε4 carrier status and physical inactivity\(^3\) have an additive effect on AD risk in older adults (attributable portion due to interaction = 0.381, 95% CI, 0.072–0.690) (189).

However, data from Canadian Study of Health and Aging has yielded conflicting results that suggest PA\(^4\) is not associated with reduced AD or dementia risk in older adult APOE ε4 carriers over a 5-year follow-up period (190) (191). Similar findings have also been shown in other population-based studies looking at AD and dementia risk in cognitively health older adults over 5 years\(^5\) (192) and 9 years\(^6\) (193). Potential reasons for these conflicting findings on the relationship between APOE genotype and PA for dementia risk are the differing lengths of follow-up, age of first follow-up (midlife vs. old age), diagnostic category (AD vs. dementia), and varying definitions of PA used in studies. More consistency in diagnostic categories and PA assessments in future research would help clarify the relationship between APOE genotype, PA, and AD risk. Research investigating whether APOE genotype influences the level of benefit gained from PA interventions for persons already living with MCI and AD is also needed.

### 2.4.5 Sex and Gender

The Canadian Institutes of Health Research define sex as, “\textit{a set of biological attributes in humans and animals... usually categorized as female or male}”, and gender as, “\textit{the socially constructed roles, behaviours, expressions, and identities of girls, women, boys, men, and gender diverse people}” (194). Both biological and social factors have been investigated as contributing factors to dementia onset and progression. Dementia due to AD is more prevalent in women than men, with two thirds of all dementia cases occurring in women (7) (195). This increased

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\(^3\) Physical inactivity is defined in the AgeCoDe study as self-reported engagement in PA one or fewer times per week, defining PA as cycling, hiking or long walks, swimming, gymnastics, housework or gardening, babysitting, or leisure-time sports

\(^4\) PA in the Canadian Study of Health and Aging was self-reported engagement in “regular” exercise, but “regular” and ‘exercise’ were not defined for participants.

\(^5\) PA in the Cardiovascular Health Cognition Study is defined as the self-reported frequency and duration of 15 types of activities over the past 2 weeks, including walking, household chores, mowing, raking, gardening, hiking, jogging, biking, exercise cycling, dancing, aerobics, bowling, golfing, general exercise, and swimming.

\(^6\) PA is defined in the Kungsholmen Project as frequency of “fitness activities” (e.g. active sports, swimming, walking, gymnastics) reported as hobbies by participants.
prevalence in women has been attributed to increased life expectancy of women relative to men, and thus living to older ages at which they there is increased risk of developing dementia. Data from the Framingham study illustrate this, indicating that the lifetime risk of AD at midlife (45 years) and old age (65 years) is twice as high for women (196) (197). Numerous epidemiological studies have shown that there is no significant difference in age-adjusted incidence or prevalence of AD between men and women, suggesting women are just as likely as men to be affected by AD or dementia at any age (37) (38) (39) (198) (199). Increased life expectancy in women is a proximal explanation for the greater prevalence of AD in women. Research indicates that biological and social factors may provide ultimate explanations for why women are more predisposed to dementia, such as differences in sex hormones between males and females or differences in social lifestyle factors to afford neuroprotective benefits (200).

The relationship between sex and gender and MCI, however, appears to vary by subtype. A recent meta-analysis (201) found no significant differences in amnestic MCI prevalence and incidence between men and women, but lower prevalence of non-amnestic MCI in men (RR=0.84, 95% CI=0.72-0.99, p<0.05). Studies in this meta-analysis that did not differentiate between MCI subtypes found no significant gender-related difference in MCI prevalence. A separate meta-analysis that did not differentiate MCI by subtype found that women have a significantly higher likelihood of progressing from MCI to AD (RR=1.33, 95% CI, 1.08-1.64) (202). This may be an artefact of longer life expectancy of women, whereby women live to an older age at which they experience a greater risk of developing AD.

Research suggests that there are sex- and gender-specific risk factors for converting from MCI to AD. Men have been shown to be more likely to progress from MCI to AD if they have cerebrovascular pathology and lower global cognitive function, while women are more likely to progress from MCI to AD if they are older, have depressive symptoms, and are APOE e4 carriers (203). Once diagnosed with dementia, functional and cognitive capacities tend to decline more quickly in women (204).

The scientific literature contains conflicting findings on whether sex and gender differences exist in the benefits of PA for MCI and AD. In one prospective study following participants over a 28-year period, leisure-time PA during mid and late life was not significantly associated with AD risk in women, but low leisure-time PA was associated with increased AD
risk in men (187). Another population-based prospective cohort study, however, found high PA levels were only significantly associated with reduced AD risk relative to inactive individuals in women, whereas a similar non-significant trend was seen in men (156). In studies investigating the effects of exercise interventions, differential effects in men and women have been observed. In one study of older adults with MCI, women who completed a 6-month, high-intensity aerobic exercise were found to have greater improvements across multiple tests of executive function relative to men (145).

2.4.6 Health-Related Factors

MCI and AD have been associated with several predisposing health states, with proposed mechanisms of effects related to the neurological, immune, and cardiovascular underpinnings of AD. Many of these health-related factors can also be prevented or controlled to some extent by PA participation, with the proposed mechanisms through which PA conveys cognitive and functional benefits in MCI and AD opposing many of the proposed mechanisms through which these health-related factors contribute to the development of MCI and AD. Metabolic risk factors for AD include T2D and obesity, which can be managed in part with chronic PA participation. (205) (206). Vascular risk factors associated with the onset and progression of MCI and AD are amenable to modification by PA. Hypercholesterolemia and hypertension at midlife are vascular risk factors associated with increased AD risk that can also be managed in part with maintaining regular PA habits (207). Significant reduction in risk for developing both cardiovascular and cerebrovascular disease can be achieved through lifestyle modifications, including maintaining regular PA participation (208) (209) (210). PA is also beneficial in preventing frailty in older adult populations (211) (212). While PA is a panacea for reducing risk of developing health conditions that predispose individuals to AD, no studies have yet investigated the impact of broad-spectrum, health-related risk reduction for AD prevention. Further research is needed to investigate the impact of managing various health-related risk factors on reducing AD risk.

2.4.6.1 Metabolic

2.4.6.1.1 Type 2 Diabetes

T2D is a major risk factor for AD, to the extent that AD has been referred to as “Type 3 Diabetes” (213) (214). A recent meta-analysis of 17 cohort studies (n=1,746,777) found risk of
AD was 53% higher in persons with T2D than those without (RR=1.53, 95% CI, 1.42-1.63) (215). A separate meta-analysis of 20 prospective longitudinal studies (n=44,714) found a 21% higher risk of MCI in persons with T2D relative to those without (RR=1.21, 95% CI, 1.02-1.45) (216).

Multiple mechanisms have been proposed to explain the link between T2D and AD. Vascular complications from T2D caused by advanced glycation end products produced during hyperglycemic states and oxidative stress associated with T2D may impair the clearance of Aβ from the brain and create a neuroinflammatory state accelerating AD neuropathology (217) (218). Insulin aids in the clearance of Aβ from the brain, and elevated insulin levels in T2D could disrupt Aβ metabolism and promote Aβ accumulation in the brain (219). Hyperglycemia-induced tau cleavage in T2D may lead to accelerated NFT formation in AD (220). Hypoglycemia, impaired ability of astrocytes to respond to insulin and transport glucose across the BBB, and impaired glucose metabolism that occur in T2D may also contribute to the development and progression of AD (221).

2.4.6.1.2 Body Mass Index

BMI is the ratio of body weight to squared height and provides a rough index of an individual’s amount of body fat. Obesity is defined as having a BMI ≥30 kg/m². Findings from the CAIDE Study associate midlife obesity with increased AD risk, both independently of other health-related risk factors (OR=1.9, 95% CI, 0.8-4.6) and additively with commonly comorbid risk factors (OR=6.2, 95%CI, 1.94-19.92) (222). Intriguingly, a meta-analysis looking at BMI found that a low BMI (<18.5 kg/m²) is also associated with increased AD risk (RR=1.96, 95%CI, 1.32-2.92) relative to individuals with a normal BMI (18.5-24.9 kg/m²), suggesting the existence of a U-shaped curve for BMI-related dementia risk in midlife (223). In late life, lower BMI (<20 kg/m²) was significantly associated with increased AD risk (HR=1.62, 95%CI, 1.02-2.64), whereas being overweight (BMI=25-30 kg/m²) was not, and obesity was actually associated with reduced dementia risk (HR=0.63, 95%CI, 0.44-0.91) (223).
2.4.6.2 Vascular

2.4.6.2.1 Midlife Vascular Risk Factors

High cholesterol and hypertension prior to the age of 65 are vascular risk factors associated with increased risk of MCI and AD, highlighting the role of vascular contributions to the development of AD and the importance of implementing prevention strategies throughout the lifespan to promote healthy cognitive aging. Some studies investigating the role of vascular risk factors do not provide a standardized age range to define “midlife” and inconsistently report baseline ages of participants followed up in old age, but other studies that do provide this information tend to define “midlife” as 40-60 years (224). A recent meta-analysis of cohort studies examining total serum cholesterol at midlife found that high cholesterol was associated with increased risk of developing AD (RR=2.14, 95%CI, 1.2-3.0). Interestingly, late-life (60 years and older) cholesterol levels were not associated with increased AD or MCI risk in this study (224). In another population-based study, individuals with high cholesterol in midlife were reported to have higher likelihood of developing MCI (OR=1.9, 95%CI, 1.2-3.0) (225). A potential mechanism for the link between high cholesterol and AD risk is the effect of increased cholesterol on AB production through increased cleavage of its precursor protein, APP (226), and increased activity of enzymes that produce the toxic fragments of AB associated with AD pathology (227).

Numerous studies have identified a link between midlife hypertension and increased AD risk in late life (228) (229) (230) (231). In the population-based FINRISK study, individuals with high blood pressure in midlife were more likely to be diagnosed with dementia on follow-up an average of 21 years later (OR=2.6, 95%CI, 1.1-6.6) (229). Midlife hypertension was also associated with increased AD pathology (more NFTs, Aβ plaques, atrophy) upon post-mortem examination in the Honolulu-Asia Aging Study which followed Japanese-American men over 36 years (232). The presence of vascular risk factors at midlife is associated with an increased likelihood of not only developing MCI in late life (233), but also of progressing from MCI to AD (167). A potential mechanism mediating the relationship between midlife hypertension and late life MCI and AD risk is the accrual of damage to the delicate vasculature of the brain from chronic exposure to high pressures. The observation of an association between white matter
lesions, a marker of small vessel disease, and midlife hypertension with a pattern of atrophy typical in AD lends credence to this hypothesis (234).

Many studies investigating the impact of late-life hypertension on AD, however, have not found a significant effect on AD risk. Rather, hypotension in late life is associated with AD risk, likely due to decreased blood pressure reducing cerebral profusion and leading to hypoxic states that contribute to AD. These findings suggest the existence of a complex, age-dependent relationship between hypertension and AD (235).

2.4.6.2.2 Cardiovascular Disease

“Cardiovascular disease” is a broad category describing various health conditions that impair cardiac function, including coronary artery disease, angina pectoris, myocardial infarction, and peripheral arterial disease. The presence of any cardiovascular disease has been associated with a 30% greater risk for AD (HR=1.3, 95%CI, 1.0-1.7) (236) and non-amnestic MCI (OR=1.93, 95%CI, 1.22-3.06) (237). In particular, the Cardiovascular Health Study, a population-based, longitudinal study of older adults, found that the presence of peripheral arterial disease more-so than other forms of cardiovascular disease was associated with AD in older adults (HR=2.3, 95% CI, 1.4-3.9) (236). A potential link between increased risk of dementia and cognitive impairment in cardiovascular disease may stem from shared small vessel pathology in distant regions of the body in the case of peripheral arterial disease, or disruption of laminar flow in coronary artery disease generating emboli that go on to obstruct cerebral vessels causing hypoxic states in the brain that trigger the production of Aβ and inhibit its clearance (238). Heart failure has also been found to be associated with increased risk of AD (HR=1.84, 95%CI, 1.35-2.51) (239) and MCI (HR=1.25, 95%CI, 1.01-1.55) (165) in older adults. Heart failure may exert this increased risk of cognitive impairment by insufficient cardiac output leading to hypoperfusion of brain tissue and increased risk of emboli leading to hypoxic damage, increased Aβ production, and reduced Aβ clearance.

Atrial fibrillation, or asynchronous and inefficient atrial contraction, is suspected to act through a similar mechanism to increase dementia risk, generating emboli to cause overt and covert strokes and hypoperfusion due to reduced cardiac output (240). Atrial fibrillation is associated with increased risk of developing dementia in persons with MCI (HR=4.63, 95%CI, 1.72-12.46) (241). In the population-based, longitudinal Intermountain Heart Collaborative
Study, atrial fibrillation was found to be significantly associated with increased AD risk in adults under 70 years of age, independent of other cardiovascular pathology (OR=2.30, p=0.001) (242). Similarly, the Rotterdam Study found that increased risk of AD associated with atrial fibrillation was restricted to people under the age of 75 years after controlling for other cardiovascular conditions, risk factors, and stroke (OR=2.9, 95%CI, 1.1-7.5) (243).

2.4.6.2.3 Cerebrovascular Disease

As outlined in Section 2.3.3 on cerebrovascular pathology in AD, cerebrovascular pathology is a key disease mechanism in AD. In this light, it is unsurprising that the presence of vascular pathology in the blood vessels of the brain and throughout the body is also associated with increased risk of AD. Upon neuropathological examination at autopsy, atherosclerosis of brain vasculature has been shown to be more common in brains with confirmed AD pathology (77%) compared to brains exhibiting normal ageing (47%), and that atherosclerosis is associated with hallmark Aβ plaque, NFT, and CAA pathologies (244). Atherosclerosis and arteriosclerosis in the brains with pathology-confirmed AD is also associated with lower scores of global cognitive function (245). In terms of assessing AD risk from cerebrovascular disease in living humans, however, measures like carotid intima-media thickness, the thickness of the two innermost layers of the carotid artery, provide a measure of the amount of plaque present within arterial walls, allowing for the assessment of atherosclerosis in vivo. Persons with MCI have been shown to have carotid intima-medias on average 20% thicker than cognitively-healthy, age-matched controls, and significantly more atherosclerotic plaques (both p<0.0001) (246).

Carotid intima-media thickness is also associated with increased progression of cognitive decline, increasing risk of both developing MCI in cognitively healthy older adults and risk of progressing from MCI to dementia (HR=1.251, 95%CI, 1.006-1.555, p=0.044) (247). Numerous longitudinal, population-based studies have confirmed this association between increased presence of atherosclerotic arterial thickening and AD risk (236) (248) (249). In patients already diagnosed with AD, the presence and progression of atherosclerosis as measured by carotid intima-media thickness is also associated with a significantly faster decline in global cognitive function (250). Current opinion is that the impact of atherosclerosis on the risk of cognitive impairment and dementia is mediated through thickening of arterial walls that reduces the
amount of blood flowing through small cerebrovasculature, resulting in hypoperfusion-related pathology (251) (252).

Small vessel disease occurs when vascular pathology in the brain causes local small infarcts and disruption of local circulation in the brain. These “mini-strokes” occurring in small vessel disease are indicated by the presence of lacunae, cerebral microbleeds, and white matter lesions on brain imaging scans. Brain infarcts resulting from occlusion of small blood vessels supplying structures deep within the brain are more commonly found in AD (OR=20.7, 95%CI, 1.5-288.0) than cognitively-healthy older adults, and are associated with poorer cognition when present in AD (253). Cortical microinfarcts are also more common in AD relative to cognitively healthy older adults (254). Infarcts have been identified in brains of individuals with MCI (255) (256), and are associated with lower cognitive function (257) and a higher rate of progression of cognitive impairment when comorbid with AD pathology (258) and other vascular risk factors for AD (259). A proposed mechanism for the impact of small vessel disease on AD risk is that the occlusion of brain vasculature and resultant hypoxic state triggers the production of Aβ and a pro-inflammatory response (260).

Dementia occurring primarily as a consequence of vascular injury, such as stroke, is classified as VaD. Independent of post-stroke dementia, however, strokes are also associated with increased risk of MCI and AD. Individuals with no cognitive impairment who have a history of stroke are at increased risk for developing MCI (165). In the longitudinal, population-based Rotterdam Scan Study, 30 of 1015 participants developed dementia over an average follow-up of 3.6 years, and 26 of the dementia cases were attributed to AD. The presence of covert strokes at baseline in this study more than doubled dementia risk (HR=2.26, 95%CI, 1.09-4.70) (261). A proposed mechanism mediating the link between stroke and dementia is that ischemia triggers increased activity of enzymes that cleave APP to produce Aβ, leading to increased Aβ production and accumulation in the brain, triggering the amyloid cascade (262).

2.4.6.3 Frailty

Frailty is a condition of the elderly marked by systemic decreases in physiological capacity and reserve (263), operationalized clinically as the presence of three or more of the following symptoms: unintentional weight loss (>10 lbs in previous 12 months), self-reported exhaustion, weakness indicated by grip strength, slow walking speed, and low PA (264). The prevalence of
frailty in community-dwelling older adults has been reported at 6.9% (264). In community-dwelling older adults, frailty is associated with greater risk of developing MCI (HR=1.63, 95%CI, 1.27-2.08) (265) and AD (HR=1.28, 95%CI, 1.00-1.63) (266). Autopsy studies have also shown an association between frailty at time of death and increased AD pathology (267). No studies to date have looked at the association between the presence of frailty in persons with MCI and rate of progression to AD, but one study examining changes in frailty states of the course of one year did, however, find different associations between frailty and cognitive function in MCI and mild to moderate AD cohorts (268). For older adults with MCI, only female sex was associated with worsening frailty, not associated age or cognitive status. For older adults with mild to moderate AD, however, cognitive function and age were associated with changes in frailty status. While more research needs to be conducted to determine the relationship between frailty and cognitive decline, this evidence suggests that frailty is more of a concern for the progression of dementia in women and older adults with greater levels of cognitive impairment.

There are multiple proposed mechanisms mediating the link between frailty and progression of MCI and AD, potentially due to the age-related accumulation of deficits across multiple organ systems collectively conferring increased risk of cognitive impairment. From a vascular standpoint, decreased cerebral blood flow due to impairments in the cardiovascular system causing decreased cardiac output and hypotension in frail older adults may create a hypoxic state in the brain, reducing the clearance of toxic Aβ and other metabolic wastes. This may lead to increased Aβ production and inflammation, triggering the amyloid cascade and promoting progression of disease processes associated with cognitive impairment (269).

### 2.5 Cognitive and Functional Benefits of Physical Activity

Aside from having a beneficial effect on reducing health-related factors associated with the onset and progression of MCI and AD, PA is associated with specific benefits in functional capacity, one’s ability to completely daily life activities, and cognition in older adults both with and without cognitive impairment. The following sections discuss the literature investigating these benefits.
2.5.1 Methodological Challenges to Physical Activity Research

Before reviewing the evidence supporting the benefits of PA for maintaining cognitive health in older adults, this section provides context for interpreting the current literature by reviewing the methodological challenges to conducting research involving PA.

First and foremost, it impossible to perform the type of study regarded as the “gold standard” of clinical research – the double-blind, randomized, placebo-controlled trial – when conducting PA research (270). The randomization aspect of this type of research can be achieved in studies involving PA as an intervention, but blinding and controlling trials is challenging. In regard to blinding, single-blind intervention trials of PA can be completed, whereby the researchers and individuals delivering interventions are blinded to the allocation and performance of participants in PA, control, or non-PA conditions. Double-blind trials where the participant is naïve to the intervention they receive, however, are impossible with PA, by virtue of the fact that PA requires conscious effort to be completed. Participants may be blind to which intervention they are receiving relative to the other conditions involved in the study (i.e. PA intervention vs. active or waitlist control groups), but it is ultimately impossible for participants to not know they are performing PA. As a result of this, they may be more inclined to self-report improved health or cognitive outcomes due to subjective perceptions of improvements. This perception of increased health or improvements could also lead to improved confidence, yielding improved performance on objective assessments of health and cognition.

In regard to controlling for the effects of PA with placebos or other conditions, many approaches have been used to control for confounding factors. There is, as of yet, no active placebo for research that directly mimics the sensations of PA without actually performing PA. Rather, intervention studies investigating the effects of PA have had to employ other conditions to attempt to control for the effects of PA interventions. Active controls attempt to control for the confounding effects of social stimulation associated with PA interventions by providing the same “dose” of interaction between researchers and participants, potentially using educational interventions, cognitive activity, social activity, or lower-intensity PA than experimental groups.

Experimental PA studies often use unique PA interventions that differ from other studies in frequency, intensity, type, and duration of PA sessions as well as intervention length, resulting in much different “doses” of PA. This creates considerable difficulty in trying to pool the results
of PA research, as few studies have comparable interventions. Practically speaking, another challenge to pooling and interpreting the results of PA research is that studies may have variable levels of attrition and adherence, which are not always reported by studies in a standardized way. Despite these challenges, systematic reviews and meta-analyses have been done to examine the evidence for the benefits of PA in AD, and these studies are reviewed in the following sections on the benefits of PA in older adults with and without cognitive impairment (271) (272).

Observational studies are critical for researching PA in the context of age-related chronic diseases like AD and allow researchers to use a lifespan approach in studying the association between PA and health outcomes. For both retrospective and prospective observational studies of PA, however, one of the greatest challenges is overcoming the impact of recall and reporting bias on the accuracy of data collected. In retrospective studies, findings are prone to both recall bias, whereby participants are not able to accurately recall PA levels from a prior point in their life, and inaccurate reporting of PA due to social desirability bias, whereby participants may be inclined to report higher PA levels to appear more “healthy” to researchers. The impact of recall bias can be somewhat managed by using a prospective approach, and collecting data on PA levels as they occur throughout the study. However, there is still some possibility of recall bias depending on the latency between PA performance and data collection (i.e. maintaining a daily PA diary vs. annually reporting average weekly PA levels). The use of subjective methods to collect PA data through self-reported scales, questionnaires, or PA diaries in these studies open the opportunity for bias from participants having unrealistic perceptions of their PA levels. Objective collection of PA data can be completed with the use of activity monitors worn on the body, but use of activity monitors on a daily basis for an extended period of time (months to years) is not realistic. Rather, studies using objective assessments of PA usually collect this data over a short latency (days to weeks).

Experimental studies are subject to similar biases, depending on the methods of data collection used in the study (subjective vs. objective). Verification and correction of subjective data with data collected using objective assessments in longitudinal prospective studies may optimize the accuracy of data collected to address biases and limitations of both methods to enhance the accuracy of findings from PA research. Despite the challenges involved in conducting PA research, intentional, creative decisions about study design can ensure accurate data is collected to support meaningful results. The following sections in Chapter 2.5 reviewing
PA research require critical consideration of findings in light of the challenges discussed in this section, but findings from this research overall support the benefits of PA in the prevention and management of MCI and AD.

2.5.2 Cognitively Healthy Older Adults

An extensive body of literature exists detailing the myriad benefits of PA for older adults without cognitive impairment. Specifically regarding cognition, functional capacity, and quality of life for cognitively healthy older adults, increased PA with has been associated with improved global cognition (273) (274), memory (275) (276) (277), executive functioning (273) (277) (278), verbal fluency (279), functional capacity (280) (281), reduced disability (282), and quality of life (283). Despite many individual studies reporting cognitive benefits of PA for cognitively healthy older adults, as well as prior Cochrane Systematic Reviews supporting the existence of cognitive benefits from PA and cardiorespiratory fitness (284), a recent Cochrane Systematic Review examined the effects of aerobic exercise on cognition in older adults and found insufficient evidence from randomized controlled trials to support the existence of cognitive benefits for healthy older adults (271).

PA in older adults without cognitive impairment or dementia is, however, correlated with reductions in imaging and plasma biomarkers of AD (285) (286) (287). Self-reported PA levels have been associated with reduced levels of tau and phosphorylated tau in cerebrospinal fluid and amyloid deposition in the brain in cognitively healthy older adults (285). Higher gray matter volume and reduced regional neurodegeneration have been associated with increased activity level (286), as well as higher integrity of white matter tracts (287), supporting the association of increased PA with reduced progression of disease-related processes. More research investigating the interactions between risk factors and biomarkers for AD, PA, and cognition is needed to clarify the potential mechanism of action supporting the cognitive benefits from PA for older adults.

2.5.3 Older Adults with Mild Cognitive Impairment and Alzheimer’s Disease

A positive effect of PA on cognition has also been shown for persons with MCI at increased risk for developing AD. A 6-month trial that randomized people with increased AD risk to a PA intervention or an education and standard care control group found significant improvements in
global cognitive function in the PA intervention group at the end of the study (absolute difference between groups=1.3 points on Alzheimer’s Disease Assessment of Cognition, 95%CI 2.38-0.22), and a significant difference in scores was maintained at 18 months following the intervention (288). Another study randomizing persons with MCI to a high-intensity aerobic exercise intervention or a stretching control group found significantly higher executive function scores at the end of the study for people with MCI in the high-intensity aerobic exercise intervention (145). A study of the cognitive and neurological effects of a 6-month progressive resistance training intervention in persons with MCI found that participation in a 6-month progressive resistance training protocol was associated with a significant improvement in global cognition over a cognitive training protocol (F(90)=4.1, p<0.05). Improvements in global cognition in the progressive resistance training group correlated with improvements in posterior cingulate gray matter volume (r=0.45, P=0.03), and this group also saw reversal in white matter hyperintensity progression (289). A separate study found that aerobic fitness in persons with at heightened risk for AD (amnestic MCI, low Aβ-42 and elevated tau in cerebrospinal fluid) yielded confirmatory findings, that increased aerobic fitness was associated with increased grey matter volume in the frontal posterior cortex and improved white matter integrity (290). Given that neurodegeneration (loss of gray matter) and poor cerebrovascular health (white matter hyperintensities) are risk factors for AD, PA in MCI may prevent or delay cognitive decline to levels associated with AD by targeting neural and vascular risk factors. Despite positive results in individual trials, a more recent systematic review of the effects of exercise on cognition in MCI failed to find significant effects on cognition, citing the methodological issues of differing MCI diagnostic criteria, under-powered studies, concerns about blinding, insufficient reporting of treatment adherence as potential reasons for its findings (291).

In looking at levels of Aβ and tau in AD, a large body of research on AD in animal models suggests that aerobic exercise is associated with reduced deposition of these biomarkers. Multiple studies using rodent models mimicking AD pathology have investigated the effects of PA (typically wheel or treadmill running) on neurological and cognitive outcomes, and shown that PA is associated with reductions in Aβ and tau pathology (292) (293) (294) (295), reduced neurodegeneration (296) (295), enhanced neurogenesis and synaptogenesis, and sustained or improved cognitive function (296) (295). In human intervention trials, however, these results have not been replicated. A 16-week, MVPA intervention for older adults with AD found no significant changes in Aβ or tau levels in the cerebrospinal fluid of intervention participants.
Negative results from in-human trials suggest that alternate mechanisms may play a more influential role in mediating the benefits of PA for persons with AD. In keeping with this, it appears that PA to maintain high levels of cardiorespiratory fitness is most important when looking at individuals who have progressed to AD. While no association has been shown between PA levels and measures of cerebrovascular health and neurodegeneration in older adults with AD (298), studies investigating peak oxygen consumption, a measure of cardiorespiratory fitness, have shown that this factor is associated with reduced degeneration (whole brain volume, parietal lobe volume, temporal lobe volume) and improved indicators of cerebrovascular health (white matter volume) (299) (300). The specific association of biomarkers with cardiorespiratory fitness suggests that failing to look specifically higher-intensity aerobic compared to general PA may explain why conflicting results have been found on the effects and associations of PA with cognition and AD pathology. Future research should more explicitly indicate the intensity and dosages of PA to help clarify the relationship between AD, cognition, and PA in older adults.

Research investigating the use of PA for secondary prevention in AD (preventing symptom progression) has shown promising results, but additional well-designed, rigorous, randomized controlled trials are needed to clarify this relationship. One study found a significant association between PA and maintained executive function in AD (14), and a meta-analysis of exercise interventions in AD identified a positive effect of exercise interventions on measures of global cognitive function in AD with an effect size of 0.75 (95% CI, 0.32-1.17) (301). Despite these positive results, a recent update to the Cochrane Review on exercise programs for people with dementia including 9 studies (n=409) concluded that there is no clear benefit of exercise interventions on cognitive function for people with dementia (ES = 0.43; 95% CI, -0.05 to 0.92; p=0.08), and that the current quality of data in these studies is very low (272).

This updated Cochrane Review did, however, support the functional benefits of exercise interventions on activities of daily living performance in dementia (ES = 0.68; 95% CI, 0.08-1.27; p=0.02) (272). This aligns with the results of a prior systematic review on the effects of exercise on activities of daily living for people with AD, which found an average effect size of 0.80 (p<0.001; 95% CI) across 6 randomized controlled trials involving aerobic and strengthening exercise interventions (19). A systematic review of randomized controlled trials using exercise for older adults with dementia, including 20 studies with 1378 participants, also
identified improved physical functioning following PA interventions for persons with dementia (302).

The key message that can be distilled from research investigating the cognitive and functional benefits of PA for older adults is that PA is of benefit, particularly in terms of reducing one’s risk of developing AD and maintaining functional capacity for those already living with AD. Impairments in functional capacity, determined by one’s ability to complete basic activities of daily living (e.g. feeding, dressing) and instrumental activities of daily living (e.g. managing household finances, shopping) have been significantly associated with a higher likelihood of institutionalization for older adults in general (303), and also specifically for persons with AD (304). Given the critical role of functional capacity in maintaining independence in aging, PA is an important health-promoting behaviour in which older adults should participate. More specific details about these benefits, such as optimal dose, benefits to specific cognitive domains, and the physiological mechanisms underlying these benefits have yet to be determined by research. Although there are conflicting results in the existing literature surrounding these topics and further research is needed, this does not diminish the importance of PA participation as a health-promoting behaviour for older adults.

2.6 Physical Activity Levels of Older Adults

In 2016, the Global Council on Brain Health published expert recommendations on the role of PA in maintenance of brain health in older adults (305), supporting weekly levels of physical activity similar to the Canadian Physical Activity Guidelines for Older Adults. The Global Council on Brain Health went further in their recommendations, however, to provide suggestions for how older adults can meet these recommendations, encouraging individuals to identify meaningful activities. While recognizing the benefits of PA for maintaining brain health, these recommendations acknowledge current gaps in the scientific literature for preventing the onset and progression of AD.

2.6.1 Physical Activity Guidelines for Older Adults

To reinforce the importance of participating in PA as per the Canadian Physical Activity Guidelines for Older Adults to support healthy cognitive aging, an evidence-based statement on the scientific evidence supporting the benefits of PA for healthy cognitive aging was recently
created. To accomplish this, a review of the literature on PA and AD was conducted and an expert panel was stuck to interpret these findings and construct a statement about the Canadian Physical Activity Guidelines for Older Adults based on the evidence, following a systematic process adapted from the Appraisal of Guidelines, Research, and Evaluation (AGREE II) (306) instrument for developing evidence-based guidelines for clinical practice. The result of this systematic process is the following evidence-based message to be used to promote PA for the prevention and management of AD: “Regular participation in PA is associated with a reduced risk of developing Alzheimer's disease. Among older adults with Alzheimer's disease and other dementias, regular PA can improve performance of activities of daily living and mobility, and may improve general cognition and balance” (307).

Physical Activity Guidelines for Older Adults

The Canadian Society for Exercise Physiology, ParticipACTION, and other public health stakeholders, supported by the Public Health Agency of Canada, have developed the Canadian Physical Activity Guidelines (“the Guidelines”) concerning the recommended weekly level of PA to maintain healthy, active living throughout the lifespan (21). The Guidelines specific to older adults are based upon a systematic review (280) of scientific evidence on the relationship between PA of community-dwelling older adults and functional and cognitive outcomes, which found the strongest evidence of an effect of PA on maintaining functional independence. A relationship between higher PA and sustained cognitive function in aging adults was supported in this review, but with mixed results concerning the strength of this relationship. The Guidelines suggest that older adults (65 years and older) perform 150 minutes of MVPA on a weekly basis in bouts of no less than 10 minutes, strength training at least twice weekly to maintain bone and muscle strength, and optional balance exercises to reduce the risk of falling in older adults with mobility issues. According to the Guidelines, PA should be performed in addition to the activities associated with daily living, and can be achieved in a variety of ways (e.g. occupational, transportation, recreational). Appendix 1 is the public communique provided by the Canadian Society for Exercise Physiology outlining the Guidelines in a one-page sheet. Similar guidelines about sedentary behaviour have been published for children and youth, but none are currently available specific to the older adult population.

Despite considerable effort put into developing and disseminating the Guidelines (21), awareness and uptake of the Guidelines by the public is very low. A recent study looking at the
awareness of Canadian adults of the Guidelines found just 12.9% of respondents from a large (n=1586), nationally representative sample were aware of the Guidelines published in 2011, and a little over 54.5% of respondents reported PA levels meeting or exceeding the Guidelines (308). A separate study has found that awareness of the Guidelines declines with age, from 48.3% in young adults (18-24 years), to 33.3% in older adults (≥65 years), as did unprompted recall of the guidelines (5.0% of older adults) (309). Public awareness and uptake of previous versions of the Guidelines released in 1998 was also low (37.3% awareness, 3.9% unprompted recall), but higher amongst women, groups with higher socioeconomic status, and greater PA levels (310) (311). This is not a uniquely Canadian problem, as similarly low awareness of PA guidelines has been reported in American samples as well, with only 36.1% of respondents aware of the guidelines, and 0.56% able to state the guidelines without prompting (312).

In regard to low uptake of the Guidelines, it’s not just a problem of low awareness. Even when people are instructed about the Guidelines, research suggests the Guidelines in and of themselves are ineffective at changing PA behaviours. In a randomized controlled trial where one group received copies of the Guidelines and a handbook, changes in MVPA over one year were no different than a control group receiving no intervention (313). Plotnikoff et al. (314) iterated this well: “The [Canadian Physical Activity] Guide should not be used as a “prescription” or a “fitness program,” much like Canada’s Food Guide is not a diet… the Guide is one component of individual- and population-based physical activity promotion programs/strategies/frameworks. Although the Guide is an important tool, the evidence suggests context must be considered when its purpose is assessed.”

2.6.2 Healthy Older Adults

Despite the myriad benefits of PA for aging adults, the overwhelming majority of older adults with and without cognitive impairment do not meet recommended PA levels for maintaining their health. Canadian data are available detailing the PA levels of Canadians across age groups (Figure 1) (Statistics Canada, 2016) (315). These data indicate that of all age groups, older adults in Canada report the lowest PA levels with just 48% reporting any leisure time PA in 2014.
There are limitations to this data, however, concerning the method of collection and the lack of contextualization to the Guidelines. This data was collected through retrospective self-report, not objectively using accelerometers, and is subject to recall bias. Additionally, these data do not provide an indication of PA as a health behaviour, which would require collecting data on frequency, intensity, type, and duration of weekly PA levels to determine the proportion of Canadians meeting the Guidelines for their specific age group.

For years following 2014, Statistics Canada has changed its format for collecting and reporting data on PA levels of Canadians to align with the Guidelines (Statistics Canada, 2017) (316). Age categories have been changed from previous years, but the older adult age range has remained the same (≥65 years). The threshold of PA participation now sits at 150 minutes per week of MVPA in bouts of 10 minutes or more, defining “moderate” activities as those which cause one to “breathe harder and sweat at least a little”. These data are illustrated below (Figure 2), and indicate a lower level of PA than suggested by previous years. From 2014 to 2015, PA
levels of older adults dropped by 7.5%, compared to yearly fluctuations of roughly 2% from 2010-2014. It is unlikely that there was such a substantial drop in PA levels from 2014-2015, but rather that fewer adults were achieving recommended PA levels in years where data on PA participation did not reflect the Guidelines.

**Figure 2 – Proportion of Persons Reporting to Meet or Exceed Age-Specific Physical Activity (PA) Recommendations, 2015 (316).**

Source: Statistics Canada. Table 105-0508 – *Canadian health characteristics, annual estimates, by age group and sex, Canada (excluding territories) and provinces, occasional (number unless otherwise noted), CANSIM (database). (accessed: 19 July 2017)*

![Proportion of Persons Reporting to Meet or Exceed Age-Specific Physical Activity (PA) Recommendations, 2015](image)

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Proportion</th>
</tr>
</thead>
<tbody>
<tr>
<td>12-17 years</td>
<td>59.4%</td>
</tr>
<tr>
<td>18-34 years</td>
<td>67.0%</td>
</tr>
<tr>
<td>35-49 years</td>
<td>59.2%</td>
</tr>
<tr>
<td>50-64 years</td>
<td>55.6%</td>
</tr>
<tr>
<td>65 years and over</td>
<td>40.2%</td>
</tr>
</tbody>
</table>

The use of PA as a health behaviour by different age groups has also been investigated by other studies. The Canadian Health Measures Survey between 2007 and 2009 was the first national, population-based study in Canada to collect accelerometer data and provide an objective measure of PA (317). Findings from this study indicate that only 4.5% of adults aged 60-79 in this sample got at least 30 minutes of MVPA, in bouts of at least 10 minutes on at least 5 of 7 days in a week, as per recommendation of a previous version of the Guidelines (318). The current Guidelines (21) were achieved by 13.1% of 60-79 year-olds participating in the study.

### 2.6.3 Adults with Mild Cognitive Impairment and Alzheimer's Disease

PA behaviours of persons with MCI, AD, and dementia have received far less research attention, but some literature is available. A study from a rural memory clinic in Canada examined PA levels and beliefs of patients and caregivers (23). 30% of the sample constituting participants diagnosed with AD, 21% diagnosed with MCI, and 19% were cognitively normal
but at risk for developing MCI or dementia. Of the total sample including patients and caregivers, 84% reported either no PA or levels that failed to meet Canadian PA guidelines, which is not far from the figure reported from data in the 2007-2009 Canadian Health Measures Survey (86.9%) (22). Another study (319) assessed physical fitness in persons with MCI and dementia using the Senior Fitness Test (320), and compared the results to validated fitness standards for maintaining physical independence in old age (321). 89% of the sample in this study had a diagnosis of MCI or dementia due to AD. This study found low levels of physical fitness, and compared to physical fitness standards predictive of ability to function independently in old age, the minority of participants met standards in domains of aerobic capacity (27% of sample), upper body strength (32% of sample), lower (23% of sample) body strength, and dynamic balance (15% of sample). The overarching message from these studies is that older adults both with and without cognitive impairment are largely failing to meet the recommended levels of PA on a weekly basis to maintain their health and independence.

2.7 Factors Influencing Physical Activity Levels of Older Adults

2.7.1 Healthy Older Adults

Barriers and facilitators to PA participation in older adults have been heavily researched in an attempt to account for the low PA levels of older adults despite PA’s well-known benefits. A meta-synthesis of 132 qualitative studies on older adults’ perceptions of PA found six emergent themes affecting participation: social influences, physical limitations, competing priorities, access difficulties, personal benefits of PA, and motivation and beliefs (322).

Social influences identified as barriers include doubting that meeting new people is beneficial (323), lack of a group identity (323), feeling that the gym environment is intimidating (324), lack of a companion to exercise with (325) (326), lack of professional guidance (327), female gender (328), and lower socioeconomic status (329). Social influences identified as facilitators to PA in older adults include social support (330) (331) (332) (333), viewing PA as an opportunity for social interaction (324) (334), recommendation from a physician (324), supportive and knowledgeable staff at PA programs (324), being married (335) (336), male gender (335), and cultural specificity of PA programs (337).
Physical limitations, such as the presence of illness or handicaps (327) (329) (338) (339) (340), frailty (332), pain (323), polypharmacy (328), feeling too tired (326), and history of falls or fear of falling (330) (339), can act as barriers to engaging in PA. Good health and functional capacity (324) (335), concerns about declining physical health (333) (340), and desire to maintain health (327) can be motivators for PA in older adults.

Competing priorities are barriers for engaging in PA, and are typically described in the literature as time constraints or a lack of time (324) (326) (339) (341) that prevent older adults from engaging in PA. PA viewed by older adults as an inconvenience in one study was found to be a barrier to participation (330).

Barriers and facilitators related to the accessibility of PA to older adults have also been described, but accessibility has been predominantly approached by research as a barrier. For older adults to access PA, the literature indicates that they need to have sufficient knowledge, resources, and environmental conditions to facilitate participation. Knowledge barriers for participation of older adults in PA include not knowing the appropriate PA options and programs (327). Lack of health literacy amongst older adults has also been associated with decreased likelihood of meeting the Guidelines (342). Environmental barriers include lack of access to transportation (323) and facilities (326). Social barriers include lack of access to affordable, convenient and stimulating PA options (327) (330), and lower education level (326).

How older adults perceive the personal benefits of PA can also facilitate or inhibit their participation. Doubting that PA is beneficial (327) is a barrier to participation, while perceiving PA to have health and psychological benefits (341) and regarding exercise as an enjoyable (333) activity are facilitators of PA.

Similarly, the internal motivations and beliefs of older adults can be barriers or facilitators to PA participation. Low expectations of acceptable PA levels for one’s age is a barrier to PA participation in older adults (343), as is a perceived lack of fitness (323) or perception that one is already active enough (326). Boredom and lack of interest (323) (324), lack of energy (323), lack of self-discipline (324), and lack of motivation (324) (326) are also barriers to PA participation. Certain motivations and beliefs alternately act as facilitators to PA in older adults, including having a history of exercise (332), perceived behavioural control and self-efficacy (332), and having positive outcome expectations for PA (330).
2.7.2 Adults with Mild Cognitive Impairment and Alzheimer’s Disease

While PA participation has been well researched for cognitively healthy older adults, much less has been done concerning PA experiences, beliefs, and factors influencing participation in older adults with MCI and AD. The comparatively small body of research on the experiences of PA in persons with cognitive impairment has yielded important findings about the meaningful nature of PA for this population. One interpretive phenomenological study, which included in-depth observations and interviews with 8 community-dwelling older adults with mild to moderate dementia, found that specific activities are of great meaning and importance to persons with dementia and being active in and of itself was particularly important to participants (344). Activities important to persons with dementia include leisure-time, household, occupational, and socially engaging activities, but activities identified as the most meaningful were those that were enjoyable, fostered a sense of connection and belonging, and provided a sense of independence. Another study using quantitative content analysis of 906 responses of caregivers for persons with dementia confirmed that meaningful activities for persons with dementia are those emphasizing social connections, promoting physical health, providing cognitive stimulation, fostering a sense of self, that are enjoyable, and promoting independence and coping skills (345). In a qualitative case study of two men with mild AD and their caregivers, the experience of PA was meaningful as part of creating a daily routine and to improve one’s perceived health and well-being (346).

Research on the perception of PA in dementia using qualitative methods has identified important information for PA promotion strategies in this population. A qualitative study by (347) exploring how persons with mild AD perceive PA in their daily lives and the meanings they associate with PA found an overarching theme of PA perceptions of persons with AD is that it is perceived as a way to maintain a sense of self in AD and that persons with AD strive to be physically active despite the barriers they encounter. Perceptions of PA held by participants in this study were shaped by their previous PA levels, public health recommendations, and social comparisons with others their age. In another study, although biased by only including participants who successfully completed a 6-month aerobic exercise intervention, qualitative inquiry was used to investigate the feasibility and perceived impact of an aerobic exercise intervention by persons with AD and their caregivers (348). Both participants with AD and their caregivers did not perceive changes in cognitive symptoms following intervention, but was regarded by participants and caregivers to be socially rewarding, improve physical strength, and
be a positive experience. Caregivers also perceived improved attitudes in their partners and a reduction in their own stress levels (348). From a caregiver perspective, activities are perceived as a respite, but can be difficult for caregivers to coordinate and for persons with dementia to be interested and engaged in (345).

Barriers to PA in dementia and strategies to overcome them have also been investigated through qualitative inquiry. Barriers to PA identified include difficulties in way-finding for outdoor activities and “peculiar behaviour” described by the caregivers (346). Adaptation strategies to facilitate PA despite these barriers include having caregivers initiate activities, building PA into daily routines, using walks to counteract morning fatigue, using communication devices for caregivers to feel confident with their spouses going for walks alone, and restricting the driving of persons with dementia. Finding meaningful and positive activities for partners with AD was identified as a challenge by caregivers (346). A study of 14 community-dwelling adults with mild AD and their caregivers identified additional barriers to PA participation, including: decreased energy levels, emotional and environmental barriers, impaired physical function, and impaired orientation abilities (347). Another study assessing PA perspectives in adults with and without cognitive impairment identified that, in addition to PA barriers experienced by cognitively healthy older adults, memory problems also act as barriers to PA participation (325). A systematic review of articles on PA participation in community-dwelling adults with dementia identified correlates of PA participation for this population, including: increased energy intake, resting metabolic rate, fat free mass, gait speed, global motor function, overall health-related and physical quality of life, higher levels social functioning, and lower levels of apathy (349). This study also identified correlates of decreased PA participation for community-dwelling older adults with dementia, including: polypharmacy equal to or exceeding 4 medications, dizziness, decreased ability to complete activities of daily living, a history of falls, fewer wakeful hours, autonomic symptoms, and delirium.

Caregiver and participant beliefs about the importance of PA also impact their likelihood of participation in PA. In a study of persons with MCI and dementia being seen at a rural memory clinic in Canada, patient-caregiver dyads were asked about their attitudes toward PA and PA levels (23). Patients were less likely than caregivers to believe in the benefits of PA for general health promotion, and general beliefs about PA for health promotion were not predictive of PA level. Rather, the specific belief of patients and caregivers that vigorous exercise was important
for health promotion was predictive of PA levels. Additionally, one half of the dyad engaging in PA was not predictive of PA participation by the other half. Caregivers’ beliefs about the importance of vigorous exercise for health promotion, rather than their PA level, were predictive of their partner’s PA level.

2.7.3 Comparison of Older Adults with and without Cognitive Impairment

In looking at the literature on factors influencing PA participation for persons with and without cognitive impairment, areas of intersection between activity, aging, and cognition can be found. The way that the literature approaches the subject of PA participation of these two groups also yields important insights for the way older adults with and without cognitive impairment conceptualize PA. A table comparing the specific barriers and facilitators identified by the literature on PA participation for older adults with and without cognitive impairment is provided at the end of this section (Table 1), and summarized as follows.

In terms of social factors influencing PA participation, the literature on persons with MCI or AD is far more positive, and focuses more on facilitators than barriers. The overarching similarity between social factors influencing PA for older adults with and without cognitive impairment is that viewing PA as an opportunity for social engagement and the presence of social support are important facilitators. Specifically in the context of AD and MCI, this social support comes in the form of caregiver management of PA engagement. The social nature of PA, particularly group-based activities, has also been noted as a barrier to participation, as cognitive challenges associated with navigating social situations that arise during group PA limit the ability of individuals with MCI or AD to participate. This can be addressed, however, by participating in activities with others who are also have cognitive impairment or appreciate the unique challenges and experiences associated with AD and MCI.

Interestingly, the literature on PA participation in older adults without cognitive impairment focuses far more on environmental factors as barriers to participation. A study of PA in persons with cognitive impairment that identified environmental barriers as interfering with participation did not elaborate on the specific nature of these barriers (347), which makes comparison of environmental barriers faced by older adults with and without cognitive impairment difficult. In another study of older adults with cognitive impairment, restriction of one’s environment because of the need for supervision to participate in PA was posed as a barrier
Literature on PA participation for older adults with cognitive impairment also reports environmental factors as facilitators of PA, like having access to natural, familiar spaces to participate in PA (346) (347) (350).

Literature on PA in persons with AD and MCI has focused on education and knowledge as a facilitator, finding that knowledge of PA recommendations and norms for one’s age group are beneficial to promoting PA participation. For older adults without cognitive impairment, this is largely the same. Additionally, literature on PA participation of older adults without cognitive impairment has indicated a more important role of “experts” in helping to promote PA participation through providing guidance about how to exercise safely and effectively. Given the dearth of research investigating education and knowledge about PA of persons with cognitive impairment, it is difficult to compare the influence of this factor on PA participation of older adults with and without cognitive impairment.

Broadly, facilitators and barriers to PA participation attributed to physical factors and health are similar for older adults with and without cognitive impairment. Being physically able to participate in activities, good overall perceptions of one’s health, and wanting to improve one’s health are facilitators for both groups of older adults. Similarly, fatigue, polypharmacy, history of falls, and the presence of physical impairments are barriers to PA participation in both groups. The literature on factors influencing PA participation in older adults with cognitive impairment, however, has found far more unique barriers to PA participation related to AD symptoms: way-finding difficulties, memory impairment, autonomic symptoms, behavioural symptoms, and delirium.

Interestingly, the literature on factors influencing PA participation of older adults with AD and MCI has barely touched on competing demands and resource limitations as barriers to participation, while a significant amount of literature on older adults without cognitive impairment has. Insufficient time and financial resources are barriers to PA participation. For older adults with cognitive impairment, these competing demands are largely faced by their caregivers, in which time is the limited resource. Caregivers have reported needing to devote extra time to ensure that PA happens for their care partners, either by making time to supervise the PA sessions themselves or transporting their care partners to and from PA programs.
For older adults with AD and MCI, beliefs, perceptions, and motivations for participating in PA have largely been reported in terms of factors that facilitate participation, while far more barriers of this nature have been reported by the literature on older adults without cognitive impairment. Facilitators shared by these two groups center on the perception of PA as something that is meaningful and beneficial, while a common barrier between the two groups is inability to motivate oneself and not finding activities meaningful or interesting. An important difference to note between the literature on older adults with and without cognitive impairment is that far more focus has been placed on the importance of PA as a way to maintain independence and a sense of self for older adults with cognitive impairment. Given that AD causes an insidious loss of one’s memory and independence in daily activities, the perception of PA as a way to counter or forestall this imminent loss appears to be a salient motivator for PA participation in older adults with cognitive impairment.

Broadly, it seems that the literature on PA participation for older adults with cognitive impairment is more positive, focusing on PA facilitators and strategies to overcome barriers, while the literature concerning the general older adult population takes a more dichotomous “Barriers vs. Facilitators” view. Additionally, the presence of cognitive impairment seems to influence multiple domains of factors influencing PA participation, with the exception of the “Environment” and “Education and Knowledge” domains, which have been marginally investigated in the existing literature for persons with cognitive impairment.

Table 1   **Barriers and Facilitators to Physical Activity (PA) Participation in Older Adults with and without Cognitive Impairment**

<table>
<thead>
<tr>
<th>Domain</th>
<th>Cognitively Healthy Older Adults</th>
<th>Older adults with AD or MCI</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td><strong>Facilitators</strong></td>
<td><strong>Facilitators</strong></td>
</tr>
<tr>
<td>Social</td>
<td>• Social support (330) (331) (332) (333)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Viewing PA as an opportunity for social interaction (324) (334)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Being married (335) (336)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Male gender (335)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Cultural specificity of PA programs (337)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Fostering a sense of connection and belonging (344)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Activities emphasizing social connections (345) (350)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Viewing PA as socially rewarding (348)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Higher level of social functioning (349)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Caregiver perception that PA is important (23)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Caregiver support for PA participation (26) (346) (351)</td>
<td></td>
</tr>
<tr>
<td>Barriers</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Barriers</td>
<td>Facilitators</td>
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<tr>
<td>------------------------------------------------------------------------</td>
<td>-----------------------------------------------------------------------------</td>
<td></td>
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<tr>
<td>Lack of access to transportation (323)</td>
<td>Being able to perform PA at home (351)</td>
<td></td>
</tr>
<tr>
<td>Feeling that the gym environment is intimidating (324)</td>
<td>Being out in nature (350)</td>
<td></td>
</tr>
<tr>
<td>Lack of access to facilities (326)</td>
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<td></td>
</tr>
<tr>
<td>Challenging social situations (26)</td>
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<td></td>
</tr>
<tr>
<td>Lack of understanding from others about AD symptoms and experiences</td>
<td></td>
<td></td>
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<tr>
<td>• Lack of a group identity (323)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Lack of an exercise companion (325)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Female gender (328)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Lower socioeconomic status (329)</td>
<td></td>
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<table>
<thead>
<tr>
<th>Education and Knowledge Facilitators</th>
<th>Barriers</th>
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</thead>
<tbody>
<tr>
<td>• Recommendation from a physician (324)</td>
<td>Presence of an environmental barrier (347)</td>
</tr>
<tr>
<td>• Supportive and knowledgeable staff at PA programs (324)</td>
<td>Lack of accessible facilities (325)</td>
</tr>
<tr>
<td>• Knowledge of public health recommendations (347)</td>
<td>Being unable to leave the house unsupervised (26)</td>
</tr>
<tr>
<td>• Social comparisons with other members of age cohort (347)</td>
<td>Poor weather (351)</td>
</tr>
<tr>
<td>• Recommendation, guidance, and oversight from a qualified health professional (325) (351)</td>
<td></td>
</tr>
<tr>
<td>Barriers</td>
<td></td>
</tr>
<tr>
<td>• Lack of professional guidance (327)</td>
<td></td>
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<tr>
<td>• Not knowing the appropriate PA options and programs (327)</td>
<td></td>
</tr>
<tr>
<td>• Lack of health literacy (342)</td>
<td></td>
</tr>
<tr>
<td>• Lower education level (326)</td>
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<table>
<thead>
<tr>
<th>Health (Physical and cognitive) Facilitators</th>
<th>Barriers</th>
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<tbody>
<tr>
<td>• Good health and functional capacity (324) (335)</td>
<td>Activities emphasizing physical health (345)</td>
</tr>
<tr>
<td>• Concerns about declining physical health (333) (340)</td>
<td>Activities emphasizing cognitive stimulation (345)</td>
</tr>
<tr>
<td>• Desire to maintain health (327)</td>
<td>Viewing PA as a meaningful part of creating a daily routine and as a way of improving perceived health and well-being (346)</td>
</tr>
<tr>
<td>• Activities emphasizing physical health (345)</td>
<td>Perception of improvements in physical strength (348)</td>
</tr>
<tr>
<td>• Activities emphasizing cognitive stimulation (345)</td>
<td>Using PA to counter morning fatigue (346)</td>
</tr>
<tr>
<td>• Viewing PA as a meaningful part of creating a daily routine and as a way of improving perceived health and well-being (346)</td>
<td>Restricting driving of persons with dementia (346)</td>
</tr>
<tr>
<td>• Perception of improvements in physical strength (348)</td>
<td>Increased energy intake (349)</td>
</tr>
<tr>
<td>• Using PA to counter morning fatigue (346)</td>
<td>Higher resting metabolic rate (349)</td>
</tr>
<tr>
<td>• Restricting driving of persons with dementia (346)</td>
<td>Higher fat-free mass (349)</td>
</tr>
<tr>
<td>• Increased energy intake (349)</td>
<td>Faster gait speed (349)</td>
</tr>
<tr>
<td>• Higher resting metabolic rate (349)</td>
<td>Higher global motor function (349)</td>
</tr>
<tr>
<td>• Higher fat-free mass (349)</td>
<td>Higher overall quality of life (349)</td>
</tr>
<tr>
<td>• Faster gait speed (349)</td>
<td>Higher physical quality of life (349)</td>
</tr>
<tr>
<td>• Higher global motor function (349)</td>
<td></td>
</tr>
<tr>
<td>• Higher overall quality of life (349)</td>
<td></td>
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<tr>
<td>• Higher physical quality of life (349)</td>
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<td>Barriers</td>
<td>Barriers</td>
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<tr>
<td>• Presence of illness or handicaps (327) (329) (338) (339) (340)</td>
<td>• Not perceiving cognitive benefits (348)</td>
</tr>
<tr>
<td>• Frailty (332)</td>
<td>• Fatigue (346) (347)</td>
</tr>
<tr>
<td>• Pain (323)</td>
<td>• Difficulty in wayfinding, “peculiar” behaviours (346) (347)</td>
</tr>
<tr>
<td>• Polypharmacy (328)</td>
<td>• Comorbid conditions and impaired physical function (347) (351)</td>
</tr>
<tr>
<td>• Feeling too tired (326) (323)</td>
<td>• Memory problems (325) (350)</td>
</tr>
<tr>
<td>• History of falls or fear of falling (330) (339)</td>
<td>• Polypharmacy (349)</td>
</tr>
<tr>
<td></td>
<td>• Dizziness (349)</td>
</tr>
<tr>
<td></td>
<td>• Reduced functional capacity (349)</td>
</tr>
<tr>
<td></td>
<td>• History of falls (349)</td>
</tr>
<tr>
<td></td>
<td>• Fewer waking hours (349)</td>
</tr>
<tr>
<td></td>
<td>• Autonomic symptoms (349)</td>
</tr>
<tr>
<td></td>
<td>• Delirium (349)</td>
</tr>
<tr>
<td></td>
<td>• Emotional dysregulation (347)</td>
</tr>
<tr>
<td></td>
<td>• Pain or physical discomfort (350)</td>
</tr>
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</table>

<table>
<thead>
<tr>
<th>Competing demands and resource limitations</th>
<th>Facilitators</th>
<th>Facilitators</th>
</tr>
</thead>
<tbody>
<tr>
<td>Barriers</td>
<td>Barriers</td>
<td>Barriers</td>
</tr>
<tr>
<td>• Time constraints or a lack of time (324) (326) (339) (341)</td>
<td>• Reliance on caregiver (347) (351)</td>
<td></td>
</tr>
<tr>
<td>• Viewing PA as an inconvenience (330)</td>
<td>• Other leisure activities (travel) (351)</td>
<td></td>
</tr>
<tr>
<td>• Lack of access to affordable, convenient and stimulating PA options (327) (330)</td>
<td></td>
<td></td>
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</tbody>
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<table>
<thead>
<tr>
<th>Beliefs, Perceptions, and Motivations</th>
<th>Facilitators</th>
<th>Facilitators</th>
</tr>
</thead>
<tbody>
<tr>
<td>Barriers</td>
<td>Barriers</td>
<td>Barriers</td>
</tr>
<tr>
<td>• Perceiving PA to have health and psychological benefits (341)</td>
<td>• Perceiving PA as meaningful (344)</td>
<td></td>
</tr>
<tr>
<td>• Regarding exercise as an enjoyable activity (333)</td>
<td>• Perceiving PA as enjoyable / a positive experience (348) (344) (345)</td>
<td></td>
</tr>
<tr>
<td>• Having a history of exercise (332)</td>
<td>• PA providing a sense of independence (344) (345)</td>
<td></td>
</tr>
<tr>
<td>• Perceived behavioural control and self-efficacy (332)</td>
<td>• PA fostering a sense of self (345) (347)</td>
<td></td>
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<tr>
<td>• Having positive outcome expectations for PA (330)</td>
<td>• Activities that foster coping skills (345)</td>
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<td></td>
<td>• Perceiving PA as beneficial for maintaining health and wellbeing (347) (26) (351)</td>
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<td></td>
<td>• Prior engagement in PA (347) (26)</td>
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<td></td>
<td>• Reduced apathy levels (349)</td>
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<td></td>
<td>• Believing vigorous exercise is important for health promotion (23)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Building PA into daily routines (346) (26)</td>
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<td></td>
<td>• Ability to self-monitor PA progress (351)</td>
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<tr>
<td></td>
<td>• Perceiving PA as a way to look and feel young (350)</td>
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</table>
2.7.4 Older Adult Perceptions of Physical Activity and Cognitive Health

While the general importance of maintaining PA for aging well and maintaining brain health is well known amongst older adults, more specific information on the relationship between PA and brain health and frequency, intensity, and duration of PA is not as well known (352). Older adults perceive the benefits of PA for cognitive health as being poorly communicated and lacking specific recommendations and referrals for additional resources and support (353) (354). Confusing messages in the media about methods for maintaining brain health have been cited as a barrier to seeking information about PA (355). Physician recommendation and counselling are facilitators for PA in older adults (324), but research suggests discussions about PA between physicians and older adults are inadequate, which can be perceived by older adults as discomfort or lack of knowledge on the part of physicians in discussing PA (356). However, when PA is brought up, it is typically in the context of a health problem, which aligns with prior research suggesting this is when older adults are most receptive to PA counselling for health behaviour change (357).

Only one qualitative study to date has examined the PA perceptions of persons with dementia and their healthcare providers (358). In this study, 9 health care providers and 9 dyads comprised of caregivers and persons with dementia residing in Bangkok, Thailand were interviewed. This study found that persons with dementia and their care partners had different concepts of PA than healthcare providers, placing more emphasis on walking and activities of daily living as ways to get PA than formal aerobic, strengthening, and balance exercises described by healthcare providers. All groups indicated that PA was beneficial both for older adults in general and for persons with dementia, particularly for maintaining functional capacity, regulating sleep-wake cycles, managing mood, and reducing caregiver burden. The ideal PA program identified by participants was specific to Thai culture and emphasized a recreational, home-based program.
Although the specific framing of this study in the Thai context limits its broader application, it still provides a valuable contribution to the small body of literature that exists on the topic of PA perceptions of persons with dementia.

2.8 Understanding Health Behaviours

In developing and implementing health behaviour change interventions, research suggests that theory-informed approaches are more effective than atheoretical approaches (359). A multiplicity of social and health psychology theories exists aiming to explain and predict human behaviour. Many of these theories have been adapted by health researchers to improve the uptake and performance of specific behaviours to improve individuals’ health and wellbeing, such as increasing PA behaviours. The remaining sections of this chapter review theoretical approaches to understanding health behaviour used in research settings to illustrate why it is important to consider the experiences, perceptions, and beliefs of individuals when studying health behaviours like PA.

2.8.1 Common Theoretical Approaches to Studying Health Behaviours

*Social Cognitive Theory* (360) is a theory of social psychology that emphasizes the influence of both social systems and the personal cognitive processes on human motivation and action. *Social Cognitive Theory* considers humans to be agents in the creation of social systems through their interactions with other agentic humans. These social structures they create in turn feedback to influence their personal development and functioning. A key component of *Social Cognitive Theory* is the concept of self-efficacy, or perceptions of one’s abilities to perform an action, which is the proposed mechanism for individuals with human agency to engage in creating social realities. Self-efficacy is critical for individuals to understand they can regulate their actions and play an active role in determining their future (361).

The application of *Social Cognitive Theory* in health promotion stems from the premise that individuals can determine their future health states by engaging in particular health behaviours, despite the influence of social influences beyond their control (362). Specifically in the context of research on PA promotion, *Social Cognitive Theory* has been used to study PA motivation and to develop interventions increasing individuals’ self-efficacy and abilities to self-regulate. Interventions based on *Social Cognitive Theory* aim to bolster participants’ beliefs in
their ability to live active lifestyles and maintain healthy PA habits despite conflicting social influences. Support for using this theoretical approach comes from research implicating exercise self-efficacy as a means of translating intention into action for PA participation (363) (364) (365). A meta-analysis of studies employing self-regulation techniques to promote PA in older adults specifically found this approach resulted in small to medium effect size for improving self-efficacy \(d=0.37, \text{95CI} \ 0.22-0.52, \ p<0.001\), but this did not translate to substantial changes in PA \(d=0.14, \text{95CI} \ 0.09-0.20, \ p<0.001\) (366). A qualitative study of nursing home residents with dementia who completed a 10-week high-intensity functional exercise program interpreted their results using Social Cognitive Theory, and determined that participation in the exercise program led to perceived increases in participants exercise self-efficacy (367).

**Self-Determination Theory**, like Social Cognitive Theory, is a social psychology theory that posits human development is the result of reciprocal interactive processes between external social influences and inherent, internal motivations. However, Self-Determination Theory focuses more on the importance of meeting certain psychological needs for optimal human development than Social Cognitive Theory. Self-Determination Theory maintains that all humans are naturally active, intrinsically motivated beings, and that specific biological and psychological environmental aspects either contribute or detract from this natural state to determine our development. The psychological needs of competence, autonomy, and relatedness must be present in our environments to ensure optimal development as active, intrinsically-motivated beings. According to Self-Determination Theory, environments where the perceived locus of control is external (low autonomy), or low levels of competence and relatedness are perceived, threaten individuals’ abilities to play active roles in their lives. These threats to an individual’s capacity for self-determination limit their ability to engage in personally significant goals (368).

In the context of health promotion, Self-Determination Theory (369) posits that environments and practices that meet the three psychological needs of competence, autonomy, and relatedness will foster intrinsically-motivated behaviour change and support individuals in achieving their self-determined health goals (368). In a longitudinal study looking at PA in middle-aged women over 15 years, women reporting satisfaction of psychological needs (competence, autonomy) outlined by Self-Determination Theory and women who had physically active social networks (relatedness) were significantly more likely to routinely engage in PA than those who didn’t (370). In the context of cardiac rehabilitation, improvements in measures of psychological needs
addressed by *Self-Determination Theory* were associated with improved PA levels following a 6-month cardiac rehabilitation program (371). However, one study comparing a web-based intervention informed by *Self-Determination Theory* with an atheoretical control found no differences in effectiveness between the groups at improving PA (372). A systematic review examining the relationship between *Self-Determination Theory* concepts and PA found that the majority of studies in the literature informed by the *Self-Determination Theory* are not experimental (7 of 66 studies examined), but findings from the few experimental studies examined (6 of 7 studies included) support the utility of *Self-Determination Theory* for informing PA behaviour promotion interventions (373). The 59 descriptive studies included in the systematic review also largely supported the applicability of *Self-Determination Theory* to effect PA behaviour change.

The *Theory of Planned Behaviour* (374) aims to understand human behaviour as a function of intentions, beliefs, and perceptions. According to the *Theory of Planned Behaviour*, actions are the result of conscious consideration of the potential outcomes of a behaviour and their relative likelihoods and values, beliefs about the social norms concerning the behaviour, and the perception of one’s ability to perform the behaviour in light of potential factors beyond one’s control. The *Theory of Planned Behaviour* (375) stems from the *Theory of Reasoned Action*, which maintains that human behaviour is the product of information, intentions, attitudes, and perceptions of social norms that we are consciously aware of rather than an automatic response to environmental stimuli. The *Theory of Planned Behaviour* is an extension of the *Theory of Reasoned Action*, with the addition of the concept of perceived behavioural control that is very similar to the concept of self-efficacy from *Social Cognitive Theory*. The *Theory of Planned Behaviour* reconciles the two other theories, addressing the limitation of the *Theory of Reasoned Action* that people who have strong intentions to perform behaviours are not always capable of doing so, while also addressing the limitation of *Social Cognitive Theory* that individuals who are highly capable of performing behaviours do not perform them if they lack the intention (376).

As an explanatory model of human behaviour, the *Theory of Planned Behaviour* aims to predict or understand the effectiveness of health promotion rather than to inform the development of interventions. In examples of contexts specific to aging adults, existing research supports that the predictive value of concepts from the *Theory of Planned Behaviour* determining
maintenance of PA in sarcopenic older adults (377), older women (378), and older adults in general (379).

The Transtheoretical Model of Behaviour Change, also referred to as the Stages of Change Model, proposes 6 stages through which individuals progress while going through the process of behaviour change (380). The first stage is “precontemplation”, during which an individual is not intending to change. Individuals thinking about making a change in the future are in the “contemplation” stage, and move to the “preparation” stage when they intend to take immediate action. Individuals actively making changes to their behaviour are in the “action” stage, and progress to the “maintenance” stage after the change has been made and they are working to prevent lapses in the new behaviour. The final stage is “termination”, in which the change has become fully integrated as a habit and there is no threat of lapsing. Movement through these stages is proposed to occur through 10 processes, with different processes being employed at different stages to create change. These processes are borrowed from other psychological theories, which is why this model is called “transtheoretical” (380).

Health research using the Transtheoretical Model of Behaviour Change has sought to increase the efficacy of health promotion initiatives by matching interventions to those that support the movement of individuals through their specific stage of change. This approach has been used to predict lifestyle changes in individuals related to smoking cessation (381) as well as PA and sedentary behaviours (382). Using the Transtheoretical Model of Behaviour Change to tailor interventions has had mixed results, with some studies showing increased efficacy of a stage-matched approach relative to atheoretical controls (383) (384), and others finding no significant effect (385) or insufficient methodological quality to support existence of a treatment effect (386).

The Health Belief Model has been used to understand how perceptions influence the likelihood of individuals engaging in health behaviours (387). According to this model, one’s likelihood of engaging in health behaviours is influenced by their perceptions of how susceptible they are to a given disease (“Am I at risk of AD?”), the severity of this disease in the context of their daily life (“If I do get AD, how much will it impact my life?”), and the benefits and drawbacks of engaging in preventive behaviours (“Do the health benefits of PA outweigh its time and energy costs?”). Modifying factors like the presence of “cues to action” that motivate an
individual to engage in a preventive health behaviour (e.g. diagnosis of a family member with Alzheimer’s disease) and sociodemographic characteristics (e.g. older age) are also proposed to influence the likelihood of a behaviour (387). The Health Belief Model has been used both to understand the relationship between perceptions and engagement in health behaviours in both healthy populations (388) and specific disease contexts (389) (390). It has also been used to inform the design of educational interventions seeking to change perceptions of individuals at risk for certain diseases to encourage engagement in preventive health behaviours (391) (392).

2.8.2 Theoretical Domains Framework

Borrowed from field of Implementation Science, defined by the National Implementation Research Network as “the study of factors that influences the full and effective use of innovations in practice” (393), the Theoretical Domains Framework (TDF) provides researchers with a set of constructs relevant to structuring and evaluating interventions supporting the adoption of evidence-based practices (394). The TDF was developed through a consensus process identifying the important theoretical constructs from existing theories employed in behaviour change, then simplifying these constructs into a set of key domains for behaviour change. These domains were then evaluated by professionals, both experts and non-experts in implementation science and health psychology, across a range of disciplines. This yielded 12 key domains relevant to understanding behaviour change (394). Later validation of these domains was performed by re-sorting 112 constructs comprising the original 12 domains into domains then validating the replicability of this revised framework. This second validation removed 2 domains from the original 12 and added 4 additional domains, yielding 14 domains based on 84 constructs that now comprise the TDF (395). These domains and their descriptions (396) are detailed in Appendix 2.

With the existence of multiple, overlapping theories of behaviour in health research, any number of theoretical approaches can be chosen in framing a research study. Choosing a single theory to inform an approach can miss important aspects of a behaviour elaborated by other theories, but using too many theories can create conflicting, circular results. The TDF addresses this concern by integrating constructs from existing theories used in health research to provide a comprehensive approach to conducting health behaviour research. Constructs in the TDF include those from theories described in Chapter 2.8.1., like “self-efficacy” from Bandura’s Social
Cognitive Theory (360), “competence” from Deci & Ryan’s Self-Determination Theory (368), “perceived behavioural control” from Ajzen’s Theory of Planned Behaviour (375), “beliefs about consequences” from Rosenstock’s Health Belief Model (387), and with the Transtheoretical Model of Behaviour Change from Prochaska et al. (380) named as a construct in its own right in the TDF (395). The TDF integrates the wealth of constructs that exist from different theories on behaviour to provide a consensus framework for understanding health behaviours.

Furthermore, the TDF is a more appropriate tool for framing investigations of health behaviours in older adults with cognitive impairment, as it does not presuppose any relationships between its concepts. While other theories of behaviour change seek to explain behaviour, the TDF does not. This is beneficial for the current stage of research on PA as a health behaviour for older adults with cognitive impairment for a number of reasons. For one, there is insufficient evidence in the literature at this time to support the development of a “theory” of PA in MCI and AD. The TDF is a useful tool that can help collect evidence to support theory development, but until this is accomplished, claiming the existence of specific relationships between social, behavioural, psychological, or other constructs to determine PA behaviour in older adults with cognitive impairment is premature. Additionally, existing theories used to study health behaviour change may not apply to older adults with cognitive impairment. Many of these theories posit that participation in a given behaviour is the product of higher cognitive processes, such as weighing potential outcomes against each other and having a clear understanding of one’s ability to perform certain behaviours. These cognitive processes (e.g. executive function, insight into one’s level of function, motivation) necessary to perform intentional behaviours according to these theories can be impaired in MCI and AD. Thus, the foundational relationships between cognition and behaviour that these theories are built upon may be compromised in MCI and AD. The TDF is likely a more appropriate approach for studying health behaviours in populations with cognitive impairment as it does not presume any relationships between constructs or provide currently unsupported explanations about behaviour.

The TDF was originally developed for use in promoting the adoption of evidence-based practices by healthcare workers. Similarities between the contexts of implementation science and PA promotion for older adults with cognitive impairment, however, may make the TDF an integrative, comprehensive tool for studying behaviour change. For example, an evidence-based practice that has been studied using the TDF is hand hygiene amongst healthcare workers.
Ultimately, both PA promotion in older adults with MCI and AD and implementing evidence-based practices for hand hygiene in healthcare workers seek to achieve a similar goal – promoting the health of a specific population by changing behaviours to align with scientifically proven methods to accomplish this goal. The World Health Organization Guidelines on Hand Hygiene in Health Care (397) provide a behavioural evidence-based practice guideline to prevent the spread of infectious disease by healthcare workers. The Canadian Physical Activity Guidelines, similar to this, are like an evidence-based practice guideline for older adults, outlining specific behaviours that are scientifically proven to create positive health outcomes (280) (307) (21). Given the parallels between these contexts, the TDF may be useful in studying the domains of behaviour change that are important for increasing the PA levels of older adults with cognitive impairment.

Prior research supports the utility of the TDF for studying health behaviours. In the context of evidence-based practices for hand hygiene, research has investigated which barriers and facilitators are associated with evidence-based hand hygiene behaviours (398) (399), and attributions made by healthcare workers to explain noncompliance with hand hygiene best practices (400). The TDF has been used in a diversity of clinical environments, and has been found to be a “useful, flexible framework” for implementation projects (401). In the context of PA guidelines, the TDF has been successfully used to identify barriers to the implementation of daily PA guidelines in Canadian elementary schools (402). The TDF thus provides a novel approach to studying factors influencing health behaviours like PA in non-professional populations.

2.9 Summary

This chapter has provided a holistic review of the literature concerning the use of PA as a health behaviour for the prevention and management of cognitive impairment and dementia in older adults. Mechanisms of PA benefits for preventing cognitive and functional decline in MCI and AD are thought to work through immunological, vascular, and immunological pathways that oppose the pathophysiological changes contributing to the onset and progression of MCI and AD.

Despite research supporting the benefits of PA for reducing the onset and progression of MCI and AD and reducing declines in cognitive and functional capacities in these conditions, the
The majority of older adults both with and without cognitive impairment do not achieve sufficient PA levels to reap these benefits and maintain their health and independence as they age. Numerous factors influencing the participation of cognitively-healthy older adults in PA have been identified in the literature, but far less research has investigated factors influencing PA participation of older adults with dementia, and no studies have included older adults with MCI. This small body of literature that does exist has not been informed by social and psychological models used to study health behaviour, which may limit the utility of their findings for informing health behaviour change interventions to promote PA in this population.

Ultimately, this review highlights a critical gap in the literature that must be addressed to move research on the benefits of PA for healthy cognitive aging of older adults into actionable strategies for the prevention and management of MCI and AD. There is a lack of information on how older adults with MCI and AD perceive PA as a health behaviour, their beliefs about its benefits, and the experiences and factors that influence their ability to participate in PA. To address this knowledge gap and support the translation of knowledge about the benefits of PA for MCI and AD, this thesis provides a qualitative study that explores the phenomenon of PA participation of older adults with cognitive impairment through seeking the perspective and experiences of experts on this topic – older adults with MCI or AD and their caregivers.
Chapter 3

3 Theoretical Approach

3.1 Preface

The culmination of research reviewed in Chapter 2 points toward the need for research to enhance our understanding of how PA can be used to help maintain health and functioning of older adults with MCI or AD. The following chapter details the benefits of using a qualitative approach to address this research question, as well as the theoretical paradigm in which this research is situated. A statement of the author’s positionality provides readers with a sense of the experiences, beliefs, and preconceptions that may have influenced this study. With an awareness of context provided by descriptions of the theoretical paradigm and positionality of the researcher, study design and findings are then elaborated in subsequent chapters.

3.2 Qualitative Inquiry in Health Research

Addressing questions in health research using qualitative inquiry allows for an in-depth exploration of complex, contextualized, social phenomena (403). In the context of health research, qualitative inquiry can be used to increase our understanding of the experiences of health and disease (404). In the case of research reported in this thesis on the perceptions, experiences, and beliefs of older adults with MCI OR AD and their caregivers concerning PA, qualitative inquiry is most appropriate in addressing the research question being posed as it allows for the open, iterative exploration of the phenomenon of PA in MCI and AD, guided by individuals who are experts on this topic by virtue of their own lived experience. Each individual’s beliefs and experiences concerning PA, while unique and shaped by numerous factors, speak to a broader truth about a lived experience (405). Especially since this phenomenon is poorly elaborated in the currently published literature, using a qualitative approach for this purpose allows for the contribution of a rich account of the beliefs and experiences of this population that speak to a broader truth about PA participation of older adults with cognitive impairment. Through consulting with the end users of this knowledge (older adults with AD or MCI and their caregivers), the beliefs, experiences, and perceptions of this population identified through in-depth interview and thematic analysis can be used to anticipate
potential barriers and facilitators to behaviour change that will need be negotiated in future behavior change interventions (406).

The decision to use a qualitative approach to investigate the research questions posed in this thesis was an intentional decision made by the author and their advisory committee following an evaluation of the purposes of this research, the existing literature available on this topic, and the nature of the information being sought by this thesis. Knowledge gained through qualitative inquiry in this thesis opens multiple avenues for future research, both qualitative and quantitative, and creates the opportunity to apply its findings to develop, implement, and evaluate health promotion interventions using PA in this population. To accomplish this, an in-depth understanding of this phenomenon from those with lived experience is essential.

3.3 Guiding Theoretical Principles

All scientific pursuits are concerned with understanding truth. The specific paradigm in which scientific inquiry is conducted, however, determines how researchers perceive what the nature of “truth” is, how they can come to know “truth”, and the appropriate approaches to determine “truth”. Before introducing the research comprising this thesis, it is thus critical to discuss the paradigm in which it is positioned to elucidate the assumptions being made about the nature of “truth”.

Guba and Lincoln (407) define a paradigm as a “basic belief system or worldview that guides the investigator, not only in choices of method but in ontologically and epistemologically fundamental ways.” Paradigm concerns itself with the broad assumptions researchers have about reality; what reality is (ontology), what can be known about reality and by whom (epistemology), and how we can come to know reality (methodology) (407). This research has been conducted within a constructivist paradigm, and thus the researcher assumes that reality is not something that is objectively knowable outside of the research process, but rather co-constructed by participants and researchers throughout the research process as a consensus surrounding a phenomenon based on their perceptions and experiences of that phenomenon. As participants have unique perceptions and beliefs concerning PA based on their unique experiences and those of the researcher are continually evolving throughout the research process, what constitutes reality is thus subjective and dynamic. Despite this subjective and dynamic nature of individual realities generated in research using a constructivist paradigm, they all speak to a broader truth
about a phenomenon and thus have value and applicability beyond the contexts in which they were created. Unique realities communicated by participants will be given the same consideration as realities shared by multiple participants in this study, as these may provide a rare perspective about the phenomenon of PA participation, and speak to a broader truth about this phenomenon.

In this sense, what “truth” and reality are varies depending on who is constructing the reality, the phenomenon in question, and the specific temporal, environmental, historical, cultural, and social contexts in which the research is being conducted. This is the concern of one’s ontological approach to research – what is real? The research supporting this thesis has been guided by a relativist ontology. The researcher assumes that reality is contextualized, subjective, and determined by an individual’s perceptions and experiences (407). Although different participants may have different notions of reality, the conflicting experiences of individual participants can contribute to describing a broader set of truths about the phenomenon being explored and thus provide practical knowledge for use beyond the scope of this study.

After establishing the position of this thesis on the concepts of paradigm (constructivist – reality is something that is co-constructed by participants and researchers based on individual perceptions and experiences) and ontology (relativist – reality is subjective and context-specific) the question of how reality and truth can be known must be addressed. This is the concern of epistemology – how do we know what is real? The epistemological approach guiding this thesis is transactional and subjectivist. In the subjective sense, this thesis assumes that reality is how individuals or groups with experiences around a phenomenon describe it. In the case of persons with dementia, then, their perceptions of reality are taken as truth, regardless of the objective factuality of what they claim.

To explore the reality of PA participation at the intersection of aging and cognition, this research sought the perspectives of both older adults with cognitive impairment as well as their caregivers as a dyad. The exact recollection of specific experiences may vary between dyad members, but this does not diminish the reality experienced and communicated by individual dyad members. This thesis assumes there is value and truth in the experiences and perceptions of persons with cognitive impairment, despite the cognitive challenges that may interfere with their factual interpretation of reality. Caregiver perspectives are not being included as a way to “fact-
check” the responses provided by participants with MCI or AD, as this would assume that older adults with cognitive impairment are not experts in their own experience. Rather, instances of conflicting realities between dyad members in this study provide opportunities to identify ways in which cognitive impairment impacts how older adults with MCI and AD perceive and experience PA participation. In this way, the inclusion of perspectives from both persons with MCI and AD and their caregivers provides context to enrich the understanding of the reality of PA participation at the intersection of aging and cognition. The approach to determining reality in this thesis assumes that reality can be known through a “transaction” between participants and researchers to actively co-construct reality about a phenomenon in question (407). In this thesis, the researcher’s role in constructing a consensus reality about a phenomenon involves engaging directly with participants to facilitate conscious discussion of this phenomenon.

After establishing how reality can be known, the remaining theoretical aspect of concern is methodology – how can we come to know reality? An interpretive phenomenological approach informed by Heidegger (408) has been used in this thesis to guide the exploration of the phenomenon of PA participation in dementia. This approach is appropriate for the aims of this research for a number of reasons. First and foremost, the focus of the phenomenological approach on understanding experiences aligns with the focus of this research on understanding the PA experiences of older adults with cognitive impairment (409).

An interpretive phenomenological approach is most appropriate for this study as it aligns with the broader constructivist paradigm in which this research is situated. Interpretive phenomenology assumes that not only is the influence of researchers on the research process impossible to remove, but it is also critical to the interpretation of findings (408) (409). The interpretation of experiences is the result of a co-construction by participants and researchers based on their experiences and perspectives, resulting in a “fusion of horizons” (410), where the experiences and perceptions of participants (experts in lived experience of a phenomenon) and researchers (experts in scientific literature about a phenomenon) have been synthesized to create new knowledge.

By using an interpretive approach to phenomenology that aims to understand the meaning of experiences rather than providing just a descriptive account of an experience, the meaning of PA participation for older adults with cognitive impairment, including their perceptions and
beliefs concerning this phenomenon, can also be explored. Interpretive phenomenology stresses the importance of social, cultural, and historical contextual factors, referred to as one’s “lifeworld” (408), for understanding the meaning of a phenomenon (409). This appreciation for the influence of context on the experience of a phenomenon aligns with this thesis’ theoretical positioning and aims, as it seeks to explore factors that influence PA participation of older adults with MCI and AD. The view of contextual factors as important for understanding a phenomenon is a critical reason why this research has taken the approach of studying care dyads rather than just persons with MCI and AD. By including caregivers in this research, a greater understanding of the contextual factors and care relationship influencing PA participation of older adults with MCI and AD can be achieved.

Consideration of contextual factors in interpretive phenomenology also provides a way to reconcile the uniqueness of individual experiences concerning a phenomenon to broader truths about these experiences. Interpretive phenomenology uses contextual factors to enhance understanding of the universal truth about a phenomenon. Lopez & Willis (409) stated this well, describing the central question asked by interpretive phenomenology as, "How does the "lifeworld" inhabited by any particular individual in this group of participants contribute to the commonalities and differences between their subjective experiences?" Using an interpretive approach in this research aligns with a relativist epistemological approach, as it allows for the truths of individual realities to be honoured, but also compares distinct, individual realities to generate greater understanding around a universal truth. The following hypothetical statement summarizes the rationale behind using this approach in the context of PA participation: if X is a PA facilitator for individual A but a barrier for individual B because their experiences differ by Y contextual factor, then Y contextual factor is important for influencing PA participation based on the lived experiences of participants A and B.

Interpretive phenomenology also recognizes the influence of researchers’ biases, preconceptions, and prior knowledge on research, and views these as important for the interpretation of findings (409). The biases and preconceptions of researchers that may influence the research process have been reflected upon through reflexive memoing and acknowledged in the following section so that readers may understand their potential influence on the research findings. Further, the assumption of prior knowledge as important for understanding and interpreting research allows for the use of a sensitizing framework in research, so that specific
aspects identified as important to a phenomenon can be explored. In this thesis, this has been reflected in the use of the TDF as a sensitizing framework (395).

To summarize, the theoretical approach taken in this thesis research is positioned within a constructivist paradigm, and aligns with a relativist ontology, subjective and transactional epistemology, and interpretive phenomenological methodology. Reality is understood or constructed as a consensus surrounding a phenomenon, not something that exists independent of the individual. Rather, it is subjective and specific to an individual’s continually evolving context and experiences. Truth about a phenomenon is something that participants and researchers co-construct throughout the research process through the processes of interpreting experiences and their meaning to discover more about the phenomenon in question.

Table 2  Theoretical Positioning of Research and Implications for Study Design

<table>
<thead>
<tr>
<th>Theoretical Concept</th>
<th>Positioning of Study</th>
<th>Description</th>
<th>Implication for Study Design</th>
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<tbody>
<tr>
<td><strong>Paradigm</strong></td>
<td>Constructivist</td>
<td>Reality is not objectively knowable outside of the research process, but co-constructed by participants and researchers to build meaning from participants’ perceptions and experiences (407).</td>
<td>Participant interviews are semi-structured, allowing for input and direction from both participants and researchers in actively building meaning around a specific topic.</td>
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<td>“Basic belief system or world view” (407)</td>
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<tr>
<td><strong>Ontology</strong></td>
<td>Relativist</td>
<td>Reality is contextualized, subjective, and determined by an individual’s perceptions and experiences (407).</td>
<td>Each participant’s responses are regarded as “truth”, despite potential conflict with responses of others. This study aims to develop a cohesive narrative that speaks to a broader set of truths concerning a phenomenon.</td>
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<tr>
<td>“What is real?”</td>
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<tr>
<td><strong>Epistemology</strong></td>
<td>Transactional / Subjectivist</td>
<td>Reality can be known through the perceptions and descriptions of individuals who have experience with a phenomenon. Knowledge can be shared with individuals who do not have experience with it through transactions with those who do. (407)</td>
<td>Perceptions of individuals with experience in PA participation in the context of MCI or AD are being sought to learn more about this phenomenon. Knowledge is being shared with researchers who are naïve to this experience through</td>
</tr>
</tbody>
</table>
**Methodology**

**How can we come to know what is real?**

<table>
<thead>
<tr>
<th>Interpretive Phenomenology</th>
<th>An understanding of reality is developed by intentionally raising a phenomenon to the level of conscious consideration, and description of that phenomenon by persons with lived experience to determine generalizable truths about that experience (409)</th>
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<td></td>
<td>Co-construction is made possible by using open-ended questions in semi-structured interviews, allowing for exploration of unanticipated responses from participants concerning a specific phenomenon. Perspectives of both dyad members are sought, as caregiver perspectives provide context for understanding responses of participants with MCI or AD. Biases and preconceptions of the author are acknowledged in the statement of positionality. Prior knowledge of the author is used to interpret findings in using the TDF as a sensitizing framework.</td>
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The following section provides context on how the author’s knowledge, experiences, and beliefs may influence the research process and findings presented in this thesis.

### 3.4 Statement of Positionality

To provide readers with a framework to understand the truths generated in qualitative research, it is important for researchers to practice “reflexivity” and undergo critical reflection on how their biases, theoretical predispositions, experiences, and other personal characteristics influence the research process in its entirety. Practicing reflexivity adds rigor to qualitative research, as it openly acknowledges the ways in which the researcher has brought to bear their own ideas and influences on the research process and findings (411) (412) (413). In this thesis, I have practiced reflexivity throughout the research process by maintaining a reflexive journal and writing reflexive memos on interview transcripts. The sum of this reflexive writing is the
following statement of positionality relative to the research comprising this thesis. Through this statement, I hope to provide readers with an account of the various ways my experiences, knowledge, values, preconceptions, and position have influenced the design, conduct, relationships, and findings of this research.

I initially became interested in studying the intersection of PA, aging, and cognition during my undergraduate studies, in which I had the opportunity to take a community-engaged learning course on PA and mental health. The “community-engaged” component of this course involved volunteering for 4-8 months at a local community or healthcare organization that provided PA programming to a specific population in the context of promoting brain health (e.g. children with developmental delay, university students, stroke survivors). I chose to volunteer with a community exercise program providing rehabilitation-like physical and cognitive activities for stroke survivors. While volunteering with this group, I was able to witness not only the benefits of participation in these activities on not just the physical and cognitive functioning of the participants, but also the social benefits from being a part of this group. Many of the participants had been attending this program for several years, and this group was a way for them to continue recovering from stroke as well as a meaningful source of social engagement. Seeing the multiple benefits of PA beyond just the health and physical benefits is what motivated me to pursue research investigating how these benefits can be made more accessible to a population that stands to gain so much from them – older adults with cognitive impairment.

In preparing to conduct this research, I extensively reviewed the available literature on PA participation of older adults with and without cognitive impairment. This research suggests that Canadian older adults are not getting sufficient PA on a weekly basis to maintain their health, as outlined in the Canadian Physical Activity Guidelines (317) (414) (23) (20) (21). It is well-known that global populations are aging, and the “65 years and older” demographic is growing much faster rate than other age groups (1). As age is a major risk factor for dementia, it is projected that a consequence of global population aging is an impending “rising tide” of dementia (43). As reviewed in Chapter 2 of this thesis, a large body of evidence supports the benefits of PA in slowing cognitive decline, managing cognitive and behavioural symptoms, and maintaining functional capacity in dementia. In light of this evidence and projected population trends, researchers are now able to ask questions about why there is a disconnect between
published health promotion guidelines and research supporting the use of PA for maintaining cognitive health, and the health behaviours of older adults with cognitive impairment.

The importance of PA for promoting and maintaining one’s health is a belief that I have personally held throughout my life, reinforced from an early age by messages from educational institutions, family members, and public health campaigns. Beyond having been exposed to messages reinforcing this belief, I also recognize that as a white, heterosexual, woman free of physical and cognitive impairment, I have experienced considerable privilege in being able to access the resources, good health, safe spaces, and leisure time that allow me to internalize these messages and manifest them in routine PA participation throughout my life. Additionally, because of the privilege I experience living with a comfortable socioeconomic status in an urban area of a developed country, my occupational and daily activities exclude physical labour. This allows me to experience PA as something that is recreational, social, and health-promoting instead of something that is forced, strenuous, and dangerous.

I believe there are numerous benefits of PA: maintaining health, preventing disease, facilitating social interaction, and managing psychological stress. I believe that the opportunity to live in good physical and mental health is a universal human right, and by extension, everyone should have access to opportunities that allow them to engage in PA to achieve positive health states. Implicit in this belief is the assumption that PA is generally regarded by others as something that is “good” and “healthy”, and that engaging in PA through whatever means available is a desired behaviour for people seeking to maintain or promote their health and well-being. In the context of this research on PA beliefs and experiences of older adults with MCI and AD and their caregivers, my personal beliefs and assumptions have lead me to approach this research from the perspective that PA is something that this population should value and prioritize to manage their declining cognitive health.

However, I recognize that many people may not share my beliefs and values concerning PA, particularly older adults who grew up in an era where messages promoting the health benefits of PA were not ubiquitous in their schooling, or communicated through mass media public health campaigns. When many of the individuals I interviewed for this study were adolescents and young adults, scientific research on the health benefits of PA was only just starting to emerge. Lifestyles have also grown progressively more sedentary as technological
advances have reduced the need for physical labour, so PA needs to be more actively promoted as its presence as a natural part of daily life dwindles. These differing developmental contexts concerning PA awareness between myself and the people I interviewed for this research were reflected by participants’ responses that they have never thought too much about PA. Rather, PA is something they “just do”. Instead of assuming this difference in conscious awareness of the role of PA in daily living is because participants do not perceive PA as a health behaviour, I have sought to gain a deeper understanding of these different experiences throughout the lifespan and how they shape their current health beliefs and behaviours concerning PA.

My position as a research student puts me in a position of power because of my knowledge on the topic of PA participation for health promotion. As such, participants may have felt during their interviews that they were being “quizzed” about their health literacy. Participants who lack knowledge about PA for health promotion may have felt compelled to appear more knowledgeable and health-conscious than they are during interviews to match assumptions they had about my expectations.

Participants who were older adults living with cognitive impairment or caregivers for these individuals may have felt that they could not relate to me as a young, healthy, able-bodied student, as I do not share their lived experiences. For this reason, my position as an “outsider” (415) from the dementia community may have prevented participants from feeling they could share all aspects of their beliefs, perceptions, and experiences concerning PA with me. Instead, they may have only felt that they could share with me what they thought I wanted to hear – that they valued PA as a health-promoting behavior, and were making every effort to engage in PA. In my experiences volunteering with recreational programs offered for persons with dementia and their caregivers by the Alzheimer Society of Toronto, however, I have made substantial efforts to gain an “insider” (415) perspective on living with dementia so that I can relate, empathize, and understand the experiences of persons with MCI and AD and caregivers participating in this research.

My experiences with PA throughout my life, the value I place in PA for promoting one’s current and future health and wellbeing, and the knowledge I possess about the scientific benefits of PA have undoubtedly influenced this research process, my research relationships with participants, and the analysis of data leading to conclusions made about this research. Through
practicing reflexivity throughout the research process, I have attempted to make transparent my influence on this research. I have attempted at every opportunity to set aside my own biases and beliefs, and place the views and experiences of participants at the forefront.

### 3.5 Summary

A qualitative approach is most suitable to address the research question posed by this thesis concerning the perceptions, experiences, and beliefs of older adults with MCI and AD and their caregivers concerning PA. Literature on this topic, as reviewed in Chapter 2, is scant, and thus an approach seeking to learn from individuals with lived experience will help to enrich the existing literature and identify avenues of future research in this field. The theoretical approach taken to understanding findings of this study assumes that participants are the experts in their own experiences. Truth about the phenomenon being studied is realized through co-construction by participants and the researcher. In light of the researcher’s involvement in the research process, a statement of their beliefs, biases, and experiences provides context for the interpretation of findings in subsequent chapters of this thesis. The following chapter details how this theoretical approach has been actualized in the specific design and methods used to conduct this research.
Chapter 4

4 Methods

4.1 Preface

The theoretical approach taken in this study informs the specific procedures for data collection and analysis used to address the research question. This chapter outlines the procedures for developing and conducting this study to enhance our understanding of how PA can be used to help maintain health and functioning of older adults with cognitive impairment by investigating the perceptions, beliefs, and experiences of older adults with MCI or AD and their caregivers concerning PA participation. First, the broad approach to study design is outlined, with special consideration of how this study was tailored to respect the abilities of participants with cognitive impairment. Following this, types of data collected in this study are identified, and detailed descriptions of data collection, management, and analysis processes are provided.

4.2 Study Design

4.2.1 Sample Size & Recruitment

The estimated sample size required for this study was 10-15 care dyads (20-30 individual participants), consisting of one individual with MCI or mild to moderate AD and their care partner. This estimate was based on sample sizes in similar qualitative studies. Sample sizes of prior qualitative studies on the topic of activity in dementia including dyads range from 2-10 dyads, or 4-20 individual participants (26) (346) (348) (351) (358). Sample sizes of other studies not including dyad perspectives range from 8-15 individuals (344) (347). Given the nature of this study and the need to include more participants to achieve saturation, upper limits of sample sizes from published qualitative studies on activity in dementia were used to formulate this estimate. The nature of this study also required collecting a diversity of perspectives to achieve a broad understanding of the phenomenon in question. As such, purposive sampling approach was used to recruit participants in this study, meaning that dyads were non-randomly selected for study participation based on their specific behaviours and experiences (416).
Dyads were recruited from a cognitive neurology clinic at an urban teaching hospital. Dyads were referred to participate in this study based on chart review and physician referral. Prior to upcoming appointments, dyads were contacted by telephone to inform them of an opportunity to participate in this study and provide them with information about the study. Participants who expressed interest in participating were given more information about the study, and a time was scheduled with them to participate. Consent to participate was gained from both dyad members at the beginning of study visits, at which point participants were considered enrolled in the study. Prior to participating in the study, participants were not given any counselling by the researcher as to PA benefits or recommendations.

Recruitment was concluded in this study when there was no appearance of novel themes from subsequent interviews with participants (417). For the purposes of this qualitative study, the threshold for a “new theme” was either a perception, belief, or type of experience that had not been previously expressed by a participant. Throughout the 20 interviews, over 11 hours of audio-recorded data were captured, generating 350 pages of interview transcripts for analysis, 45 pages of research memos, and 10 pages of field notes. This extensive corpus of data speaks to the thickness (quantity) (418) of data collected and analyzed in this study. Richness (depth) of data is evident in the diversity of perspectives that were included in this study through use of purposive sampling to achieve a broad understanding of the phenomenon of PA participation at the intersection of aging and cognition. As detailed in Chapter 5.1.1, a diversity of PA levels, apathy levels, levels of cognitive impairment, and dyad relationships are represented in this study.

4.2.2 Inclusion and Exclusion Criteria

Participation in this study was limited to dyads, including one an older adult (≥65 years) diagnosed with MCI or probable AD by a neurologist and their care partner. Only community-dwelling dyad members were recruited. Participants with MCI or AD had to have mild to moderate levels of cognitive impairment, indicated by a Mini-Mental Status Examination (MMSE) (419) score between 18-28 out of 30 (higher scores indicate higher global cognitive function) (420), and had to have been diagnosed with MCI or AD for at least 6 months. Participants with MCI or AD had to have a level of English proficiency and cognitive functioning sufficient to participate in interviews, and be free of any impairments interfering with their ability to verbally communicate. Participants with MCI or AD also had to be able to
provide capacity to consent or assent to study participation, and have insight into their level of cognitive function and diagnosis.

An adult (≥18 years) care partner also had to be available to participate in the study. Care partners needed to be informal primary or secondary caregivers to the person with MCI or AD, and interact with them on a routine (daily to weekly) basis. Care partners also had to have a sufficient level of English proficiency to participate in the interviews, be able to provide consent to participate and act as a substitute decision maker for their care partner if needed, and have insight into their care partner’s level of functioning and PA behaviours.

In regard to dyad members with cognitive impairment, individuals with physical or other impairments preventing them from participating in PA were excluded from the study, as this limits their experiences of PA to be discussed in interviews. Individuals who were actively enrolled in any studies using PA as an intervention were excluded from the study, as this created an artificial condition that does not accurately reflect the experiences of PA participation in a community setting. An itemized list of inclusion and exclusion criteria for this study and justifications for decisions about the criteria can be found in Appendix 3.

4.2.3 Ethical considerations

Ethical review and approval to conduct this study was obtained from the Sunnybrook Health Sciences Centre Research Ethics Office (Appendix 4) and the University of Toronto Research Ethics Board (Appendix 5). As this study involved participation of individuals with cognitive impairment, deemed a “vulnerable” population (421), care was taken by the researcher (L.B.) to ensure free, informed consent or assent was obtained from all participants. Voluntary, written, informed consent was required for participation in this study and obtained from participants with MCI or AD and their accompanying care partners. In the consent process, the informed consent form was reviewed with dyad members simultaneously by the researcher, outlining the purpose, potential harms and benefits, and procedures involved in the study. Capacity to consent of dyad members with MCI or AD was assessed by the researcher by asking them to summarize key details, potential risks and benefits of study participation, and implications of study findings. For individuals with MCI or AD who assented to participate, but were unable to demonstrate capacity to provide free, informed consent, care partners acted substitute decision makers and provided consent on their behalf. To address potential
fluctuations in cognitive capacity of participants with MCI or AD, consent was confirmed verbally prior to each study activity by describing the next activity and asking participants if they wished to continue. As this study was conducted in a medical setting, it was made clear to both dyad members that their decision to accept or decline participation in this study would not impact the care they received from the organization where this study was conducted.

Given that study procedures consisted of completing interviews and questionnaires, there were minimal potential risks associated with study participation. There was a potential risk of fatigue for participants with cognitive impairment associated with participating in the interview. To prevent this, the researcher conducting interviews monitored participants’ speech and behaviour for signs of fatigue and offered participants the option to stop the interview and resume at another time. Another potential risk related to study participation was the experience of emotional distress as a result of reflecting on one’s cognitive decline or other negative experiences. To reduce the likelihood of this occurring, the researcher asked the caregiver about any sensitive topics to be aware of when interviewing their partner with cognitive impairment. No other potential harms were identified for this study, and none were experienced during the study or subsequently reported by any of the participants.

There were no direct benefits for participants from being involved in this study, but participants may have enjoyed the interview process or felt a sense of fulfillment from their scientific contributions. It is the aim that in the future, the findings of this research will benefit older adults with cognitive impairment like those who participated in this study through the development of programs and strategies to increase PA participation for this group.

To ensure the confidentiality of participant information and data collected in this study, all study data have been de-identified. Information that could be used to identify participants have been anonymized in the interview transcripts and excerpts from participants used to illustrate the research findings in this thesis. Study numbers and pseudonyms have been used instead of names. The names of specific places or organizations have been removed or recoded with generic descriptors (e.g. “the gym”, “the corner”).
4.2.4 Inclusive Research Design for Persons with Cognitive Impairment

Not only does inclusive research design enhance the quality of data collected using these methods, but it also enables persons with cognitive impairment to take an active role in the creation of scientific knowledge by respecting their abilities and recognizing that they can make valuable contributions to research. To ensure the inclusion of older adults with cognitive impairment in this research respected participants’ needs, abilities, and preferences, literature on respectful inclusion of individuals with cognitive impairment in research was consulted to inform study design and procedures (422) (423) (424).

Many aspects of study design in this research support the inclusion of persons with cognitive impairment. In qualitative studies involving persons with AD, smaller sample sizes are typical as they allow for more in-depth analysis of the available data which may be thin upon initial readings. This study used a relatively small sample size of 10 dyads (20 individuals), allowing for deeper analysis of data to generate more meaningful findings (423). Study visits were arranged with the dyads to occur at a convenient time and place, during the late morning or early afternoon to minimize the impact of daily fluctuations in mood and cognition due to disrupted sleep cycles or sundowning (425). Study activities were conducted in a private research area with minimal background noise and distractions. An interview schedule was designed with consideration for the communication abilities of persons with cognitive impairment, using straightforward question structure and minimal inclusion of memory-taxing questions. After being initially developed by the author based on constructs from the TDF, the interview schedule was circulated to the research team (thesis supervisor and advisory committee members). Feedback was provided by the research team on aspects of question structure, order, and content that may affect the ability of persons with MCI and AD to provide rich, accurate responses. The interview schedule was revised based on their feedback, and the final version used in interviews is provided in Appendix 6.

An understanding of effective communication strategies is essential for interviewing persons with MCI or AD, and the researcher conducting the interview gained this through studying the literature on this topic and through first-hand experience in healthcare and community settings. Persons with MCI or AD may take longer to process and respond to verbal stimuli, have word-finding issues, exhibit fluctuating attention, or have difficulty with complex
questions or those requiring abstract reasoning (424). Effective communication must be respectful, marked by attentive listening, acceptance of individuals’ abilities, and openness to learning about the participant’s experiences and point of view (423). This was accomplished by the researcher through employing the following techniques: using a respectful (non-patronizing) tone, making eye contact with participants, smiling, using participants’ preferred names and pronouns, allowing long pauses to happen, being comfortable with sharing emotional experiences, not talking down to participants, not contradicting participants, not belabouring participants over details, empathizing with participants, not hiding behind a clipboard or jotting notes for the duration of the interview, and using participants’ words during interviews (423). Interviews followed the participant’s lead within a defined topic area, respecting that they are the experts on their own experience. When participants veered off topic in interviews, it was assumed they did so because they were sharing something personally meaningful. Off-topic responses from participants were validated by the interviewer, and then efforts were made to help them link this back to the topic of discussion.

The quality of the relationship between interviewers and participants is crucial to the success of the interview for both parties. Gaining consent or assent from participants with cognitive impairment to grant an interview, beyond being ethically required, is a way to build a sense of trust with participants by showing respect for their autonomy. A brief informal discussion was also held between participants and the interviewer prior to commencing the interview to build a sense of rapport and gauge their alertness and communication style. It is important for all participants to feel they have accomplished something and made a meaningful contribution at the conclusion of their participation in this study, so upon completion of participation, participants were given a personalized thank-you letter (Appendix 7) and a small token of appreciation for their participation.

### 4.3 Study Visits

Participation of dyad members in this study occurred at an urban teaching hospital in a private interview room. Following provision of informed consent to participate in this study, any demographic data not contained in the participant with cognitive impairment’s hospital chart was collected with both dyad members present. One-on-one semi-structured interviews were completed with individual dyad members by a member of the research team, unless the dyad
member with cognitive impairment preferred to have their care partner present (but not participating) during their interview. The dyad member with cognitive impairment was interviewed first, followed by their care partner.

After completing their interviews, individual dyad members completed questionnaires assessing their own PA levels (dyad members completed individual questionnaires) and dyad members without cognitive impairment completed a questionnaire assessing their partner’s level of apathy and the distress they felt in relation to this.

Study activities were typically completed within a single, 2-hour visit at an urban teaching hospital. For dyads where participation could not be completed in a single visit due to time constraints or fatigue, a second visit to be held at the same location was scheduled at which point consent to participate was reconfirmed and study participation was completed. Appendix 8 provides a depiction of the sequence of events for study visits.

4.4 Study Data

The following section details the types of data collected for this study and the processes implemented to ensure data collected and products of analysis accurately reflect the responses of participants.

4.4.1 Data Collection

4.4.1.1 Physical Activity Experiences, Beliefs, and Perceptions

Semi-structured interviews were used to collect data on participants’ experiences, beliefs, and perceptions of PA in MCI and AD. Semi-structured interview schedules for caregiver participants and participants with MCI and AD were informed by domains identified in the TDF (395). Using the TDF as a sensitizing framework for interviews provided a way to orient discussions in interviews towards factors known to be important for studying health behaviours. Appendix 6 provides the question schedule that was followed in interviews with caregivers and participants with MCI or AD, and the associated TDF constructs addressed by each question. While the interview schedule ensures that certain topics relevant topics were covered in all interviews, it was not used as a script for interviews. Questions in the interview schedule
provided a springboard for starting conversations on participants’ perceptions, beliefs, and experiences concerning PA. Participants were encouraged to elaborate on topics not covered in the schedules as they saw relevant. Lines of questioning not included in the interview schedule were also pursued by the interviewer if they thought they provided relevant information to addressing the research question.

Interviews were conducted by the researcher (L.B.) at an urban teaching hospital. Interviews were only conducted with participants once, and there were no subsequent interviews with participants. Interviews were audio-recorded and transcribed verbatim, and reviewed by reading the transcripts while listening to recordings to ensure accuracy of the transcripts. Field notes were taken during the interviews to capture the thoughts and reflections of the researcher conducting interviews in the moment. Observations from field notes were added to NVivo (Version 11, QSR International) where all interview data was housed and linked to their corresponding interview transcripts and memos. Reflexive memos were created by the interviewer following completion of the interviews and throughout the process of analysis. Memos for interviews were linked to the transcripts and field notes of their corresponding interviews in NVivo. Memos about the general research process were also stored in NVivo, but not linked to specific participants.

4.4.1.2 Demographic Information

Data on demographic information, PA level, cognitive status, and apathy were collected to characterize the study sample and ensure a diverse range of perspectives were captured in this study. Demographic data collected were age, gender, level of education, ethnicity, dwelling, and dyad relationship. Diagnosis and level of global cognitive functioning ascertained by the MMSE (419) were also collected for dyad members with cognitive impairment. Demographic and health data were collected from participants’ hospital charts, and data that was not detailed in hospital charts was collected from dyads prior to commencing interviews during study visits.

4.4.1.3 Physical Activity Levels

Weekly self-reported PA levels were collected from individual dyad members using standardized questionnaires following the completion of individual interviews at study visits. The interviewer was present during questionnaire completion to clarify any confusion
participations had about items contained on the questionnaires. For participants aged 65 years and older, the Physical Activity Scale for the Elderly (PASE) (426) was used to collect PA level data, while the International Physical Activity Questionnaire (IPAQ) was used to collect PA level data from participants under the age of 65 years (427). Two different assessments of PA were selected for use in this study because older adults, particularly those with cognitive impairment and their care partners, may partake in different types of activities than younger adults (e.g. reduced occupational activity after retirement, higher levels of recreational or caregiving activities). The PASE collects information on the frequency, duration, and types of activities for various intensity levels. The PASE was developed for use in older adults to be administered at home, in person, or via telephone, demonstrates high internal consistency of items (Cronbach’s α=0.694), higher test-retest reliability (r=0.75; 95% CI, 0.69-0.80), and construct validity demonstrated through significant correlations with scores of grip strength, balance, leg strength, peak oxygen uptake, systolic blood pressure, objective assessment of PA by Actigraph and accelerometer devices, and energy expenditure measured using the doubly labeled water method (426) (428) (429) (430) (431) (432). The PASE has also been validated for use in culturally diverse populations (433).

The IPAQ version used in this study was the long form questionnaire, which assesses PA across domains including: occupation, transportation, recreation, and habitual PA (427). The IPAQ collects information on the frequency and duration of activities for various intensity levels. Unlike the PASE, however, the IPAQ does not collect data on specific types of activities engaged in by respondents. The IPAQ long form shows good concurrent validity with objective activity monitors (r=0.55, P<0.001), good construct validity with self-reported PA log books (r=0.67, P<0.001), and higher reliability (r=0.81; 95% CI, 0.79-0.82) of self-assessed PA level (427) (434). The IPAQ has been validated for use in numerous cultures (427). Items on both the PASE and IPAQ report the frequency and duration of their participation in given activities over the previous 7 days (426).

4.4.1.4 Apathy and Caregiver Distress Levels

The Neuropsychiatric Inventory (NPI) is a tool used to assess the frequency, severity, and distress related to behavioural disturbances common in dementia (435). The Apathy Subscale from the NPI is a valid, psychometrically robust assessment of apathy (436), and was used in this
study to collect information about the frequency and severity of apathy expressed by participations with cognitive impairment and the related distress perceived by caregivers. The Apathy Subscale from the NPI was administered by the interviewer to the caregiver following their interview.

4.4.2 Data Analysis

Qualitative thematic analysis was used to analyze the data collected in semi-structured interviews (verbatim transcripts, field notes) (437). Thematic analysis provides a flexible method of creating a rich description of data, and was chosen as the method of analysis in this study due to the clearly-defined, parsimonious, and adaptable approach it takes to qualitative analysis. The flexibility of thematic analysis allows for the superimposition of theoretical assumptions onto these methods to guide analysis and adaptation of this method to a variety of methodological approaches (437). The methodological approach taken in this thesis is interpretive phenomenology, and thus thematic analysis was adapted to identify important “patterned responses or meanings” (437) in participants’ responses about experiences of PA participation as older adults with cognitive impairment and the meaning of these experiences captured in their perceptions and beliefs about PA. As interpretive phenomenology views prior knowledge as important for interpreting experiences and their meanings, the TDF (24) was used to sensitize thematic analysis in this study to aspects of experiences and their meaning relevant to health behaviour change. Data analysis in this study was thus inductive, with the themes identified based on lived experiences of participants, not the domains of the TDF.

Thematic analysis in this study was conducted at the semantic level, and stayed close to the data by focusing on the experiences, perceptions, and beliefs described by participants. Analysis in this study took into consideration broader socio-cultural contextual factors indicated by participants to influence the phenomenon in question, but did not endeavor to make unsupported inferences about influences of specific contextual factors on the experience and meaning of PA for older adults with cognitive impairment.

The unit of analysis in this study was at the level of the individual, but the dyadic relationship was preserved in analysis so caregiver interviews could be used to provide context for understanding the interviews of partners with cognitive impairment. Initial coding of transcripts from interviews with individual participants was performed separately from their
dyad partners, but analysis of interviews was done sequentially within dyads (i.e. analysis of transcripts from interviews with participant with AD or MCI followed by analysis of caregiver transcript) so comparisons could be drawn between responses provided by dyad members. Data sources from interviews with caregivers and older adults with MCI and AD were classified as either “caregiver” or “AD/MCI participant” cases and data sources from individual dyad members were linked as a set to preserve the dyad relationship in analysis. Instances where participants discussed the other dyad member in the interviews were coded as an aspect of the dyad relationship (e.g. dyad members as PA partners). In axial coding and thematic development, codes from interviews with all dyad members pooled, but attention was paid to instances where only caregivers or participants with cognitive impairment provided specific responses (e.g. only participants with MCI or AD noted that they understood but didn’t “believe” the cognitive benefits of PA whereas caregivers did).

To gain familiarity with the data, the researcher who conducted the interviews completed transcription of the audio-recorded interviews. NVivo was used to organize the data from interviews (transcripts, audio recordings, and digital copies of memos and field notes) and as a platform for conducting thematic analysis. Interview transcripts and field notes were read repeatedly and annotated by the author with initial thoughts and observations about the data to inform the development of a coding scheme. Once familiar with the transcripts, open coding was of transcripts was done by the author, identifying important concepts in the data for addressing the research question. Initial coding labels used were predominantly based on generic constructs from the TDF (e.g. “environmental barrier to PA”, “knowledge of PA guidelines”), with occasional use of terms provided by participants as coding labels for concepts that were more specific to the context of PA participation of older adults with MCI and AD (e.g. “PA as a team effort”, “uncertainty over cognitive benefits of PA”). Initial open codes with supporting quotations from participants were presented to the research team to gain consensus and input on coding structure. While the TDF was used to develop the initial coding structure based on constructs incorporated into the interview schedules (See Appendix 4), feedback from research team members suggested adjusting coding labels to more accurately reflect the words and phrases used by participants, moving away from coding labels based on constructs included in the TDF in line with the inductive approach to analysis taken in this study.
After open coding, the author synthesized open codes into thematic elements. In this process, open codes and supporting data with shared thematic elements relevant to the experiences, beliefs, and perceptions of PA by older adults with MCI or AD were grouped into broader categories. This process involved re-reading through supporting quotations associated with specific codes to ensure the supporting data were consistent with their coding categories. Any redundant open codes were merged into single codes. Thematic elements combined related open codes to provide general statements about ideas captured in the research, but the relationships between thematic elements were not yet determined at this stage of analysis. At this point, thematic elements were presented to members of the research team and colleagues in the field of rehabilitation science who were external to the study. Feedback from members of the research team and colleagues highlighted the relationships between specific thematic elements.

Following the development of thematic elements, related thematic elements were organized by the author into thematic groups that outlined specific relationships between them. In this process, the dataset was re-read to ensure representativeness of themes, and that the ideas communicated by themes reflect what was communicated by participants. To ensure supporting codes were coherent with each other and their overarching theme, the thematic development matrices were reviewed by other researchers involved in the study. Following review and revision of themes, the themes were named and defined by the author after reviewing the supporting codes and excerpts from the dataset. Themes and descriptors were presented to the research team, and feedback was provided about phrasing of these to better reflect the supporting data. This final revision process with the research team resulted in clear, coherent descriptors of themes. Appendix 9 provides an exemplar of the thematic development matrix used to organize themes, descriptors, supporting codes, and illustrative quotations, with a coding tree to demonstrate how specific codes are nested into thematic groups and themes.

As analysis progressed from open coding, to thematic elements, and then thematic development, constructs included in the TDF became implicit components of broader thematic ideas as opposed to names for specific themes and codes. Descriptors of themes and their supporting codes increasingly reflected the specific perceptions, beliefs, and experiences voiced by participants in their interviews rather than the broad, generic constructs of the TDF. Thus, the TDF in this study provided a way to sensitize analysis in the early stages until coherent, meaningful themes could be determined from the data collected.
Demographic information, PA level, apathy level, and cognitive status data were analyzed using descriptive statistics to determine mean, range, and standard deviation (SD). Quantitative data were managed using Microsoft Excel (Microsoft, 2010).

4.4.3 Maintaining Data Quality

Ensuring the processes of data collection and analysis accurately capture and reflect the reality of a phenomenon is critical to creating knowledge that speaks to a broader truth and is usable beyond a study’s specific research context. The following sections on rigor, credibility, transferability, dependability, and confirmability outline specific strategies employed in this study to maintain data quality in this study and the rationale supporting these methodological decisions.

4.4.3.1 Rigor

Rigor in qualitative research supports the truthfulness and transferability of findings, and addresses concerns that qualitative inquiry is unscientific, anecdotal, inherently biased, and ungeneralizable. Rigor in qualitative research refers to how closely the findings of a study reflect the truth surrounding the phenomenon it investigates (438). Enhancing rigor in qualitative research means enhancing its validity, or “trustworthiness”, and can be achieved by improving the credibility, transferability, dependability, confirmability of the research and its findings (439).

4.4.3.1.1 Credibility

Credibility refers to an assessment of the truthfulness of findings (439). Strategies to enhance credibility of qualitative research involve ensuring that researchers have an understanding of the study population and phenomenon in question, willingness of participants to discuss the phenomenon in the research context, and checking with participants, other researchers, and reference back to the dataset to ensure findings are “close” to the data and accurately reflect participants’ realities.

In this study, the researcher conducting data collection and analysis was an “Outsider” to participants, being neither an older adult with AD or MCI nor a caregiver. While the “Outsider” status of the researcher does provide an opportunity to look at the phenomenon being
investigated with a fresh perspective, lacking an “Insider” appreciation of the unique experiences of participants may pose a barrier to understanding the nuances and implications of experiences shared by participants (440). In order to balance objectivity with understanding, the researcher in this study sought to gain more “Insider” experience to complement their “Outsider” objectivity. The researcher conducting the interviews gained familiarity with the population and phenomenon in question through conducting cognitive assessments in the cognitive neurology clinic where participants were being recruited from and volunteering in community-based recreational programs for persons with dementia and their care partners at a local chapter of the Alzheimer Society. While the researcher did not routinely interact with the specific participants in this study through these experiences, these engagements provided the researcher with some understanding of daily realities persons with dementia face, providing context for interpreting study data. Observation of the interactions between healthcare providers, community workers, persons with dementia, and care partners in these experiences also helped the researcher appreciate the variety of factors that may influence PA beliefs, experiences, and perceptions of older adults with MCI or AD and their care partners. Overall, these engagements and observations support credibility of the research by ensuring the person conducting data collection and analysis was close to the population and phenomenon in question, and had a base understanding of the reality of the study population concerning PA participation.

To ensure data collected were accurate and consistent, triangulation between and within interviews was used. Triangulation refers to the use of multiple sources and instances to develop a more complete understanding of a phenomenon by comparing responses of participants to other responses they have given on the same topic in the same interview, as well as to responses made by other knowledgeable informants on the same topic (439) (441). In the context of this study, triangulation of specific topics was accomplished by using multiple interview questions to probe the same topic from different approaches, providing a richer understanding of these topics. Both care partners were interviewed in this study, but the subject of both interviews was the partner with cognitive impairment. Caregiver interviews provided a context for understanding interviews of partners with cognitive impairment. Interviewing the caregivers and asking them about the same topics in relation to their partners provided an opportunity to understand the diverging perspectives of dyad members. Comparing data on PA behaviours, apathy, and care partner distress collected through qualitative interviews and quantitative questionnaires also
provided a way to determine consistency of responses that supports the credibility of findings. Points of divergence between participants and data sources also provided insights into the phenomenon of PA participation that would have been missed by using only one source or approach to explore the phenomenon.

Multiple methods of “checking” interpretations of data with their original sources were used to enhance credibility of the data (439) (438). To ensure that what the interviewer heard and interpreted during interviews was an accurate reflection of what participants were trying to communicate, the interviewer would frequently summarize and reiterate a participant’s response to a question during interviews to check that the interviewer’s interpretation of participants’ responses was accurate. In cases where the interpretation was not accurate, the interviewer asked for further elaboration from participants and reiterated their new understanding until there was consensus. Member checking in this study was used at a single point for clarification of ideas in interviews, not for post hoc verification or validation of data collected or analysis products (442).

Checking with members of the research team and uninvolved scientific peers by discussing the research process and evolving findings is a way to identify approaches and potential biases not previously considered by the researcher (439). In the context of this study, the researcher conducting interviews and data analysis discussed evolving findings of the study and analysis with the research team who questioned her about methods of analysis and other potential implications of the data and findings. As well, feedback on the research was sought from uninvolved peers during presentations made by the researcher to other graduate researchers and faculty in their department and institutional research group.

Using purposive sampling in this study supports credibility by trying to capture a variety of perspectives about the phenomenon in question, rather than only the most common or expected perspectives. Specifically, in the context of this research, divergent perspectives from older adults with MCI and AD and care partners with different activity levels and motivational dispositions were sought out. Comparing instances from interviews within and between dyads cases where participants’ experiences, beliefs, and perspectives diverge and conflict offers insights that support a greater understanding about the phenomenon in question and more accurately captures the reality of the diversity of perspectives present in this population (439) (443).
4.4.3.1.2 Transferability

Transferability refers to whether or not the findings of research can be applied in other contexts, similar to the concept of external validity as a measure of rigor in quantitative research (439). If research findings mirror the “reality” of a certain phenomenon, then the findings should be applicable in similar contexts. In this study, transferability is supported through providing detailed accounts of the research context, processes, and interactions so other studies investigating similar phenomena can understand how the findings from this study emerged. This “thick description” (444) is achieved through providing details about the research context in the methods, results, and discussion chapters of this thesis, supported by research memos and reflexive journaling that have been ongoing throughout the research process.

4.4.3.1.3 Dependability

The findings generated in qualitative research are highly contextually and temporally subjective, and reproducing this exact research context with the same participants and researchers is impossible. The notion of reproducibility of qualitative research, rather, is referred to as dependability (439). Dependability can be assessed through external audits, whereby someone independent to the study assesses whether the research procedures and products support the conclusions drawn from the research (445). Given that this study was conducted within a constructivist paradigm, assessing the dependability of research procedures and findings through this method is not an appropriate assessment of validity in this study. However, the research conducted as a part of this thesis must undergo examination, so a formal external audit will ultimately be conducted on this research during the defense of this thesis.

4.4.3.1.4 Confirmability

Confirmability as a measure of rigor in qualitative research refers to the extent to which the interpretation of data and the conclusions drawn from research findings are not unduly influenced by researcher bias (439). In the constructivist paradigm, influence of the researcher on findings and conclusions drawn from the data is unavoidable as they are co-constructing meaning with participants throughout the research process. However, research findings should still ultimately represent the experiences and perceptions of participants viewed through the lens of the researcher, not the experiences and perceptions of the researcher themselves. Several steps were taken to ensure findings in the present study reflect the experiences and perceptions of the
participants first and foremost. Triangulation, as previously described as a strategy to enhance credibility, also supports conformability (439). The use of multiple sources and instances in the data can provide a deeper understanding of a phenomenon and reduce the likelihood that it is misinterpreted or misconstrued by researchers in light of their biases. Reflexivity (discussed in Chapter 3.4) enhances the confirmability of research (439), and was practiced in this study to ensure researcher bias was acknowledged and information provided by participants was not unduly influenced by the researcher. Reflexivity was practiced throughout this study in reflexive journaling and memoing (446) (447). A summary of this reflexive practice is provided in this thesis as a statement of positionality (Chapter 3.4).

### 4.4.3.2 Quality Appraisal

The Consolidated Criteria for Reporting Qualitative Research (COREQ) (448) were consulted to ensure that the reporting of this study meets established quality standards for qualitative research using interviews. Briefly, the COREQ outlines 32 items related to the domains of research team and reflexivity, study design, and analysis and findings. These are important for qualitative researchers to report so their research can be appropriately evaluated by readers. The study comprising this thesis achieves 31 of the 32 criteria outlined in the COREQ. The single exception to observation of these criteria pertains to item 23 of the COREQ, “Transcripts returned”. In this study, transcripts were not returned to participants for comment or correction, as this is not appropriate given the population being studied in this thesis. The researchers deemed that returning transcripts to individuals with cognitive impairment, particularly individuals with more severe memory impairment, would not add anything to the data and only serve to muddy the results of interviews as participants were no longer in the mindset of reflecting upon their PA perceptions, experiences, and beliefs. Caregivers would only have been able to review their own transcripts, as having them review their partners’ for comments and corrections would have yielded an interpretation of these transcripts through the eyes of the caregivers, not a first-hand account from participants with MCI or AD. Given that the perceptions, beliefs, and experiences of older adults with MCI or AD being explored in this study, with caregiver interviews included to provide a richer contextual understanding of this, having the caregivers review their own transcripts would likely not have added meaningful data. Rather, returning transcripts to caregivers for review would have presented an opportunity for
them to self-correct, and potentially edit their responses to reflect what they think they should say, rather than what they actually said spontaneously in an unscripted interview.

4.5 **Summary**

The study procedures used to collect data about the PA perceptions, beliefs, and experiences of older adults with MCI or AD were designed to respect the specific abilities of older adults with cognitive impairment and enhance the rigor and quality of study findings. Dyads, including one older adult with MCI or AD and a familial care partner, were recruited to participate in this study. Questionnaires and semi-structured interviews with individual participants were used to collect data about PA levels, apathy levels, and participants’ perceptions, experiences, and beliefs concerning PA. Descriptive analysis of quantitative data on PA and apathy levels was performed to describe the PA and motivational profiles of participants and ensure a diversity of activity and apathy levels were included. Qualitative thematic analysis of interview transcripts was used to address the research question, “*What are the perceptions, beliefs, and experiences, of community-dwelling older adults with MCI or AD and their caregivers concerning PA as a health behaviour?*” The results of this analysis are addressed in the following chapter.
Chapter 5

5 Results

5.1 Preface

This chapter is the culmination of preceding chapters, and details the findings of a qualitative study addressing the research question, “What are the perceptions, beliefs, and experiences, of community-dwelling older adults with MCI or AD and their caregivers concerning PA as a health behaviour?” To provide a sense of the cognitive, PA, and motivational levels of dyads who participated in this study, data on participant demographics, PA levels, and apathy levels are first presented to provide a context for understanding the findings yielded by qualitative analysis of interviews with older adults with MCI or AD and their caregivers.

5.2 Demographics

Ten dyads (n=20 individuals) were recruited to participate in this study. All participants were able to successfully complete the study, with none dropping out or refusing to participate after enrollment. The participants included in this study constituted a diverse group in respect to age, level of global cognitive function, diagnosis, and dyad relationships. There was a lack of diversity in respect to ethnicity, level of education, and dwelling. All participants had completed at least a high school-level of education, and were predominantly Caucasian. All but two dyads involved in the study lived in an urban area. Demographic characteristics are summarized in Table 3.

<table>
<thead>
<tr>
<th>Table 3</th>
<th>Demographic Characteristics of Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Characteristics</td>
<td>Caregivers (n=10)</td>
</tr>
<tr>
<td>Sex (# female)</td>
<td>5</td>
</tr>
<tr>
<td>Age (years)</td>
<td>65.9 (SD=17.4) (Range=23-83)</td>
</tr>
<tr>
<td>Diagnosis</td>
<td>N/A</td>
</tr>
<tr>
<td>Global Cognitive Function (MMSE, score out of 30)</td>
<td>N/A</td>
</tr>
<tr>
<td>Dyad Relationship (# participants)</td>
<td>8 Spouse 1 Child</td>
</tr>
<tr>
<td></td>
<td>1 Grandchild</td>
</tr>
<tr>
<td>--------------------------</td>
<td>--------------</td>
</tr>
<tr>
<td><strong>Education (# &gt; 12 years)</strong></td>
<td>10</td>
</tr>
<tr>
<td><strong>Ethnic Diversity (# not Caucasian)</strong></td>
<td>2</td>
</tr>
<tr>
<td><strong>Dwelling (# urban)</strong></td>
<td>8</td>
</tr>
</tbody>
</table>

5.3 **Apathy and Caregiver Distress**

A range of apathy levels in persons with MCI or AD were reported by caregivers.
Caregivers reported the presence of apathy in 7 participants with MCI or AD. All caregivers of participants with AD reported apathy, and half of the caregivers of participants with MCI reported apathy. For individuals who reported apathy, the average apathy score on the NPI was similar for persons with AD and MCI. Table 5 summarizes study findings concerning apathy levels in participants with MCI or AD reported by caregivers.

**Table 5**  
Apathy Levels in Participants with Mild Cognitive Impairment (MCI) or Alzheimer’s Disease (AD)

<table>
<thead>
<tr>
<th></th>
<th>Participants with AD (n=4)</th>
<th>Participants with MCI (n=6)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Apathy present (# of participants)</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Apathy Score (/96)</td>
<td>17.8 (SD=12.4) (Range=9-36)</td>
<td>17.7 (SD=17.6) (Range=1-36)</td>
</tr>
</tbody>
</table>

Caregiver distress as a result of apathy expressed by persons with cognitive impairment is also captured on the NPI apathy subscale. In total, 7 caregivers reported experiencing distress as a result of their partner’s apathy. Table 6 summarizes study findings concerning apathy-associated distress experienced by caregivers of persons with MCI or AD.

**Table 6**  
Apathy-Associated Distress in Caregivers

<table>
<thead>
<tr>
<th></th>
<th>Care partner of person with AD (n=4)</th>
<th>Care partner of person with MCI (n=6)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Experiencing distress due to partner’s apathy (# of participants)</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Apathy Distress Score (/40)</td>
<td>4.0 (SD=1.4) (Range=3-6)</td>
<td>7.0 (SD=3.6) (Range=4-11)</td>
</tr>
</tbody>
</table>

5.4 **Physical Activity Levels**

Two caregiver participants were under the age of 65 years and completed the IPAQ, but all the other participants completed the PASE to report weekly PA levels. To determine the total minutes per week of MVPA, the product of the frequency and duration of various activities
reported for various domains of activity were summed. On average, older adults with cognitive impairment achieved 156 min/week of MVPA (SD = 376 min/week; range 0-1215 min/week) and their care partners achieved 440 min/week MVPA (SD = 502 min/week; range 0-1215 min/week) on average. To facilitate meaningful interpretation of this data, continuous data on total weekly minutes of MVPA were converted to interval data to create “high”, “moderate”, and “low” activity level categories. PA levels are summarized in Table 4.

Table 4  Moderate to Vigorous Physical Activity (MVPA) Levels of Participants

<table>
<thead>
<tr>
<th>Activity level</th>
<th>Caregivers (n=10)</th>
<th>Participants with Cognitive Impairment (n=10)</th>
</tr>
</thead>
<tbody>
<tr>
<td>High (≥150min MVPA/week)</td>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td>Moderate (100-149min MVPA/week)</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Low (0-99min MVPA/week)</td>
<td>1</td>
<td>6</td>
</tr>
</tbody>
</table>

If the sum of weekly total minutes of MVPA met or exceeded 150 minutes, the recommended minimum amount of PA needed to maintain health as per the Canadian PA Guidelines, the participant was considered to have a “High” activity level. Figure 3 plots the PA levels of persons with cognitive impairment (ADMCI) and care partners (CG) in increasing order. The existence of two plateaus in the data, at 0 min/week and between 100-150 min/week of MVPA were the basis of selected cut-off values for the “Low” activity level (0-99min/week) and “Moderate” activity level (100-149min/week) categories. PA levels were self-reported by each individual participant, meaning that caregivers confirmed, but did not report, PA levels of participants with MCI or AD.
Within dyads, self-reported levels of MVPA were frequently discordant between care partners and older adults with MCI and AD. Figure 4 illustrates the differences between PA levels of dyad members, categorized as high, moderate, or low activity. In no instances was a dyad member with cognitive impairment (ADMCI) in a higher activity category than their care partner (CG).

**Figure 3 – Range of Total Weekly Minutes of Moderate to Vigorous Physical Activity (MVPA) Reported by Cognitively Impaired (ADMCI) and Caregiver (CG) Participants.**
In addition to describing the demographic characteristics, apathy levels, and PA behaviours of dyads who participated in this study, case descriptions of a selection of dyads are included to provide a framework for understanding the results discussed in the following section. These cases were selected to help further illustrate the diversity of dyad dynamics, motivational levels, and PA behaviours of dyads who participated in this study. Names and identifying details of dyads have been changed, and pseudonyms or generic descriptors have been used instead to maintain anonymity of participants.

5.5 Case Descriptions

In addition to describing the demographic characteristics, apathy levels, and PA behaviours of dyads who participated in this study, case descriptions of a selection of dyads are included to provide a framework for understanding the results discussed in the following section. These cases were selected to help further illustrate the diversity of dyad dynamics, motivational levels, and PA behaviours of dyads who participated in this study. Names and identifying details of dyads have been changed, and pseudonyms or generic descriptors have been used instead to maintain anonymity of participants.

5.5.1 Dyad 3 – Phyllis and Greg

Phyllis is a highly active older woman with MCI who I interviewed for this study while she was in town with her husband, Greg, for an appointment. Prior to retirement, Phyllis worked in a longterm care home as a nurse, while Greg was a business man. By all accounts, Phyllis and Greg are the embodiment of active aging throughout the lifespan and continue to be partners in PA. Both have been active throughout adulthood, enjoying running and hiking outdoors outside the city. Phyllis has been a lifelong runner, but lately, her running has been curtailed by episodes where she has gotten lost on familiar routes. Despite the challenges posed by her cognitive changes to maintaining her lifelong PA habits, Phyllis and Greg are adapting to their new
realities and striving to keep living active lifestyles. They are both looking for new activities that they can do together outdoors to stay active, like Nordic walking and community exercise classes in their neighbourhood.

5.5.2 Dyad 4 – Bill and Anne

Bill is an older man with MCI whom I interviewed while at the hospital for another appointment with his wife, Anne. Bill is a retired engineer, but is still very engaged in his community as a handyman for neighbours in his condominium community. While he enjoys the problem solving involved with this retirement occupation, he has difficulty remembering the names of his neighbours that he has known for many years. Bill’s memory and attention have been on the decline lately, leading to his diagnosis with MCI. Bill also has trouble remembering to get up and be active throughout the day. He has previously been very successful at maintaining stable PA habits, which he credits to the support of a structured exercise program where he can objectively track improvements in his health and physical fitness. PA, however, has not been a lifelong habit for Bill, and he does it when some external source indicates that he should, be that a healthcare provider, trusted scientific publication, or his wife, Anne. Anne is a retired social sciences researcher, and believes that maintaining a stable PA habit is important, but has trouble getting her husband Bill to keep a consistent PA habit. Both Bill and Anne are somewhat active, and try to do as much as they can, but waning motivation and competing demands on their time can derail the best of their intentions. Currently, Bill is having trouble maintaining stable PA habits for numerous reasons, some of which are his troubles with remembering to be active and getting distracted by other projects when he is planning to be active. In addition to his declining cognitive function, a worsening sense of balance has prompted Bill to be more cautious when engaging in PA to avoid falling. Thankfully, Bill’s wife, Anne, helps him with these challenges.

5.5.3 Dyad 8 – Catherine and Jenny

Catherine is an older woman with more severe cognitive impairment, and came in with her daughter, Jenny, to be interviewed before an appointment at the hospital. Although Catherine’s mobility and balance are somewhat limited, she is still able to engage in PA with the aid of a walker or support from a partner. Catherine initially did not have much to say about PA, but as soon as she started talking about dancing, especially polka, she had quite a lot to say.
Catherine has been active throughout her life, typically in the context of socializing and bringing people together. One of her jobs in adulthood involved planning social events for the office she worked at, which frequently involved hosting dance classes over lunch hour. Now, Catherine continues to dance every week in a program that is specifically for older adults with cognitive impairment. Outside of this programming, Jenny, along with Catherine’s other children, has arranged attendant care to help get her up and active throughout the day, even if it’s just walking up and down the hallway in her apartment building. For Jenny in particular, keeping her Mum active is of great importance. Jenny herself is a fitness instructor, and holds a strong personal belief in the benefits of PA for mental and physical health at all ages.

5.6 Emergent Themes

Combined interview durations for both dyad partners were 1:06:23 hours on average (Range=47:52-1:22:18), and all interviews ran uninterrupted for their duration. Interviews with caregivers tended to be lengthier than interviews with participants who had MCI or AD, with caregivers tending to provide more elaborate answers to semi-structured interview questions and richer discussions about the phenomenon of PA participation in their partners with cognitive impairment. Qualitative thematic analysis of interview transcripts yielded 4 distinct themes concerning the perceptions, beliefs, and experiences of older adults with MCI or AD concerning PA participation. These themes are elaborated in the following section, and are summarized in Table 7 with their supporting subthemes.

<table>
<thead>
<tr>
<th>Theme</th>
<th>Subthemes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Physical activity as a meaningful activity</td>
<td>i. Perceptions of recommended physical activity levels for older adults</td>
</tr>
<tr>
<td></td>
<td>ii. Physical activity is more than just a health behaviour</td>
</tr>
<tr>
<td>2. Feeling is more important than thinking</td>
<td>i. Needing to see the benefits to believe them</td>
</tr>
<tr>
<td></td>
<td>ii. Influence of the embodied experience of physical activity on participation</td>
</tr>
<tr>
<td>3. Participation is possible despite dementia</td>
<td>i. Desire and drive to be active</td>
</tr>
<tr>
<td></td>
<td>ii. Physically capable, cognitively adapted</td>
</tr>
<tr>
<td>4. Caregivers as enablers of physical activity</td>
<td>i. Role of caregiver as enabler varies between dyads</td>
</tr>
</tbody>
</table>
5.6.1 Theme 1: Physical activity as a meaningful activity

This first theme pertains to how older adults with MCI and AD and their care partners personally define PA and conceptualize PA as a health behaviour for the general older adult population. This theme consists of two prevailing components: (i) perceptions of recommended PA levels for older adults, and (ii) participants conceptualize PA not just as a health behaviour, but as a way to add personally meaningful activities to their daily lives. When older adults with MCI or AD and their care partners think of PA, there is great diversity in how individuals define PA. No two individuals have the same personal definition of PA, and their notion of what activities constitute PA are equally varied. Common to all though is the idea that PA is more than just structured exercise, and that it is a broad class of activities with some embodied aspect. Recommended PA levels for older adults in general as perceived by older adults with MCI or AD and their caregivers do not refer to a prescriptive minimum weekly frequency, duration, type, and intensity. Rather, the concept of recommended PA levels for older adults is person-specific, with an emphasis on doing as much as one can to maximize benefits and minimize risks associated with PA. The end goal of PA for older adults with MCI or AD and their caregivers, while to some extent involves promoting and maintaining health, largely focuses on participation in meaningful activities. PA can be meaningful in and of itself, but also ensure the ability to continue participation in other non-physical meaningful activities. PA is more than just a health behaviour, and plays a role in how some older adults with MCI or AD view themselves either as “active” or “inactive” persons. In this respect, older adults with MCI or AD conceptualize PA in a more personally meaningful way, rather than as a health behaviour or medicine used to achieve positive health states.

5.6.1.1 Perceptions of recommended physical activity levels for older adults

To understand how older adults with cognitive impairment and their care partners conceptualize PA, participants were first asked to define PA in their own terms. Participants provided a diversity of responses, with no two individuals defining PA in the same way. For some participants, this was a difficult question to answer and they provided non-specific
responses like, “anything that gets you up and active” (Caregiver, Dyad 5). Other participants voiced uncertainty about how to define PA, and didn’t know “how to put this [definition] so it makes sense” (Participant with AD, Dyad 5). In looking at aspects from all definitions, however, common threads emerged. When defining PA, multiple participants spoke of PA as a way to engage one’s cardiovascular system, expend energy, and move one’s bones and muscles. These definitions of PA highlight the roles of the cardiovascular, respiratory, digestive, and musculoskeletal systems in PA, and point to an embodied, physical concept of PA perceived by older adults with cognitive impairment and their care partners. Definitions by some participants also included a setting for PA, noting that PA was anything that “gets you going… gets you outside” (Participant with AD, Dyad 5) or involves “getting a bit of fresh air” (Participant with MCI, Dyad 9). The scope of what constitutes PA was also very broad, which for some participants was any activity other than being sedentary.

“[Physical activity] means to use your body as much as you can in order to implement as many muscles as you have in the body”

(Participant with MCI, Dyad 2)

“Physical activity is any activity that... causes one to not be sedentary... but to engage in motion that... has a favourable impact on heart, lungs, strength, muscles”

(Caregiver, Dyad 8)

Consistent with this broad definition of PA was the recognition amongst participants that PA is more than just structured exercise. Examples of PA provided by participants were as diverse as their definitions, ranging from unstructured PA like activities of daily living or taking the stairs instead of the elevator, to occupational activities, to structured activities like yoga and dancing. Aside from implicitly differentiating PA and exercise through examples they provided, some participants were also able to explicitly describe a distinction between the two concepts. Still, others noted no distinction. Walking was the most commonly referenced example of PA, and was referenced as an example of both structured exercise as well as an unstructured physical activity, depending on the context it is being performed in (e.g. walking for transport, or walking for exercise)

“Physical activity probably involves a lot more activities than just straight exercise. It [exercise] is more routinized and more...”

“Physical activity... it doesn't necessarily mean going to a gym or going cycling, it can just be that you're active, even within...”
of a different regime, where physical activity - well, it's a lot of different movements.”

(Participant with MCI, Dyad 2)

your own house, or workplace, or whatever. Like climbing the stairs instead of taking the elevator. That kind of thing.”

(Caregiver, Dyad 3)

How older adults with MCI or AD and their care partners conceptualize recommendations about PA, much like how they define PA, is broad but specific to individuals. Recommendations as perceived by older adults with MCI or AD and their care partners were not limited to a specific minimal frequency, intensity, type, and largely were not informed by age-specific PA recommendations. With the exception of one care partner who had experience working in the fitness industry, participants either had never thought about the concept of age-specific PA recommendations. Rather than providing specific recommendations about the frequency, intensity, type, and duration of PA, participants tended to provide general heuristic recommendations on their idea of recommended PA levels. These heuristic recommendations ultimately centered on doing what suits the individual, aiming to get as much PA as one can to get its associated benefits, but not to the extent of causing oneself harm from PA participation.

“I - I couldn't summarize it [physical activity recommendation] in a number of things, but I think that the more the better, actually... I think you, you know, you have to know - who’s the person you’re talking about. Are they putting themselves in jeopardy if they’re doing too much or the wrong kind of thing?”

(Participant with AD, Dyad 10)

“I'd say keep it [physical activity] up as much as you can as long as you can. And then after - be sensible about it... but to try and I think - the more you can do, for as long as you can do it, the better it is, but that depends a lot on one's personal abilities because everybody ages slightly differently and what one person can do at ninety another person can't. But you know, you should probably get as much activity as you can for as long as you can.”

(Caregiver, Dyad 2)

Despite the question being posed in interviews as a weekly recommendation, participants framed recommendations on a daily instead of weekly basis, proposing at least 20 minutes of PA per day up to 1 hour. Older adults with MCI or AD and their caregivers noted that PA should be a daily occurrence and utilized throughout the day to break up sedentary behaviour.
“I think regularly every day - we should form a habit of a having your [physical activity] time set, right? From this time to this time, your breakfast. After your breakfast, you relax, then I - I do [walking]. I have a long hallway.”

(Participant with AD, Dyad 1)

“I think everybody [older adults] should try to get some kind of exercise, even if it’s walking. If you can get out there every day and do something, I think it’s fantastic. I think that people have to, if they want to have a good life as a senior, they have to keep moving. I really believe that, because once you stop using it, you lose it.”

(Caregiver, Dyad 3)

Recommendations about the intensity older adults should aim for in PA was highly consistent throughout participants, with moderation being the key. Participants largely believed that PA intensity should be sufficient to engage the cardiovascular system, but not to the point of overexertion. How “moderate” was defined varied between participants. Some provided target heart rates, while others described intensity in terms of breaking a sweat or maintaining a specific walking speed.

“Well at my age I think you have to think of safety... so moderately? Moderately active, I guess.”

(Participant with MCI, Dyad 6)

“I think it [intensity] should be as - as close to pushing cardio as they can because you know, unless you exercise the heart muscle, it's decaying really... to the best of their ability, they should be moving in such a way that they actually put a little bit of tension on that heart muscle... once you get into a situation with atrophy, it's too late.”

(Caregiver, Dyad 8)

Recommended types of PA according to participants varied, but centered around the notion of aerobic, balance, flexibility, and resistance training exercises. Aerobic “cardio” type activities mentioned included walking, cycling, swimming, and running, whereas stretching and strengthening activities mentioned were yoga, weights, and balance training. One of the caregivers specifically noted being uncertain about recommendations for weight training, however. These largely align with what is recommended by the Canadian Physical Activity Guidelines, with a few exceptions. Aerobic and resistance types of activities are recommended, as well as balance training exercise if falls are a concern. PA to improve flexibility, however, is
not included in the Canadian Physical Activity Guidelines for Older Adults, as insufficient evidence has been found to support its health benefits for older adults.

“Well I guess the best one or the prime one would be walking... then after that it - depending on what you're feeling like or what you do, or what you have been doing in the past, you could exercise and, and do [a] run, and go to a ... what do you call those places where they do it? A gym.”

(Participant with AD, Dyad 10)

“I think you do need to do some cardio activity... and most people should do some weights... and then you need to do things that help you with your balance, that sort of thing. So you need a range of activities, really.”

(Caregiver, Dyad 4)

“Yoga, for one thing... if you do [yoga] ... make sure it's really low-level kind of yoga.”

(Caregiver, Dyad 9)

“Strength training? Umm, I think it's important, although I don't know how much is, how much to do.”

(Caregiver, Dyad 9)

Older adults with MCI or AD and their caregivers in this study do not conceptualize the “recommended” level of PA for older adults as a standardized minimum “dose” for all older adults, but rather base recommendations on heuristics that individuals can adapt to strike an optimal balance between benefits and risks associated with PA. The specific benefits and risks older adults with MCI and AD associate with PA are outlined in the subsequent themes, “Theme 2, Feeling is more important than thinking” and “Theme 3, i.i. Physically capable, but cognitively adapted”, respectively.
5.6.1.2 Physical activity is more than just a health behaviour

All older adults with cognitive impairment and care partners interviewed recognized the positive health benefits of PA, and for many, these acted as motivators to be physically active. The desire to manage one’s overall health, reduce age-related disease risk, and reduce the amount and cost of medication were noted as driving forces for being physically active. In instances where health benefits are a motivator for engaging in PA, participants often noted a personally meaningful connection was a component in why that benefit motivates them to be physically active, such as caring for a family member who experienced a health condition largely preventable through PA that they wanted to prevent personally experiencing.

“You know, I’m getting to the age where [there is]... the potential for health problems like strokes and whatever, which runs in our family, and I said, “Well, I better do something about it”. So, it’s uhh... probably a negative motivator, in a way, but it's positive too I guess.”

(Caregiver, Dyad 3)

“It [gym membership fee] is a small portion to pay... I'm thinking like, "This is cheaper to pay than most medications are"... This is cheaper than going to a physiotherapist or a psychologist.”

(Participant with MCI, Dyad 3)

“You know, things like that [stroke]... you start thinking about that more. And I know of... well it’s not a blood relation, but there’s people I've known that have had severe strokes and it’s... not pretty.”

(Participant with MCI, Dyad 3)

Older adults with MCI or AD and their care partners noted in the interviews, however, that PA is more than just a way to achieve health. PA provides a way to add value to their daily lives. While not explicitly recognized by participants, their responses also suggest that PA experiences and attitudes held throughout the lifespan contribute to how older adults with cognitive impairment and their partners perceive themselves. This was evident in some of the non-health related motivators iterated by participants for engaging in PA, such as providing a better outlook on life, keeping oneself alive, limber, and youthful, and a way to set a good example for one’s family.
“It’s - I think it’s definitely of benefit. So I think we keep... part of our youth a little bit more because we are - if we are active.”

(Participant with MCI, Dyad 6)

“It [physical activity] is a good way [to] keep up with my four daughters and eight grandchildren... as an example to my wife, and my daughters, and their families, it's a good example.”

(Caregiver, Dyad 6)

PA was noted by participants as a way to infuse meaning into their lives, and a reciprocal relationship between participation in PA and meaningful activities emerged from their responses. Certain activities that participants discussed participating in held personal significance, and engaging in these meaningful activities provides a way for them to increase their PA levels. Being able to engage in activities they have participated in throughout their life and activities participants find personally enjoyable are motivators to engage in PA. As well, being able to walk to desirable destinations, going on vacations centered on PA, and valuing time spent being active outdoors are ways that meaningful activities can in turn promote PA.

“At the moment... one of our daughters is living with us too... it’s lovely having her around... I’m more active because she’s living with us... She likes to do things, and, actually I like doing things with her! Sometimes we walk, sometimes we shop - I LOVE shopping! Well that’s right - as the girls say, when I say, "I'm tired," the girls say, "Well what about maybe we go shopping?" They say I get a second wind!”

(Participant with MCI, Dyad 6)

“My mum [participant with AD] loves dancing - she always ever did... I don't know the whole history, but I think when my mum worked years and years ago... she worked at a company where she was what they called a "social convenor"... she also had these occasions to have like 4 weeks of tap dancing lessons brought into the company... all the women that worked there, who mostly were secretaries back then, would go down on their lunch and learn tap dancing! And this is the kind of thing that my mum did! So she loves dancing, and I think she kind of grew up in a German household where there was a lot of polka-ing and all of that stuff, so I think... what comes full circle is that we were able to get her into this seniors centre program where they actually have a music therapy component that has the dance, which is just fantastic.”

(Caregiver, Dyad 8)
Conversely, maintaining one’s health through PA provides a way for older adults with MCI or AD to sustain their involvement in other activities that they find meaningful, like traveling, keeping up with grandchildren, having enough energy to participate in meaningful activities, meeting with friends and family, and enjoying more food or a cool, relaxing beer. Just as meaningful activities can provide a way to increase PA levels, however, a lack there of can be a barrier to PA participation – not having engaging PA options or finding more value in activities that are sedentary rather than physical. As well, injuries resulting from engaging in PA were noted by one participant as limitation to engaging in meaningful activities, and thus a reason not to engage in certain types of PA.

“Well actually, you know, that [physical activity] helps me also for my prayers… That also gives me energy to pray.”

(Participant with AD, Dyad 1)

“All I have as my list of meds is thyroid medication and I’d like to keep it that way. So, that’s a good motivator right there. We do want to see the world, so it’s nice if we are able to do that - physically, to be able to do that. So when you go on a tour, you’re able to walk, you’re able to, you know, go up a big hill or whatever.”

(Caregiver, Dyad 3)

Personally meaningful experiences with PA throughout the life course also contribute to current PA participation for older adults with MCI or AD. Memories recollected by participants spanned the life course, from participating in school sports teams during childhood, to trying to balance PA for health promotion with competing familial and occupational demands from as an adult, to the resumption of PA in older adulthood as retirement yielded more time for leisure.

“I'm not good on team sports. My coordination isn't that great on say badminton, or tennis... I always feel like I'm letting the other people down... you know how you used to pick things? I would always be the last to be picked, "Oh... Hi... You'll come on over to our side."

(Participant with MCI, Dyad 2)

“I think you have to consider it a number one or two priority... you need to put that whole physical activity as part of your routine. I believe it’s that important because I see the way it has affected me, and I also see how it’s affected my husband [participant with MCI].... When he was still working, my three kids asked, "What do we get Dad for Christmas?" So I said, "Let’s get him personal training lessons.” He got the gift certificate, and it actually was expiring because he didn’t
(Participant with MCI, Dyad 2) get in there. Because you know, he was busy, and didn’t take the time to set it up, and he tried to go to the gym maybe on the weekend, and sometimes work gets in the way, and…”

(Caregiver, Dyad 3)

“In terms of swimming, I only just decided I think when I retired that I wanted to go swimming, and I had some time to do it. And I went and did it... When I was working, there was no time for anything. No time for anything because I was really busy with the kids.”

(Participant with MCI, Dyad 2)

In addition to discussing specific memories of PA, participants also noted broader trajectories of their PA behaviours and perceptions across the life course. For some, stable habits and attitudes were the trend, whereas others noted punctuated turning points in their PA behaviours and perceptions.

“We're not doing a daily exercise, we're not... I think it's because we just never started doing it, and we never did it much, you know. So we're not... not driven to it anyway”

(Participant with AD, Dyad 10)

“I started running about 35 years ago. And uhh... that was mainly just to stay healthy and I just - I just never stopped... When my practice got larger, I ended up just managing it. I became aware fairly quickly I wasn't getting any exercise, so I started running. I would run the shortest - I remember it took me a year to get so that I could run continuously. When I started out I could run for 30 or 40 seconds then I’d have to slow down to walking for a while and try to cop a breath, and... so after that I just never stopped”

(Participant with MCI, Dyad 7)

“I think it [physical activity] is definitely worthwhile, and I think they're learning the benefits of physical activity more all the time. Like when I was a child, nobody talked much about physical activity... but now, it's very, very popular to be physically active, and there are a lot of women my age, you know, who go out and have exercises in classes.”

(Participant with MCI, Dyad 6)

In discussing PA, participants tended to reminisce on their personal experiences with PA throughout their life and make a connection between these experiences and how active they currently are as older adults. In these reflections, it became apparent that PA plays a role throughout the lifespan in how one interprets certain behaviours as aspects of their identity.
Participants described how they either are, or are not, “active”, “athletic”, or “sportsy” people, and that this personal attribution of their PA level has influenced their PA behaviours throughout the life course into old age. PA in this sense isn’t just a behaviour for older adults with MCI or AD, but a manifestation of an inherent personal characteristic. Poor physical performance or appearing to be “bad” at something were threats to self-concept noted by participants as reasons not to partake in certain types of PA. Thus, PA bears meaning not just as a behaviour, but also in how older adults with MCI or AD view themselves.

L.B.: Can you please tell me what the phrase physical activity means to you?
Participant with AD, Dyad 10: Very little!
L.B: Why is that?
Participant with AD, Dyad 10: I'm just a lazy person!

“We've never been physically active as a kid. I came in last in racing, and when I became old enough to say, "No, I will not do that," I said, "No, I will not do that," to my teachers. That was grade 8 or 9 or something around there, and I thought, "Enough of this already because I just can't do it - I'm sick and tired of being the looking awful." I don't like looking awful. I like to do it well or not at all. So there's that part. So that's one reason I haven't been doing very much physical activity as a lifestyle.”

(Participant with MCI, Dyad 4)

“Well, she's [wife with MCI] not a sports person, sports was not - and she still isn't. I mean, she tolerates me, but if I watch baseball or hockey or something like that she wouldn't watch unless she's trying to do a favour for me... but you know, it's just something she's not - and she never grew up in a family that sports was not anywhere a part of their life.”

(Caregiver, Dyad 2)

Thus, how PA is perceived by older adults with MCI or AD and their care partners is different than how published health guidelines discuss PA. Additionally, the benefits older adults with MCI or AD associate with PA extend beyond the maintenance of health. In this sense, PA is not just a health behaviour, but a way to add meaning to their daily lives that influences how older adults with MCI or AD perceive themselves.
5.6.2 Theme 2: Feeling is more important than thinking

Older adults with MCI or AD and their care partners largely recognized that there are cognitive benefits associated with being physically active, but without personally experiencing these benefits, they find it difficult to believe in them and be motivated by them. Older adults with cognitive impairment place more emphasis on the aspects of PA they have personally experienced rather than purported cognitive benefits associated with PA of which they are uncertain. Rather than rationalizing PA participation through these cognitive benefits they recognize but cannot personally attest to, older adults with MCI or AD tend to focus on the influence of embodied experiences and effects of PA, both negative and positive, on PA participation.

5.6.2.1 Needing to see the benefits to believe them

The responses provided by older adults with cognitive impairment when discussing the purported cognitive benefits of PA clearly indicated that in order to be motivated by these benefits, they needed to be able to personally experience and perceive them. Participants noted that they are aware of specific cognitive benefits associated with PA participation, particularly in terms of alertness and mental clarity, and the potential beneficial effects of PA to counteract AD.

“I think it [physical activity] really - it helps you to focus your mind on what you want to do for the day and sort of clarifies your mind. Kind of declutters, sort of like house cleaning. You get rid of all sorts of thoughts while you’re walking and it kind of helps you focus on what you want to do for the day.”

(Participant with MCI, Dyad 2)

“I think their mood can change to better. I think just by taking care of their body, they may be slowing down the progress of the disease.”

(Caregiver, Dyad 7)

However, participants with cognitive impairment also voiced uncertainty about the existence of these benefits. This uncertainty arose from not personally being able to see objective improvements in their cognition or having a benchmark to which they can compare themselves. Despite this lingering uncertainty about the cognitive benefits of PA, participants noted they were still open to the possibility of these benefits even if they couldn’t perceive them and wanted to learn more about the benefits of PA for cognition. They also indicated an openness to trying...
anything that may improve their cognition, like PA. Ultimately, PA was noted by many participants with cognitive impairment not as a behaviour they rationalized in terms of its health-or disease-specific benefits, but something they just do.

“Well, I can't see any [benefits] that I'm actually seeing, unless I search under stuff. For example, I can - if I walk up stairs a lot, I can walk up stairs better, but I have to do that to see... A lot of these things I don't have [a] control on, so I don't know what my number would have been if I do it. Like how fast can I walk – that sort of thing. So I don't see any real evidence that physical activity aids me, because I can't measure it, and I'm a measuring kind of guy. I can believe what the book says, what you'll say what the doctors will say about mental health and physical health being improved by physical activity. I believe that, but I can't prove it.”

(Participant with MCI, Dyad 4)

“Do you know my favourite two words? “So what”... So what? I want to - disagree with the theory that nothing can be done. With MCI, let's say, it's either going to stay the same, get a little worse, or get a little better. So let's try it on - let's find out which, at least, don't worry about the end result, concern yourself with activating whatever's there, and checking it out. So that's what I'm trying to do with her [wife with MCI]”

(Caregiver, Dyad 6)

“Well, quite truthfully, I've never really thought a lot about it [physical activity]. Like it's... I've never really spent any time thinking about it other than signing up for a class or going and doing it.”

(Participant with MCI, Dyad 2)

5.6.2.2 Influence of the embodied experience of physical activity on participation

Relative to the cognitive benefits associated with PA, the embodied experiences of PA are more immediate and recognizable. These experiences as benefits and motivating factors for participating in PA were more accessible to participants with MCI or AD than abstract benefits for cognition, and were often the first to be mentioned during interviews. Positive embodied experiences resulting from PA, such as feeling energized and invigorated, feeling more rested and improving one’s sleep, and feeling a “boost” in mood and attitude are benefits motivating
participation in PA. Embodied experiences that occur while engaging in PA were also noted as reasons for participation, with one participant with MCI describing the embodied experiences such as breathing deeply and feeling of blood coursing through one’s body as motivators to being active.

“I think I feel more alive when I have some walking, and especially if it’s outside, and you get fresh air... and you know, it just feels good when you come back.”

(Participant with MCI, Dyad 6)

L.B.: So can you tell me what you think some benefits are to physical activity?
Participant with AD, Dyad 8: You feel better.
LB: How do you feel better?
Participant with AD, Dyad 8: You feel more energetic.

“It’s really nice to breathe deeply. When I was young, I had a lot of allergies and a lot of asthma. Part of it was my diet and part of it I didn’t move much. So it’s really wonderful to feel your lungs clear, to feel the blood coursing around your body... Umm the way it clears your head, focus for your day.”

(Participant with MCI, Dyad 2)

Other participants noted that feeling bad as a result of being inactive for too long, and remembering how good it feels to be active compelled them to be physically active as well.

“If you can remember how you felt... and I think that - that was a motivator [to be active], because I - I went back almost to my childhood - and I, well... "I remember feeling a lot better. Can I get some of that back?" And yeah, you do.”

(Participant with MCI, Dyad 3)

In particular, participants noted that the embodied experience of engaging in PA outdoors was a salient motivator for them, and facilitated their participation in PA. Participants noted that living in walking distance to aesthetically pleasing environments like gardens, rural and woodland areas, and urban green spaces encouraged them to engage in PA outdoors.

“Biking's beau[tiful] – its’ great this time of year. You can't beat it. The weather's been great, especially the last couple days... and because you're outside, you’re changing scenery, everything’s changing. Whereas in the gym, it’s okay, umm... but you know, after a while, I get... you don't have... now I look forward to it [biking].”

(Participant with MCI, Dyad 3)

“Well, my husband [participant with MCI] and I walk a fair amount... We'll be getting - in the summer - not so much because it was just too hot a lot of days this summer, but in the spring and winter and in the fall, where we're living now it's really nice. We back on to a green area and then there's a golf course, and in the winter the golf course, they actually plow the paths for the carts and we can walk
During the winter."

(Caregiver, Dyad 3)

Just as positive feelings and experiences can facilitate PA, negative feelings and experiences, or being unable to feel or experience the benefits of PA, can be a deterrent to PA. Participants noted that negative feelings and experiences following exercise, like aching muscles or feeling stiff or tired were deterrents to engaging in PA. Not enjoying how PA feels in the moment, such as disliking the feeling of sweating in more vigorous exercise or being in water while swimming, were provided as reasons why some participants tended to shy away from certain types of PA.

“I don’t feel particularly wonderful because I did it, and there’s no buzz that gets to me saying, "Isn’t this feeling nice because I’m doing it!" which is the lack of motivation there. It would be nice if it did - If I got to a point somehow that say, "Oh isn't that wonderful! You’re a great guy! Keep doing it!”"

(Participant with MCI, Dyad 4)

Interestingly, two participants with MCI also noted that they thought one of the reasons why they are less motivated to exercise is that they don’t get a positive post-exercise “high” and PA hasn’t led to improvements in their mood. In this way, an inability to experience the positive feelings resulting from PA is a deterrent to being active. Ultimately, participants noted that while there are some negative feelings resulting from being physically active, you need to look beyond those to make PA happen.

“I'm more of a flat person - just not as many highs and lows because of the medication I'm on. I don't have the big highs... and therefore I don't have enough of those trigger situations to say I’ll go and do a whole bunch of this [physical activity]. I've never been that way.”

(Participant with MCI Dyad 4.)

“During the exercise, you know - it's just drudgery for me, in a way...you've got to look beyond that [feeling of drudgery].”

Caregiver, Dyad 4: He [husband with MCI] wouldn't come to the pool. He doesn't do the pool.

L.B.: Okay, does he know how to swim?

Caregiver, Dyad 4: Yes, but he hates the water.
5.6.3 Theme 3: Participation is possible despite dementia

5.6.3.1 Desire and drive to be active

Older adults with cognitive impairment in this study had a desire to be active, either by maintaining or increasing their current PA levels. In addition to health, embodied experiences, caregiver-related, and personally meaningful motivators for engaging in PA elaborated in other themes, participants with MCI or AD noted several other motivators for wanting to be active. Extrinsic motivators were those mentioned by participants that were external to themselves. For some participants, feeling compelled to be active because it’s “good” for you was an extrinsic motivator, viewing PA as something that “should” be done, as opposed to something they were internally driven to do. For others, having some way of tracking one’s PA and using technology like pedometers and activity trackers provided motivation as objective proof of one’s accomplishments and progress. A number of motivators resulting from one’s social surroundings were also noted as extrinsic motivators for PA, such as being surrounded by active family members or being in a group exercise program.

“I think I should have more, actually… I don’t believe that I’m as active as I should be. So I’m hoping to - increase that… We’ve got a wonderful exercise place downstairs. I really - I should be doing that, but I don’t know. Things just keep happening in ours [lives].”

(Caregiver, Dyad 4)

“I think I should have more, actually… I don’t believe that I’m as active as I should be. So I’m hoping to - increase that… We’ve got a wonderful exercise place downstairs. I really - I should be doing that, but I don’t know. Things just keep happening in ours [lives].”

(Participant with MCI, Dyad 6)

“Yes, and he [husband with MCI] was a very good candidate [for an exercise program] because he – he did it, and he kept the chart. Keeping the chart is a good thing for him. He likes to be able to see that he’s done it. And, and that helps to - it helps in a way to motivate him.”

(Caregiver, Dyad 4)

For others, more intrinsic, or internally-driven, motivators were noted as reasons to engage in PA, such as maintaining one’s weight and positive body image, maintaining a normal sleep schedule, and simply finding PA enjoyable.

“The thing that really motivated me to [be active] was we were on holiday, and I thought I was, you know, doing pretty good. I looked at a photograph, and thought, "Oh my god! I look terrible there!"... I said, “I’ve got to do something about it.””

(Participant with MCI, Dyad 3)

L.B.: So what do you like about physical activity?
Participant with MCI, Dyad 9: Well you feel better... because you can get lazy, and you're... What's the way - if you don't exercise or move around a lot, things will start to
go bad. You know? Your back will start to hurt you, you sleep too much.”

For some participants with cognitive impairment, the prevention of declines in physical and mental capacities through PA was an intrinsic motivator for PA participation. AD was acknowledged by one participant as a motivator for them to be physically active, as they perceive it as a way for them to take action against this disease. While PA for this participant isn’t a way to impact specific cognitive symptoms, it is a way that they feel they can manage their mood and negative feelings about having AD. Another participant noted that their motivation for being physically active was the recognition of that they only have one body and one brain, which they need to take care of.

“Well, I’ve just - I’m in a happy frame of mind [when I’m active] … it just sort of lifts, you know… because I’m - I’m not happy that I have Alzheimer’s disease, but there’s nothing I can do about it. But it [being active] just, you know, sort of lifts me up. I feel good, about life in general.”

(Participant with AD, Dyad 5)

“Well, I agree that you have to be uhh… looking after yourself and your brain, and your, you know? This body is the only body I have. You've gotta look after it.”

(Participant with MCI, Dyad 9, discussing PA and the brain)

Not only did participants with cognitive impairment in this study have a desire to be more physically active, but they also identified a number of factors that enable them to do so and strategies they use to make PA happen. External facilitators noted by participants with cognitive impairment and their caregivers were aspects of social and physical environments that support PA, such as access to facilities and equipment promoting PA or living in built environments that encourage PA. Among these, participants specifically identified proximity to community resources, access to exercise equipment, fitness facilities they can use during the winter, and abilities-focused supportive care as facilitators. External facilitators to PA participation also included access to reliable educational sources and encouragement from health professionals. Social environments that foster PA, like having an exercise partner or belonging to an exercise group were noted by participants as social facilitators to PA participation.

“If I see stuff enough from trusted sources, and we get publications that are trustable, like consumer reports and the thing with national - things out of the States… Johns Hopkins - people who you’d expect to be telling the truth… And

“At the community centre just a little west of our street there, and that's where she [wife with MCI] goes swimming… and the yoga was at a local church that a woman ran... but she’s [wife with MCI] started going to yoga classes at the community
there's another thing coming up that I think my neurologist has suggested because I'm under the care of a neurologist as well because of this MCI thing... and she suggested, so we're signing up on that. So we're - we're looking for these kinds of opportunities.”

(Participant with MCI, Dyad 4)

“It [physical activity program for people with dementia] had cognitive stimulation, it had physical exercise and activity, and then it sort of had that social component, right? Which is very important... my Mum [participant with AD] was a teacher so when it comes down to the raw tacks with Mum, it's things like social clubs and dancing and all of that she just loves! And you put that in front of her, and she just jumps right in.”

(Caregiver, Dyad 8)

And we [participant with MCI and neighbour] go down into the valleys, you know, all through the city, there are all these places, and you're down there, you'd always have the route... We'd have a beer, we eat... It's a nice thing, and we're talking all the time about this, that, and the other thing.”

(Participant with MCI, Dyad 9)

“I just do what I want to do. And I mean I - you can always work around other people and the things that you need to do for your other kids, but I'm not working full-time. It's a long day - you can fit anything in. You know, if I can't make a class, you can always go for a walk. I mean, you can always go for a walk.”

(Participant with MCI, Dyad 2)

Interestingly, participants also noted that certain cultural and religious predispositions facilitated PA, like cultural attitudes toward PA for specific gender roles or social strata. One participant with MCI also connected their reasoning behind PA participation to their atheistic beliefs. Since they believe this life is all there is, they are going to do everything they can to

Internal facilitators were those mentioned by participants that were aspects of their own psychological, cognitive, and physical predispositions or their current life situation that foster PA participation. Having strong internal motivation and discipline to exercise, time management skills, and being able to adapt to changing schedules are examples of some of these internal facilitators mentioned by participants.
make the most of it. In the context of PA, this means doing what they can to maintain their physical and cognitive health for as long as possible by engaging in PA.

“Many of the people going there [to the symphony] are women, older women, sort of our age. They're almost always unaccompanied, so they're probably widows, but I don't know... But very well to do, and they come from a culture where women don't do any work. The Europeans, and I'm just imagining that these women have never shoveled snow or carried the garbage, or walked anywhere, etcetera, etcetera. Now the poor women are just - they're 75 years old, and it takes them 5 minutes to climb up the stairs to their seat. So, and it's just a culture. I'm sure they come from a culture where privileged - privileged people - didn't do any work, especially women didn't.”

(Participant with MCI, Dyad 7)

“To paint a picture, I'm an atheist. Totally... and I'm not going to die in a nursing home. I'm going to live my life out, and end it either by my children or by myself when I've decided I had enough. So I'm never going to be disabled. I'll be dead first, if that's tomorrow or 10 years from now.”

(Participant with MCI, Dyad 7)

To illustrate how these motivators and facilitators made participation possible despite having cognitive impairments, participants provided numerous examples of persons with MCI or AD achieving and excelling at PA.

“I'm doing it [balance exercise class] without chairs with the strongest band I can get my hands on and making the muscles work properly, instead of just making the movements. So I continue on with that - that's working fairly well. I'm pretty sure I'm a little stronger than I used to be, just because of this exercise. It's highly recommended from me... It's - it's small stuff, it doesn't get you sweating - well, a little wee bit, but not much unless you work at it. And I try to work at it.” (Participant with MCI, Dyad 4)

5.6.3.2  Physically capable, cognitively adapted

Older adults with cognitive impairment interviewed in this study clearly have the desire, motivation, and means to engage in PA, and both they and their care partners believe they are capable of doing so. Caregivers were specifically asked about their beliefs on this matter, and indicated that they believe older adults with cognitive impairment are capable of achieving the same recommended PA levels as cognitively healthy older adults. How PA happens, however, needs to be adapted to accommodate for their differing cognitive abilities. Participants noted that, largely, age is a more important factor than cognition in determining one’s PA level, but that some mental barriers also exist when it comes to engaging in PA. The result of these barriers
is that older adults with MCI or AD need to have more external motivation and supervision to participate in PA.

“I think they [older adults with AD] should be held to the same standards, I mean you've got age requirements, you've got age issues, and... just because they have a lack of capacity issue shouldn’t really impact on the physical. Except it does, because as people move forward, getting increasingly less able mentally, the apathy sets... there's no self-direction. So now I think it's more important than ever that physical activity be kicked in, but the piece of the puzzle that's going to be missing is the person that's going to come in and help them do that.”
(Caregiver, Dyad 8)

“Well she [wife with AD] certainly seems to be able [to do physical activity] with some coaching. Like when we do the strength piece, she can't work through the exercise program herself, so she needs me there to coach her, to say, "Okay, now we're doing sit ups, now we're doing squats, now we're doing push ups"... she wouldn’t remember the routine, and if I wrote it down on a piece of paper, she'd have trouble remembering, "Okay, we're at number 3"... so I suppose if someone's on their own, and doesn't have somebody to help them do that, they would have difficulty with it.”
(Caregiver, Dyad 5)

Certain changes associated with the transition into older adulthood can affect PA levels of older adults with cognitive impairment. Retirement, for example, was recognized as a life event leading to increased PA levels, as more time becomes available for recreation after the suspension of occupational activity. Decreases in levels and intensities of PA, however, were also noted by participants as they age, related to the declining physical function of aging bodies, diagnosis with other health conditions, and accumulation of injuries. Diagnosis with cognitive impairment was noted as a salient turning point in decreasing PA levels for persons with MCI or AD.

“I've been, I either cycle or I go to the gym pretty well every day now... for the last at least the last six months or so, maybe the last year. So I’ve been trying to, because I find obviously that since I’m retired, I have the time to do it now.”
(Participant with MCI, Dyad 3)

“It [physical activity level of husband with MCI] is less... much less. He will not get up, and I, as I said, I don't know whether he thinks he might get lost. If I - I've sent him down - there's a grocery store right at two blocks down, so you can walk there and walk back. So I've sent him to get something, you know, "Go buy some strawberries," and he'll come home, and he'll have strawberries. Can't give him two things to get, because even though he has a list, he'll forget he has a list... and he will do that, or he has done that, but he
hasn't done it lately. So, and I’m almost nervous about sending him now, because he does look around and he won't - we walk down the street, he literally is behind me. He doesn't know which way to turn when we come to an intersection, so yeah... he does less. And I don't know if it's - why. I just don't... it was pretty definite.”

(Caregiver, Dyad 9)

These declining PA levels appear to be due, in part, to the interacting risks and barriers associated with PA at the intersection of activity, aging, and cognition. In discussing risks associated with PA, both participants with cognitive impairment and caregivers noted general age-associated risks that were predominantly related to potential health consequences from overexertion of aging bodies and falling. On the other hand, some participants noted no risks or minimal risks associated with PA, and that these general risks didn’t influence their activity level.

“"If I catch my toe on that [sidewalk], either one but often my left, I can be flat before I know it. And once again [I’ve been getting older - when I was 50 to 60 I could probably have caught myself a little bit better. I still do that, but I suspect not as well.””  

(Participant with MCI, Dyad 4)

“I can't think of any risks unless you have a heart condition, you’re throwing yourself into something rigorous... If you're active every single day, to a certain degree, I don't see any risk.””  

(Caregiver, Dyad 1)

In addition to risks associated with PA for older adults in general, participants with MCI or AD and their care partners noted that they also experienced additional risks related to cognitive impairment. While the amount of risk was more related to the level of an individual’s specific impairments, many of these barriers related to memory, judgment, attention, and balance. The specific risks associated with memory impairment for engaging in PA were noted as being unable to remember how to safely exercise and wayfinding issues for outdoor exercise. Related to impaired judgment, not being careful when exercising leading to injuries was noted as
one risk. Impaired attention was also noted as a risk, potentially leading to falling if individuals were not attending to their environment. Balance impairments as a result of cognitive changes in dementia were mentioned as a falls risk in PA. Ultimately, the culmination of these risks led to the perception that unsupervised exercise was risky for persons with cognitive impairment. Caregivers in particular told of their personal experiences of these risks with their partner.

“I think if there's a risk, if you have an individual who cannot self-direct appropriately and can't read their own physical signs and symptoms. You know, if they've got a congestion that could be weighing on their heart, or if there's something that's making them a little bit more dizzy that day and then they proceed to do [physical activity], thinking everything's fine as everyone with Alzheimer's does, they think everything is just the way it was when it was, then of course there's a risk.”
(Caregiver, Dyad 8)

“She [wife with AD] did go out for a run, about a year and a half ago or two years ago and she got lost... it was interesting because when I've heard about Alzheimer's people getting lost, you don't think they have any idea where they are, but she knew where she was... she didn’t realize it was the wrong way to get home. There was a much shorter route to get home, so she ended up going on a huge route... so, that scared her a little bit. So she'll go out and take the dog for a walk around the neighbourhood on her own now, but she doesn't - she wouldn't run like she used to run on her own.”
(Caregiver, Dyad 5)

Some participants noted though that age-related and cognitive risks they associate with PA can easily be managed by being smart about exercise. Personally, this can be done by being careful, and acknowledging where your own limits of safety are. Other participants noted that they managed risks associated with physical activity by deferring to someone who is knowledgeable about how to safely exercise.

L.B.: Does that risk of maybe overdoing it - does that stop you from exercising sometimes, or that's not really a risk you think that you experience?  
Participant with MCI, Dyad 9: Well, I think... I have a trainer. She comes down - and she's careful about it. You know, she's not asking me to do something stupid. She's very aware of it [risk].
LB: So you think you're at a pretty low risk of hurting yourself?  
Participant with MCI, Dyad 9: Yeah, as long as I do that... and I don't do something stupid.

Not all participants, however, were confident in their ability to manage risks associated with PA. Rather, these risks of being physically active can translate into perceived barriers for PA participation that older adults with MCI or AD must overcome in addition to the age-related
barriers they perceive. Specifically for individuals with cognitive impairment, barriers noted by participants stemmed from various aspects of cognitive impairment. While participants with MCI or AD tended not to make the connection between specific cognitive functions and being able to participate in PA, caregivers noted that apathy, memory, attentional deficits, and inability to self-direct were among the most common barriers their partners experienced.

| “And I'm trying to remember, "Just damn well get up off the chair every half hour, run around a bit, and sit back down again". At least that - but even that's - I get busy at something, I got blinders that go on and I keep doing it. In this case I'll say, "Well, right after I finish this,"... but, the way my head works now, increasingly so, is that if I'm on to something I'll stay on it. If I'm pulled to do something and I do something else, I forget that [first thing]. That's my... the memory loss that I'm experiencing is of that kind - it's the umm "amnesic" [amnestic] variety of MCI that I've got.”
(Participant with MCI, Dyad 4) | “He [participant with MCI] is not a disciplined person in terms of working out what he wants out of life or what he wants to do. He's kind of in the moment.”
(Caregiver, Dyad 4) |
| “Like I would run forever, honestly! And I miss it if you know for some reason if I can’t – well, I can't get out on my own anymore. Even in the neighbourhood... I don’t blame - I had a couple episodes where I got kind of turned around, anyway... so, I have a very small space that I - you know - small area in our neighbourhood that umm... I do go on my own there, but I'm very close to home”
(Participant with AD, Dyad 5) | “I think because the way the circumstances are at home and stuff, she [grandmother with AD] is independent because of that... I feel like the reason why she works out the way she does is only because - she doesn't drive, right? And that's a really important thing. She relies on I guess her daughter as a form of transportation if she needs to get anywhere. So that's the reason why she probably exercises just at home or independently.”
(Caregiver, Dyad 1) |

The need for supervision in order to participate in PA was also noted as a barrier, leading to restrictions of active spaces and independence for older adults with MCI or AD, decreasing the number of opportunities they have to engage in PA.
In social settings, a lack of understanding from friends or fitness professionals about cognitive impairment can create uncomfortable situations deterring older adults with MCI or AD from participating in social PA opportunities. One caregiver in particular recounted multiple instances of how negative experiences their partner with AD had at exercise classes made it unlikely that they will go and seek out these classes in the future.

“I hope she [wife with AD] goes back, I'm not sure she will, but I hope she will. The problem she had was that some of it included some of the exercises where... you had to move your feet a certain way, not a dance routine, but that kind of exercise... and she has difficulty doing that, and so the instructor was coming over to help her, which kind of singled her out. And so she did go to the instructor after and said, "Look, I have Alzheimer's, I have difficulty with that kind of thing, just let me do what I'm doing"... so hopefully the instructor picked that up, and will just kind of let her do what she does.”
(Caregiver, Dyad 5)

Despite these risks and barriers associated with PA for older adults with cognitive impairment, there are still multiple ways in which they are able to engage in PA. For many participants, this involved both exercising independently as well as using local residential, community, and healthcare resources at their disposal. Among the different dyads who participated, there were a variety of patterns of PA behaviours for persons with cognitive impairment. While some were highly independent in their PA, choosing to develop their own programs as a dyad and exercising in their home and neighbourhood, others were well-connected with available programs and services in the community, some of which are offered specifically to persons with dementia. Still others were uncertain of what options were available, but recognized that they did not utilize all potential options or were not able to engage in PA as they know they should.

L.B.: It sounds like you use a lot of community services, and you guys [caregiver, participant with MCI] are really well connected with the hospital, Alzheimer's Society, here... that’s good!
Caregiver, Dyad 9: We've gone to courses at the other hospital so we're - yeah. I think I am quite in-tune with whatever's going on... I think there's a lot of things going on, but I also think I'm missing out on a lot of things, because some people say to me, "Oh, what about this group over here?" and I don't know about them... but then again, I just - we're sort of busy!

Caregivers in particular noted a number of gaps in services offered in the community. Of these gaps, many stemmed from the inability of services to adapt to the needs of individuals, creating difficulty in finding programs that suit an individual’s physical and cognitive abilities.
Based on the experiences of older adults with MCI or AD and their caregivers who were interviewed for this study, it seems that many programs specifically for people with cognitive impairment aren’t appropriate for people who are still very physically fit or only have mild levels of cognitive impairment.

“So probably [we would use it] if the Alzheimer’s Association or Society or something had that kind of [physical activity] programming available... but honestly the people that we’ve seen who are accessing those services are - are quite elderly. I think she [wife with AD] would describe it - she worked in long-term care, so she would say, like, “God they're... It's like going to work, you know? It's like people I used to take care of”... There seems to be quite an age gap.”
(Caregiver, Dyad 5)

“I think I would like to see... something where you can just go and, you know, guys can just be together and do things... for instance, there's a place up north and it's expensive, and it's hard for us to get to. I don't really want to send him [husband with MCI] there, but we did go there for a trial, and they were playing bocce ball when I walked in, and that sort of a mild activity type of thing, but they're also interacting with one another. You know, like something that is available for mild cognitively impaired people, which is not related to... that you don't sit around in a circle and do stuff. You know, just a little bit more unstructured, but still... I think that would appeal to someone like him, who isn't really cognitively impaired, or he... visions himself as not being cognitively impaired.”
(Caregiver, Dyad 9)

Caregivers noted a need for services that adapt to the needs of the individual and can be adjusted as older adults with MCI and AD progressively decline. Services like this do exist in the community, but they tend to be the exception, not the usual experience. In fact, one caregiver voiced ways in which typical one-size-fits-all services are structured and delivered could be changed to improve PA participation of older adults with MCI and AD receiving these services. The notion of a “keeper of the care” role, where one central person helps older adults with cognitive impairment living in the community navigate the healthcare system, was proposed by this caregiver to address identified limitations in current services.

“In my opinion, if we were to put some kind of a thing - some kind of a mechanism, which is the keeper of the care idea, where you have a model that somebody's whole job is to mitigate and arrange and anticipate and send the wheel trans over, and all of that stuff. Rather than a CCAC [Community Care Access Centre] where someone sits in an office and waits for someone to call. You know, it's ridiculous... the max service is 90 minutes! So you try to - like, knowing both of my parents, even before Dad got severely needy, 90 minutes! You know? And the whole idea of trying to keep them in their home, knowing that only for 90 minutes somebody’s actually going to be double checking that they have
things shut off, and... it's kind of scary."
(Caregiver, Dyad 8)

5.6.4 Theme 4: Caregivers as enablers of physical activity

The relationship between care dyads is an influential factor for making PA happen in MCI and AD. The care dyad relationship itself can be a motivator for engaging in PA for older adults with cognitive impairment. Caregivers are the enablers of PA, but the level of effort and responsibility that falls to caregivers in making PA happen is variable between dyads. For some, PA is a team effort, with both parties motivating, encouraging, and supporting each other. For others, substantial effort must be made on the part of caregivers to overcome their partner’s motivational, logistical, and disease-related barriers to engaging in PA. In doing so, caregivers experience their own barriers, such as choosing PA options that are appropriate for their partners or having to quell their frustration at their partner’s reluctance to be active despite their best efforts to facilitate it.

5.6.4.1 Role of caregiver as enabler varies between dyads

Interviewing both older adults with cognitive impairment and their partners allowed for the influence of the dyad relationship on PA to be investigated. In terms of the PA relationship between dyad members, the dispersion of responsibility to make PA happen varied between different dyads. In all dyads, the caregiver member had an equivalent or higher PA level than their partner with cognitive impairment, but the level of motivation required on the part of care partners to make PA happen for persons with MCI or AD varied. For some dyads, responsibility for driving PA largely fell on the caregiver. If they were not there to overcome their partner’s motivational barriers and provide some sense of accountability, PA would not happen for their partner.

L.B.: Does your wife [caregiver] motivate you to go be active? Is she kind of pushing you to go be active?
Participant with AD, Dyad 10: Oh yes, oh yes, yes. Now you've - now you've got it! You've picked the right one, that's for sure. Yes, she is definitely inclined towards *smacking table* “Let's do something!”

“He [husband with AD] thinks he should do something [physical activity], but he doesn't do it. I think I probably have to motivate him... I tell him, "Go and do the treadmill today!". You know? Because I - I go to physio, and I come home, and I say, "I'm too tired, I'm not going walking today."

(Caregiver, Dyad 10)
In dyads where the caregiver is the driving force behind making PA happen, they also help their partner overcome certain logistical barriers to PA related to their cognitive impairment, such as driving them to PA programs, seeking out programs and opportunities to engage in PA, and making plans to ensure PA happens. As well, for dyads where the partner with cognitive impairment was not able or willing to exercise independently, caregivers make PA happen by personally supervising exercise themselves or arranging for support services to do this.

“It [the gym] is a ways - it's 5 or 6 kilometres from our house so... My wife is the driver.”

(Participant with MCI, Dyad 7)

“She [wife with AD] depends on having me available mostly to participate in physical activity. It would be it might be nice - I say "would be" - it might be nice if she could participate in some of that on her own without me, to get a little more independence and a little more self-confidence.”

(Caregiver, Dyad 5)

In other dyads, PA is a partnership between members, and equal effort and responsibility is held by both members to ensure PA happens. In these dyads where PA is a team effort, persons with cognitive impairment and their caregivers support and motivate each other to do PA, often doing so together. These individuals can rely upon each other to ensure PA happens.

“I stay with a program and stick with it, even on rainy black November days... so we [caregiver and wife with AD] are pretty regimented about that. Fortunately, both do it, so we kind of... if one [of us] doesn't feel like going, the other one moves them along, so we're kind of each other’s exercise buddy, I guess.”

(Caregiver, Dyad 5)

Caregivers reported being both satisfied and dissatisfied with their partners’ PA levels. In dyads where caregivers were satisfied with their partners PA levels, there was more of an equal partnership in making PA happen, regardless of whether the partner’s activity level actually met published guidelines. In dyads where the caregiver was dissatisfied with their partner’s activity level, they tended to bare more of the responsibility in ensuring PA happened, regardless of whether the partner’s activity level was actually in accordance with published guidelines.
5.6.4.2 The care relationship as a motivator to be physically active

Interestingly, the care relationship also appeared to be a motivator for both dyad members to engage in PA. For caregivers, PA was noted as a way to help manage and cope with the caregiving role through helping to manage stress and providing structure to help juggle the caregiving role with other responsibilities caregivers hold in their lives. A driving force as to why one caregiver promoted PA for their partner was that they saw it as a way to help make their relationship last longer. Likewise, older adults with MCI or AD noted that part of the reason they participate in PA is because they recognize their care partners are asking them to do so out of love, even though they may have to repeatedly request them to do it. When discussing the benefits and risks associated with PA, one participant with MCI noted that being active and maintaining their physical fitness is a way for them to reduce the burden of the caregiving role felt by their partner.

L.B.: So why do you think your wife [caregiver] tells you to exercise? Participant with MCI, Dyad 9: Because she loves me!

“If I don’t exercise for 2 days, that third day I’m a wreck. I can, you know, bark up at everybody. [I] become depressed because of all the other things going on in my life that are not nice, then I can become very depressed.” (Caregiver, Dyad 9)

“And in terms of my wife [caregiver]... she’s gone through a lot with me, and she’s probably mentioned that, but she’s been very supportive... And hopefully, you know, I can relieve a lot of her stress.” (Participant with MCI, Dyad 3)

“He’s [husband with MCI] caring and he’s - he’s loyal, and he’s so... I have invested my life in this community with him, and I just hope that he can last a little bit longer.” (Caregiver, Dyad 7)

5.6.4.3 Caregiver challenges in making physical activity happen

Although caregivers are the drivers in making PA happen for their partners, they experience their own barriers in doing so. One caregiver noted having a hard time determining what activities their partner likes because of their reluctance to initiate new activities. For others, the need to constantly remind and push their partners to be physically active was noted as frustrating. As much as caregivers had to sometimes “harangue”, in the words of one caregiver,
their partners into being physically active, they were mindful that they still needed to be patient and encouraging with their partners.

“We did an exercise class for people with dementia and he [husband with MCI] did not like it. But on the other hand, while we were there, he enjoyed it. So I have a hard time figuring out what his real opinion is. Because, you know, he'll say, "Oh I didn't like that", but in the middle of doing it, he's fine, and he's happy. So, you know, I don't know what to do really.”
(Caregiver, Dyad 9)

L.B.: Do you think that your wife [participant with MCI] wants to be more physically active than she is right now?
Caregiver, Dyad 6: In theory... you can lead a horse to water, but you can't make them drink.

5.7 Summary

The participants included in this study represent a diversity of ages, levels of cognitive function, PA levels, apathy levels, and dyad relationships. Qualitative thematic analysis of interviews with participants yielded several key themes pertinent to addressing the research question, “What are the perceptions, beliefs, and experiences, of community-dwelling older adults with MCI or AD and their caregivers concerning PA as a health behaviour?”

In terms of PA perceptions, older adults with cognitive impairment and their caregivers conceptualize PA as both broadly defined and unique to individuals. PA does not just refer to structured activities to maintain one’s health, but rather various activities in one’s daily life that can have much deeper personal meanings. Older adults with MCI or AD and their caregivers do not conceptualize age-specific recommendations about PA levels in terms of a “dose” with a minimum frequency, intensity, type, and duration, but rather as something that individuals should do on a daily basis at a level that suits their abilities and resources. The ability of PA to support engagement in meaningful activities as well as provide positive embodied experiences are reasons why older adults with cognitive impairment participate in PA.

Older adults with MCI and AD believe that there are specific cognitive benefits of PA, but these do not motivate them to participate in PA, as older adults with cognitive impairment cannot perceive these benefits for themselves. Thus, benefits that they both believe in and have personally experienced, particularly how PA makes one “feel” in the moment, are far more salient motivating factors. All participants believed that PA can and should be done regardless of
one’s age or cognitive abilities, but that cognitive impairments occurring in MCI and AD require adaptations to be made in how PA is performed by individuals. In particular, impairments in physical function associated with aging and impairments in memory, executive function, and motivation associated with MCI and AD pose barriers that need to be overcome to make PA happen.

Despite these barriers, however, it is evident from the experiences of older adults with cognitive impairment and their caregivers that activity is possible despite dementia. Instances of encountering barriers in PA participation were shared by both participants with cognitive impairment and their caregivers, as well as strategies and facilitators they use to circumvent these barriers. In large part, the caregivers and the care dyad relationship is an enabling factor for making PA happen. Caregivers bridge the gap between intention and activity to varying extents for their partners with cognitive impairment, and the importance of this relationship is recognized by both dyad members.

These findings should be interpreted with consideration of the context they were collected in and the existing body of literature in which they are situated. A critical discussion of the strengths and limitations of these findings and how they relate to the existing literature on PA participation at the intersection of aging and cognition is provided in the following chapter, along with a discussion of what these findings mean for the use of PA as a strategy to prevent and manage cognitive impairment in the older adult population.
Chapter 6

6 Discussion

6.1 Preface

The previous chapter detailed the findings of a qualitative study investigating the perceptions, beliefs, and experiences of older adults with MCI or AD and their caregivers concerning PA participation. This chapter provides a critical appraisal of the strengths and limitations of this study and its findings, with a discussion of what these findings mean in the context of the existing literature on PA participation of older adults with cognitive impairment. Ways in which findings from this research may be implemented at the levels of individuals, care networks, communities, and public policy to use PA as a strategy to prevent and manage cognitive impairment in older adult populations are outlined at the end of this chapter.

6.2 Comparison to Existing Literature on Physical Activity Participation of Older Adults with Cognitive Impairment

In relation to the existing literature on PA participation of older adults with cognitive impairment, this study yields both confirmatory and novel findings. All prior studies on PA participation in community-dwelling older adults with cognitive impairment have only involved individuals with mild to moderate dementia, typically AD. Thus, this study is novel in that it includes the perspectives of older adults with more mild impairment in the form of MCI. A key finding yielded by including participants with MCI is that, despite the label of “mild” cognitive impairments, the ability of older adults with MCI to engage in PA is still affected, and the role of caregivers in enabling PA at this early stage of cognitive impairment is still very important. According to responses from participants in this study, available PA options in the community do not cater to these older adults who are only mildly impaired but still physically fit. Earlier detection of cognitive impairment and predementia diagnoses are important for taking preventive action against cognitive decline and progression to dementia. In order to do so, however, there must be appropriate options in the community to support older adults with MCI and their care partners in being proactive with
their health. Findings from this research highlight a gap that exists in the community regarding health promotion for older adults with MCI.

This study is also novel in that it was informed by a framework for health behaviour change, whereas prior studies on PA in dementia are not (26) (344) (346) (347) (348) (350) (351) (358). The TDF (24) was selected as a sensitizing framework for analysis in this study as it does not assume causal relationships between factors influencing behaviors as other theories do (see Chapter 2.8). Further, other established theories of behaviour change rely on specific cognitive capacities to be intact to explain the occurrence of behaviours, such as outcome evaluation, perceived behavioural control, and awareness of one’s physical abilities. These capacities can be impaired in MCI or AD, limiting the relevance of these theories for studying health behaviours in older adults with cognitive impairment. In particular, older adults with MCI and AD mentioned in this study that they have difficulty perceiving their own cognitive abilities and changes in these consequent to PA participation. This limits the applicability of theories of behaviour change relying on this capacity, such as the Social Cognitive Theory (361) and the Health Belief Model (387), for studying PA as a behaviour to promote healthy cognitive aging in older adults already experiencing cognitive impairment. Caregivers also note impairments in their partners’ abilities to self-direct, limiting the applicability of theories of behaviour change relying upon self-regulation and executive function, such as the Self-Determination Theory (368), Theory of Planned Behavior (374), and the Transtheoretical Model of Behaviour Change (380). Thus, the TDF was an appropriate approach to use in this study exploring PA in persons with cognitive impairment, as it did not presuppose the importance of specific elements that may play a role in behaviour change. By incorporating domains from the TDF, the findings of this study are uniquely positioned to support the development of interventions to promote PA participation in this population. Table 8 contextualizes key findings from this study to domains specified in the TDF. The implications of these findings are discussed in Chapter 6.7, and potential future research directions based on these findings are discussed in Chapter 7.

Table 8

Comparison of Study Findings to Items in the Theoretical Domains Framework
<table>
<thead>
<tr>
<th>Domain</th>
<th>Description</th>
<th>Relevant Study Findings</th>
</tr>
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<tbody>
<tr>
<td>1. Knowledge</td>
<td>An awareness of the existence of something</td>
<td>Older adults with MCI or AD are aware of the benefits and risks of PA, but are not aware of the evidence-based recommendations on PA as a health behaviour for older adults.</td>
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<tr>
<td>2. Skills</td>
<td>An ability or proficiency acquired through practice</td>
<td>Physically, older adults with MCI or AD are capable of completing PA. Cognitively, however, they experience some difficulties in completing PA.</td>
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<tr>
<td>3. Social/Professional Role and Identity</td>
<td>A coherent set of behaviours and displayed personal qualities of an individual in a social or work setting</td>
<td>Older adults with MCI or AD incorporate PA as part of their identity, which is influenced by their previous experiences with PA, both personally and professionally. The caregiver identity is associated with increased responsibility to ensure that PA happens. Socially, being an older adult with MCI or AD can create challenges for engaging in social PA due to lack of awareness or understanding of cognitive symptoms from fitness professionals or exercise partners.</td>
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<tr>
<td>4. Beliefs about Capabilities</td>
<td>Acceptance of the truth, reality, or validity about an ability, talent, or facility that a person can put to constructive use</td>
<td>Older adults with MCI or AD, as well as caregivers, believe that older adults with cognitive impairment can achieve PA participation to recommended levels for their age group.</td>
</tr>
</tbody>
</table>
| **5. Optimism** | **6. Beliefs about Consequences** | **Older adults think that participating in PA will lead to the associated benefits, but that there is also the opportunity to experience negative effects from risks associated with PA.**  
Older adults with MCI or AD believe that PA is beneficial, for both health-related and non-health-related reasons.  
Older adults with MCI or AD have difficulty believing in the cognitive benefits of PA unless they can personally experience or perceive them.  
Older adults with MCI or AD believe that PA is a way to add meaningful activities to their daily lives. |
|---|---|---|
| **7. Reinforcement** | **Increasing the probability of a response by arranging a dependent relationship, or contingency, between the response and a given stimulus** | **Both intrinsic and extrinsic motivating factors drive PA behaviour. Intrinsically, perceiving or experiencing the benefits of PA (i.e. health, embodied experiences, physical, meaningful activity) can motivate and reinforce PA participation. Externally, factors that reinforce PA can be aesthetically pleasing outdoor environments as well as socially engaging PA.**  
Reinforcement by caregivers enables PA.  
Negative experiences with PA or cognitive symptoms can negatively reinforce PA (i.e. prior injury, embarrassing experiences, limitations to outdoor PA as a result of getting lost). |
| **8. Intentions** | **9. Goals** | **Older adults with MCI or AD have a desire to be active, either by increasing or maintaining their current PA levels.** |
| **A conscious decision to perform a behaviour or a resolve to act in a certain way**  
**Mental representations of outcomes or end states that an individual wants to achieve** | **The confidence that things will happen for the best or that desired goals will be attained**  
**Acceptance of the truth, reality, or validity about outcomes of a behaviour in a given situation** | **Older adults with MCI or AD believe that participating in PA will lead to the associated benefits, but that there is also the opportunity to experience negative effects from risks associated with PA.**  
Older adults with MCI or AD believe that PA is beneficial, for both health-related and non-health-related reasons.  
Older adults with MCI or AD have difficulty believing in the cognitive benefits of PA unless they can personally experience or perceive them.  
Older adults with MCI or AD believe that PA is a way to add meaningful activities to their daily lives. |
| 10. Memory, Attention, and Decision Processes | The ability to retain information, focus selectively on aspects of the environment and choose between two or more alternatives | Impairments in memory, attention, and executive function impair ability of older adults with MCI or AD to participate in PA independently. Guidance and facilitation by caregivers and other healthcare or exercise professionals can overcome this barrier. |
| 11. Environmental Context and Resources | Any circumstance of a person's situation or environment that discourages or encourages the development of skills and abilities, independence, social competence, and adaptive behaviour | PA behaviour is a result of the unique barriers, facilitators, and resources that individuals encounter. Enabling PA participation depends on addressing these factors for each individual. Older adults with MCI or AD experience a number of age-related and cognition-related barriers to PA participation. Facilitators to PA for older adults with MCI or AD include environmental factors as well as caregiver support. A lack of understanding or awareness of cognitive impairment in social settings can create embarrassing or distressing experiences for older adults with MCI or AD. Access and awareness of available PA resources promotes participation, especially for outdoor PA options. |
| 12. Social Influences | Those interpersonal processes that can cause individuals to change their thoughts, feelings, or behaviours | Being a member of an active family, having an active partner, or being surrounded by examples of active aging, can positively influence older adults with MCI or AD to be more active. Social support provided by active friends and family (especially caregivers) is also important to promoting PA participation of older adults with MCI or AD. Some older adults with cognitive impairment are still highly physically fit. The available programs in the community do not always cater to this group of cognitively impaired but physically capable individuals. Participation of these individuals in PA classes for people who are not cognitively impaired, however, can create feelings of embarrassment if they are singled out for not being able to perform certain movements as directed. |
| 13. Emotions | A complex reaction pattern, involving experiential, behavioural, and physiological elements, by which the individual attempts to deal with a personally significant matter or event | PA is a strategy for older adults with MCI or AD to regulate their emotions, and manage negative moods and stress. |
| 14. Behavioural Regulation | Anything aimed at managing or changing objectively observed or measured actions | Older adults with MCI or AD experience substantial difficulty in regulating their own behaviours for planning and executing PA participation. This largely falls to caregivers. Self-monitoring can aid older adults with MCI or AD in maintaining PA habits by providing an external way to track their progress and achievements. This overcomes memory impairments and lack of insight into their own abilities that limits their ability to do so internally. Making PA a habit by building it into part of one’s routine helps to make PA happen for older adults with MCI or AD. |
The findings of this thesis concerning PA participation of older adults with MCI or AD in relation to previous research conducted in older adults with dementia are summarized below and organized as they pertain to themes identified in this research.

**Theme 1: Physical activity as a meaningful activity**

Only one prior study has examined how older adults with dementia and their caregivers define PA (358), with participants indicating that daily activities could be considered as “exercise”. This study, however, does not distinguish exercise from PA. Despite this lack of distinction, this definition of PA coincides with what participants in the present study defined as PA, including both structured and unstructured activities. Regarding recommended PA levels for older adults with dementia, this prior study by Karuncharernpanit et al. (358) found that older adults with dementia and their caregivers viewed walking in addition to daily activities as the ideal PA, with no recognition of the importance of muscle strengthening activities (358). Walking was widely regarded in the present study as a “staple” PA that almost anyone could do, and several, but not all, participants identified the importance of muscle strengthening activities. Participants in the study by Karuncharernpanit et al. (358) did not indicate that balance training as a recommended PA for older adults with dementia, while numerous participants in the present study did and actively participated in balance and falls prevention classes. A potential reason for this difference is that the study by Karuncharernpanit et al. (358) is specific to the Thai context, and public health messaging and promotion of recommended PA guidelines in Thailand is likely different than the Canadian context.

The Canadian Physical Activity Guidelines for Older Adults recommend accumulating at least 150 weekly minutes of weekly MVPA, which is at odds with the concept of PA voiced by participants. Despite the question being posed in interviews as a weekly recommendation, participants framed recommendations on a daily instead of weekly basis, proposing at least 20 minutes of PA per day up to 1 hour. While the Canadian Physical Activity Guidelines for Older Adults don’t indicate a specific frequency of PA, older adults with MCI or AD and their caregivers noted that PA should be a daily occurrence and utilized throughout the day to break up sedentary behaviour.

Participants’ recommendations of moderate intensity are comparable to recommendations from the Canadian Physical Activity Guidelines, but the Canadian Physical Activity Guidelines
themselves don’t define “moderate to vigorous” (21). A publicly available information sheet published by the Canadian Society for Exercise Physiology outlining these recommendations (Appendix 1) describes “moderate” as activities that cause one to “sweat a little” or “breathe harder”, and “vigorous” activities as those causing older adults to “sweat” and be “out of breath”. These descriptions are aligned with how older adults with cognitive impairment and their caregivers conceptualize PA intensity. Recommended types of PA according to participants largely align with what is recommended by the Canadian Physical Activity Guidelines, with a few exceptions. Aerobic and resistance types of activities are recommended, as well as balance training exercise if falls are a concern. These types of activities were also indicated as “recommended” for older adults by participants. PA to improve flexibility was also mentioned as a recommendation, however, this is not included in the Canadian Physical Activity Guidelines for Older Adults as insufficient evidence has been found to support its health benefits for older adults. Thus, how older adults with MCI and AD and their care partners conceptualize PA and perceive its use as a health behaviour is highly personalized and does not necessarily conform with Canadian Physical Activity Guidelines for Older Adults.

Previous research investigating perceptions about PA held by older adults with cognitive impairment and their caregivers also indicates that PA is viewed as a meaningful activity (344) (345) (347). According to this research, the most meaningful activities for older adults with cognitive impairment are those that are enjoyable, provide a sense of connection and belonging, and foster a sense of independence. The research detailed in this thesis confirms these findings about PA being a meaningful activity for older adults with cognitive impairment. Relative to other motivating factors for engaging in PA, the perception of PA as a meaningful activity seems to hold particular significance for older adults with cognitive impairment above and beyond motivators outlined in PA guidelines, especially since they can have difficulty perceiving disease-specific benefits of PA. Thus, the findings of this study help to contextualize similar findings about the perception of PA as a meaningful activity for older adults with cognitive impairment to health promotion, and provide a stepping stone for using this knowledge in health promotion initiatives.

One study of older adults with AD and spousal caregivers found that the “self” was an important theme to PA participation, and engaging in past activities that one has enjoyed throughout life is a facilitator for sustained activity in dementia (26). How individuals with
dementia perceive PA throughout their lifespan has also been found in previously published research to influence how they perceive PA after diagnosis with dementia (347). The present study has yielded similar findings, in that the ability to engage in meaningful activities one has done throughout the lifespan help to maintain PA levels of older adults with MCI or AD.

Prior research indicates that knowledge of PA guidelines is a facilitator to PA participation for older adults with cognitive impairment (347), but responses of participants in this study call this finding into question. Virtually none of the participants in this study were aware of PA guidelines, yet a wide range of PA levels were reported by participants. Research on awareness of PA guidelines in non-impaired populations has also shown awareness to be low (see Chapter 2.6.1). Clearly, further research is needed to better understand the utility of PA guidelines for health promotion and ways to improve their impact on changing health behaviours in older adults with cognitive impairment.

Thus, prior research supports what this study has found concerning the value of meaningful activities that reflect the preferences and personhood of older adults with cognitive impairment. The present study differs from existing qualitative literature on PA in dementia, but coincides with quantitative studies, concerning the influence of PA guidelines on PA participation in this population.

*Theme 2: Feeling is more important than thinking*

PA is regarded by older adults with cognitive impairment and caregivers in both this research and prior studies as beneficial for maintaining physical and functional capacity in older adults with cognitive impairment (346) (348) (358). Regarding the cognitive benefits of PA, this study also confirms what has been found in prior studies. One study investigating reasons of persons with AD and caregivers for commencing an exercise program found that they viewed it as a way to take action in reducing AD symptoms (351), which aligns with recognition by participants in this study of the purported benefits of PA on cognition in MCI and AD. The inability of older adults with cognitive impairment to perceive PA-related improvements in their cognitive function was also noted in a prior study investigating the perceptions of participants with cognitive impairment who had completed a 6-month aerobic exercise intervention (348). In both this prior study and the study detailed in this thesis, the participants noted the lack of a “control” to compare to as a barrier to perceiving these benefits. Despite the inability to perceive
these benefits, both studies indicate that older adults with cognitive impairment still enjoy PA because of its physical, social, and psychological benefits.

Previous research has noted that older adults with AD perceive PA as something that can lead to improved mood (348) (358), which participants in this study also identified as an important benefit that motivated them to participate in PA. PA has been noted in one study of older adults with AD to improve one’s sense of wellbeing and cause one to “feel better” (350), which was also a key motivator for PA participation noted by participants in the present study. Conversely, participants in a separate study noted that being physically inactive for too long can cause one to feel physically uncomfortable and that they needed to stay active to prevent this negative embodied experience (347), which was also mentioned by participants in the present study as a motivator to being active.

The emphasis on embodied and emotive aspects of PA as motivators and benefits of PA participation is poorly elaborated in prior research, with more of an emphasis on health-related benefits and motivators. This emphasis on the emotive and affective experience of PA in the present study provides a previously unelaborated facet to explore in promoting PA for older adults with cognitive impairment. Future research should seek to elaborate understanding about the relationship between positive embodied experiences and PA participation, as this may be a viable adjunct or alternative to health-centered messaging on PA.

As noted in Chapter 2.7, environmental factors are largely viewed in the literature on PA participation of older adults as a barrier, but both the present study and prior research on PA participation of older adults with cognitive impairment suggest that environmental factors can be salient motivators to PA. One qualitative case study of two men with dementia and their wives indicated that participation in outdoor activities was valued, and that being in nature was a motivator for engaging in PA (347). Other studies on PA perceptions of older adults with dementia found a similar predilection for outdoor activity (350) (347). In the present study, particular emphasis was placed on the importance of outdoor activity in terms of its positive affective and embodied effects. Being within walking distance of desirable destinations or urban green spaces was a facilitator to PA participation in this study as well. Future research focusing on the environmental factors influencing PA participation of older adults with cognitive
impairment is needed to confirm and elaborate these findings, but this initial research speaks to presently underutilized strategy to get older adults to engage in more PA by getting them outside.

In the present study, the health-related benefits of PA were noted by older adults with cognitive impairment and their caregivers alike, which is at odds with the findings of a previous study that indicated caregivers were more likely than their partners to agree with beliefs about PA for general health promotion (23). While the present study did not aim to determine the statistically significant differences between perceptions and beliefs held by older adults with cognitive impairment compared to their caregivers, it is possible that findings from this study can help to explain this difference found in previous research. In this study, older adults with cognitive impairment placed substantial emphasis on the non-health related benefits of PA, such as adding meaning to one’s daily life or improving one’s mood. Thus, the difference found in prior research on the differences in beliefs of caregivers and care recipients on the health benefits of PA may reflect the greater emphasis of care recipients on the non-health related benefits of PA. More research comparing the beliefs and importance of various benefits of PA for older adults with cognitive impairment and their caregivers would help to reconcile this difference, and provide insight into how PA should be promoted for this group.

Thus, in regard to prior qualitative literature on motivators for engaging in PA, this study confirms findings that access to outdoor PA options is important for promoting PA in older adults with cognitive impairment. Findings from the present study go beyond this, however, to elaborate the importance of positive embodied and emotional aspects for facilitating PA. Given that older adults with cognitive impairment largely recognize, but don’t personally believe in, the cognitive benefits of PA, tapping into other perceived benefits may provide a new avenue to promote PA. However, seasonal variations in weather and climate need to be considered when planning PA outdoors, and other appropriate and desirable indoor options made available.

Theme 3: Participation is possible despite dementia

As indicated in both the present study and prior research, older adults with cognitive impairment have a desire to be active despite the various limitations and barriers they face (347). Barriers to PA indicated in previous research align with findings from the present study in some respects, but deviate in others. In particular, activity restrictions resulting from restrictions in unsupervised outdoor activity and the inability to drive were found in prior research and
confirmed by this study (26) (346) (347). Barriers to PA specific to cognitive symptoms of AD, such as impaired memory, wayfinding difficulties, apathy, and impaired gait and balance have been noted in previous research, and also found in this study (325) (346) (349) (350) (351).

Advice and support from healthcare professionals in one qualitative study examining adherence to a home-based exercise program was viewed by participants with AD and caregivers as a factor influencing commencement and adherence to PA (351). In this study, a number of participants noted guidance from healthcare professionals as important to promoting PA, but also experienced encounters with healthcare and exercise professionals had negatively impacted their PA participation. Thus, the present study confirms the influential power healthcare and exercise professionals have in promoting PA, and the importance of ensuring positive experiences with them for supporting PA.

Participants in the present study noted that an important facilitator to PA participation was having a way to objectively track one’s progress, which has also been found by prior research investigating factors influencing adherence of adults with AD to a home-based exercise program (351). Based on these findings, providing tools to support self-management or feedback and audit systems for older adults with cognitive impairment may help to enhance the maintenance of PA participation.

Prior research has noted that older adults with AD and their caregivers perceive PA as a socially rewarding activity, which can be a motivator for engaging in PA (348) (350) (351). Some participants in the present study echoed this sentiment, noting that being able to do activities with others, particularly family members or people who understand cognitive symptoms associated with MCI and AD, are social aspects that facilitate PA. However, some participants in the present study also noted that doing PA by oneself was preferable, which two previously published studies have also found (348) (344). Participants in the present study as well as in prior studies including care dyads indicate that understanding on the part of others about the effects of dementia is an essential component of social PA options. A lack of understanding from others can create uncomfortable social situations for older adults with cognitive impairment (26), and just one negative experience can be enough to turn them off of a potential PA opportunity. The ability to adapt PA to one’s social preferences and having the
appropriate options available is thus an important takeaway from the present study and previously published findings.

Synthesizing findings of the present study with those from previously published research highlights the interaction of numerous contextual factors on influencing PA participation of older adults with cognitive impairment. Despite the various barriers they encounter, cognitive and otherwise, older adults with MCI and AD have a desire to be active. To accommodate the diversity of factors that must be negotiated in making PA participation happen, PA options that can adapt to individuals’ specific resources, needs, preferences, and abilities need to be available, as there is no one-size-fits-all solution to promoting PA.

Theme 4: Caregivers as enablers of physical activity

Only a subset of research on PA in the context of dementia has included the perspectives of both caregivers and individuals with cognitive impairment (26) (346) (348) (351) (358). The present study adds to this small body of literature by exploring the perceptions, experiences, and beliefs of both members within care dyads concerning PA.

In the present study, caregivers in all dyads had an important role to play in ensuring that PA happened for their partners. Of the previously published literature on PA participation of older adults with cognitive impairment, one study reporting the findings of a qualitative case study of two men with dementia and their spouses has highlighted this role (346). In this study, caregivers were noted as important for initiating activities for their spouses. Findings from another study also suggest caregivers can experience difficulty getting their partners with cognitive impairment to engage in activity and difficulty coordinating PA opportunities (348). Yet another qualitative study investigating factors influencing participation in a 6 month home exercise program found that caregiver support was critical for participants who could not independently complete the exercises (351). These findings align with what caregivers in the present study noted, in that they play an important role in helping their partners overcome motivational barriers to engaging in PA, but experience challenges doing so. A specific challenge faced by caregivers echoed in the findings of this thesis is the difficulty they face in finding appropriate or meaningful activities for their partners with MCI or AD. One caregiver of a participant with MCI in the present study spoke to this challenge when discussing the lack of services available that meet the needs and preferences of their partner. Prior research has also
found that when caregivers experience activity limitations, such as declines in their own health, the result is an activity limitation for their partner (351). This contingency of PA participation for older adults with cognitive impairment upon the abilities of their partner was also noted in this study, with one caregiver voicing how their risk of injury from engaging in PA with their partner caused a limitation in the PA participation of the partner with cognitive impairment.

A prior qualitative case study (346) on PA in dementia also highlighted the use of certain strategies by caregivers to enable PA, such as building PA into a daily routine, or using communication devices to overcome wayfinding issues to allow partners with dementia to independently engage in PA outside the home. The use of these and other specific strategies by participants in the present study was variable. While multiple dyads noted the importance of building PA into one’s daily routine, only one caregiver specifically spoke of using communication devices to allow their partner to exercise independently. This was ultimately not an appropriate strategy for them, as the partner with cognitive impairment either forgot how to use the device or forgot they had the device with them.

A few previous studies have also touched upon the care relationship as a motivator for engaging in PA. In the present study as well, maintaining one’s health through PA to reduce the burden felt by caregivers was mentioned as a motivator for older adults with cognitive impairment to participate in PA (351). Interestingly, caregivers in the present study did not indicate that their partner’s PA reduced their stress, but prior research has indicated this (348) (358). A potential reason for this disparity is that the present study did not explore a “before and after” comparison in perceptions following a PA intervention, and thus caregivers might not have been sensitized to recognize changes in their perceived burden or stress levels related to their partner’s PA.

Thus, the findings of the present study confirm what prior research has found regarding the role of caregivers in promoting PA for older adults with cognitive impairment, but suggest further research is needed to understand the role of the care relationship in this context. This study and previous findings both indicate caregivers take an active role in enabling PA for their partners, but experience challenges in doing so. While both the present study and previous research identify specific strategies used by caregivers to overcome disease-related barriers to enabling PA, the present study indicates that the appropriateness of strategies varies for different
dyads depending on their resources and the specific cognitive and physical abilities of individuals with cognitive impairment. Not only is the caregiving relationship a conduit to enabling PA participation, but it is also a motivating factor for older adults with cognitive impairment to participate in PA out of love and concern for their caregivers. Research specifically exploring the experiences of caregivers in promoting PA for their partners should build upon these findings to improve scientific understanding of the role of caregivers in promoting PA for older adults with cognitive impairment and provide more specific recommendations on how caregivers can be supported in enabling PA for their partners.

6.3 Comparison of Caregiver and Care Recipient Responses

The results of this study introduced 4 major themes on the phenomenon of PA participation of older adults with MCI or AD. As an overall trend, responses provided by caregivers in this study were more complex and well-developed than those provided by individuals with MCI or AD, which was expected. The responses provided by participants with AD, in particular, tended to be more “thin”, with fewer descriptive answers and voluntary details, and more tangential than those provided by participants with MCI and cognitively healthy caregivers. As a result, responses from caregivers and persons with MCI lent themselves better to be used as illustrative quotes in reporting the results of thematic analysis. Despite this, conscious efforts were made to include supporting quotes in discussing the results of thematic analysis from participants with all levels of cognitive functioning interviewed for this study.

In the responses concerning how participants define and conceptualize PA, the content of responses provided by older adults with MCI or AD and their care partners were largely similar. Caregivers tended to provide more well-developed definitions of PA and more immediately identified exemplar activities without the need for specific prompting by the interviewer compared to participants with MCI and AD. The types of activities identified by participants as meaningful were unique to individuals, and thus differences between activities identified by participants with cognitive impairment and their caregivers likely do not reflect differences in how these individuals determine what is “meaningful” due to their different dyad roles.

Responses to questions concerning the influence of cognitive impairment on PA had the greatest disparity between participants with MCI or AD and caregivers. While caregivers were
able to provide elaborate responses on how they thought their partner’s cognitive impairment influenced their partners’ PA levels, participants with cognitive impairment tended to disagree that there was any influence. When they did indicate they perceived an influence of their cognitive functioning on their behaviours, it was usually a poorly elaborated answer or did not truly relate to PA participation, but more to general life situations like forgetting names in social settings. It is unlikely that the observations of participants with cognitive impairment are factually accurate in this instance, as caregivers provided specific, detailed examples of how cognitive impairments have influenced their partners’ PA levels, and the situations described in these examples were confirmed when brought up with during interviews with participants who have AD and MCI. In this instance, the responses provided by caregivers were taken to be the more accurate account than responses by participants with MCI and AD. Thus, there are two likely reasons why this disparity is seen in the data. It is possible that due to their impairments, participants with AD or MCI who participated in the interviews did not have sufficient insight into their own cognitive abilities to appreciate how they affected their PA participation. Alternately, it’s possible that older adults with MCI or AD did not wish to acknowledge or confront the idea that they were unable to do something like PA because of their cognitive impairment, or did not feel comfortable discussing this limitation during the interviews. Regardless of the reason why, the inclusion of both dyad members in this instance has yielded an important insight into how older adults with cognitive impairment view the impact of their cognitive symptoms on their participation in PA.

In terms of the fourth theme of caregivers being the enablers of PA, both participants with cognitive impairment and their caregivers recognized the existence of this dynamic within the dyad relationship. Dyads in which both participants with cognitive impairment and their caregivers viewed PA participation as a partnership recognized the mutual involvement of each member in promoting PA. Some participants went so far as to use the pronoun “we” when discussing their PA behaviors, emphasizing just how engrained this partnership is into their concepts of their PA participation.

6.4 Physical Activity Levels of Participants

Participants with a range of PA levels participated in this study, allowing for an exploration of perspectives, experiences, and beliefs of dyads who are both successful and
struggling with PA participation. For the sake of comparison to established guidelines, individuals considered to have a “high” PA level were those whose self-reported weekly PA levels met or exceeded recommendations provided by the Canadian Physical Activity Guidelines. While labelled as “high” relative to others included in this study, it should be noted that this category represents those individuals doing at least the minimum recommended to maintain their health. In terms of distinguishing between “moderate” and “low” PA levels, this distinction is based on a plateau seen in the data between 100-150 minutes per week of MVPA, not on published trends in PA levels for older adults. While the existence of this clustering of PA levels below, but not quite meeting, recommended PA levels is intriguing, identification of statistically significant trends in PA levels was not the aim of this study. Future research should investigate the existence of this “moderate” PA level further to determine whether this is a meaningful distinction that can be used to categorize older adults, and whether this distinction relates to psychological factors influencing PA level, like self-efficacy or specific health beliefs about PA.

The proportion of participants achieving recommended PA levels in this study is not statistically comparable to those determined in other studies with sufficiently powered samples or nationally representative samples (e.g. Canadian census data (315), Canadian Health Measures Survey (317)). The number of caregivers meeting or exceeding the recommended weekly levels of PA was also very high in this study, which may have biased their responses towards more positive experiences, beliefs, and perceptions of PA. In order to understand how PA levels of caregivers for persons with dementia and older adults with dementia compare to other non-caregiver and dementia-free groups, more data on PA behaviours of caregivers and older adults with cognitive impairment needs to be collected. Collection of this data as a part of routine practice in specialized dementia clinics would be one possible strategy to accomplish this. Accumulation of a large body of data on PA levels of caregivers and older adults with cognitive impairment in these settings would provide insight into how PA levels change in the context of dementia and dementia care provision. Participants also did not all complete the questionnaires at the same time, and seasonal variations in weather may have affected the levels and types of activities reported on their questionnaires.

In this study, more caregivers reported achieving “high” levels of PA than did participants with MCI or AD, and more participants with MCI or AD reported “low” PA levels
than caregivers. Based on the responses of participants during interviews in this study, this may be due to numerous additional activity restrictions faced by older adults with MCI and AD, such as driving restrictions, need for supervision to do exercise, difficulty remembering to do daily exercise or executing exercise routines, and NPS like apathy. While this study has made progress in exploring what barriers older adults with MCI or AD face when trying to participate in PA, it is beyond the scope of the study to determine the impact of specific perceived barriers on overall PA level. Future research should seek to determine the relative influence of these barriers on PA levels of older adults with MCI or AD. Doing so would provide direction in setting priorities for community services and programs seeking to increase PA participation of this group.

It is also possible that the higher PA levels of caregiver participants is an artefact of the assessment used to determine PA levels. While validated for older adults, the validity and reliability of the PASE has not been determined for older adults with cognitive impairment. It is possible that the wording, sequence, and target responses of the PASE are not as well understood by older adults with MCI or AD as they are by cognitively healthy adults. Research seeking to determine the measurement properties of the PASE for cognitively impaired older adults should be conducted by comparison to objective measures and observational study of daily PA patterns. Additionally, development of a new instrument specific to assessing PA levels of persons with cognitive impairment may be warranted. Given the importance of PA to healthy physical and cognitive aging, a concise, accurate, reliable tool to assess PA behaviours in this population is needed to support research on this topic as well as to measure PA in clinical and community settings to support exercise prescription and counselling.

In no instances did dyad members with cognitive impairment fall into a higher PA level category than their caregivers. This observation, while anecdotal, combined with information provided by dyad members in interviews about the importance of caregivers as enablers of PA for their partners highlights the influence of caregiver behaviours on those of older adults with MCI or AD. Prior research in the Canadian context supports the observation that caregivers tend to have higher PA levels than individuals with cognitive impairment, but opposes the idea that caregivers’ PA levels are related to those of their care recipients (23). This prior study is one of few examining PA attitudes and behaviours within dyads, and found that the relationship between PA levels of caregivers and their care recipients with MCI or AD is not statistically significant (23). Rather, this prior study found that caregiver beliefs about the importance of
vigorous exercise for maintaining health was related to PA levels of their care partner with cognitive impairment (23). The attitudes of persons with cognitive impairment toward exercise investigated in this prior study were not significantly associated with the PA levels of their caregivers. As this is the only study that has investigated this topic, and findings of this thesis research do not align with this, more research on PA in the context of the care relationship for older adults with MCI or AD is needed. If care recipient PA behaviours are in part influenced by the behaviours and attitudes of caregivers, then one strategy to increase PA participation of persons with MCI or AD living in the community may be through targeting caregivers with programs, services, and educational interventions to alter caregiver PA behaviours and attitudes, and the PA levels of their care recipients with AD or MCI by proxy.

6.5 Apathy and Caregiver Distress

In this study, an assessment of apathy was included to ensure that perspectives of cognitively impaired older adults with a range of motivational drives were included. Apathy has been defined in many ways in the psychiatric literature (450), but in the context of this study refers to disordered interest or motivation manifesting as a lack of emotion, initiation, and enthusiasm (435). Apathy is one of the most prominent behavioural symptoms in AD and MCI, with one study of patients at a memory clinic finding apathy present in 64.6% of mild AD patients and 50.5% of MCI patients relative to 6% of healthy controls (451). A population-based study found apathy was present in 27% of participants with MCI (46), suggesting that prevalence of MCI may be higher in clinical populations. Similarly, another study compared reported prevalence rates of apathy in dementia (not specifically AD) in population-based studies relative to clinical samples (452). This study found apathy prevalence ranged from 27-57% (median 44.5%) in population-based studies, and from 42-74% (median 61.5%) in clinical samples (452). Only one population-based study included was specific to AD, reporting a 53% prevalence of apathy, while eight studies included used AD-specific clinical samples and reported apathy prevalence ranging from 42-74% (median 60%). In light of this prior research showing higher prevalence of apathy in clinical samples, the relatively high proportion of participants for whom caregivers reported symptoms of apathy in the present study may be due to the fact that participants were recruited from a clinical population.
6.6 Limitations and Opportunities

There are some potential sources of bias that may have influenced the results of this research. During the recruitment phase, it is possible that individuals who were more active or believed more in the importance of PA for health promotion were more inclined to participate in the study. This bias, known as the “healthy volunteer effect” (453), is well-documented in the literature, and supports the idea that individuals who are healthier are more inclined to participate in research. The influence of this bias was reduced by using a purposive sampling approach for recruitment to provide a broad understanding by including a diversity of perspectives on PA participation.

During data collection, participants may have inaccurately represented their beliefs about PA and their current behaviours so that they would appear to be engaging in healthier, more active lifestyles than they actually are, as they know they should be doing this to promote their health. This is a well-documented phenomenon in research known as the “social desirability bias” (454), where the desire of participants to represent themselves in a way that aligns with socially accepted behaviours and beliefs influences the responses they provide to researchers. The influence of social desirability bias on self-reported PA specifically has been documented, with a tendency towards over-reporting PA levels associated with social desirability (455) (456). Likewise, care partners of individuals with “low” PA levels may have not wanted to appear like they were not doing enough to care for their partners by encouraging PA as a health-promoting behaviour, and responded to the interview questions in such a way that made them appear to be more supportive and successful at encouraging PA for their partners than they actually were. Potential influence of social desirability bias on study findings was managed through interviewing both members of care dyads, providing an opportunity to determine if there were discordant accounts of PA perspectives and potential instances where participants’ responses were influenced by a desire to appear more “healthy” or “supportive”.

Interestingly, there were no instances of discordance between PA behaviours of participants with cognitive impairment reported by these individuals and confirmation provided by their care partners. Participants with cognitive impairment were well aware of their PA levels. Individuals getting high amounts of PA on a weekly basis knew that they were, as did their partners. Individuals getting insufficient or inconsistent levels of PA were aware of this, and aware that
their care partners were aware of this. While individuals with cognitive impairment could not always recollect their exact PA behaviours throughout the week, they were able to recognize if they usually did or did not achieve sufficient PA levels. At present, no research has investigated the influence of social desirability on self-reported PA levels of older adults with and without cognitive impairment. Given the immense research interest in PA as a way for older adults of all cognitive abilities to manage various age-related health conditions and the use of self-reported PA measures as outcomes in these studies, research is needed to determine the potential influence of this bias on research outcomes.

It is also possible that the results of this study were biased due to the influence of cognitive impairment on participants’ responses during the interview and completion of the questionnaires. Word-finding difficulties (457) (458) and declines in working memory (459) are symptoms that can occur in dementia that may have influenced the way participants with MCI and AD understood interview questions and their ability to articulate accurate responses. Potential effects of cognitive impairments on study data were managed through conscious decisions about study design and the interviewer’s interaction style with the participants. Participants with aphasia or variants of AD associated with impaired language production and comprehension were not included in the study (see Appendix 3, “Inclusion and Exclusion Criteria”). As detailed in Chapter 4.2.4 on inclusive research design for persons with cognitive impairment, the interview schedule for participants with cognitive impairment was also structured in a way to reduce the effect of language impairments on question comprehension.

To ensure that only participants with confirmed MCI and AD were included in the study, participants were recruited exclusively from a cognitive neurology clinic in an academic teaching hospital. As such, individuals from socioeconomic groups who are less likely to use health resources like memory clinics would not likely be included in this sample. Research has shown that individuals with more years of education and a higher income are more likely to seek health services for dementia (460). This may be a contributing factor to the low socioeconomic diversity of participants in this sample.

Related to the notion of access to healthcare, this study does not reflect the perceptions, experiences, and beliefs of individuals residing outside of urban areas. As this research was conducted at an urban teaching hospital, only two dyads participating in the study were from
The majority of participants had access to the environmental resources afforded to them by living in a city—a well-developed transportation system, numerous health and fitness facilities, and dedicated urban green spaces within walking distance of their homes. The increased access to activity- and health-promoting resources as well as more habitual PA from residing in walkable neighbourhoods may not be the typical experience for individuals with cognitive impairment living in more rural or remote locations. Research investigating the experiences, perceptions, and beliefs concerning PA of persons living in rural areas should be conducted to explore how environment influences PA levels of older adults with cognitive impairment.

To gain a deeper understanding of how individuals with cognitive impairment think about and engage in PA, the perspectives of caregivers were sought in this research. Participants needed to have a care partner available to participate in this study, and unless someone else was available to accompany them, this precluded the participation of individuals with MCI or AD who are single, widowed, estranged, or living alone in the community for any other reason. The absence of someone in a care partner role to enable and encourage PA may mean that they have different perceptions, experiences, and beliefs concerning PA. Individuals with caregivers who were unable to spare time to participate in the study, such as “sandwich generation” caregivers balancing caring for young children, aging parents, and occupational commitments (461), may have been excluded from the study. Future research should endeavor to seek the perspectives of individuals with cognitive impairment living alone in the community and younger adult caregivers, as socioeconomic factors associated with these roles and life circumstances may affect their ability to engage in PA and their beliefs about its benefit.

The caregivers who did participate in this study were all familial, which was a requirement of the inclusion and exclusion criteria. The majority of caregivers were spousal, with one child caregiver and one grandchild caregiver. For reasons stated previously, it is likely that fewer multigenerational dyads were included in this study because dyads with younger care partners had occupational or family commitments precluding participation in this study. More research is needed to understand challenges faced by caregivers at different life stages and how the care relationship evolves throughout the lifespan so that the appropriate services can be developed to support caregivers at any age and any stage.
In order to participate in interviews, participants needed to have the cognitive abilities that this activity requires, such as sustained attention, working memory, and awareness of their own level of functioning. Individuals who were too impaired in these capacities were necessarily excluded from this study, which may also be why more individuals with MCI rather than AD participated in the study. As such, this study may be missing the perspectives of individuals who experience more substantial barriers to PA participation than less-impaired older adults. Future research should be conducted to explore how older adults with more advanced cognitive impairment participate in PA, potentially through observation or more embedded ethnographic methods that require less interpretation by individuals with cognitive impairment. This research may yield important insights into how PA can be promoted across the continuum of cognitive aging.

Participants also needed to have the language abilities to participate in an interview about their perspectives, experiences, and beliefs in English. As such, individuals who are not fluent in English, such as immigrants and older adults who never learned to speak English, were excluded from this study. Their perspectives on PA participation may be influenced by different cultural norms regarding PA for health promotion, limited access to resources due to a language barrier, or increased opportunities to engage in PA through membership in specific cultural groups. In this study, only one of the participants with cognitive impairment and two of the care partners involved in the study were of non-Caucasian ethnicities. Future research should investigate the interaction between cultural factors in diverse groups and perceptions and beliefs concerning PA as a health behaviour.

While both men and women were represented in this study in almost equal proportions for dyads (50% female participants with MCI and AD, 60% female care partners), individuals with diverse sexual orientations were not represented. The influence of sexual orientation on PA participation has been documented for younger age groups, with young adults who identify as non-heterosexual being more likely to have reduced PA participation (462) (463). One study including older adults in their sample found that adults who identified as homosexual or bisexual, however, did not report significantly different achievement of PA recommendations than heterosexual adults. More research on how sexual diversity interacts with PA as a health promoting behaviour across the lifespan is needed, and future research should examine how sexually diverse older adults perceive, experience, and access PA.
6.7 Implications for Dementia Prevention and Management

Each of the themes concerning PA participation for older adults with cognitive impairment in this thesis carry with them important, practical implications for promoting PA and using it as a strategy for managing and preventing cognitive and functional declines in older adults with MCI or AD. These implications have been separated into strategies that can be used by individuals with MCI or AD and members of their care networks, communities, and policy development to promote healthy, active aging for older adults of all cognitive abilities.

6.7.1 Individuals and Care Networks

For individuals with MCI or AD and their caregivers looking to increase PA participation, the findings of research in this thesis identify a number of strategies to do so. These strategies are both ones specifically used by participants and shared during their interviews, as well as strategies developed based on a more holistic interpretation of the collective responses of participants about their experiences, perceptions, and beliefs concerning PA.

One strategy pertains to the first emergent theme, which emphasizes the importance older adults with MCI and AD place on participating in PA that is personally meaningful, enjoyable, and fulfilling, and respects their unique physical and cognitive abilities. Providing options of PA that respect an individual’s “personhood” (464) may be one way to increase the motivation of older adults with MCI or AD to participate in PA. For example, if someone enjoys social exercise options and has enjoyed dancing for their whole life, offering PA that incorporates aspects of dancing in a group setting may help engage that individual more in PA. More broadly, respecting an individual’s personhood by providing a variety of PA options and allowing individuals to select options that meet their interests and abilities is a practical strategy supported by the findings of this research to increase PA participation.

Another potential implication for promoting PA for older adults with MCI or AD based on the findings of this research is that shifting focus to the positive embodied and affective aspects of PA may be more effective than trying to convince older adults with MCI to be active because of purported health benefits they are unable to immediately experience or perceive. This relates to the second emergent theme from this research that emphasizes the preferential perception of more positive embodied and affective effects of PA by older adults with MCI or
AD over the cognitive benefits of which they are uncertain. This shift in strategy to “go by feel” for discussing the benefits of PA to promote participation could potentially be used by caregivers or community stakeholders in motivating individuals with MCI or AD to participate in PA.

Similarly, caregivers and community exercise professionals could employ another strategy to promote PA that involves taking an “inventory” of an individual’s unique physical and cognitive abilities and available resources when planning and selecting PA options with them. The third emergent theme from this research supports the use of this strategy, as it maintains that PA is desirable and attainable for persons with MCI or AD despite the unique barriers that individuals encounter. In keeping with this, using this strategy to figure out what the most appropriate PA plan is for older adults with cognitive impairment may prevent negative experiences with PA, like trying options that are too challenging or not challenging enough, that deter older adults with MCI or AD from engaging in new PA options in the future.

The fourth and final emergent theme in this research pertains to how the care dyad relationship can be leveraged to enable PA participation. By making PA a team effort, dyads interviewed in this study were able to form and maintain stable PA habits. For other dyads, caregivers were the driving force for PA participation, responsible for helping their partners overcome motivational and logistical barriers to PA. In this sense, a practical recommendation for individuals with MCI or AD and their care networks is to make PA a team effort. One way this can be done is by getting family, friends, and caregivers who understand the impact of cognitive impairment on social and physical functioning. In doing so, PA becomes a more meaningful, social experience, in which older adults with MCI or AD may be more inclined to participate.

6.7.2 Community Resources and Public Policy

Beyond the actions that can be taken by individuals with MCI or AD and their care networks, there are broader, system-level actions that can be taken by communities and policy developers who are stakeholders in dementia care and public health to support PA participation of older adults with MCI and AD.

In relation to the first and second emergent themes concerning how older adults with MCI or AD and their caregivers perceive PA and its benefits, there is a potential opportunity for
public health stakeholders to reframe the messaging surrounding the benefits of PA participation to align more with how this audience perceives PA. Long-term health benefits that are not immediately recognizable or improvements in cognitive function that older adults with MCI or AD can’t perceive due to lack of insight into their own symptoms may not be the most relatable or accessible benefits to refer to when motivating older adults with MCI and AD. Rather, the benefits that they can immediately experience and have the insight to perceive as they are engaging in PA may be more salient motivators to include in messaging promoting PA participation. On a policy level, this could take the form of framing benefits as more affective or personally meaningful outcomes (i.e. independence, aging in place, social networks) in published PA guidelines and health promotion campaigns. In community settings, healthcare professionals and community exercise professionals counselling older adults with MCI or AD on PA participation could include more discussion about PA as a way to retain their ability to participate in meaningful activities when discussing the health benefits of PA.

In relation to the third emergent theme concerning how PA participation is desirable and attainable despite barriers experienced by older adults with MCI or AD, there is an opportunity to remove some of these disease-specific barriers by providing more dementia-friendly PA options in community settings. From community centres, to gyms, to disease-specific PA programs, there is an overwhelming number of opportunities available for older adults to participate in PA in the community. What creates a barrier for older adults with MCI or AD, however, is having to navigate the multitude of options available to select an option that is appropriate for their abilities and resources. Many programs for older adults cannot accommodate people with cognitive impairments, and can create embarrassing or potentially physically harmful experiences for older adults with cognitive impairment if they are not designed with this population in mind. As such, the creation of a resource for older adults with MCI or AD to navigate and identify the appropriate PA programs existing in their community would be one useful tool in removing this access barrier to PA. For programs and services already existing in the community, a dementia competency training program for professionals leading PA programming that provides basic education on how to safely and respectfully engage older adults with cognitive impairment in PA would go a long way in creating more safe, dementia-friendly active spaces in the community. Identifying these programs with some form of dementia-friendly “check mark” or symbol may
also help older adults with MCI or AD and their caregivers immediately recognize suitable PA opportunities.

Finally, communities and public policy developers also need to focus on bolstering programs and services for caregivers that enable them to enable PA for their partners with cognitive impairment. This relates to the fourth emergent theme in this research, which emphasizes the critical role of caregivers in making PA happen for their partners. The responsibility to seek and coordinate PA opportunities can be burdensome for caregivers who are juggling numerous other commitments. As well, trying to motivate partners who are experiencing apathy can create feelings of tension and frustration for caregivers. Thus, the provision of programs and services to help caregivers help their partners would address this, potentially by providing more programs that help caregivers develop coping skills for managing NPS like apathy in daily life. Having more PA programs that include both caregivers and individuals with MCI or AD may also be a way to increase participation by making PA a team effort, and positively affect the health and wellbeing of both dyad members in the process.
Chapter 7

Future Research Directions

The findings reported in this thesis suggest potential avenues for future research to provide a deeper understanding of the phenomenon of PA participation for older adults with AD or MCI, and also identify opportunities to apply knowledge generated in this thesis to improve the use of PA for the promotion of healthy cognitive aging in community settings.

Research on PA in older adults with cognitive impairment is a growing field, as PA poses a potential affordable, effective way to address a growing global health crisis. Despite how critical this area of research is, the tools available to study PA in this population are limited. Objective assessment of PA levels through the use of activity monitors remains the gold standard, but this approach is not feasible for much needed large, longitudinal studies. Rather, subjective self-report questionnaires are typically used either alone or in combination with objective assessments. Currently, there are no PA questionnaires specifically tailored to the cognitively impaired older adults, and the questionnaires validated for use in older adults like the PASE are not validated for use in older adults with cognitive impairment. Research is needed to determine the accuracy and reliability of these measures for assessing PA levels in cognitively impaired populations. If these measures do not provide reasonably accurate and reliable measures of PA for older adults with cognitive impairment, then such a tool needs to be developed so research in the field of dementia and PA can generate meaningful findings.

In relation to the disparity between how older adults with cognitive impairment and their caregivers perceive PA relative to how public health messaging promotes PA, there are a number of questions that need to be addressed before considering making changes to how public health messaging portrays the benefits of PA in MCI and AD. This thesis suggests that more embodied, emotive emphasis in messaging appealing to the perceptions held by older adults with MCI or AD and their caregivers of PA as a way to add meaningful activities to their lives and attain a sense of wellbeing may be a more powerful motivator than health beliefs. Prior to changing public health messaging to align with this perception, however, research is needed to confirm these findings using a larger, more representative sample. Thus, research investigating the impact of informational (e.g. evidence-based statistics on objective health benefits of PA) versus
emotive and embodied emphasis in messaging (e.g. social and mood benefits) on motivations and changes in behaviour to increase PA level in older adults with AD or MCI is needed.

As well, research investigating how PA is promoted through other information sources is needed to gain an understanding of how older adults with AD or MCI are being educated about the benefits of PA. Information from physicians, exercise professionals, and scientific reports were mentioned by participants in this study as sources of information from which they learned about the benefits of PA. A scoping review of the different ways these information sources frame messages about the benefits of PA for healthy cognitive aging would help provide a sense of what other strategies are being used to communicate the benefits of PA to this group beyond the evidence-based messaging of the Canadian Physical Activity Guidelines. It is possible that another messaging strategy is more effective, and should be used to promote PA participation in older adults with MCI or AD instead of a guideline-based approach.

The findings reported in this thesis speak to how older adults with cognitive impairment and their care partners overcome barriers they encounter in accessing PA, and the facilitators and strategies they leverage to make PA participation happen despite these barriers. Apathy and a lack of self-regulation or discipline were noted by both participants with cognitive impairment and caregivers alike as significant barriers to PA participation for older adults with MCI or AD. Caregivers participating in this study reported that apathy was present in the majority of participants with MCI and all participants with AD, and that they experienced varying levels of distress as a result of this apathy. Research investigating the influence of NPS like apathy on PA participation in MCI and AD is needed, and may yield findings that pose relevant solutions for older adults with MCI or AD and their caregivers to overcome this barrier.

The findings reported in this thesis also highlight the need to adapt currently available community programs and services to suit the unique needs and abilities of older adults with cognitive impairment and their care partners. While the findings of this thesis highlight this need by identifying the broad gaps that exist in the surrounding community where this study was conducted, they neither speak for the needs of all communities nor provide solutions to address specific gaps. In order to identify and address the gaps related to PA participation of older adults with MCI or AD in specific community contexts, environmental scans should be done by individual communities to identify how they can support older adults with MCI or AD and
caregivers in enabling PA. This is an enormous undertaking, and would likely not be the responsibility of a sole team of researchers or one organization. In the Canadian context, however, there is infrastructure in place that could potentially support the conduct of environmental scans in smaller community contexts. The Alzheimer Society has national, provincial, and regional chapters that support dementia research in Canada and provide free dementia programming to communities. Environmental scans could potentially be accomplished through joint efforts by research and community initiatives across the different levels of the Alzheimer Society, defining regional chapters as the units to be studied in environmental scans and leveraging the funding and expertise possessed by researchers receiving funding from the Alzheimer Society to conduct this research. The findings of these environmental scans would be critical for informing the development of new programs and services or adapting existing programs to meet the needs of older adults with cognitive impairment.

This study accounted for the perceptions, beliefs, and experiences of the care dyad in exploring PA participation of older adults with cognitive impairment. In doing so, this thesis captured an important facet of PA participation, which is that caregivers are the enablers of PA, and must overcome significant motivational barriers with their partner to make PA happen. Caregivers in this study reported frustration at the effort required to get their partners with MCI or AD to engage in a health promoting behaviour like PA. In this sense, research investigating how to support caregivers could indirectly provide a way to support PA participation of older adults with MCI or AD. Research identifying effective coping skills and strategies for caregivers to overcome apathy as a barrier to PA participation in MCI and AD is needed.

For some dyads who were successful at making PA happen on a regular basis, both members reported PA being a partnership between members. In this sense, increasing PA levels of caregiver partners may be a strategy to indirectly increase PA levels of older adults with MCI or AD. Research investigating the relationship between PA levels of caregivers and their partners with MCI or AD, and the effectiveness of interventions delivered to caregivers at causing second-hand increases in PA levels of care recipients with AD or MCI, is needed to provide a better understanding of how the dyad relationship can be leveraged to increase PA participation in older adults with cognitive impairment.
Chapter 8

8 Conclusions

The research question addressed by this thesis asks, “What are the perceptions, beliefs, and experiences, of community-dwelling older adults with MCI or AD and their caregivers concerning PA as a health behaviour?”

i. Physical Activity Perceptions

To explore PA perceptions, care dyads were asked to describe how they define PA and provide exemplar activities they associate with it. Participants broadly defined PA, and provided numerous examples of types of PA spanning both structured and unstructured activities. PA definitions were unique to individual participants, but all involved some embodied aspect. To understand how older adults with MCI or AD and their caregivers perceive PA as a health behaviour, participants were asked to indicate their perception of the “recommended” levels of PA older adults both with and without cognitive impairment should perform. Participants indicated that older adults in general should do as much PA as possible every day, balancing PA-associated benefits and risks. Older adults with cognitive impairment were perceived as being as capable as cognitively healthy older adults at achieving these recommendations, but may need additional guidance and supervision to reduce risks associated with cognitive impairment.

ii. Physical Activity Beliefs

To explore PA beliefs, participants were asked to describe the potential risks and benefits they associate with PA, as well as what factors motivate them to participate in PA. Older adults with MCI or AD and their caregivers associate numerous benefits with PA, such as maintaining one’s health, achieving feelings of wellbeing, and adding meaning to one’s daily life. Cognitive benefits of PA were acknowledged, but participants with cognitive impairment noted that they were uncertain about these benefits because they could not readily perceive them personally. Risks associated with PA by participants included both age-related declines in health and functioning as well as to cognitive impairments associated with MCI and AD. Largely, participants felt that the benefits of PA outweighed its associated risks, and that safe PA participation could be achieved by being sensible about one’s abilities. Beliefs of older adults
Motivators to engage in PA were numerous, and many of them stemmed from the benefits perceived by participants. PA was viewed by participants as a way to not only maintain one’s physical health, function, and wellbeing, but also to sustain participation in enjoyable, personally meaningful activities and provide enjoyable embodied experiences.

### iii. Physical Activity Experiences

To explore PA experiences, participants were asked to discuss activities they typically participate in, as well as activities they have engaged in at various points throughout their life. Participants reported a variety of PA patterns throughout their lifespans, often relating previous experiences with PA to current activity levels. Older adulthood was associated with several factors that influence PA participation, such as retirement, experiences with age-related conditions, and diagnosis with cognitive impairment. To understand the influence of aging and cognition on PA participation for this population, participants were asked to describe the factors influencing their ability to engage in PA (i.e. barriers and facilitators). Participants were also asked to elaborate on theirs (or their partners’, in the case of caregivers) experiences engaging in PA as older adults with cognitive impairment and their experiences with PA-promoting programs and services available to them in the community. Older adults with MCI or AD have to contend with barriers arising at the intersection of aging and cognition to participate in PA, which was illustrated through stories of their experiences provided by them and their caregivers.

Not only do older adults with MCI or AD need to overcome barriers like age-related declines in health and function, but they also need to overcome barriers related to cognitive impairment such as memory loss, apathy, wayfinding difficulties, and executive dysfunction. Caregivers play a crucial role in overcoming these barriers, providing guidance and organization to ensure that PA happens. Caregivers, however, note that enabling PA is no easy feat, and they have to contend with their own barriers like competing demands and distress related to their partner’s cognitive decline.

In terms of available community resources to promote PA, participants noted the importance of walkable neighbourhoods and outdoor spaces for engaging in PA. Experiences engaging with programs and services in the community that are not tailored to older adults with
cognitive impairment were shared by participants. In instances where cognitive abilities interfered with the ability to perform activities in these programs, these experiences were socially uncomfortable for older adults with MCI or AD. PA experiences of older adults with MCI or AD and their caregivers captured by this study highlight the need for a diversity of adaptable options for this population to promote PA participation.

iv. Summary of Study Results and Implications

The results reported in this thesis contribute important conclusions to the scientific literature on the perceptions, beliefs, and experiences of older adults with MCI or AD and their caregivers surrounding PA participation and provide a starting point for future research to enhance knowledge on this topic. Findings of this thesis provide an important stepping stone in translating knowledge on the benefits of PA for older adults with MCI or AD into strategies to prevent and manage cognitive and functional decline in the rapidly growing older adult population.

The first conclusion that can be drawn from findings presented in this thesis is that the way PA is discussed in public health messaging (21) (307) to guide healthcare professionals and the general public in using PA for health promotion does not align with how older adults with MCI or AD and their caregivers perceive PA. The Canadian Physical Activity Guidelines for Older Adults (21) provide evidence-based recommendations on the minimum frequency, intensity, and duration of specific types of PA that should be done by older adults to maintain their health. More specifically, the relevance of adhering to these recommendations to reduce one’s risk of AD and manage cognitive and functional decline in AD have been captured in an evidence-based statement for healthcare providers and the general public (307). While these evidence-based recommendations provide direction in how to participate in PA as a health behaviour, the messaging around the guidelines may not be the most relatable way to communicate this to older adults with cognitive impairment. Participants with MCI or AD in this study, while aware of the reported benefits of PA for maintaining cognition, explicitly stated their uncertainty about the existence of these benefits due to an inability to consciously experience or perceive these benefits themselves. Rather, they noted personal enjoyment and fulfilment in relation to PA as motivating factors for PA participation. Therefore, in promoting PA for older adults with cognitive impairment, messaging that focuses on the positive embodied
and emotive aspects derived from participating in PA may be more effective at promoting PA participation.

The second conclusion that can be drawn from the findings presented in this thesis pertains to how older adults with MCI or AD go about engaging in PA in community settings. Presently, a very small body of literature exists on this topic (reviewed in Chapter 2.7.2), consisting of a handful of qualitative studies that are not informed by theory on behaviour change in health promotion contexts. Findings from this thesis indicate that older adults with cognitive impairment value and enjoy participating in PA, but must negotiate numerous barriers arising at the intersection of aging and cognition to do so. The factors influencing PA participation of older adults with MCI or AD identified in this thesis align with those found in prior research on PA participation in dementia, but also contribute new findings. In particular, this thesis includes perspectives of older adults with MCI, which previous studies have not included.

The third conclusion that can be drawn from this study is that PA participation can be achieved by older adults with MCI or AD despite the barriers they face. Findings from this thesis identify strategies used by older adults with MCI or AD and their caregivers to make PA participation possible despite the barriers they encounter. Older adulthood comes with its own challenges to PA participation, such as increased likelihood of having comorbid health conditions that limit one’s ability to be active (e.g. osteoarthritis, cancer). It does, however, also present new opportunities to increase PA participation, as the cessation of occupational activity after retirement allows more time to pursue leisure time PA for the purposes of enjoyment and health promotion. Diagnosis with cognitive impairment poses its own challenges to PA participation, as cognitive decline can impair one’s motivation to be active or ability to plan and execute structured PA, ultimately resulting in restrictions in one’s independence and life space that limit the number of available opportunities for PA participation.

The fourth and final conclusion that can be drawn from this thesis flows from the conclusions stated above. In large part, the sustained participation of older adults with MCI or AD in PA is due to enablement by caregivers. In order to promote PA for older adults with MCI or AD, more opportunities to participate in PA need to be created that are “dementia-friendly” and can adapt to the needs and abilities of both the person with cognitive impairment and their caregiver. There are innumerable opportunities available for older adults to participate in PA in
community settings. The difficulties that older adults with cognitive impairment experience in accessing these opportunities largely stem from the inability of current programs to adapt to their individual needs and abilities. PA programs for non-impaired older adults cannot accommodate older adults who are as physically fit as their age mates, but are experiencing cognitive impairments. Programs for older adults with cognitive impairment typically cater to the lowest common denominator of physical and cognitive fitness, and fail to adequately stimulate and challenge those who are cognitively impaired, but only mildly so, and still more physically fit than other older, more impaired people using these programs. As well, the burden for accessing these programs falls to caregivers, placing additional responsibility on already strained individuals. Caregivers interviewed in this study noted that programs accommodating both theirs and their partners’ unique needs and abilities are lacking in the community.

Ultimately, the conclusions drawn from findings reported in this thesis can be distilled to a single statement and a call to action. Older adults with MCI or AD are able and willing to engage in PA despite the unique age- and disease-related barriers they encounter, but their perceptions, beliefs, and abilities do not align with public health messaging promoting PA for brain health or currently available opportunities to engage in PA in community settings. More effectively engaging older adults with MCI and AD and their care partners in PA may require shifting how healthcare professionals and public health stakeholders communicate with older adults about the benefits of PA for maintaining cognitive and functional abilities, and adapting existing community resources to be more flexible in accommodating the unique needs and abilities of older adults with MCI or AD and their care partners to support enablement of PA participation.


316. Statistics Canada. Table 105-0508 - Canadian health characteristics, annual estimates, by age group and sex, Canada (excluding territories) and provinces, occasional (number unless otherwise noted); 2017 [cited 2017 July 19. Available from: http://www5.statcan.gc.ca/cansim/a47.


472. Statistics Canada. Table 051-0001 - Estimates of population, by age group and sex for July 1, Canada, provinces and territories, annual (persons unless otherwise noted).


Appendices

Appendix 1  Canadian Physical Activity Guidelines for Older Adults

Canadian Physical Activity Guidelines

FOR OLDER ADULTS - 65 YEARS & OLDER

Guidelines

To achieve health benefits, and improve functional abilities, adults aged 65 years and older should accumulate at least 150 minutes of moderate- to vigorous-intensity aerobic physical activity per week, in bouts of 10 minutes or more.

It is also beneficial to add muscle and bone strengthening activities using major muscle groups, at least 2 days per week.

Those with poor mobility should perform physical activities to enhance balance and prevent falls.

More physical activity provides greater health benefits.

Let’s Talk Intensity!
Moderate intensity physical activities will cause older adults to sweat a little and to breathe harder. Activities like:

• Brisk walking
• Bicycling

Vigorous intensity physical activities will cause older adults to sweat and be “out of breath”. Activities like:

• Cross-country skiing
• Swimming

Being active for at least 150 minutes per week can help reduce the risk of:

• Chronic disease (such as high blood pressure and heart disease) and.
• Premature death

And also help to:

• Maintain functional independence
• Maintain mobility
• Improve fitness
• Improve or maintain body weight
• Maintain bone health and
• Maintain mental health and feel better

Pick a time. Pick a place. Make a plan and move more!

☐ Join a community urban poling or mall walking group.
☐ Go for a brisk walk around the block after lunch.
☐ Take a dance class in the afternoon.
☐ Train for and participate in a run or walk for charity!

☐ Take up a favourite sport again.
☐ Be active with the family! Plan to have “active reunions”.
☐ Go for a nature hike on the weekend.
☐ Take the dog for a walk after dinner.

Now is the time. Walk, run, or wheel, and embrace life.
### Appendix 2  Theoretical Domains Framework from Cane et al., 2012 (395), with definitions from the American Psychological Association (396)

<table>
<thead>
<tr>
<th>Domain</th>
<th>Description</th>
<th>Supporting Constructs</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Knowledge</td>
<td>An awareness of the existence of something</td>
<td>Knowledge (knowledge of condition/scientific rationale)</td>
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<tr>
<td></td>
<td></td>
<td>Procedural knowledge</td>
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<tr>
<td></td>
<td></td>
<td>Knowledge of task environment</td>
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<tr>
<td>2. Skills</td>
<td>An ability of proficient acquired through practice</td>
<td>Skills</td>
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<td></td>
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<td>Skill development</td>
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<td>Competence</td>
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<td>Ability</td>
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<td></td>
<td>Interpersonal skills</td>
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<td>Practice</td>
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<td></td>
<td></td>
<td>Skill assessment</td>
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<tr>
<td>3. Social/Professional Role and Identity</td>
<td>A coherent set of behaviours and displayed personal qualities of an individual in a social or work setting</td>
<td>Professional identity</td>
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<td></td>
<td></td>
<td>Professional role</td>
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<td>Social identity</td>
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<td></td>
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<td>Identity</td>
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<td></td>
<td></td>
<td>Professional boundaries</td>
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<td></td>
<td></td>
<td>Professional confidence</td>
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<td></td>
<td></td>
<td>Group identity</td>
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<td></td>
<td></td>
<td>Leadership</td>
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<td></td>
<td></td>
<td>Organizational commitment</td>
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<tr>
<td>4. Beliefs about Capabilities</td>
<td>Acceptance of the truth, reality, or validity about an ability, talent, or facility that a person can put to constructive use</td>
<td>Self-confidence</td>
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<tr>
<td></td>
<td></td>
<td>Perceived competence</td>
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<td>Self-efficacy</td>
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<td></td>
<td></td>
<td>Perceived behavioural control</td>
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<td>Beliefs</td>
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<td>Self-esteem</td>
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<td></td>
<td>Empowerment</td>
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<td></td>
<td></td>
<td>Professional confidence</td>
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<tr>
<td>5. Optimism</td>
<td>The confidence that things will happen for the best or that desired goals will be attained</td>
<td>Optimism</td>
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<td></td>
<td></td>
<td>Pessimism</td>
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<td></td>
<td></td>
<td>Unrealistic optimism</td>
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<td></td>
<td></td>
<td>Identity</td>
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<tr>
<td>6. Beliefs about Consequences</td>
<td>Acceptance of the truth, reality, or validity about outcomes of a behaviour in a given situation</td>
<td>Beliefs</td>
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<td></td>
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<td>Outcome expectancies</td>
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<td>Characteristics of outcome expectancies</td>
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<td></td>
<td></td>
<td>Anticipated regret</td>
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<td></td>
<td></td>
<td>Consequents</td>
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<tr>
<td>7. Reinforcement</td>
<td>Increasing the probability of a response by arranging a dependent relationship, or contingency, between the response and a given stimulus</td>
<td>Rewards (proximal / distal, valued / not valued, probable / improbable)</td>
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<tr>
<td></td>
<td></td>
<td>Incentives</td>
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<td></td>
<td></td>
<td>Punishment</td>
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<td></td>
<td></td>
<td>Consequents</td>
</tr>
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<td></td>
<td></td>
<td>Reinforcement</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Contingencies</td>
</tr>
<tr>
<td>8. Intentions</td>
<td>A conscious decision to perform a behaviour or a resolve to act in a certain way</td>
<td>Sanctions</td>
</tr>
<tr>
<td>9. Goals</td>
<td>Mental representations of outcomes or end states that an individual wants to achieve</td>
<td></td>
</tr>
<tr>
<td>10. Memory, Attention, and Decision Processes</td>
<td>The ability to retain information, focus selectively on aspects of the environment and choose between two or more alternatives</td>
<td></td>
</tr>
<tr>
<td>11. Environmental Context and Resources</td>
<td>Any circumstance of a person's situation or environment that discourages or encourages the development of skills and abilities, independence, social competence, and adaptive behaviour</td>
<td></td>
</tr>
<tr>
<td>12. Social Influences</td>
<td>Those interpersonal processes that can cause individuals to change their thoughts, feelings, or behaviours</td>
<td></td>
</tr>
<tr>
<td>13. Emotions</td>
<td>A complex reaction pattern, involving experiential, behavioural, and physiological elements, by which the individual attempts to deal with a personally significant matter or event</td>
<td></td>
</tr>
<tr>
<td>14. Behavioural Regulation</td>
<td>Anything aimed at managing or changing objectively observed or measured actions</td>
<td></td>
</tr>
</tbody>
</table>
## Appendix 3  
### Inclusion and Exclusion Criteria

<table>
<thead>
<tr>
<th>Person with MCI or mild to moderate AD</th>
<th>Justification</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Inclusion Criteria</strong></td>
<td></td>
</tr>
<tr>
<td>1. A diagnosis of MCI or probable AD from a neurologist at the Sunnybrook Health Sciences Centre cognitive neurology clinics (&gt;6 months).</td>
<td>To define a clinically-relevant study population. Participants had to have lived with dementia for at least 6 months (typical latency between appointments at the cognitive neurology clinic) to provide time to accrue experience living as a person with cognitive impairment.</td>
</tr>
<tr>
<td>2. Aged 65 years or older.</td>
<td>65 years and over is the demographic group most common social and academic definition of “older adult” (465).</td>
</tr>
<tr>
<td>3. Cognitive impairment as indicated by a Mini-Mental State Examination (MMSE) (160) score between 18-28.</td>
<td>Indicates a level of cognitive impairment typically associated with mild to moderate AD and MCI using a standard measure of global cognitive function (420).</td>
</tr>
<tr>
<td>4. Presence of a primary or secondary familial or spousal caregiver willing to participate in the study as a knowledgeable informant.</td>
<td>Familial caregivers may have increased familiarity with the participant’s cognitive and PA histories relative to paid, formal caregivers. To accommodate a range of caregiving networks where different family members may be responsible for different aspects of care, both primary and secondary caregivers were included (466).</td>
</tr>
<tr>
<td>5. The participant is community-dwelling.</td>
<td>This study aimed to support knowledge translation for developing community-based physical activity programs for persons with MCI and AD, and thus collected data from target populations of these programs.</td>
</tr>
<tr>
<td>6. Ability to speak and understand fluent English without the aid of a translator.</td>
<td>The person conducting interviews was only fluent in English.</td>
</tr>
<tr>
<td>7. Capacity to consent or assent to study participation.</td>
<td>Although the population being sampled in this research is vulnerable due to cognitive impairment, it is not anticipated that the level of cognitive impairment of participants will interfere with their capacity to consent.</td>
</tr>
<tr>
<td>8. Insight into diagnosis and symptoms confirmed by caregiver report.</td>
<td>For participants to meaningfully comment on their experiences of PA as an individual with MCI or AD, they must be aware of their diagnosis and the impact of its symptoms on daily life.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Exclusion Criteria</th>
<th>Justification</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Presence of other mental or physical conditions judged by the Principal Investigator to interfere with the ability to participate in the study or provide meaningful data.</td>
<td>Exclude individuals unable to participate due to conditions interfering with the ability to understand and respond in research interview or lacking experiences engaging in PA beyond limitations that may be experienced due to MCI or AD or normal age-related declines.</td>
</tr>
<tr>
<td>2. Unwilling or unable to comply with study protocol.</td>
<td>Precludes the participant from participating in study visits and providing meaningful data.</td>
</tr>
<tr>
<td>3. Currently enrolled in a research study using PA as an intervention.</td>
<td>Individuals concurrently enrolled in a study using PA as an intervention may not be experiencing the...</td>
</tr>
<tr>
<td>Inclusion Criteria</td>
<td>Justification</td>
</tr>
<tr>
<td>----------------------------------------------------------------------------------</td>
<td>-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>1. The individual is a spouse or family member of the participant with MCI or AD, and provides care on a routine basis.</td>
<td>Defining the relationship of the individual to the person with MCI or AD as an informal primary or secondary caregiver.</td>
</tr>
<tr>
<td>2. Aged 18 years or older.</td>
<td>Caregiver must be an adult.</td>
</tr>
<tr>
<td>3. Available and willing to accompany the participant to study visits and participate in the study as a knowledgeable informant.</td>
<td>Required for completion of the questionnaire and participation of both the patient with MCI or AD and their caregiver in semi-structured interviews.</td>
</tr>
<tr>
<td>4. Ability to speak and understand fluent English without the aid of a translator.</td>
<td>English is the only fluent language shared by all research personnel. All study materials and data must be in English for communication and analysis.</td>
</tr>
<tr>
<td>5. Ability to provide written informed consent.</td>
<td>Necessary for ethical conduct of research involving humans.</td>
</tr>
<tr>
<td>6. Insight into care recipient’s diagnosis and symptoms.</td>
<td>To meaningfully comment on the care recipient’s experiences of PA as an individual with MCI or AD, they must be aware of the care recipient’s diagnosis and the impact of its symptoms on daily life.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Exclusion Criteria</th>
<th>Justification</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Presence of other mental or physical conditions judged by research personnel to interfere with the ability to participate in the study or provide meaningful data.</td>
<td>Anything that may inhibit an individual’s ability to understand and respond in research interview.</td>
</tr>
<tr>
<td>2. Unwilling or unable to comply with protocol requirements.</td>
<td>Unable to participate in study visits and provide meaningful data.</td>
</tr>
<tr>
<td>3. Currently enrolled in a research study using PA as an intervention.</td>
<td>PA participation for individuals currently enrolled in another research study using PA as an intervention may not be experiencing the barriers and facilitators for the majority of community-dwelling caregivers.</td>
</tr>
</tbody>
</table>
Appendix 4  Letter of Ethical Approval (Sunnybrook Research Institute)

Research Ethics Board (REB) RENEWAL FORM

The Renewal Form is an application for continuing ethics approval and must be submitted for review and approval prior to the study's expiry date. Ethics approval expires each subsequent year from the day REB approval was initially granted unless otherwise indicated by the Sunnybrook REB. Failure to submit this form prior to the expiry date signifies that the study does not have REB approval and all research activities must be suspended. Conducting research without REB approval may result in a notice of non-compliance involving corrective action, up to and including, termination of the research study.

Principal Investigator (PI): Dr. Sandra Black

REB Project Identification Number (PIN): 110-2016

Full Study Title: Physical Activity Behaviours, Perceptions, and Participation: Factors in Mild Cognitive Impairment and Alzheimer's Disease

1. Date of initial Sunnybrook REB approval (dd/mmm/yyyy).
   03/May/2016

2. Type of REB review requested. (Final decision rests with the REB Chair.)
   - [ ] Delegated Review
   - [X] Full Board Review

3. Is this an Industry-Sponsored/Supported study?
   - [ ] YES (If YES, complete the table below.)  - [X] NO (If NO, proceed to question 4.)

Invoicing Information for Industry-Sponsored/Supported Studies
A fee of $500 Cdn is invoiced for all Industry-Sponsored/Supported Studies applying for continuing ethics approval.

Invoice to the Following Company:

Contact Name: 
Telephone:  
E-mail:  
Street Address:  
Suite:  
City:  
Province/State:  
Country:  
Postal/Zip Code:  

4. Is this study open for enrollment at Sunnybrook?  - [X] YES  - [ ] NO

If YES, attach a copy of the current Informed Consent Form(s).
If NO, provide reasoning:

5. How many participants at Sunnybrook:

<table>
<thead>
<tr>
<th>Were planned for enrollment</th>
<th>20</th>
</tr>
</thead>
<tbody>
<tr>
<td>Were consented</td>
<td>19</td>
</tr>
<tr>
<td>Were enrolled</td>
<td>19</td>
</tr>
<tr>
<td>Are currently receiving study treatment/intervention</td>
<td>0</td>
</tr>
<tr>
<td>Completed study treatment/intervention &amp; are currently on follow-up</td>
<td>19</td>
</tr>
<tr>
<td>Completed study treatment/intervention &amp; follow-up</td>
<td>19</td>
</tr>
<tr>
<td>Withdrew consent</td>
<td>0</td>
</tr>
<tr>
<td>Were planned for inclusion in a chart review (retrospective or prospective)</td>
<td>0</td>
</tr>
<tr>
<td>Were included in a chart review (retrospective or prospective)</td>
<td>0</td>
</tr>
</tbody>
</table>

6. Have all reportable Serious Adverse Events (SAEs) experienced by a Sunnybrook participant been reported to the REB?

☐ YES ☐ NO, will submit immediately ☑ NO reportable SAEs have occurred

7. In the opinion of the PI, is there a concern or trend in the SAEs that have occurred with Sunnybrook participants?

☐ YES ☑ NO ☑ NO SAEs have occurred

If YES, provide details and action taken.

8. Have all significant protocol deviations/violations been reported to the REB?

☐ YES ☐ NO, will submit immediately ☑ NO significant deviations/violations to report

9. Since the last REB approval, is there any new ethical or scientific information outside of a protocol amendment that would be relevant to the continuing review of this study?

☐ YES ☑ NO

If YES, provide details.

10. Since the last REB approval, is there any change in the conflict of interest information provided to the REB for any of the investigators, study staff or members of their immediate family? ☐ YES ☑ NO

If YES, provide details.
11. Person completing this form.

<table>
<thead>
<tr>
<th>Title: Ms.</th>
<th>First Name: Lauren</th>
<th>Last Name: Bechard</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dept/Div:</td>
<td>Hurvitz</td>
<td>Institution: Sunnybrook Research Institute</td>
</tr>
<tr>
<td></td>
<td>Brain Sciences Program</td>
<td></td>
</tr>
<tr>
<td>Full Address:</td>
<td>2075 Bayview Avenue, Toronto, ON, M4N 3M5</td>
<td>Room Number: M6-192</td>
</tr>
<tr>
<td>Telephone:</td>
<td>416-480-6100</td>
<td>Extension: 85420</td>
</tr>
<tr>
<td>E-mail:</td>
<td><a href="mailto:lauren.bechard@mail.utoronto.ca">lauren.bechard@mail.utoronto.ca</a></td>
<td></td>
</tr>
</tbody>
</table>

12. Statement of Principal Investigator (PI).

I assume full responsibility for the scientific and ethical conduct of this study and agree to conduct this study in compliance with the Tri-Council Policy Statement: Ethical Conduct for Research Involving Human Subjects (TCPS), Personal Health Information Protection Act (PHIPA) and any other relevant regulations or guidelines. I certify that all researchers and personnel involved in this study at this institution are appropriately qualified and trained to fulfill their role in this study.

Signature of Principal Investigator  
28 April 2017

Date (dd.mmm.yyyy)
Appendix 5   Letter of Ethical Approval (University of Toronto)

PROTOCOL REFERENCE # 33085

June 2, 2016

Dr. Sandra Black  Ms. Lauren Bechard
DEPT OF MEDICINE  DEPT OF MEDICINE
FACULTY OF MEDICINE  FACULTY OF MEDICINE

Dear Dr. Black and Ms. Lauren Bechard,

Re: Administrative Approval of your research protocol entitled, "Physical activity behaviours, perceptions, and participation: Factors in mild cognitive impairment and Alzheimer's disease"

We are writing to advise you that the Office of Research Ethics (ORE) has granted administrative approval to the above-named research protocol. The level of approval is based on the following role(s) of the University of Toronto (University), as you have identified with your submission and administered under the terms and conditions of the affiliation agreement between the University and the associated TAHSN hospital:

- Graduate Student research - hospital-based only
- Storage or analysis of De-identified Personal Information (data)

This approval does not substitute for ethics approval, which has been obtained from your hospital Research Ethics Board (REB). Please note that you do not need to submit Annual Renewals. Study Completion Reports or Amendments to the ORE unless the involvement of the University changes so that ethics review is required. Please contact the ORE to determine whether a particular change to the University’s involvement requires ethics review.

Best wishes for the successful completion of your research.

Yours sincerely,

Daniel Gyewu
REB Manager

Research Oversight and Compliance Office - Human Research Ethics Program
McMurrich Building, 12 Queen's Park Crescent West, 2nd Floor, Toronto, ON M5S 1S8 Canada
Tel: +1 416 946-3272  Fax: +1 416 946-5763  ethics.review@utoronto.ca  http://www.research.utoronto.ca/for-researchers-administrators/ethics/
## Appendix 6  Interview Schedule

<table>
<thead>
<tr>
<th>Question</th>
<th>Parameters / Rationales</th>
<th>Corresponding TDF Component</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1.</strong> What does the phrase “physical activity” mean to you?</td>
<td>Beliefs about physical activity Establish a common language for the interview, beginning with “grand tour” question</td>
<td>1. Knowledge 3. Social/Professional Role and Identity</td>
</tr>
<tr>
<td><strong>2.</strong> Do you think that there are any benefits to being physically active? What are some of the benefits you associate with physical activity?</td>
<td>Beliefs about physical activity Assess for presence of perceived benefits of physical activity, which may act as a motivator/facilitator</td>
<td>1. Knowledge 6. Beliefs about Consequences</td>
</tr>
<tr>
<td><strong>3.</strong> So you mentioned that ___ (reiterate response about benefits) ___. Do you think there are any risks caused by physical activity?</td>
<td>Beliefs about physical activity Assess for presence of perceived risks of physical activity, which may act as a barrier</td>
<td>1. Knowledge 6. Beliefs about Consequences</td>
</tr>
<tr>
<td><strong>4.</strong> Do you enjoy being physically active? <em>(Upon response, prompt why/why not)</em></td>
<td>Beliefs about physical activity Enjoyment/aversion to physical activity affects motivation to be physically active</td>
<td>13. Emotions</td>
</tr>
<tr>
<td><strong>5.</strong> How much physical activity do you think adults your age should be getting on a weekly basis?</td>
<td>Beliefs about physical activity Assess awareness of physical activity recommendations Get an idea of what is considered “acceptable” for adults their age</td>
<td>1. Knowledge 3. Social/Professional Role and Identity 9. Goals 12. Social Influences</td>
</tr>
<tr>
<td><strong>6.</strong> Based on this, do you think that you get enough physical activity on a weekly basis?</td>
<td>Personal physical activity behaviours Assess awareness of personal physical activity behaviours – compare with caregiver response</td>
<td>2. Skills 4. Beliefs about Capabilities 14. Behavioural Regulation</td>
</tr>
<tr>
<td><strong>7.</strong> Do you want to be more physically active?</td>
<td>Personal physical activity behaviours Assess motivation, perceived physical activity needs</td>
<td>4. Beliefs about Capabilities 5. Optimism 8. Intentions 9. Goals 14. Behavioural Regulation</td>
</tr>
<tr>
<td><strong>8.</strong> Can you think of anything that makes it difficult for you to be physically active?</td>
<td>Perceived barriers to being physically active</td>
<td>4. Beliefs about Capabilities 5. Optimism 7. Reinforcement 9. Goals</td>
</tr>
<tr>
<td><strong>9.</strong> Can you think of anything that makes it easier for you to be physically active?</td>
<td>Perceived facilitators to being physically active</td>
<td>4. Beliefs about Capabilities 5. Optimism 7. Reinforcement 9. Goals</td>
</tr>
<tr>
<td>Question</td>
<td>Beliefs about physical activity</td>
<td>Corresponding TDF Component</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>------------------------------------------------------------------------------------------------</td>
<td>---------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>10. Do you think that having difficulties with your memory affects your ability to be physically active?</td>
<td>Assess whether AD/MCI diagnosis affects experiences and self-efficacy in relation to physical activity</td>
<td>10. Memory, Attention, and Decision Processes</td>
</tr>
<tr>
<td>11. Do you have any additional comments or thoughts that you would like to share?</td>
<td>Opportunity to provide any additional comments, thank participant for their times and responses, wrap up the interview</td>
<td></td>
</tr>
<tr>
<td><strong>INTERVIEW SCHEDULE – CAREGIVER PARTICIPANT</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Question</strong></td>
<td><strong>Parameter / Rationale</strong></td>
<td><strong>Corresponding TDF Component</strong></td>
</tr>
<tr>
<td>1. What does the phrase “physical activity” mean to you?</td>
<td>Beliefs about physical activity Establish a common language for the interview, beginning with “grand tour” question</td>
<td>1. Knowledge 3. Social/Professional Role and Identity</td>
</tr>
<tr>
<td>2. Do you think that there are any benefits to being physically active?</td>
<td>Beliefs about physical activity Assess for presence of perceived benefits of physical activity, which may act as a motivator/facilitator to participation</td>
<td>1. Knowledge 6. Beliefs about Consequences</td>
</tr>
<tr>
<td>3. Do you think there are any risks to being physically active?</td>
<td>Beliefs about physical activity Assess for presence of perceived risks of physical activity, which may act as a barrier to participation</td>
<td>1. Knowledge 6. Beliefs about Consequences</td>
</tr>
<tr>
<td>4. Do you think there are any risks or benefits of physical activity that are specific to (Alzheimer’s disease/Mild Cognitive Impairment)?</td>
<td>Beliefs about physical activity specific to AD/MCI Assess for presence of perceived risks of physical activity, which may act as a barrier to participation</td>
<td>1. Knowledge 3. Social/Professional Role and Identity 6. Beliefs about Consequences 10. Memory, Attention, and Decision Processes</td>
</tr>
</tbody>
</table>
told me, do you think it’s realistic for people with Alzheimer’s disease/Mild Cognitive Impairment to get the same amount of weekly physical activity as older adults without memory problems?

| 7. | If it’s okay with you, I’d like to ask you a couple questions about (name of care recipient). How much physical activity do you think (name of care recipient) gets on a weekly basis? | Physical activity behaviours  
Compare with response of AD/MCI participant for fact-checking |
|---|---|---|

| 8. | We were talking a bit earlier about how much physical activity you think older persons and persons with Alzheimer’s disease/MCI should get, and whether or not they should be getting the same amount of physical activity in a week. Based on what we discussed, do you think that (name of care recipient) is getting enough physical activity on a weekly basis? | Physical activity behaviours  
Compare with response of AD/MCI participant for fact-checking |
|---|---|---|

| 9. | Do you think that (name of care recipient) should be more physically active than they are right now? | Physical activity behaviours  
Assess motivation, perceived physical activity needs |
|---|---|---|

| 10. | If it’s okay with you, I’d like to ask you a question about (name of care recipient) being diagnosed with Alzheimer’s disease/Mild Cognitive Impairment and how that affects what they’re able to do on a day-to-day basis. Since (name of care recipient) was diagnosed, do you think that their physical activity level has changed? Could you elaborate? | Beliefs about effects of cognitive impairment on physical activity participation  
Assess whether AD/MCI diagnosis impacts physical activity levels and nature of impact |
|---|---|---|

| 11. | Is there anything that makes it difficult for (name of care recipient) to be physically active? | Perceived barriers to encouraging physical activity  
Goals (TDF) |
<table>
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<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>15.</td>
<td>Do you have any additional comments or thoughts that you would like to share?</td>
<td><strong>Opportunity to provide any additional comments, thank participant for their times and responses, wrap up the interview</strong></td>
</tr>
</tbody>
</table>
Appendix 7  Participant Thank-you Letter


PARTICIPANT THANK-YOU LETTER

Dear Participant,

I would like to thank you for your participation in this study. As a reminder, the purpose of this research study is to explore the experiences, beliefs, and influences on physical activity participation for older adults with Mild Cognitive Impairment and Alzheimer’s disease. The results of this study will help inform the development of community-based programs promoting physical activity for older adults with Mild Cognitive Impairment and Alzheimer’s disease.

Please remember that any data pertaining to you and your family member as participants will be kept confidential. Once all data are collected and analyzed for this study, the results of the study will be shared with the scientific community and community stakeholders interested in physical activity promotion. This will be done through presentations at seminars and conferences, publication in scientific journals, and as a part of a graduate thesis. If you are interested in receiving more information about the results of this study, would like a copy of your interview transcript, or have any questions or concerns, please feel free to contact via the phone number or email address provided at the end of this letter.

As with all research projects involving human participants, this project has received ethical approval through The Sunnybrook Research Ethics Board. Should you have any comments or concerns resulting from your participation in this study, please contact the Chair of the Sunnybrook Research Ethics Board at (416)-480-6100 ext. 88144.

Once again, thank-you for your contribution.

Dr. Sandra Black
Sunnybrook Health Sciences Centre
416-480-4551
Sandra.black@sunnybrook.ca
Appendix 8  Study Visit Schedule

1. Screen dyad
2. Consent dyad
3. Collect demographic information
4. Semi-structured interview
5. PASE or IPAQ
6. Administer NPI (caregiver only)
7. Study completion
MEANINGFUL ACTIVITIES ARE MORE IMPORTANT THAN MEETING GUIDELINES

When older adults with MCI and AD and their care partners think of physical activity, there is great diversity in how individuals define this concept for themselves. Common to all concepts though is the idea that physical activity is more than just structured exercise, and that it is a broad class of activities with some embodied aspect. Recommended physical activity levels for older adults as perceived by older adults with MCI and AD and their caregivers do not refer to a prescriptive minimum weekly frequency, duration, type, and intensity as the Canadian Physical Guidelines do. Rather, the concept of recommended physical activity levels for older adults is person-specific, with an emphasis on doing as much as one can to maximize benefits and minimize risks. The end goal of physical activity for individuals with MCI and AD and their caregivers, while in some respects aligning with the goal of the Canadian Physical Activity Guidelines to promote and maintain health, largely deviates to focus on participation in meaningful activities. Physical activities can be meaningful in and of themselves, but also ensure the ability to continue participation in other non-physical meaningful activities. Physical activities are more than just behaviours, and play a role in how some older adults with MCI and AD view themselves either as “active” or “inactive” persons. In this respect, older adults with MCI and AD conceptualize physical activity in a more personally meaningful way, rather than as a health behaviour or medicine used to achieve some health state.

<table>
<thead>
<tr>
<th>THEMES &amp; DESCRIPTION</th>
<th>CODING TREE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Perception of physical activity and recommendations isn’t informed by guidelines (1.1)</td>
<td>1.1 Perception of physical activity and recommendations isn’t informed by guidelines</td>
</tr>
</tbody>
</table>
| To determine a base understanding of how persons with cognitive impairment and their care partners conceptualize physical activity, participants were first asked to define physical activity in their own terms. Participants provided a diversity of responses, with no two individuals defining physical activity in the same way. For some participants, this was a difficult question to answer, and non-specific, vague, or uncertain responses were provided (1.1.1.1.1.3). In looking at aspects from all definitions, however, common threads emerged. When defining physical activity, multiple participants spoke of the exercise as a way to move nutrients and waste through the body (1.1.1.1.1.1.1), energy expenditure (1.1.1.1.1.1.2), and moving one’s bones and muscles (1.1.1.1.1.1.3). These highly embodied definitions of physical activity highlight the roles of the cardiovascular, respiratory, digestive, and musculoskeletal systems in physical activity point to an embodied (1.1.1.1.1.1), physical concept of physical activity for persons with dementia and their care partners. Included in definitions by some participants was a setting for physical activity, with being outdoors as a component of their definition (1.1.1.1.1.1.2). The scope of what constitutes physical activity was also very broad, which for some participants was the opposite of being sedentary (1.1.1.1.1.1.4). Consistent with this broad concept of “physical activity” was the recognition that physical activity is more than just structured exercise (1.1.1.2.1). Examples provided by participants of physical activities were similarly diverse (1.1.1.1.2.2), ranging from unstructured physical activity (1.1.1.1.2.2.1) like activities of daily living (1.1.1.1.2.2.1.1) and taking the stairs instead of the escalator (1.1.1.1.2.2.1.6), to occupational activities (1.1.1.1.2.2.2), to structured activities (1.1.1.1.2.2.3) like yoga (1.1.1.1.2.2.3.17) and water aerobics (1.1.1.1.2.2.3.2). Walking was the most commonly referenced example of physical activity, both as a structured and unstructured activity.

| 1.1.1.1.1.1 - Circulatory |
| 1.1.1.1.1.1.2 - Energy Expenditure |
| 1.1.1.1.1.1.3 - Moving your body, bones, and muscles |
| 1.1.1.1.1.1.4 - Respiratory |
| 1.1.1.1.1.1.2 - Getting outside |
| 1.1.1.1.1.1.3 - Non-specific, vague, or uncertain definition |
| 1.1.1.1.1.4 - The opposite of sedentary |
| 1.1.1.1.1.2 - “Physical activity” is more than just structured exercise |
| 1.1.1.1.1.2.1 - Identified difference between physical activity and exercise |
| 1.1.1.1.2.2 - Diverse examples of physical activity |
| 1.1.1.1.2.2.1 - Non-structured physical activity |
| 1.1.1.1.2.2.1.1 - Activities of daily living |
| 1.1.1.1.2.2.1.2 - Around the house |
| 1.1.1.1.2.2.1.3 - Gardening |
| 1.1.1.1.2.2.1.4 - Going out to the store |
| 1.1.1.1.2.2.1.5 - Standing instead of sitting |
| 1.1.1.1.2.2.1.6 - Taking the stairs instead of the escalator |
Thus, how persons with MCI and AD and their care partners define and identify physical activity is both person-specific and broad.

In keeping with this, how older adults with cognitive impairment conceptualize recommendations about physical activity (1.1.2) is both person-specific and not delimited to a specific minimal frequency, intensity, type, and duration as stipulated in the Canadian Physical Activity Guidelines for Older Adults. With the exception of one care partner who had experience working in the fitness industry (1.1.2.1.1 / 1.1.2.1.4), participants either had never thought about the concept of age-specific physical activity recommendations, much less heard of the Canadian Physical Activity Guidelines (1.1.2.1.2), or were uncertain about what the guidelines recommended (1.1.2.1.3). Canadian Physical Activity Guidelines for older adults recommend accumulating at least 150 weekly minutes of activity, which was iterated, which is at odds with the concept of recommended activity voiced by participants. Firstly, despite the question being posed as a weekly recommendation, participants framed recommendations on a daily instead of weekly basis (1.1.2.2.2). While the Canadian Physical Activity Guidelines don’t indicate a specific frequency of physical activity, older adults with MCI and AD and their caregivers noted that physical activity should be a daily occurrence and utilized throughout the day to break up sedentary behaviour. The current Canadian Physical Activity Guidelines do not discuss sedentary behaviour as part of their recommendations for older adults, but the concept of movement on a daily basis as a way to oppose sedentary behaviour is progressive. The Canadian Physical Activity Guidelines for youth have been recently republished as the 24-hour movement guidelines and include recommendations about sedentary behaviour. In this way, the ideas of older adults with MCI and AD and their care partners about recommended levels of physical activity are somewhat progressive and change faster than the speed of implementing research into public health. In terms of daily durations of physical activity, participants recommendations about the amount of daily activity that older adults should get on a daily basis ranged from 20 minutes per day on the lower end to up to an hour daily (1.1.2.2.1).

Recommendations about the intensity older adults should aim for in physical activity was highly consistent throughout participants. “Moderate” was the key. Participants largely believed that the intensity should be sufficient to engage the cardiovascular system with some stress, but not to the point of overexertion (1.1.2.2.3). How participants defined “moderate” varied between participants, with some providing target heart rates, with others describing it in terms of breaking a sweat or maintaining a specific walking speed. These recommendations of moderate intensity are comparable to recommendations from the Canadian Physical Activity Guidelines, but the methods for determining “moderate” intensity are much different. In contrast to how older adults with MCI and AD assess intensity, the Guidelines use a 20-point scale of rating of perceived exertion and the ability to maintain a conversation as indicators of intensity.
Recommended types of physical activity according to participants were varied, but centered around the notion of aerobic, balance, flexibility, and resistance training exercises. Aerobic “cardio” type activities mentioned included walking, cycling, swimming, and running, whereas stretch and strength activities like yoga, stretching, weights, and balance training (1.1.2.2.4). These largely align with what is recommended by the Canadian Physical Activity Guidelines, with a few exceptions. Aerobic and resistance types of activities are recommended, as well as balance training exercise if falls are a concern. Activity to improve flexibility, however, is not included in the guidelines, as insufficient evidence has been found to support its health benefits for older adults. One of the caregivers specifically noted being uncertain about recommendations for weight training as well.

Prior to being asked to provide specific recommendations about the frequency, intensity, type, and duration of physical activity, participants provided general rules and heuristics as their idea of recommended physical activity levels that were based on the individual in question (1.1.2.3). These heuristic recommendations ultimately centered on doing what suits the individual (1.1.2.3.2), aiming to get as much as one can to get the benefits (1.1.1.2.3.3), but not to the extent of causing harm (1.1.2.3.1).

Thus, the how older adults with MCI and AD and their care partners conceptualize physical activity and perceive its use as a health behaviour are highly personalized and do not necessarily conform with published guidelines. The notion of “guidelines” is unfamiliar to these individuals. Their ideas about recommended activity levels for older adults largely differ from published guidelines in terms of frequency, intensity, type, and duration. Moreover, participants didn’t conceptualize the “recommended” level of activity for older adults as a standardized minimum “dose” for all older adults, but rather specific to the individual and striking an optimal balance between benefits and risks associated with physical activity.

1.1.1.1.1.3 Non-specific, vague, or uncertain definition
“anything that gets you up and active” (Caregiver)
“I’m not sure how to put this [definition] so it makes sense” (Participant with AD)

1.1.1.1.1 Embodied definition of physical activity / 1.1.1.1.4 The opposite of sedentary
“Anything to get my blood flowing, get up my heart rate... just any way I can break out a good sweat” (Caregiver)
“Physical activity is any activity that... causes one to not be sedentary... but to engage in motion that... has a favourable impact on heart, lungs, strength, muscles” (Caregiver)
“Muscles Moving... Opposite to sedentary - getting up, moving about in various ways” (Caregiver)
“Physical activity is doing the things that require you to use your muscles and... your energy” (Participant with AD)
“It [physical activity] means to use your body as much as you can in order to implement as many muscles as you have in the body” (Participant with MCI)
“It can be as simple as not sitting down all day... getting up and walking around, but also participating in things that are more rigorous. Like exercise programs.” (Caregiver)
“it [physical activity] means... not sitting in one place all the time... Whenever you can, sit for little while, get up, walk, come and sit.” (Participant with AD)

1.1.1.1.2 Getting outside
“Get you going, you're outside” (Participant with AD)
“getting a bit of fresh air” (Participant with AD)

Unstructured activities (1.1.1.2.1.1.)
“Physical activity... it doesn't necessarily mean going to a gym or going cycling. It can just be that you're active, even within your own house, or workplace, or whatever. Like climbing the stairs instead of taking the elevator. That kind of thing.” (Caregiver)
“But also, like I'm on my feet pretty much in the morning, just tidying things, and you know - just housework... so, I think I'm relatively active” (Participant with MCI)

1.1.1.2.2.3 Structured activities
“...and I even believe yoga is a type of physical activity too, and as to relax.” (Caregiver)

1.1.1.2.2.4 Walking
“Generally walking is a physical activity I do... walking flat - I do stairs occasionally if I'm confronted with them and they're not too many of them... far as walking’s concerned - easy enough to do, and exercises my leg muscles, lower body.” (Participant with MCI)
“It can be a variety of things - walking, swimming, playing games like tennis, umm... just taking a walk.” (Participant with MCI)

1.1.1.2.1.2 Identified difference between physical activity and exercise
“Physical activity probably involves a lot more activities than just straight exercise. It [exercise] is more routinized and more of a different regime, where physical activity - well, it's a lot of different movements.” (Participant with MCI)
L.B.: would you consider physical activity and exercise to be the same thing, or do you think there's distinction between the two?
Participant with AD: No, I think they're all part of the same thing, really.

1.1.2.1.2 Never head of guidelines / 1.1.2.1.3 Uncertain about guidelines / 1.1.2.3.2 Doing what suits you
“I never thought about [recommendations for] other people. I have no idea... I guess it sort of depends on where you live, what’s accessible, and... I've never thought about other people.” (Participant with MCI)
“I'd say keep it up as much as you can as long as you can. And then after - be sensible about it... but to try and I think - the more you can do, for as long as you can do it, the better it is, but that depends a lot on one's personal abilities because everybody ages slightly differently and what one person can do at ninety another person can't. But you know, you should probably get as much activity as you can for as long as you can.” (Caregiver)
“I - I couldn't summarize it [physical activity recommendation] in a number of things, but I think that the more the better, actually... I think you, you know, you have to know - who’s the person you're talking about. Are they putting themselves in jeopardy if they're doing too much or the wrong kind of thing?” (Participant with AD)

1.1.2.3.3 Enough to get the benefits
“They [older adults] should be getting enough so that [it] gives you energy.” (Participant with AD)

1.1.2.3.1 Not hurting yourself
“I haven't the faintest idea... As much as you can get, within reason, without hurting anything, and without destroying something else.” (Participant with MCI)

1.1.2.2.2 Frequency / 1.1.2.2.2.1 A little bit everyday
“I think everybody [older adults] should try to get some kind of exercise, even if it's walking. If you can get out there every day and do something, I think it's fantastic. I think that people have to, if they want to have a good life as a senior, they have to keep moving. I really believe that, because once you stop using it, you lose it.” (Caregiver)
“I think regularly every day - we should form a habit of a having your [physical activity] time set, right? From this time to this time, your breakfast. After your breakfast, you relax, then I - I do [walking]. I have a long hallway.”
1.1.2.2.2 Break up sedentary behaviour

“Every single day, and I would recommend a full hour, however you're going to break that up... In my mum's case, we have a personal support worker... If it's bad weather, she'll even just get her out into the hallway of her condo and she'll go up and down you know, for a few minutes. Physiotherapists that I've talked to with elderly people suggest they get up every hour.” (Caregiver)

1.1.2.2.3 Intensity

“Well at my age I think you have to think of safety... so moderately? Moderately active, I guess.” (Participant with MCI)

“I think it [intensity] should be as - as close to pushing cardio as they can because you know, unless you exercise the heart muscle, it's decaying really... to the best of their ability, they should be moving in such a way that they actually put a little bit of tension on that heart muscle... once you get into a situation with atrophy, it's too late.” (Caregiver)

1.1.2.2.4 Type

“I think you do need to do some cardio activity... and most people should do some weights... and then you need to do things that help you with your balance, that sort of thing. So you need a range of activities, really.” (Caregiver)

“Well I guess the best one or the prime one would be walking... then after that it - depending on what you're feeling like or what you do, or what you have been doing in the past, you could exercise and, and do [a] run, and go to a... what do you call those places where they do it? A gym.” (Participant with AD)

“Young, for one thing... if you do [yoga]... make sure it's really low-level kind of yoga.” (Caregiver)

“Strength training? Umm, I think it's important, although I don't know how much is, how much to do.” (Caregiver)
Appendix 10  Statistics Canada Open Licence Agreement

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