

# Perceived Barriers to Exercise among Older Adults with MCI and Early Dementia

by

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## **Author's Declaration**

I hereby declare that I am the sole author of this thesis. This is a true copy of the thesis, including any required revisions, as accepted by my examiners.

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## **Abstract**

Increasing evidence suggests that exercise can benefit physical and cognitive function among older adults with mild cognitive impairment (MCI) and early dementia (MCI/dementia). Unfortunately, many older adults with MCI/dementia are not sufficiently active to achieve these benefits. Older adults with MCI/dementia experience barriers to exercise, some of which may be shared with older adults in general. There are likely to also be factors unique to their condition. Further, the social-ecological model (SEM) suggests that characteristics of the social and physical environmental factors may interact with individual factors and play important and dynamic roles in influencing health behaviours, including exercise. The objective of this study was to explore and characterize the perceived barriers, motivators, and facilitators to exercise among community-dwelling older adults with MCI/dementia guided by the SEM as a framework, from the perspectives of both older adults with MCI/dementia and their care partners. Additional objectives were to explore the perceived acceptability of exercise options among older adults with MCI/dementia and their care partners and to explore the supports and accommodations that may be needed to create inclusive conditions for persons with MCI/dementia to participate in community-based exercise programs. Ten older adults with MCI/dementia and 7 care partners were conveniently recruited to the study. Perspectives, experiences, and opinions of both persons with MCI/dementia and their care partners regarding exercise among persons with MCI/dementia were gathered qualitatively through four focus group discussions. Focus groups ranged in size from 3 to 6 participants. Pairs of focus groups, one for each participant group, ran simultaneously with a separate moderating team for each group. Group discussions were audio-recorded, transcribed verbatim, and reviewed to ensure consistency. Data analysis followed the general inductive thematic approach outlined by Braun

and Clarke (2006). Thematic analysis revealed a complex and dynamic interplay between factors across levels of the SEM influencing exercise behaviour among persons with MCI/dementia. Key themes indicate that persons with MCI/dementia and their care partners viewed exercise as a positive, meaningful, and beneficial activity that had physical, mental, and social benefits. However, several barriers to exercise participation emerged including low intrinsic motivation, physical and mental health challenges and stigma against dementia. Despite challenges to engage in exercise, external support at the individual and community level could help overcome barriers. Low motivation to exercise among persons with MCI/dementia could be mediated by encouragement from their care partners and availability of enjoyable, social exercise opportunities. By providing transportation and acting as an exercise companion, the care partners could also help the person with MCI/dementia's physical and cognitive limitations. Further, access to exercise opportunities that meet the individual physical and mental needs of the person with MCI/dementia could reduce the negative impact of physical and mental challenges experienced by persons with MCI/dementia on exercise engagement. The results suggest that increasing availability of preferred exercise opportunities, such as walking outdoors and exercise in social settings with others with whom they identify, is likely a worthwhile venture that may motivate and enable exercise among persons with dementia. Future research should determine and assess strategies to augment motivators and facilitators to exercise and reduce barriers, especially at the social and community-levels. Results should, however, be interpreted with caution as this study included primarily active participants from a single region and future studies should specifically target persons with MCI/dementia who are sedentary and from broad social and geographical environmental, as the factors that influence exercise are likely to be different.

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## **List of Abbreviations**

**AD** – Alzheimer’s disease

**ADLs** – Activities of Daily Living

**CSEP** – Canadian Society for Exercise Physiology

**MCI** – Mild Cognitive Impairment

**SEM** – Social-Ecological Model

**SOCQ** – Stages of Change Questionnaire

## **1.0 Introduction and Overview**

The number of older adults in Canada is expected to grow, with older adults accounting for almost a quarter of the entire population of Canada by 2050 (Statistics Canada, 2011). The 2016 census indicated that Canada's 65 years and older population is greater than the number of youths 14 years and under for the first time (Statistics Canada, 2016b). Population projections suggest that the gap between these two groups will only widen in what is termed a "generational shift" (Statistics Canada, 2016b).

Aging typically is accompanied by decline in physical and cognitive function as well as functional disability (Anton et al., 2015, Bherer, Erickson, & Liu-Ambrose, 2013). Cognitive and physical decline often occur together and are experienced to varying degrees among aging adults (Atkinson et al., 2005). In addition to age-associated changes in cognitive function, some older adults have faster cognitive decline than is expected for a given age, termed as mild cognitive impairment (MCI) or dementia (Anton et al., 2015).

Dementia is defined as a clinical syndrome of cognitive decline and impairment that is severe enough to interfere with social, functional, or occupational functioning. The prevalence of dementia in Canada is expected to double within the next generation, with direct and associated costs reaching upwards of \$153 billion dollars per year (Smetanin et al., 2011). Dementia has a profound impact on Canadian society, whether measured in economic or social costs (Alzheimer's Society, 2016). Currently, there is no cure or disease modifying treatment for most dementias. Therefore, preventative measures are important for slowing the progression of the disease as well as for modifying the trajectory of the impact of dementia. One factor that appears to modify the rate of cognitive decline and the risk of dementia is exercise (Colcombe & Kramer,

2003, Larson et al., 2006, Laurin, 2001, Taaffe et al., 2008). However, older adults face many barriers to exercise, individuals with MCI and/or dementia (MCI/dementia) perhaps more so.

Relatively few studies have investigated the unique barriers to exercise faced by older adults with MCI/dementia (Cedervall et al., 2014, Cedervall & Aberg, 2010, Chong et al., 2014, Dal Bello-Haas, Connell, Morgan, & Crossley, 2014, Malthouse & Fox, 2014, Suttanon, Hill, Said, Byrne, & Dodd, 2012, Tak & Uffelen, 2012, Yu & Kolanowski, 2009, Yu, Kay-Savik Wyman, & Bronas, 2011). A recent systematic review identified 7 studies examining barriers to either exercise or physical activity among persons with dementia (Van Alphen et al., 2016a). However, studies are currently limited by a focus on a specific exercise program, mode, or intervention, small sample sizes, poor representativeness (more often males, sometimes recruited from drug trials), restrictive methods (interviews rather than focus groups), and the presence of the care partner during interviews. Reviews identified few community barriers (Stubbs et al., 2014, Van Alphen et al., 2016a,) which one study suggested was due to limited probing of community-level factors (Malthouse & Fox, 2014). This suggests that the list of factors that influence exercise behaviour among persons with MCI/dementia may be incomplete. There is also a poor understanding of preferred exercise options and the accommodations and supports needed for this population to participate in existing programs and at existing facilities targeted to seniors or adults in general. As a result, this study seeks to understand the perceived barriers, motivators, and facilitators to exercise as well as the accommodations and supports needed for exercise which could possibly be used to inform strategies to help persons with MCI/dementia achieve exercise levels for the prevention and management of dementia.

The literature review will provide an overview of the cognitive and physical changes associated with aging as well as the benefits of physical activity and exercise to cognitive and

physical function among persons with MCI/dementia. Factors that influence exercise among older adults and, specifically, persons with MCI/dementia are inclusive of barriers, motivators and facilitators and will be reviewed. Finally, the study rationale, objectives, and methodology are outlined.

## **2.0 Literature Review**

### **2.1 Aging and Cognitive Decline, MCI, and Dementia**

Aging is often accompanied by both cognitive and physical decline, which may contribute to loss of functional independence and decreases in quality of life (Atkinson et al., 2005, Black & Rush, 2002). Cognitive decline may occur across a broad range of cognitive domains including memory, attention, and executive function (Anton et al., 2015, Bherer et al., 2013). Processing speed and working memory tends to be particularly age-sensitive (Penke et al., 2010).

Brain changes appear to accompany cognitive changes. The hippocampus, in particular, shows decreases in volume with aging (>1% per year) (Raz, Ghisletta, Rodrigue, Kennedy, & Lindeberger, 2010). However, rates of change in cerebral structural are still unclear due to insufficient evidence from longitudinal research. Cerebral function is also altered with age, showing reductions in the uptake of oxygen and glucose and reduced blood flow. Recent research has found that age-associated reductions in cerebral blood flow occurred independently of regional reductions in brain volume (Chen, Rosas, & Salat, 2011).

Although the rate of cognitive decline typically increases with age, cognitive impairment is not an inevitable consequence of aging processes (Black & Rush, 2002). However, the risk of developing mild cognitive impairment (MCI) and dementia doubles every five years after the age of 65 (Hugo & Ganguli, 2014). Dementia is diagnosed when cognitive impairment is severe enough to interfere with daily function, including social, functional, and/or occupational abilities (Hugo & Ganguli, 2014). Alzheimer's disease (AD) is a progressive dementia characterized by the accumulation of neuritic plaques and neurofibrillary tangles (McKhann et al., 1984). It is estimated that the prevalence of dementia will grow to 1.4 million people in Canada by 2031 and

to 115 million worldwide by 2015 if effective treatments or preventative measures are not implemented (Alzheimer's Society, 2016, Hugo & Ganguli, 2014). MCI is diagnosed when older adults experience a greater rate of cognitive decline than is expected for their age and educational level but retain intact daily function (Eshkoo, Hamid, Mun, & Ng, 2015, Gordon & Martin, 2013, Hugo & Ganguli, 2014), where the prevalence of MCI is thought to be four times greater than dementia (Eshkoo et al., 2015). Persons with MCI are at a greater risk of progression to dementia (Strout & Howard, 2012), with annual conversion rates of MCI to dementia of approximately 7% (Mitchell & Shiri-Feshki, 2008). Some consider MCI an intermediate state between healthy cognition and dementia, though not all persons with MCI progress to dementia (Hugo & Ganguli, 2014).

Cognitive decline may lead to apathy and irritability, which can further affect social and functional activities (Anstey & Low, 2004, Eshkoo et al., 2015). Cognitive decline is also associated with altered mood, depression and anxiety (Anstey & Low, 2004, Yates et al., 2017). Other neuropsychiatric symptoms may accompany dementia, in particular, including euphoria, irritability, and agitation, which may adversely affect social relationships and activities of daily living (ADL) (Lyketsos, Lopez, Jones, Fitzpatrick, & DeKosky, 2002).

Although the predominant perspective of dementia frames it as a relentless decline and a condition to be feared, persons with dementia can continue to lead meaningful and engaging lives. Problematizing and medicalization of those with dementia devalues the person and can lead to a loss of selfhood (Mitchell, Dupuis, & Kontos, 2013). Persons with dementia, instead, place emphasis on remaining competencies, experiencing meaning and a sense of self through activities they feel emotionally connected to (Holst & Hallberg, 2003).



## **2.2 Physical Decline among Persons with MCI and Dementia**

Physical decline experienced by older adults and, specifically, persons with MCI/dementia is wide ranging but includes decreased aerobic capacity, poorer balance and gait, and reduced muscle mass, which likely contribute to commonly reported impairment in ADLs (Tolea, Morris, & Gavin, 2015). Although physical function generally declines with increasing age, older adults with MCI/dementia experience greater physical impairment compared to those with intact cognition (Alencar, Dias, Figueiredo, & Dias, 2013).

Aerobic capacity usually decreases with aging (Burtscher, 2013), with differences of approximately 5% to 10% per decade among older adults (Fleg et al., 2005). Lower aerobic capacity leads to increased breathlessness and greater perceived exertion during daily activities (Fleg et al., 2005). Aerobic capacity is lower among older adults with dementia than those with intact cognition (Yu et al., 2011). Of note, the decline in aerobic capacity appears to be associated with the level of neurodegeneration in the brain and may be a contributor to brain atrophy (Burns et al., 2009).

Older adults with MCI/dementia are at an increased risk of mobility impairment and falls compared to cognitively intact older adults (Manckoundia, Pfitzenmeyer, d'Athis, Dubost, & Mourey, 2006, Pedersen et al., 2014, Thomas & Hageman, 2003). Performance on gait measures, such as preferred gait speed and figure of 8 walk, is worse among persons with MCI than among healthy older adults (Pedersen et al., 2014). Longitudinal studies show that persons with dementia experience a steeper decline in mobility compared to older adults who remain cognitively intact (Tolea, Morris, & Gavin, 2016). Gait dysfunction and postural instability are linked to the structural brain changes, such as decreases in whole-brain volume, which occur with dementia (Makizako et al., 2011).

Age-related declines in muscle mass and strength, known as sarcopenia, impair the ability to perform daily activities (Lauretani et al., 2003, Taylor et al., 2004b). Age-related loss in muscle mass appears to be fairly consistent at a rate of 1-2% per year over the age of 50 years among both active and sedentary aging adults (Hughes et al., 2002, Thomas, 2007). Neuromuscular weakness, a prominent symptom in persons with dementia, leads to an increase in difficulty performing ADLs and reduced functional independence, which may decrease quality of life (Thomas & Hageman, 2003).

Frailty can be defined as a state of increased vulnerability to stressors due to age-related decline across multiple systems (Alencar et al., 2013, Gray et al., 2013). Frailty is often operationally defined as a combination of three of five criteria: low strength, low energy, slowed gait speed, low physical activity, and unintentional weight loss (Fried et al., 2001). Universal decreases in physical function resulting in frailty reduce an individual's ability to be functionally independent (Chen, Mao, & Leng, 2014). Persons with cognitive impairment are more likely to be frail than cognitively intact older adults (Alencar et al., 2013, Gray et al., 2013). However, there is no consensus across literature regarding the direction of the relationship between physical frailty and impaired cognitive function (Gray et al., 2013); that is, whether cognitive impairment leads to frailty or the reverse. In combination, frailty in a person with cognitive impairment increases the individual's risk for accelerated physical and cognitive decline (Alencar et al., 2013). Consequently, there has been an increasing research focus into physical activity and exercise as preventative and therapeutic strategies to maintain and improve physical and cognitive function among older adults with MCI/dementia.

### **2.3 Benefits of Physical Activity to Older Adults with and without MCI and Dementia**

Physical activity can be defined as any bodily movement produced by skeletal muscles which results in the expenditure of energy (Caspersen, Powell, & Christenson, 1985). Exercise is physical activity that is specifically planned, repetitive and purposive towards improving or maintaining physical fitness (Caspersen et al., 1985). Physical activity guidelines recommended by the Canadian Society for Exercise Physiology (CSEP) suggest that adults over the age of 65 engage in at least 2.5 hours of moderate- to vigorous-intensity aerobic activity each week in sessions of at least 10 minutes (Canadian Society for Exercise Physiology, 2017). They further recommend taking part in strengthening activities at least twice a week to help with muscle and bone strengthening which may subsequently improve balance and posture (Canadian Society for Exercise Physiology, 2017, Ontario Brain Institute, 2013). Recent guidelines for physical activity in the prevention and therapy of dementia suggest adhering to these general physical activity guidelines for older adults (Ginis et al., 2017). Evidence suggests persons with MCI/dementia are likely to gain physical, functional, psychological, and cognitive benefits from an exercise program (De Souto Barreto, Demougeot, Pillard, Lapeyre-Mestre, & Rolland, 2015, Taaffe et al., 2008, Young, Angevaren, Rusted, & Tabet, 2015).

There is a large base of research that indicates regular exercise is associated with better health in aging. Physical activity is associated with lower risk of various diseases including cardiovascular disease, cancer, and depression as well as all-cause mortality (Blondell, Hammersley, & Veerman, 2014, Prakash, Voss, Erickson, & Kramer, 2015). Specifically, long-term prospective studies show that the relative risk of all-cause mortality decreases by 20-35% among men and women who are physically active, with evidence supporting an inverse linear dose-response in relation to volume of physical activity (Lee & Paffenbarger, 2000, Macera,

Hootman, & Sniezek, 2003). The benefits of physical activity and exercise also include better physical function, improved psychological health, and better cognitive function (Prakash et al., 2015, Warburton, Nicol, & Bredin, 2006).

The physical benefits of exercise for older adults are best documented. Exercise increases muscle mass and improves energy metabolism, arterial compliance, and functional capacity (Young et al., 2015). Further, evidence suggests that exercise plays an important role in maximizing bone mass, attenuating bone loss, and potentially reducing the risk for fractures (Gomez-Cabello et al., 2012). The benefits of exercise to physical function seem to translate into improved mobility and balance among persons with and without dementia (Asmidawati, Hamid, Hussain, & Hill, 2014, Pitkala, Savikko, Poysti, Strandberg, & Laakkonen, 2013).

The efficacy of exercise training programs among older adults for physical function seem to be consistent irrespective of cognitive status. For example, a randomized-controlled trial that assessed the impact of a 3-month exercise training intervention among cognitively health adults aged 75 years or older observed that functional balance and strength training twice a day demonstrated improvements in ambulatory capacity as assessed by walking speed, frequency and duration (Helbostad, Sletvold, & Moe-Nilssen, 2004). Similarly, among individuals with dementia, exercise training programs, whether focused on aerobic or strength training, improve walking speed and endurance, balance, and strength compared to control groups, indicating reductions in functional limitations (Bossers, 2014, Heyn, Abreu, & Ottenbacher, 2004, Pitkala et al., 2013; Steinberg et al., 2009, Toulotte, Fabre, Dangremont, Lensele, & Thevenon, 2003), indicating improvements in functional limitations. Longitudinal studies also show that exercise may reduce the likelihood of frailty in older adults. Results from one study showed that individuals who regularly exercised at baseline were less likely to develop frailty after a five-

year follow-up compared to demographically and health-matched sedentary individuals (Peterson et al., 2009).

Despite homogeneity of results regarding the functional benefits of exercise for both older adults with and without cognitive impairment, studies that include persons with dementia often have a significant number of drop-outs due to poor health, complications or hospitalizations (Rolland et al., 2007, Shaw et al., 2003). Understandably, this may alter the ability to generalize findings to more broad populations of persons with dementia as recruited sample sizes may not be fully representative. It appears to be important to tailor exercise programs to the unique needs of persons with dementia in order to attain high-compliance and adherence. This will ultimately increase the ability of persons with cognitive impairment to achieve benefits from these programs.

Physical activity and exercise also improve psychological health. Exercise interventions are associated with decreased depressive symptoms and improved self-esteem and quality of life (Taylor, Dodd, McBurney, & Graham, 2004a). A recent meta-analysis indicated that exercise training reduces depressive symptoms specifically among persons with dementia relative to control groups (Barreto et al., 2015). Evidence also suggests that exercise improves quality of life among persons with AD (Teri et al., 2003). Increases in quality of life seem to translate into better satisfaction with physical capacity and well-being among older, frail adults (Bherer et al., 2013), and is likely to carry similar benefits to those with MCI/dementia.

Longitudinal studies also show that people with higher levels of physical activity have better cognitive function and a lower risk of cognitive decline, MCI, and dementia compared to those with lower levels (Geda et al., 2010, Kirk-Sanchez & McGough, 2014, Taaffe et al., 2008,

Weuve et al., 2004). The association between physical activity and cognitive decline is supported by neuroimaging studies. Older adults (70 years or older) who were more physically active at baseline had greater volume in brain regions sensitive to atrophy later in life (e.g., hippocampus) after a 9-year follow-up (Erickson et al., 2010). Another study by Rovio and colleagues (2010) similarly showed that physical activity levels in a mid-life baseline were associated with greater volume in the prefrontal cortex 21 years later.

Randomized controlled trials also provide evidence that exercise benefits cognitive function, though evidence is not consistent. Even systematic reviews have differing conclusions, likely due to varying inclusion criteria (Smith et al., 2011, Young et al., 2015). The Cochrane review of the effects of exercise on cognitive function among older adults concludes that there is no evidence of cognitive benefits (Young et al., 2015) whereas another recent meta-analysis concludes that there are moderate positive effects across a number of cognitive domains including attention, executive function, processing speed, and memory; with similar magnitudes of effect across studies (Smith et al., 2011). The Cochrane review included fewer studies because it required measurement of peak aerobic capacity as an outcome. The Cochrane review also limited the studies to those that studied older adults with intact cognition. Of note, reviews of exercise interventions among persons with MCI/dementia find cognitive benefits more consistently than those among cognitively healthy older adults (Bherer et al., 2013, Heyn et al., 2004). Aerobic or strength training appears to improve global cognitive function and also benefit several specific cognitive domains including attention and executive function (Forbes et al., 2013, Ohman, Savikko, Strandberg, & Pitkala, 2014). Benefits to cognitive function associated with exercise may be more likely observed among persons with MCI/dementia compared to cognitively healthy older adults due to a ceiling effect of potential improvements (Bherer et al.,

2013). Given the promising benefits that are associated with exercise for older adults with cognitive impairment, it remains increasingly important to understand the factors that facilitate or get in the way of engaging in an active lifestyle.

Among persons with dementia, maintenance of routines and activity can be meaningful (Genoe & Dupuis, 2013, Phinney, 2006). Further, older adults with dementia state that meaning comes from activities that address their psychological and social needs are most meaningful, as determined by primarily by the quality of an activity rather than the type of activity (Harmer & Orrell, 2008). As a result, it is reasonable to suggest that persons with MCI/dementia could derive meaning from participation in high-quality exercise opportunities. In a study focused on exploring the meaning of competitive sports among older adults, Dionigi, Baker and Horton (2011) found that older adults competing in the World Masters Games found meaning in competitive sport through opportunities to participate, maintained health, companionship, and regular social interaction. Similarly, in a study assessing concepts of meaningful activity in the lives of community-dwelling older adults, being active and doing “as much as they possibly could” was a major driving factor for participating in activities, including leisure activities, house-hold chores, work-related tasks, and social involvement (Phinney, 2006). It is reasonable to suggest that, much like dementia-free older adults, persons with dementia may find meaning in exercise that addresses their unique needs.

## **2.4 Barriers and Facilitators to Physical Activity among Older Adults with MCI and Dementia**

Despite the physical, psychological, and cognitive health benefits of physical activity and exercise, many older adults are not regularly physically active. Results from the 2012 and 2013 Canadian Health Measures Survey indicated that only 12% of adults aged 60-79 met physical

activity recommendations, much lower than among younger adults (32%) (Statistics Canada, 2015). Trends consistently show that physical activity progressively decreases with age (Hallal et al., 2012). Levels seem to be particularly low among persons with MCI/dementia possibly due measurement error in self-report being greater in this group (Watts, Vidoni, Loskutova, Johnson, & Burns, 2013). Only one study objectively measured physical activity levels among community-dwelling older adults with and without dementia and found that persons with dementia were sedentary for a greater portion of their day compared to those with healthy cognition, performing very little physical activity (Van Alphen et al., 2016b).

Older adults, particularly persons with MCI/dementia, often experience co-morbid health conditions and functional limitations that make initiating and maintaining regular exercise challenging (Schutzer & Graves, 2004). To enable older adults with or at risk for dementia to be physically active, it is important to both identify and reduce barriers and augment motivators and facilitators for exercise. Most barriers to physical activity and exercise that exist broadly among older adults in general are likely to be relevant to persons with MCI/dementia, often to a greater degree (Burns and Zaudig, 2002). Furthermore, progressive cognitive decline may lead to an exacerbation of previously existing barriers over time (Burns and Zaudig, 2002). Research on barriers specific to physical activity and exercise among older adults with MCI/dementia is scarce. The next sections will firstly introduce a theoretical framework that will be used to discuss and identify factors that influence health behaviours in general, and exercise behaviours specifically.

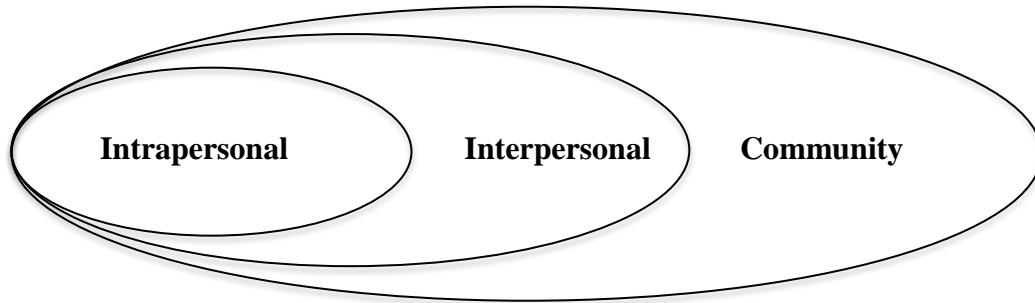
## **2.5 The Social-Ecological Model as a Framework**

In considering the wide-array of factors that influence exercise behaviour of persons with MCI/dementia, it is useful to direct attention to its determinants at multiple levels (McLeroy,



Bibeu, Steckler, & Glanz, 1988). Factors that affect participation in exercise can be classified within the conceptual framework of the social-ecological model (SEM). The SEM posits that behaviour is affected by the complex and dynamic interaction of factors on multiple levels (McLeroy et al., 1988). The levels within the SEM can be described in different ways but, for the purpose of this thesis, will include intrapersonal factors (e.g. individual characteristics, psychological, and history), interpersonal factors (e.g. formal or informal social environments and social support systems), and community factors (e.g. the built or man-made environment, policies, norms, inequalities) (**Figure 2.5**) (McLeroy et al., 1988, Sallis et al., 2006). This model was adapted from McLeroy et al. (1988) ecological model for health promotion. The SEM has the advantage over other models employed in exercise behaviour change, such as the stages of change model or self-efficacy model, in that it considers the environmental determinants of behaviour explicitly (Sallis et al., 2006).

**Figure 2.5 Social-Ecological Model**



The SEM provides a framework to understand the multi-level factors that restrict or facilitate exercise in a synergistic way. The SEM acknowledges the complex associations between individual practices, social and structural factors, and their environments and provides depth to understanding the multiple levels that may influence behaviour. Previous research regarding exercise in dementia has failed to account for the interactions between the individual and their social and physical environments, instead distinctively categorizing that which prevents, motivates, and facilitates persons with dementia to exercise. Discussion about the interaction of these factors at different levels in other studies was omitted or not even probed (Chong et al., 2014, Cohen-Mansfield, Marx, & Guralnik, 2003). Framing issues within the SEM can help to illustrate how macro-level systems (e.g. the social and physical environment) influence micro-level (e.g. individual) decisions, behaviours and attitudes (Henderson & Baffour, 2015).

Ecological models such as the SEM are regularly used in health promotion research to inform multilevel interventions that target the individual, their social environments, and the built environment and policy to better support health behaviours including exercise (Lavizzo-Mourey & McGinnis, 2003). A recent systematic review of the factors that influence physical activity

participation in community-dwelling adults with dementia failed to identify any study that purposely and specifically probed the influence of the physical environment or policy-level factors (Stubbs et al., 2014). Furthermore, the previous review did not incorporate qualitative studies in their analysis, thus, excluding the persons with dementia's experiences, perceptions and knowledge regarding different factors that influence physical activity and exercise (Stubbs et al., 2014). In absence of such studies, the authors concluded that factors related to the individual such as age and global cognition may be of greater importance for moderating physical activity participation than those factors relating to the environment (Stubbs et al., 2014). A more recent meta-analysis identified a few societal-level barriers such accessibility within the environment (Van Alphen et al., 2016a). However, primary studies included in this review indicated insufficient probes to adequately address societal and environmental issues (Malthouse & Fox, 2014). Concluding that environmental-level factors are of little importance without exploration of these factors could be misleading. In this thesis, the SEM was employed as a guiding framework in order to specifically investigate multi-level determinants (including community factors such as the natural and built environments) of exercise among persons with MCI/dementia. The SEM was used to inform the methodology, the analysis, and the interpretation of this qualitative inquiry (Henderson & Baffour, 2015).

### *2.5.1 Intrapersonal Factors that Influence Exercise*

Within the SEM, the individual is positioned as the center. This level is composed of personal factors (for example, age, sex, health status, beliefs and attitudes) (McLeroy et al., 1988). The individual is then embedded within multiple levels of influence (**Figure 2.5**), and thus, reciprocally interacts with subsequent levels. Individual behaviour and experiences are the result of the interaction of a person with their environment (Sallis et al., 2006) and, therefore, the

two are always connected. Considering domains of the SEM separately precludes the notion that an individual's "positionality", or how they position themselves in the world, is important and can change over time (Jaffe & Miller, 1994, Sallis et al., 2006).

Intrapersonal factors that broadly influence exercise among older adults include physical and cognitive status. Further, physical and mental health may influence self-efficacy and outcome expectations (Costello, Kafchinski, Vrazel, & Sullivan, 2011), which may influence motivation. Cognitive challenges such as poor memory, which influence the ability to exercise, may be more prominent among persons with dementia compared to healthy older adults due to their limited cognitive and physical function (Baert, Gorus, Mets, Geerts, & Bautmans, 2011). Prominent intrapersonal factors that influence exercise among both older adults with and without MCI/dementia are described in the following sections.

### **Physical and Mental Health**

In contrast to young adults, who cite lack of time as the most common constraint, older adults often report poor health as the leading barrier to participating in regular physical activity (Schutzer & Graves, 2004). In an investigation of community-dwelling older adults, participants most frequently reported health problems and pain as barriers to exercise (Cohen-Mansfield et al. 2003). Similarly, declining physical ability and health are associated with decreasing levels of physical activity (Booth, Owen, Bauman, Clavisi, & Leslie, 2000, Cohen-Mansfield et al., 2003). Persons with dementia also specify that both physical and mental health are prominent barriers to physical activity (Van Alphen et al., 2016a).

Physical health problems of older adults may also indirectly affect exercise participation by affected people's confidence that they can exercise (Schutzer & Graves, 2004). Some older adults believe exercise may exacerbate pre-existing health problems (including pain) and so

avoid exercise as a way to maintain current health (Cohen-Mansfield et al., 2003). Fears of chest pain, injury, or falling with physical activity may further contribute to older adults refraining from exercise (Moschny, Platen, Klaassen-Mielke, Trampisch, & Hinrichs, 2011). A number of studies have determined that poorer perceived physical ability is associated with lower physical activity among older adults (Booth et al., 2000, Cohen-Mansfield et al., 2003). Furthermore, older adults who have poorer self-perceived health status are more likely to report health as a prominent barrier to physical activity (Cohen-Mansfield et al., 2003).

Older adults with MCI/dementia have worse physical function and more frequent co-morbidities compared to cognitively healthy older adults (Schubert et al., 2006). As a result, it is reasonable to suggest that health would be an even greater barrier to exercise among persons with MCI/dementia. Older adults with dementia report that they avoid physical activity due to health conditions that cause pain during activity and also due to the risk of falling (Malthouse & Fox, 2014). In a recent focus group study among older adults with MCI/dementia, health problems and disability were reported to be the most prominent barriers to being physically active (Chong et al. 2014). In addition, among community-dwelling older adults diagnosed with MCI, illness, pain, physical limitations, and other health complaints were among the most frequently cited reasons for dropping out of a 12-month exercise trial, which had only 53% adherence (Tak & Uffelen, 2012).

Cognitive problems directly related to dementia such as memory impairment, poor attention, executive dyscontrol, aphasia, and apathy can also make participating in physical activity challenging (Cedervall & Aberg, 2010, Galik, Resnick, & Pretzer-Aboff, 2009, Van Alphen et al. 2016a). Age-related deficits in planning, self-control, organization and physical function due to physical or cognitive decline are likely to affect an individuals' ability to perform

regular exercise (Booth et al., 2000). Memory impairment may lead to feelings of insecurity and increase the possibility of getting lost in unfamiliar and even familiar environments, which can also deter older adults with dementia from being physically active (Cedervall & Aberg, 2010). In contrast, memory problems have not previously been noted as a barrier to physical activity among older adults with intact cognition (Chong et al., 2014).

Among reviews of exercise barriers in dementia, however, contrasting conclusions regarding the influence of cognition were drawn. Whereas Stubbs and colleagues (2014) found that global cognition as assessed by the Mini Mental State Exam, did not affect physical activity participation, Van Alphen et al. (2016a) concluded the problems with attention and memory appeared to inhibit participation. The prior study concluded that care partner support to engage individuals with dementia in physical activity may have compensated for cognitive status (Stubbs et al., 2014).

It is important to note that health may also be viewed as a motivator to physical activity among older adults (Boehm et al., 2013, Park et al., 2014). In a study on motivational strategies for physical activity, older Koreans reported that they believed that physical activity was associated with health benefits (Park, Elavsky, & Koo, 2014). As a result, deteriorations in health among older adults may motivate them to increase physical activity levels (Cohen-Mansfield et al., 2003). Older adults with MCI/dementia also report that benefits to health and well-being are motivators for being physically active (Chong et al., 2014, Van Alphen et al. 2016a).

### **Experience and Self-Efficacy**

Self-efficacy is defined as the belief of an individual in their own capacity to perform a course of action (Park et al., 2014). Among older adults, self-efficacy for exercise is a powerful determinant of exercise behaviours (Schutzer & Graves, 2004). Greater perceived self-efficacy

for exercise is associated with higher physical activity levels (Booth et al., 2000). However, lack of confidence in one's ability to successfully participate in physical activity deters older adults from initiating or maintaining physical activity (Costello et al., 2011). Self-efficacy for exercise is closely related to other factors such as experience, skill, and knowledge. Older adults with dementia indicate that a positive prior experience with physical activity or exercise is a major motivator to being physically active (Van Alphen et al., 2016a).

Older adults with dementia are more likely to experience feelings of insecurity (James et al., 2014, Woods, 2010), especially under circumstances when a task is difficult or unfamiliar. Perhaps as a result, older adults with MCI/dementia report preference for simple, light, and safe exercise (Chong et al., 2014). This may align with their perceived self-efficacy for this type of exercise versus more challenging, variable choices. In the long-term, participating in exercise may increase confidence among older adults with dementia (Olsen, Telenius, Engedal, & Bergland, 2015). Similarly, participating in exercise may introduce a sense of mastery, which may have positive implications on older adults' self-efficacy (Olsen et al., 2015).

As proposed by Bandura (1977), the stronger an individual's self-efficacy, the more likely that individual is to initiate and persist in a given activity. Self-efficacy may be moderated by external factors such as the social and physical environment (Stubbs et al. 2014). For example, Gecas (1972) describes that self-efficacy is sensitive to power relationships within social contexts. In this case, self-efficacy is lower when an individual is in a subordinate position (Gecas, 1972). This may be the case with MCI/dementia, where the person with MCI/dementia is often perceived in stigmatized ways by the larger social community.

### *2.5.2 Interpersonal Factors that Influence Exercise*

Surrounding the individual in the SEM is the social environment (**Figure 2.5**). The social environment is composed of the immediate relationships, friendships, and social environments within which the individual interacts (McLeroy et al., 1988). Social relationships may provide extrinsic motivation and support to accommodate individual challenges to moderate exercise behaviour. Interpersonal factors such as social support and encouragement from friends, family and health care professionals play an important role in influencing exercise participation. Consistent with Bandura's (1977) ideology of self-efficacy, when encouragement exists from these sources, older adults are more likely to participate in exercise (Resnick et al., 2002).

#### **Care Partners and Social Support**

Social support may be an important facilitator that motivates physical activity among older adults (Booth et al., 2000). Older adults' frequency of exercise is associated with the degree of social support they receive for physical activity (McAuley, Szabo, Gothe, & Olson, 2011). Social support may come from a variety of sources including care partners, family and friends.

Older adults frequently cite family support for exercise as a motivator for wanting to become active (Costello et al., 2011). Care partners to persons with dementia, in particular, can influence physical activity by encouraging regular walks and providing transportation to facilities designated for exercise (Malthouse & Fox, 2014). Family care partners of persons with dementia indicate that an important benefit of exercise is that the person with dementia may be more likely to be able to independently complete ADLs (Karuncharemanit, Hendricks, & Toye, 2015). Because individuals with dementia may depend on the support of their partners for transportation or even to find their way around their community (Van Alphen et al., 2016a), it is



likely that care partner support may modify intrapersonal predictors of exercise (Stubbs et al. 2014).

Unfortunately, opportunities for physical activity outside of the house among older adults with dementia may also be restricted if care partners are anxious about exercise, sometimes due to the risk of falling or becoming lost (Malthouse & Fox, 2014). Furthermore, care partners of persons with dementia experience high rates of depression, stress, and physical health problems themselves compared to other older adult partners (Zhu et al., 2015), which may restrict their own motivation or ability to support the exercise activities of their partners.

The actions of friends and family can also influence exercise behavior, particularly by partnering in exercise programs. Exercising with others motivates older adults to increase physical activity levels (Cohen-Mansfield et al., 2003). Further, persons with dementia may need a companion during exercise for safety or for transportation, which means friends and family may be critical to enabling exercise as well as motivating. Indeed, persons with MCI/dementia indicate that lack of a companion is a major barrier to participating in physical activity (Chong et al., 2014, Van Alphen et al., 2016a).

### **Health Care Providers**

Some suggest that family physicians may be the most effective for giving exercise advice to older adults (Schutzer & Graves, 2004). Older adults with chronic health conditions visit their family physician more often than younger populations (Schutzer & Graves, 2004). In a survey of 146 older adults in public housing, 94% of the respondents reported visiting their physician at least once within the past year (Balde, Figueras, Hawking, & Miller, 2003). Both older adults with healthy cognition and individuals with MCI/dementia report that they are likely to modify their physical activity levels after conversations with their family physicians (Chong et al., 2014,

Cohen-Mansfield et al., 2003, Schutzer & Graves, 2004). Older adults who receive exercise advice from their physician, on average, perform more moderate exercise per week than those who do not receive advice (Balde et al. 2003).

Unfortunately, studies indicate that physicians do not regularly give advice regarding physical activity to their patients (Balde et al., 2003, Calfas et al., 1996). One survey indicated that only 62% of respondents ever received advice regarding exercise from their physicians (Balde et al., 2003). Barriers to physician intervention include lack of time during office visits, lack of training, and perceived effectiveness as behavioural counsellors (Calfas et al., 1996).

### *2.5.3 Community Factors that Influence Exercise*

Community-level factors that influence behaviour include the physical environment as well as legislation and policies that regulate society (McLeroy et al., 1988). The physical environment includes aspects related to natural factors, such as weather or geography, but also factors related to the built environment, such as transportation, perceived safety, community design, accessibility, and opportunity (McLeroy et al., 1988, Sallis et al., 2006).

### **Environment**

The built and natural physical environment can be barriers to exercise for older adults (Moschny et al., 2011, Schutzer & Graves, 2004). This is also true for older adults with MCI/dementia (Chong et al., 2014, Van Alphen et al., 2016a). Commonly cited environmental barriers to physical activity include the accessibility and quality of facilities and weather (Chong et al., 2014, Van Alphen et al., 2016a). Transportation, geographical location, and perceived safety may also be barriers to initiating and maintaining exercise among older adults and persons with dementia specifically (Van Alphen et al., 2016a).

Sidewalks, parks, fitness facilities, and recreation centers make it easier for people to be active (Schutzer & Graves, 2004). Conversely, lack of these resources, or perceived lack of, is associated with less frequent initiation and maintenance of physical activity (Booth et al., 2000, Moschny et al., 2011). For example, in a study that examined distance as a barrier to use of a fitness program for managed Medicare enrollees, older adults indicated that their geographic location largely determined participation in the organized physical activity program (Berke et al., 2006). In this study, distance to facilities was correlated with the frequency of participation (Berke et al., 2006). Individuals living in rural or remote locations are particularly likely to identify environmental aspects such as distance or geographical location as barriers to exercise (Boehm et al., 2013).

Affordable transportation may also be an important determinant when exercise facilities are not within walking distance. In particular, transportation might be an important barrier if the person does not drive. With aging, some individuals give up or lose their driving license or reduce driving in challenging conditions (e.g., bad weather, bad traffic, at night) (Moschny et al., 2011). Among older adults with MCI/dementia, this is particularly common. With a reduction or cessation of driving, reliance on public transport or another individual (driver) increases. Use of public transport is not only time-consuming but also may evoke uncertainty and exhaustion, especially among individuals with mobility issues (Moschny et al., 2011). Research has shown that older adults cite limited public transport as a barrier to being active (Wilcox, Oberrecht, Bopp, Kammermann, & McElmurray, 2005), specifically due to its inconvenience (Holley-Moore & Creighton, 2015). Among persons with dementia, concerns for safety and security may result in infrequent use of public transportation (Taylor & Tripodes, 2001). Furthermore, older adults with dementia report that they do not like relying on care partners for transportation

(Chong et al., 2014, Tak & Uffelen, 2012). Research has also shown that older adults with dementia experience feelings of perceived losses of personal freedom and increasing reliance on care partners (Malthouse & Fox, 2014), partly due to lack of accessibility by way of transportation.

Safety of the environment also contributes to physical activity levels among older adults. People who live in neighborhoods with high crime rates are less likely to be physically active (Schutzer & Graves, 2004). More generally, poor perceived neighbourhood safety deters older adults from becoming physically active (Booth et al., 2000). In particular, fear for safety, including lack of safe places to exercise and presence of animals and traffic, is associated with reduced walking as a form of exercise (Centers for Disease Control and Prevention, 1999, Heath & Stuart, 2002).

Conversely, low cost activities and a conducive environment may promote physical activity and exercise among older adults (Mathews et al., 2010). As older adults reach retirement, compensatory financial support, such as pensions as well as cut backs on paid work by care partners; devoting greater proportions of spending allocated towards dementia health care, and fewer financial resources, may drastically influence accessibility and opportunities to exercise (Brodaty & Donkin, 2009). Environmental factors such as safe footpaths, connected street networks, public open spaces and accessible shops facilitate exercise among older adults (Boehm et al., 2013, Booth et al., 2000), though some of these factors may be less facilitative among older adults with dementia.

#### *2.5.4 Interactions across the SEM*

The individual and the social and physical environmental interactively influence exercise and physical activity (McNeill, Wyrwich, Brownson, Clark, & Kreuter, 2006, Yi et al., 2016). The interaction between these factors translates into complex and dynamic situations that influence exercise participation and experiences among older adults with MCI/dementia. Individual deficits may magnify the effect of social or environmental barriers. Conversely, social and environmental supports may counteract individual deficits.

Physical and cognitive deficits, including memory loss and mobility issues, have the potential to exacerbate previously identified environmental barriers. Older adults with MCI/dementia experience more significant functional limitations than older adults without cognitive impairment and may have more difficulty maneuvering the environment, especially when it is not age or dementia-friendly (Benzinger et al., 2014). The docility hypothesis posits that individuals with lower functional capacity are more vulnerable to environmental demands than those with high capacity (Lawton & Nahemow, 1973). Poor availability of exercise programs that accommodate their challenges is a barrier that is often cited among older adults with MCI than among cognitively healthy older adults (Chong et al., 2014). This is likely to become a more important determinant of exercise behavior as cognitive function deteriorates (Chong et al., 2014). Persons with MCI/dementia would likely benefit from programs and facilities designed to accommodate their unique needs (Chong et al., 2014, Cohen-Mansfield et al., 2003).

Social support may also compensate individual challenges. Social support including motivation and encouragement may act to increase exercise levels among persons with MCI/dementia, especially in the presence of low intrinsic motivation (Cedervall & Aberg, 2010).

Provision of supervision or safety may help overcome individual health challenges. Individual behavioural choices may further be influenced either consciously or unknowingly by the social and cultural networks with which they interact with (McLeroy et al., 1988). On a higher level, social advocacy on behalf of individuals has the potential to bring about policy change, which may eventually change community-level barriers (Sallis et al., 2006).

Accessibility in the physical environment can counteract individual-level barriers such as health and intrinsic motivation. For example, appealing neighbourhood characteristics can influence intrinsic motivation for exercise, and particularly walking, among older adults (McNeill et al., 2006). Conversely, low self-efficacy, intrinsic motivation and lack of social support may restrict an individuals' ability to make use of social support and available programs and facilities (McNeill et al., 2006).

In exploring how the environment may moderate exercise behaviour, it is important to consider that the individual's perception of the environment may be more important than the actual environment. For example, factors such as convenience, accessibility, and safety are determined both by the environment and the individual's perceptions of the environment. In fact, how one perceives the world can shape their actions and experiences in profound ways (Jaffe & Miller, 1994). The social or cultural contexts individuals find themselves, what Jaffe and Miller (1994) term structural embeddedness, can also play an important role in how individuals come to understand themselves and the world around them.

Policy development and implementation also influence behavior, including exercise behaviour. Policy-level factors overlie the entire SEM within the community-level (**Figure. 2.5**) and have the ability to influence every level of the model, from intrapersonal to physical

environment. Examples of influential policies that affect both intrapersonal and interpersonal levels include policies regarding public transportation, government subsidized health care and disability funding, supports for accessibility to exercise and recreational facilities, and health and environmental regulation. However, there currently exists limited research regarding the potential influence of such policies on the physical activity and exercise behaviours of older adults in general, and even less among persons with MCI/dementia (Sallis et al., 1998).

Unfortunately, multi-level approaches to understanding the factors that influence exercise among persons with MCI/dementia are scarcely adopted. There is no published research that discusses the interaction of multi-level influences of the social and physical environment on exercise behaviours of persons with MCI/dementia.

## **4.0 Current Study**

### *4.0.1 Study Rationale*

The prevalence of dementia in Canada is expected to reach 1.4 million by 2031 (Alzheimer's Society, 2016). Since there is no treatment or intervention to reverse or slow the progression of dementia, preventative measures are crucial. Physical activity is one potential strategy. Older adults with MCI/dementia are likely to gain cognitive, physical, mood and functional benefits from physical activity (Ginis et al., 2017). Unfortunately, few older adults, including individuals with MCI/dementia, are sufficiently physically active (Ontario Brain Institute, 2013, Public Health Agency of Canada, 2012, Statistics Canada, 2015). Only 12% of older Canadians met recommended physical activity guidelines in 2013 (Statistics Canada, 2015). Persons with MCI/dementia are more inactive than older adults with healthy cognition (McGuire, 2014).

Persons with MCI/dementia may experience barriers to physical activity and exercise that are shared with older adults, in general. However, persons with MCI/dementia are also likely to experience barriers unique to their condition. In fact, the barriers to physical activity among individuals with MCI/dementia are poorly understood. Relatively few studies have investigated barriers to physical activity among persons with MCI/dementia (Cedervall & Aberg, 2010, Cedervall et al., 2014, Chong et al., 2014, Dal Bello-Haas et al., 2014, Malthouse & Fox, 2014, Suttanon et al., 2012, Tak & Uffelen, 2012, Yu & Kolanowski, 2009, Yu et al., 2011) and those few have often focused on AD. Most studies had very small sample sizes (2 or 4 person-care partner dyads) and explored barriers and motivators associated with participation in specific exercise modes or programs. Of the studies of barriers to physical activity among persons with MCI/dementia, only 5 were conducted among samples of more than 4 persons with dementia –



care partner dyads (Cedervall et al., 2015, Chong et al., 2014, Malthouse & Fox, 2014, Suttanon et al., 2012) and two of these investigated barriers to general physical activity rather than a specific exercise mode or program (Chong et al., 2014, Malthouse & Fox, 2014). Of the two studies examining barriers to general physical activity, one included people with healthy cognition, subjective cognitive impairment, and MCI but not care partners, which appear to be a major factor in determining physical activity practices among persons with cognitive impairment (Van Alphen et al., 2016a). The other study only recruited care dyads where the person with dementia was participating in drug trials. These people are likely to be more active and have fewer co-morbidities than persons with dementia in general. As a result, the barriers and relative importance of barriers to physical activity are likely to be different.

There are other weaknesses to existing studies. Most studies also used interview format and only one study used focus groups to elucidate the barriers to physical activity among persons with MCI/dementia (Chong et al., 2014). Use of focus groups instead of interviews as a qualitative research technique may elicit a greater breadth of responses and discussion and, thus, broaden the scope of subsequent analyses and conclusions (Malthouse & Fox, 2014). Focus groups serve to provide a naturalistic advantage and serves to elicit information from a combined local perspective based on a synergistic social environment while allowing the researcher to remain sensitive to topics pertinent to the research objectives. In addition, most research has been conducted among male persons with MCI/dementia, which may be different than the female experience (Moschny et al., 2011). It is then essential to gather the perceptions and experiences from an inclusive perspective in order to translate knowledge into practical solutions that will aid in healthier living for persons with MCI and early dementia.

Furthermore, previous research regarding exercise in dementia has failed to account for the multiple levels of influence between the individual and their social and physical environments, instead distinctively categorizing that which prevents, motivates, and facilitates persons with dementia to exercise. Discussion about the interaction of these factors at different levels was omitted or not even probed (Chong et al., 2014, Cohen-Mansfield et al., 2003). This could be misleading as little importance to social and physical environmental factors is given. Framing issues within the SEM can help to identify barriers at multiple levels and illustrate how macro-level systems (e.g. the social and physical environment) influence micro-level (e.g. individual) decisions, behaviours and attitudes (Henderson & Baffour, 2015). The SEM provides a framework to understand the interconnections between multi-level factors that restrict or facilitate exercise in a dynamic way.

Using the SEM as a guiding framework, the overarching aim of this study was to identify and understand the barriers and facilitators of exercise among persons with MCI/dementia from the perspectives of persons with MCI/dementia and their respective care partners. This study further investigated what the ideal exercise program might look like and specific supports and accommodations necessary to enable persons with MCI/dementia to participate in existing programs and at existing facilities.

## **4.1 Study Goals and Objectives**

### *4.1.1 Overall Study Purpose*

Although there is substantial research identifying the barriers to physical activity and exercise among community-dwelling older adults (Cohen-Mansfield et al., 2003, Costello et al., 2011, Lees, Clark, Nigg, & Newman, 2005, Mathews et al., 2010, Park et al., 2014, Schutzer & Graves, 2004), relatively little is known regarding the unique and overlapping barriers to

physical activity among older adults with MCI/dementia (Cedervall & Aberg, 2010, Cedervall et al., 2014, Chong et al., 2014, Dal Bello-Haas et al., 2014, Malthouse & Fox, 2014, Suttanon et al., 2012, Yu & Kolanowski, 2009, Yu et al., 2011). Furthermore, no published research has specifically probed the influence of barriers and facilitators at multiple levels of the SEM. This lack of knowledge limits the development of exercise programs and policies that best suit the needs of persons with MCI/dementia.

The goal of the present study was to identify and characterize perceived barriers as well as motivators and facilitators to participation in regular exercise among older adults with MCI/dementia from the perspectives and experiences of persons with MCI/dementia and their care partners. Specifically, this study explored the barriers to and accommodations and supports needed for persons with MCI and early dementia to meet physical activity recommendations at the intrapersonal, interpersonal and community levels of the SEM. The study also explored the accommodations and supports needed to enable participation in current programs and at existing facilities (e.g., seniors centres, YMCA, private fitness facilities) to better understand how we can create inclusive conditions for exercise.

#### *4.1.2 Study Objectives*

1. To explore current perceptions and practices of exercise, perceived barriers, and supports needed for exercise among community-dwelling older adults with MCI or early dementia, from the perspectives of care partners as well as persons with MCI or early dementia.
2. To explore supports and accommodations needed to create inclusive conditions for persons with dementia to participate in existing exercise programs and facilities.

## **4.2 Methodology and Methods**

### *4.2.1 Epistemology*

Epistemology refers to the theory of knowledge (Carter & Little, 2007) and can be defined as the inquiry to discover the patterned reality which exists in the world (Daly, 2007). From an objective standpoint, there is a concrete and knowable reality that exists independent of our own thoughts (Daly, 2007). In this way, epistemology from an objective perspective is concerned with separation of the knower and what is known in a particular field, where the researcher attempts to explain reality without influencing it (Daly, 2007).

Strauss and Corbin (1990) suggest that reality cannot fully be known but is always interpreted and so is a product of such interpretation. The researchers' experiences, beliefs and biases will influence the methodology of the study as well as interpretation of the results (Annells, 1997, Carter & Little, 2007). Paradigms of inquiry are used and act as frameworks to explain how the world is perceived by the researcher (Annells, 1996, Guba & Lincoln, 1994). There are several epistemological paradigms used for inquiry by researchers including positivism, post-positivism, interpretivism and social constructivism including critical theory (Annells, 1996, Guba & Lincoln, 1994). The epistemological perspective influences the study methodology, how the data is collected and interpreted, and ultimately, how data is analyzed and shaped (Carter & Little, 2007). Identifying or disclosing the epistemological standpoint prior to the beginning of qualitative research allows the researcher to understand personal views around the research question (Carter & Little, 2007).

This study will take a post-positivist approach. Post-positivism asserts that reality exists and can be understood, if not fully (Annells, 1996). Researchers can discover truths about reality from participants in an unbiased manner (Annells, 1996). This requires the researcher to remain

as objective as possible throughout data collection and analysis in order to uphold the validity and reliability associated with this paradigm (Annells, 1996, Guba & Lincoln, 1994). This will be important so that conclusions can be representative of the data acquired (Guba & Lincoln, 1994) – that is, of the knowledge that was discovered by the researcher and not constructed by the researcher (Guba & Lincoln, 1994).

### **4.3 Sample Recruitment**

This section details inclusion criteria for the participants as well as the recruitment strategies and procedures that were used.

#### *4.3.1 Inclusion Criteria*

To be eligible for this study, individuals with MCI/dementia were required to:

- Live in the community
- Have a self-reported clinical diagnosis of either MCI or dementia
- Be over the age of 55 years

Care partners of participants were similarly recruited. To be eligible for this study, care partners were required to:

- Be the primary care partner for someone diagnosed with MCI or dementia
- Live in the community
- Not have a current clinical diagnosis of MCI or dementia

#### *4.3.2 Sampling*

Participants were conveniently recruited to take part in this study. The aim was to include individuals who would be the most information-rich cases regarding the research objectives, in

order to yield an in depth understanding (Morse & Field, 1995, Patton, 1990). Recruitment specifically targeted both individuals who were physically active and those who were inactive to portray a broad spectrum of experiences and ideas regarding barriers to exercising. In this way, eligibility criteria were left specifically broad to better reflect the realistic aspects of the populations in practice and to provide opportunities for fluid discussion and thick descriptions of personal experiences among homogenous strangers in a formal setting.

#### *4.3.3 Recruitment Strategies*

Participants were recruited from the Kitchener-Waterloo surrounding area. Recruitment was ongoing from January 2017 to February 2017. The student investigator (NH) and lab coordinator (KR) recruited participants according to a standardized procedure. The coordinator of both the First Link and Minds in Motion programs was provided with study packages containing: study brochures with a brief overview of the study's purpose and involvement, and an information letter providing a more in-depth overview of the study's purpose and what involvement would include. All recruitment material can be viewed in (**Appendix A**). Potential participants were made aware of this study through local advertisement in conjunction with Alzheimer's Society Waterloo Wellington. Study brochures (**Appendix A**) were also distributed to local memory and geriatric clinics and to local community centers and libraries. Specifically, brochures were delivered to the Medical Centre at The Boardwalk, Kitchener's Downtown Community Centre, and the Kitchener Public Library (KPL) located in downtown Kitchener which subsequently distributed research brochures to surrounding KPL libraries. Finally, study information was distributed at a local event for persons with dementia ("A Changing Melody", a learning and sharing forum for persons living with dementia). During the forum, an information booth was set up in conjunction with the Murray Alzheimer Research and Education Program,

which allowed NH to answer any questions that potential participants had about the study. Interested individuals were instructed to contact NH or KR via email or phone.

Each individual who expressed interest in the study was contacted by NH by phone to review procedures and asked if they were still interested in participating. At this time, potential participants were able to ask any questions and additional information was provided when needed. Each participant was phoned by NH the week of their scheduled focus group discussion as a reminder. Telephone scripts for these phone calls can also be viewed in (**Appendix A**).

#### *4.3.4 Sample*

Seventeen participants were recruited to the study, including 10 persons with MCI/dementia (5 with MCI, 5 with dementia) and 7 care partners. Participant characteristics by participant group are described in **Table 4.3a**. Persons with MCI/dementia and care partners were similar except for cognitive status, gender, and exercise levels. Care partners were more often female than persons with MCI/dementia. Individuals with MCI/dementia reported exercising more frequently and for longer durations. However, stage of change for exercise, that is, individuals' readiness to engage in exercise, based on the Stage of Change Questionnaire (SOCQ) were similar among groups **Table 4.3b**. The majority of participants in both groups had at least two health conditions. Prominent health conditions experienced by participants included: high cholesterol, knee and hip injuries and other conditions such as arthritis, respiratory issues and chronic pain. Of note, the types of health conditions experienced by those with MCI/dementia were different from care partners, where they were more likely to express conditions associated with their diagnosis such as sensory flooding or stroke.

**Table 4.3a: Participant characteristics by group (mean (sd) or % (n)).**

<b>Characteristic</b>	<b>Person with MCI or Early Dementia (n=10)</b>	<b>Care Partner (n=7)</b>
Age	75.3 (6.5)	74.4 (7.0)
Gender, female	30.0 (3)	85.7 (6)
Body Mass Index, kg/m <sup>2</sup>	26.5 (5.0)	25.6 (3.1)
Years of Education	14.2 (4.0)	14.1 (4.8)
Marital Status, married	80.0 (8)	100 (7)
Diagnosis, MCI	50 (5)	-
Time of Diagnosis, <5 years	90.0 (9)	-
Residence		
Urban	70.0 (7)	57.1 (4)
Alone	10.0 (1)	-
Mobility Aid Required	10.0 (1)	14.3 (1)
Falls, in past two months	20.0 (2)	14.3 (1)
Number of Health Conditions Experienced	3 (2)	3 (1)



**Table 4.3b: Exercise characteristics by participant group.**

<b>Characteristic</b>	<b>Person with MCI or Early Dementia (n=10)</b>	<b>Care Partner (n=7)</b>
<i>Stage of Change (n)</i>		
Not exercising, no intention to start in next 6mos	1	2
Not exercising but intend to start in next 6mos	1	1
Exercising but not regularly for less than 6mos	3	2
Exercising regularly for past 6mos	3	2
<i>Exercise Levels (median (range))</i>		
Volume, min/wk	105	60
Frequency, days/wk	3.5 (7.0)	2.0 (7.0)
Duration, min/session	30 (120)	30 (60)

## 5.0 Data Collection

### 5.1 Study Protocol

This study gathered information through questionnaires and focus group discussions. Four separate focus groups were conducted at the University of Waterloo's Toby Jenkins Applied Health Research Building. The information letter and consent form (**Appendix A**) were given to participants upon arrival to the facility prior to the start of the focus group. During this time, individual dyads consisting of an individual with MCI/dementia and their care partner were brought to a quiet room with an interviewer where they were free to ask any questions they had and were also free to withdraw their consent at any time. For any participant who did not have the capacity to sign for themselves, an option was presented for care partners to provide consent on their behalf. However, this option was not used by any participants. After consent was obtained, participants completed a brief questionnaire (**Appendix B**) which was conducted in a structured interview format for both participants. The questionnaires captured individual demographic and health information. Following completion of the questionnaire, participants were invited to one of two separate board rooms to participate in a focus group discussion. Persons with dementia and their care partners participated in separate focus groups, occurring simultaneously, creating relatively homogenous environments of participants to avoid any power imbalances and allow participants to share freely in an open and comfortable environment. At the end of each focus group, each participant received a letter of appreciation from the researcher stating the value and appreciation for their time and energy to this study (**Appendix A**).

#### 5.1.1 Questionnaires

Brief questionnaires were completed by all participants in a structured interview format prior to engaging in focus groups (**Appendix B**). Persons with MCI/dementia and their care

partners completed the questionnaires similarly and simultaneously which captured demographic and health information of both participants. Specifically, questionnaires captured information regarding participant education and current exercise levels, type and time of diagnosis (for persons with MCI/dementia), marital status, type and location of living arrangements, and health status in terms of health conditions experienced. The SOCQ was administered as part of the demographic questionnaire in order to examine current individual exercise levels and the stage to which participants would undertake exercise (Chong et al., 2014, Marcus, Selby, Niaura, & Rossi, 1992).

### *5.1.2 Focus Groups*

Suggested focus group methodology indicates that well-designed focus groups consist of between 6 and 12 participants, which promotes the collection of a diversity of information in order to reach saturation while allowing participants to feel comfortable in a smaller, more cohesive setting (Krueger, 2000, Onwuegbuzie, Dickinson, Leech, & Zoran, 2009). In this study, focus groups consisted of a maximum of 6 people. Participants with cognitive impairment may benefit from smaller group sizes and may be more comfortable and more likely to share their thoughts in this dynamic group process (Sutcliffe, Roe, Jasper, Jolley, & Challis, 2015). A total of two focus groups with persons with MCI/dementia (4 persons, 6 persons) and two focus groups with care partners (3 persons, 4 persons) were conducted.

A moderator team consisting of a moderator (NH or MV) and an assistant moderator (CM or MB) facilitated each focus group, one pairing for each participant type. The moderators facilitated the discussion, referring to the focus group discussion guide as appropriate altering the discussion of each group in a focused and/or open manner. The moderator was responsible for taking notes which informed potential questions and aided in prompting further discussion within

the group. The assistant moderator was responsible for recording the session (audio-recording), taking notes of verbal and behavioral responses, providing verification of data collected, and recording the length of each focus group.

At the start of each focus group, the moderator (NH or MV) explained the study briefly, its purpose, the role of the moderator and assistant moderator (CM or MB), the use of the audio recorders, and how the confidentiality of responses through the use of coded identifiers would be maintained. They further explained a set of ground rules pertaining to the discussion (**Appendix B**), which then lead into an introductory question.

Focus group discussions lasted between 60 and 90 minutes ( $79 \pm 7$  mins) with a brief break midway, in line with recommendations (Costello et al., 2011, Mathews et al., 2010, Onwuegbuzie et al., 2009). At any time, participants were told to come back as soon as they could if they needed to leave for any reason. The goal was to promote discussion and conversation until “natural” expiration was perceived.

A focus group guide with relevant open-ended questions and prompts, specific to each participant group, was used to prompt discussion when necessary (**Appendix B**). The focus group discussion guides were developed by the research team, which consists of several experts in areas related to physical activity, cognitive impairment, and strategies to increase physical activity among older adults to probe experiences, opinions, and thoughts related to the research questions. The underlying framework of the SEM informed discussion guide construction however, in order to probe deeper insights to reflect socio-cultural and environmental contexts of exercise, the moderator (NH or MV) consciously probed questions at each level of the SEM.

Each focus group discussion was audio recorded and field notes were documented throughout for the purpose of debriefing and providing clarity.

At the conclusion of each focus group, the assistant moderator provided a brief summary of the main points that were raised during the discussion and also gave participants the opportunity to verify or clarify these points. Providing a summary confirmed that their thoughts and opinions had been adequately and appropriately depicted by the research team. The researcher then thanked the participants for their time and willingness to participate and discussed briefly an intent to share the completed research project with them. The audio recordings lasted the entirety of each focus group and ended upon completion of closing remarks.

## **6.0 Data Analysis**

A general inductive approach was used for the analysis of qualitative data. This approach required detailed readings of raw data in order to derive concepts and themes, and a framework of interpretations from the raw data (Thomas, 2006). The primary premise of the inductive approach is to allow findings to emerge from frequent or significant themes in the data without being limited by the structure imposed by specific methodologies (Thomas, 2006). This process allows for the organization and description of data in rich detail to interpret data related to a research topic (Braun & Clarke, 2006). Further, the general inductive approach allows the researcher to condense extensive and varied raw data in order to establish links between the research objectives. The summary findings can be used to develop a framework of thinking regarding the underlying experiences (Thomas, 2006).

Thematic analysis is flexible in that it can be applied across a variety of epistemological perspectives (Braun & Clarke, 2006). Taken from an essentialist or realist perspective, inductive thematic analysis was applied to identify experiences, meanings, and the reality of the participants with regards to the barriers that are associated with participating in exercise (Braun & Clarke, 2006). Using an inductive approach allows the themes to be strongly linked to the data and attempts to avoid personal bias from the researcher (Patton, 1990). As a result, the data taken is not driven by the researcher's interests and is therefore a data-driven process (Braun & Clarke, 2006). This further allows the researcher to fully capture the intricacy of meaning within the data that is being collected (Braun & Clarke, 2006).

### **6.1 Coding**

The general inductive approach was used to develop themes from the data that were most relevant to the research questions. The first stage of coding occurred when the focus group

auditory recordings were transcribed verbatim, which was done by hand, without the aid of an automated software program. The inductive coding process began with close, repeated readings of the transcribed focus group data, where NH immersed himself in the data in order to gain familiarity and in-depth understanding regarding the content, patterns, and meaning of the data (Braun & Clarke, 2006, Thomas, 2006). This process defined the early stages of analysis and helped develop a thorough understanding of the data (Braun & Clarke, 2006). Preparation of the raw data in this way (data cleaning) allowed the researcher to format and organize the data for further formal stages of coding (Thomas, 2006).

The second stage of coding involved generating initial codes from the data so that raw data could be assessed in a meaningful way relative to the research questions. This was completed by hand through line-by-line coding, where each line of the transcribed data was reviewed and given a code for each idea or event found. The goal was to describe the key concept of each particular line. This process was completed by putting each code into an excel file along with the supporting in vivo quote.

The third stage of coding involved sorting the codes into potential themes or categories. Initially, coded data was categorized based on similarities of content. Categories that emerged from the coded data were selected based on how well they were bounded to the research questions (Strauss & Corbin 1998). During this stage, some initial codes were categorized to form main themes regarding the overarching research objectives while others formed sub-themes and others not relevant to the research questions were discarded. The structure of the SEM was utilized at this stage to classify and categorize codes into potential themes. For example, individual factors influencing exercise were classified as intrapersonal moderators of exercise behaviour.

Next, codes, themes, and sub-themes were reviewed and refined. This involved reviewing all collated text under an individual theme to determine whether they formed a coherent pattern and were relevant. It became evident through revision that themes were not all distinct. Multiple separate categories often converged to form a main theme. Themes were also broken down to create several categories. The data within a particular category should cohere in a meaningful way and there should be clear and identifiable distinctions between each theme (Braun & Clarke, 2006). This process created a thematic depiction which presented an accurate representation or reflection of the themes in the data set. Overlapping coding and redundancy among categories or themes was also reduced during this refinement stage. Refinement was continued until all data were coded into exhaustive and exclusive categories. Notably, given segments of text were coded into one, several, or no category.

The final stage of coding defined and named themes and sub-themes. Themes and categories were organized coherently with accompanying quotations that conveyed the core theme of a category. Finally, themes were then combined or linked under core concepts in order to create a framework that describes the phenomenon and findings regarding the research topic. Upon revision of each theme, a cross-level thematic picture emerged. The thematic figure created and refined for this study is shown in (**Appendix C**).

## **6.2 Memo Writing**

Memoing also occurred throughout data collection and analysis. The researcher reflected on the data at all stages but did not limit his reflection to just the data but broadly reflected everything that came to mind when collecting or analyzing the data.



In this study, memos, including both field notes and code notes were used. Field notes were taken by the researcher and note-taker during focus groups. Field notes recorded verbal and non-verbal physical cues, providing contextual insights for use during analysis. Code notes were also taken during the analysis to document the researcher's thought progression. The code notes illustrated the meaning behind the development of core ideas and themes. A reflexive journal was kept during the course of this study and aided in the researcher's scrutiny over their individual research experience and decisions made.

### **6.3 Assessing Trustworthiness**

Qualitative research embraces multiple standards of quality, more generally referred to as trustworthiness, validity, credibility, or rigor (Morrow, 2005). Criteria used to assess trustworthiness in qualitative research are closely related to the paradigmatic stance of the researcher (Morrow, 2005). Guba and Lincoln (1994) suggest that a post-positivist standpoint logically attaches itself to standards of inquiry that are framed as conventional "benchmarks" of rigor. These include: credibility (internal validity), generalizability or transferability (external validity), dependability or stability (reliability) and confirmability (objectivity) (Guba & Lincoln, 1994). Others believe these criteria of rigor should be framed as "parallel criteria" whereby the criteria are similar to validity, reliability, which emerged outside qualitative research, but are intended to achieve similar purposes as internal validity, external validity, reliability and objectivity in quantitative research (Lincoln & Guba 2000, Morrow, 2005). Importantly, research using qualitative methodologies cannot truly be assessed for validity (e.g. legitimation, generalizability) as assessing legitimation "does not lead to a dichotomous outcome" such as being valid or invalid but rather, represents a circumstance of degree (Onwuegbuzie & Leech, 2007).

Although there is no way to guarantee valid or trustworthy data, assessments of procedures used in qualitative work remain imperative for ruling out interpretations of data and either to help or increase legitimation (Onwuegbuzie & Leech, 2007). In this study, trustworthiness was demonstrated by addressing credibility, transferability, dependability and confirmability (Onwuegbuzie & Leech, 2007, Shenton, 2004), as outlined below.

### *6.3.1 Credibility*

One of the key criteria that must be addressed to ensure reliability of qualitative data is that of internal validity or, in a qualitative terminology, credibility whereby the study measures what it was intended to measure (Shenton, 2014). Credibility is one of the most important factors in establishing trustworthiness (Lincoln & Guba 2000). Credibility deals with how well the data and analysis address the intended research focus.

Several provisions were employed to increase the likelihood of credibility. Firstly, at the level of the researcher and the participants, techniques were employed to reduce researcher bias as well as to help ensure honesty in participants when contributing to discussions (Shenton, 2014). Bias on the part of the researcher was reduced by intentionally remaining as objective as possible at all stages of data collection and making the intentions of the researcher clear from the start of each focus group. Researcher bias was also reduced by prolonged engagement during each focus group discussion, in conjunction with persistent observation by both the moderator and assistant moderator (Shenton, 2014). Prolonged engagement involved conducting focus groups for a sufficient period of time in order to obtain an adequate representation of the perception and experiences of the participants. This allowed the researcher to further understand the socio-culture of the group and to develop trusting rapport with the participants. Focus groups were conducted until no new information was obtained marking a level of information saturation.

Persistent observation at the level of the moderator and assistant moderator allowed for the identification of characteristics and attributes that were most relevant to the research questions and further sensitized a focus on these extensively (Shenton, 2014). The researcher was able to separate relevant from irrelevant observations and iteratively challenge and question what was of importance to the study. In this way, prolonged engagement with the participants provided a scope of their experiences whereas persistent observation on the part of the researcher added depth (Shenton, 2014).

Other recommended moderating practices were consciously observed by the researcher which further contributed to their objective position within the group. Physical and verbal affirmations such as head nodding and reinforcing participant opinions as correct or incorrect were avoided. It was further stated at the beginning of each focus group that there are no right or wrong answers in the discussion. Tactics to ensure honesty from each participant began with initial phone calls from the researcher during recruitment. At this time, rapport was established which progressed into trusting relationships. At the time of consent, each individual was given multiple opportunities to refuse participation in the study with no explanation to ensure that focus groups consisted of those who were most willing to give their opinions and offer data freely. During focus group discussions, the researcher's independent role and position within the study and group itself was emphasized as neutral and only served to facilitate the discussion. Despite these techniques, it is important to note that no qualitative study is free from bias. Although attempts to reduce bias at the level of the researcher and participant may increase the credibility of findings, response biases such as social-desirability bias and predispositions of the researcher, may be consciously or subconsciously prevalent.

Frequent debriefing sessions were held between the student investigator (NH) and the primary investigator (LM) as well as committee members and numerous colleagues. Through discussion, this allowed a widening of perspective for the researcher as others were able to bring forth their experiences and perceptions surrounding the study (Shenton, 2014). These collaborative discussions allowed the researcher to discuss alternative approaches where in the case of the primary investigator (LM), as a supervisory role to the researcher, drew attention to potential pitfalls and flaws in the proposed course of action. Frequent debriefing sessions also allowed for the opportunity for peer scrutiny of this study, which is suggested as an important technique to ensure credibility (Onwuegbuzie & Leech, 2007, Shenton, 2014). Feedback from colleagues, peers and supervisors was welcomed, incorporating fresh perspectives which allowed the researcher to challenge their assumptions and ways of thinking. This is important as the researcher's closeness to the study may inhibit their ability to view it from an objective or detached standpoint (Shenton, 2014). Critical discussions and critiques helped to better establish greater explanations for the research design, strengthen arguments regarding feedback gained and refine the methodology associated with this study. Furthermore, as another opportunity to externally evaluate the research process, debriefings were held between the moderator and assistant moderator directly following each focus group.

Guba (1981) outlines that one of the most important provisions to ensure a study's credibility is to conduct member checks. Member checks were conducted at the end of each focus group where the assistant moderator gave a brief synopsis of their perspective of the data collection dialogue and then asked if what they had reported was consistent with the opinions of the group. The emphasis on this procedure was to determine whether the participants felt that what they had contributed to the group was consistent with how they were perceived by the

moderating team. Similarly, this offered an opportunity to ensure that what the moderating team had heard accurately depicted the perspectives of the group. This allowed for verification of data collected and also offered an opportunity for participants to add any further thoughts regarding topics that had been discussed. In addition, member checks and debriefings provided an opportunity for the moderator and assistant moderator to iteratively question any outstanding query they had, drawing a deeper level of transparency to the ideas collected and potentially uncovering any discrepancies in thoughts.

Finally, the different investigators (moderating teams), were used to obtain corroborating evidence in what is called triangulation (Guba, 1981). The process of having two different moderating teams conducting focus group discussions which occurred simultaneously, reduced the possibility of systematic biases due to a specific methodology being used and thus, allowed for greater confidence in the interpretations that were made (Guba, 1981, Shenton, 2014). Coupled with debriefing sessions held directly following each discussion between moderating pairs and then moderating teams (of separate focus groups that occurred at the same time), this permitted the researcher to be more certain of findings as well as uncovered contradictions and opposing perspectives, leading to richer, more descriptive data. Newman and Benz (1998) further note that the more sources that a researcher is able to examine, the more likely they are to obtain an adequate and rather wholesome representation of a phenomenon. In this case, corroboration using investigator triangulation in conjunction with immediate debriefing deepened the researcher's understanding of this study and ultimately lead to more precise and thicker interpretations of the participants' perceptions and experiences.

### 6.3.2 *Transferability*

Transferability refers to premises regarding external validity and is concerned with the extent to which the findings in a study can be applied or generalized to other situations or populations (Guba, 1981, Shenton, 2014). Naturalistic inquirers adopt differing perspectives with respect to generalizations in qualitative reasoning whereby a concern in post-positivist work lies in demonstrating that the results of a study can be applied to a wider population (Shenton, 2014). Since these findings are specific to a small number of individuals in a particular environment, and all social and behavioural phenomenon are contextually bound (Guba, 1981), many qualitative researchers believe that even conventional generalizations of findings are never possible, as all observations are dependent on the specific contexts in which they occur (Erlandson, Harris, Skipper, & Allen, 1993, Shenton, 2014). Transferability and generalizations of findings should be pursued with a level of caution, as they may undermine the magnitude to which contextual factors influence the perspectives and experiences of the cases involved (Shenton, 2014). Lincoln and Guba (2000) suggest that it is the responsibility of the researcher to ensure that sufficient contextual information be provided in order to increase clarity and transparency throughout the research process and in this way, enable the “reader” to make generalizations thus, conveying the context in which the study was conducted. At the outset, results of a qualitative study must be understood within the context of the particular characteristics of the study itself; the job of the researcher is to fully assess the extent to which findings may be understood on a broader level.

Nevertheless, provisions can be made to ensure transferability which might enable a more inclusive overall picture of a study. This study developed a detailed and thick description of the phenomenon being explored, strengthening the credibility of this study as this description helped

to convey the contextual situations under investigation (Shenton, 2014). Rich, thick descriptions of the study ultimately inform the reader to be able to transfer information to other settings and contexts (Erlandson et al., 1993). As such, to facilitate transferability, the researcher in the current study provided a detailed description of the study's setting as well as contextual information about participant populations and how they were selected. Verbatim transcripts of focus group discussions coupled with descriptive note-taking about specific and explicit events, behaviours and observations also provided considerable transparency to the data collection process. Furthermore, detailed descriptions were provided of the data collection methods, number and length of data collection sessions, the time period over which the study took place and analysis processes. At the outset, a rich and vigorous presentation of the study's findings in conjunction with relevant and appropriate quotations is meant to enhance transferability of findings.

### *6.3.3 Dependability*

The dependability of a study refers to its reliability or, if the study were to be repeated in the same context with the same methods and participants, similar results would be obtained (Shenton, 2014). However, it is important to acknowledge the ever-changing nature of the phenomenon being studied may be problematic towards replicating qualitative research (Shenton, 2014). Participants' feelings, thoughts, and opinions regarding an issue are subject to change due to environmental and contextual factors. Alternatively, Lincoln and Guba (1985) suggest that measures to ensure the dependability of a qualitative study should take into account factors of instability as well as factors of the phenomenon itself that induce change, or the degree to which data change over time create alterations made in the researcher's decisions regarding analysis. They further suggest a close relationship between credibility and dependability, arguing

that, demonstrating credibility of a study goes a long way towards ensuring its dependability (Lincoln & Guba, 1985).

In order to more directly address dependability of this study, processes within this study were reported in great detail with the goal of ensuring repeatability. Establishing an audit trail provides an external evaluator the possibility to examine the processes whereby data was collected and analyzed, and interpretations were made (Guba, 1981). This study involved the researcher maintaining extensive, detailed documentation of reflexive thoughts and data collection processes. Detailed records stemming from this study include: raw data (e.g. written notes, questionnaire results, and audio recordings), process notes (e.g. methodological notes and trustworthiness notes), data analysis products (e.g. transcribed audio recordings, write-ups of field notes) and reflexive commentary throughout all stages of this study. The research design and implementation described what was planned and executed, and the practical details of data gathering addressed what was completed before, during and after each focus group discussion. Furthermore, reflective appraisal (Shenton, 2014) of this study was carried out by the researcher in the form of a continuous reflexive journal which allowed for the evaluation of the effectiveness of all aspects of the research process. Self-reflective commentary in this journal allowed the researcher to assess the efficacy of techniques used in exploring the research questions. The reflexive journal was used to record the researcher's initial impressions of each data collection session as well as emerging patterns and themes. Reflective commentary ultimately informed deeper levels of analyses which impacted the project's results and further, what Lincoln and Guba (1985) describe as "progressive subjectivity" whereby the researcher was able to monitor developing constructions, also pertinent to ensuring credibility. Maintaining a detailed reflexive journal further acknowledged the dispositions, expectations and intentions of



the researcher, also facilitating provisions to ensure both the credibility and confirmability of this study.

#### *6.3.4 Confirmability*

The idea of confirmability is qualitatively synonymous with that of the objectivity of a study (Shenton, 2014). In maintaining real objectivity, methods employed by the researcher are inevitably subject to their individual preconceived notions and biases (Guba, 1981, Shenton, 2014). A key criterion for confirmability, as suggested by Miles and Huberman (1994), is the extent to which the researcher can demonstrate or acknowledge an understanding of their own predispositions. In this way, beliefs which underpin the decisions that are made to implement certain methodologies should be addressed and explained by the researcher.

As previously described, reflexive commentary was undertaken by the researcher in order to intentionally reveal to the reader, their epistemological assumptions that framed the researcher questions and the way in which this study was carried out. The reflexive journal contained introspections throughout data collection and analysis processes which further contributed to the audit trail, allowing the reader to trace the course of this study in a step-by-step fashion via the decisions and procedures described. Detailed methodological descriptions in conjunction with self-reflective commentary further enable the reader to determine to what extent the data and the emerging interpretations are transferable (Shenton, 2014). The role of investigator triangulation, as previously described, drew upon a variety of sources from the level of data collection to peer scrutiny and debriefing. With this, the researcher's predispositions were confronted and tested from a multitude of different perspectives. Including another moderating team acted to balance out predispositions by offering a unique set of arguably similar yet distinct perspectives.

Furthermore, confirmability was enhanced by establishing the audit trail by preserving audio recordings, field notes and each level of data analysis.

### *6.3.5 Coding Consistency*

To ensure consistency during analyses, several provisions were carried out by the researcher and research team. The organization of the analysis team included the researcher (NH) and two research assistants (CM and MB). Firstly, in order to reduce transcription bias, verbatim transcription was carried out by NH almost immediately following the conclusion of each focus group. Transcriptions were conducted in a quiet environment where the researcher could direct total focus to listening intently. Focus group audio recordings were listened to at least three times post-transcription to ensure accuracy. Secondly, independent parallel coding was carried out by the analysis team where the initial coder (NH) developed a set of codes that constituted preliminary coding. Secondary coders (CM and MB) were then given the evaluation objectives and the raw transcriptions in their entirety from which the initial codes were developed (Thomas, 2006). Each research assistant was asked to create a second set of codes without seeing the initial code list based on arbitrary portions of the raw text selected at their discretion (at least 60 lines of text). Each assistant coded two focus group transcripts. The second set of coding was then compared to the original set by the researcher to evaluate the extent of overlap that existed. It is suggested by Thomas (2006) that when overlap between both coding sets is low, further analysis and discussion is required to develop a more robust coding scheme. Alternatively, upon discussion, coding schemes may be merged into a combined set (Thomas, 2006). However, neither case directly pertained to this study as both sets of coding aligned with high accuracy. Although not quantitatively assessed, examination of transcripts by independent coders ensured accuracy and consistency of the developed codes which logically relates to measures of inter-

rater reliability. The high consistency among both coding sets (researcher's and assistant researchers') does not however, preclude the introduction of bias into the analysis process. Each research assistant acted as an assistant moderator in the group for which they secondarily coded for thus, presenting a possibility of contributing their own predispositions and experiences within that group to their coding efforts.

Furthermore, developed categories and themes were scrutinized for consistency and clarity. Research assistants were given the evaluation objectives, categories or themes that were developed by the researcher, and descriptions of each category or theme. Each research assistant was asked to assign coded text to the different categories. A consistency check was then carried out to determine the extent to which the secondary coders (research assistants) allocated the same raw text segments to the initial categories or themes that were developed. There was a high degree of overlap of coding categorization, supporting consistency and clarity of categories and themes between coders.

In addition, member checks were held at the conclusion of each focus group (as indicated above), which further enhanced the credibility of findings allowing participants to verify interpretations and conclusions or to immediately correct any errors of fact or challenge interpretations (Thomas, 2006). This provision marked a foundation for consistency of coding as each individual step in the analysis was based on these interpretations and conclusions.

## 7.0 Results

Themes and subthemes presented were inductively developed based on the focus group discussions. Thematic analysis revealed a complex and dynamic interplay between factors influencing exercise behavior. Those factors, including barriers, motivators, and facilitators, occurred across all three levels of the SEM. **Table 7.0** summarizes the themes and subthemes and by level of the SEM.

**Table 7.0: Key themes from focus group discussions at different levels of the social-ecological model**

SEM Level	Theme	Subtheme	Description of Theme
1. Intrapersonal	Challenges with Physical and Mental Health	Physical impairment MCI/D, CP	Individual health problems make it more difficult to exercise
		Cognitive challenges MCI/D	
	Perceptions of Exercise as Beneficial	Exercise and health benefits MCI/D, CP	Belief that exercise can maintain or improve health and well-being
		Exercise/well-being MCI/D, CP	
		Combination effects of exercise and mental activity MCI/D	
	Contrasting Perceptions of Dementia		Persons with MCI/dementia and care partners have different views of dementia, which alter motivation for exercise
	Being Motivated		Intrinsic motivation MCI/D, CP
Space apart as motivation to exercise CP			
Boredom as a barrier and motivator to exercise MCI/D			
Perceived abilities for exercise MCI/D			
Experiencing Time Constraints		Real or perceived lack of time restricts exercise	
Individual Preferences for Exercise		Walking outdoors MCI/D, CP	Preferred modes of exercise and program characteristics among persons with MCI/dementia
		Preferences for exercise programming MCI/D, CP	

Lack of interest in home-based exercise  
MCI/D

2. Interpersonal	Social Identification	<p>Identification with other persons with MCI/dementia and care partners <sup>MCI/D, CP</sup></p> <p>Identification with others of the same gender <sup>MCI/D, CP</sup></p> <p>Identification with others of the same age <sup>MCI/D, CP</sup></p>	<p>The ability to socially engage with others with whom persons with MCI/dementia identify motivates exercise participation</p>
	Social Support from Care Partners	<p>Encouraging exercise by care Partners <sup>MCI/D</sup></p> <p>Facilitation of exercise by care Partners <sup>CP</sup></p>	<p>Support and encouragement for exercise by care partners increases motivation to exercise</p>
	Social Support from Others	<p>Encouragement and support for and during exercise from others <sup>MCI/D, CP</sup></p> <p>Pets as motivation for walking <sup>MCI/D, CP</sup></p> <p>Support from knowledgeable and encouraging exercise providers <sup>MCI/D</sup></p> <p>Physician encouragement and recommendations <sup>MCI/D</sup></p>	<p>Support and encouragement for exercise by others increases motivation to exercise</p>
	Social Engagement During Exercise		<p>Persons with MCI/dementia believe that social engagement during exercise is beneficial and motivational</p>
3. Community	Physical Environment	<p>Weather as a barrier and facilitator of exercise <sup>MCI/D, CP</sup></p>	<p>Factors within the natural and built physical environment can facilitate or hamper exercise</p>

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	Neighbourhood infrastructure limiting walking MCI/D Perceived safety MCI/D, CP	
Accessibility to Exercise Facilities and Opportunities	Access to appropriate exercise settings MCI/D, CP Access to exercise programs with preferable characteristics MCI/D, CP Unsupportive policies limiting accessibility and motivation to exercise MCI/D, CP	The ability to access preferable exercise opportunities can motivate and/or enable exercise
Availability of Appropriate Exercise Opportunities		Availability of exercise opportunities that encompass preferred exercise characteristics

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**MCI/D Theme identified by persons with MCI/dementia**

**CP Theme identified by care partners**

## 7.1 Intrapersonal Level

At the intrapersonal level of the SEM, several themes related to exercise in dementia emerged that related to individual health, the perceived benefits of exercise, individual perceptions of dementia, intrinsic motivation, time constraints and preferences for exercise. Of note, the impact of barriers and facilitators to exercise at intrapersonal levels could often be lessened or accentuated by factors at the interpersonal and community-levels, discussed below.

### *7.1.1 Challenges with Physical and Mental Health*

Challenges with physical and mental health influence both the capability and willingness of the persons with MCI/dementia to exercise. Furthermore, the care partners' physical and mental health challenges may also restrict exercise among persons with MCI/dementia, as they are the primary facilitator of exercise (described in detail in section 2.4). Participants reported that these health limitations made exercising difficult and sometimes prevented it all together.

#### *Physical Impairment*

Both persons with MCI/dementia and their care partners expressed that poor physical health limited exercise among persons with MCI/dementia. Physical impairments including mobility restrictions, pain and arthritis, visual impairment, and other health problems limited their ability to exercise and, particularly, walking for exercise. Restrictions to walking were particularly burdensome as this was frequently identified as a preferred mode of exercise, further discussed in section 7.1.6. For example, one person with MCI/dementia indicated,

I would love dearly to get down there [to the forest] but my hips won't let me right now... my arthritis is worse, pain and the movement I could do... I can't keep it up.  
(MCI/dementia – FG 1)

The care partners' physical impairments also limited their ability to facilitate exercise for the person with MCI/dementia. One care partner said,



[We] used to walk a lot... but for the last year or so, this knee has completely stopped all that. (Care Partner – FG 1)

Opportunities to exercise were also said to be limited among persons with MCI/dementia by low energy and fatigue where decreased energy levels often prevented exercise,

It's just that... I don't have the energy, I'm tired and so I just don't do it [exercise]. (MCI/dementia – FG 2)

### *Cognitive Challenges*

Cognitive challenges and mental health problems influenced both the ability to exercise and exercise opportunities, but only among persons with MCI/dementia. Poor availability of exercise opportunities that accommodate these health problems are discussed at social and environmental levels, below.

Persons with MCI/dementia indicated that memory problems and confusion particularly limited engaging in and tracking home-based exercise,

Remembering is a really big problem. Did I do that one [exercise]? (MCI/dementia – FG 1)

Furthermore, cognitive challenges associated with MCI/dementia (e.g., problems with learning) led to an increasing reliance on their care partners as a companion and exercise chaperone.

Cognitively he just seems to struggle. He can't remember...it almost seems as if he can't retain the information...and so I have to be there with him to do it [exercise]. (Care Partner – FG 2)

Other deficits such as visual and auditory flooding (body's sense experiencing overstimulation from the environment) also contributed to increased dependence of persons with MCI/dementia's on their care partner for exercise. In some cases, persons with MCI/dementia were unable to exercise alone due to challenges in sensory perception and so, required their care partner participate as well. One person with MCI/dementia stated,

I have a little bit of a balance problem and I also have a visual... and auditory flooding thing so I need somebody to go with me... I can't exercise alone. (MCI/dementia – FG 1)

Care partners also indicated that mental health problems thought to be related to dementia (for example, depression and confusion) negatively influenced the person with MCI/dementia's exercise levels, perhaps more so than cognitive symptoms. Exercise was said to be more significantly limited when the person with dementia was "having a bad day". Care partners also suggested that lack of mental clarity or mental "fogginess" decreased motivation to exercise.

Care partners generally agreed that their partners condition (MCI/dementia) did not significantly interfere with exercising,

Nothing gets in the way of exercising unless he was ill and [we] couldn't get out of the house. (Care Partner – FG 2)

However, care partners were concerned for the safety of their partners with MCI/dementia, particularly when their partners were alone. Care partners acknowledged that prior accidents such as falls due to environmental conditions led them to worry about their partners' safety when exercising, as they may not always be present to supervise. Some care partners indicated that their partners' wavering independence was "scary". They expressed uncertainty and concern over their partners with MCI/dementia's changing abilities,

You're fine up to a certain point [cognitively] but after that you can't be trusted. (Care Partner – FG 1)

### *7.1.2 Perceptions of Exercise as Beneficial*

Both persons with MCI/dementia and their care partners viewed exercise as beneficial, not only to health but also to well-being more broadly. Both knowledge and experience gave them a positive view of exercise and led them to believe that exercise was generally beneficial and meaningful. One person with MCI/dementia explains,

From what I hear and what people tell me, it [exercise] works. However, common sense tells me to keep it up... From what I've experienced so far, I've found that exercise really helps and I would recommend anybody just keep exercising. (MCI/dementia – FG 1)

### *Exercise and Health Benefits*

Persons with MCI/dementia expressed a general belief that exercise was beneficial to health. They believed that exercise could help them both physically and cognitively,

It's kept my weight good, uh... [keeps] my whole body good [exercising]. It also feeds the mind very strongly. (MCI/dementia – FG 1)

Perhaps more importantly, persons with MCI/dementia have experienced benefits to their own health, which prompted them to do more. One person with MCI/dementia stated,

Especially if you can notice the difference [of exercise on health], I mean that makes you motivated to keep doing it. (MCI/dementia – FG 1)

Noticeable benefits of exercise on their health appeared to moderate their exercise behaviour.

Moreover, some also indicated that exercising consistently was necessary in order to maintain or improve their health,

I certainly want to keep at it [exercising to improve physical health]. (MCI/dementia – FG 1)

Care partners also believed that exercise improved both the physical and mental health of their partner with MCI/dementia and their own health. They observed positive physical and mental changes in their partner with MCI/dementia with exercise,

Definitely the exercise keeps him sharper [mentally]. He gets much more dull [when sedentary] and quietness. [Exercise] keeps his heart in good shape... We gotta keep him exercising to keep the cholesterol down. (Care Partner – FG 2)

Care partners also indicated that there are negative impacts of inactivity to their own mood, which is a motivation to exercise,

You get depressed, I find I'm depressed when I'm not doing enough exercise or not outgoing and I don't have any enthusiasm. (Care Partner – FG 2)

### *Exercise and Well-being*

Persons with MCI/dementia indicated the exercise benefited their overall well-being,

If you're out walking or doing something... you just feel uplifted. From my point of view, [exercise] has really helped me [personally]. (MCI/dementia – FG 2)

Persons with MCI/dementia also expressed that their perceptions of exercise as being beneficial were influenced by socially bound understandings. Participants described inherent perceptions of exercise in society using phrases such as “through word of mouth” and “common sense” to describe how exercise was generally viewed. Common perceptions of exercise coupled with improvements seen in their own health strengthened their positive perceptions of exercise,

There's no question that it's good, y'know, the benefit is there [of being active] apart from the sense of well-being and a sense of worth. (MCI/dementia – FG 1)

In addition to the increased sense of well-being due to exercise, participants found exercise to be enjoyable, especially compared to “swallowing pills” for treatment,

I'd like to introduce a phrase... the sense of well-being that I personally enjoy [when exercising]. (MCI/dementia – FG 1)

Care partners expressed a particularly deep, almost existential connection to exercise.

They describe exercise as both meaningful and essential to their life and that of their partner with MCI/dementia. Care partners describe exercise as having irreplaceable significance in their lives,

I have a phobia that if I'm not exercising, I've lost my aliveness and so for me, exercise is a constant validation of being alive, of being with capacity...It's a purpose in life [exercising], it's just essential. (Care Partner – FG 2)

### *Combination Effects of Exercise and Mental Activity*

Persons with MCI/dementia believe it is important to be both physically and mentally active. Participants believe that exercise in tandem with mental activity was especially beneficial for the preservation of cognitive function, that there are additive benefits. One person stated “one being as important as the other” for health and well-being. Another participant elaborated,

I exercise and I also play a lot of music so the combination of the two of them keeps my mind very active, especially with the music part. (MCI/dementia – FG 1)

Care partners also believed that the combination of exercise and mental activity was beneficial for the brain,

It's a combination of mind, exercise [that] is imperative for thinking. The brain needs oxygen. It has to be consistent. (Care Partner – FG 2)

Participants reported participating in a variety of mentally stimulating activities, such as playing music and completing crossword puzzles and Sudoku. One person with MCI/dementia described the importance of mental stimulation for their thinking,

[Doing mental activities] makes you think and so, little problems but it keeps the mind working. If you don't work the mind, then of course you'll go into dementia a whole lot faster. If I only did physical exercises, I think it would not be anywhere near as good as doing both. (MCI/dementia – FG 2)

### *7.1.3 Contrasting Perceptions of Dementia*

Both persons with MCI/dementia and care partners discussed their perception of and experience with dementia. However, persons with MCI/dementia and their care partners had highly contrasting perspectives both in their view of dementia and their perception of how dementia impacted their lives and exercise behaviours.

Persons' with MCI/dementia perception of dementia was rooted in optimism for the future and suggested that having the disease is manageable,

I would like to let people know that uh, if you do have it [dementia], it's not the end of the world. (MCI/dementia – FG 1)

They felt relatively unaffected by the disease and suggested that being diagnosed with MCI/dementia had little impact on their life at this stage,

...it hasn't affected me in the least... I mean, the fact that I have [dementia]. Not worried about it and, so, I just carry on as usual as if I never had it. (MCI/dementia – FG 1)

Persons with MCI/dementia also did not generally believe that their condition affected exercise opportunities in a negative way.

Care partners' interpretations of their partners' experiences living with dementia contrasted greatly with their partner with MCI/dementia's view. The care partners described dementia as an experience of loss,

Dementia's called the long goodbye because the person you knew is going away and somebody else is coming. (Care Partner – FG 1)

Care partners also expressed that they were affected by their partners' diagnoses more so than their partner with MCI/dementia. They specifically stated that their partners' with MCI/dementia were not bothered as much as they were when they received the diagnoses,

I think it bothered me more when I heard [the diagnosis], he's [spouse with MCI/dementia] been a real trooper through it all. (Care Partner – FG 1)

Despite the profound impact of their partners' diagnoses of MCI/dementia, care partners indicated that it is necessary to be proactive when confronted with the observable and significant symptoms of MCI/dementia. Often, their perspective was informed by prior experiences with family members who had AD,

I would like people to watch out for its [dementia's] early stages and not leave it out till it's too late. I noticed she had symptoms of dementia about 6 years ago because her mother passed away ten years ago after Alzheimer's so I knew all the things to expect. (Care Partner – FG 1)

#### *7.1.4 Being Motivated*

Motivation was an important determinant of whether or not exercise as a behaviour was initiated. Low motivation was viewed as something that prevented persons with MCI/dementia from exercising due to decreases in intrinsic motivation and reduced self-efficacy for exercise. However, factors such as care partners' intrinsic motivation, space away from their care partner and general boredom could mediate sedentary behaviours. Although intrinsic motivation was seen as a barrier to exercising among both groups, persons with MCI/dementia suggested that their exercise had actually increased since being diagnosed.

### *Intrinsic Motivation*

Both persons with MCI/dementia and their care partners reported that motivation, particularly intrinsic motivation, was a major limiter of exercise behaviour. Persons with MCI/dementia and their care partners expressed that they sometimes had too little intrinsic motivation to exercise. They knew that they needed to exercise more but they “just don’t do it.” Persons with MCI/dementia also say that they get in the way of their own exercise, being too lazy to do it sometimes,

I get in the way [of exercising]... I don’t know, sometimes I think I’m just too lazy.  
(MCI/dementia – FG 1)

Their care partners often indicated that the partner with MCI/dementia’s lack of initiative to exercise was of such magnitude that their partner would simply not exercise if they were not present,

If I wasn’t there, he wouldn’t do it. He wouldn’t go for a walk on his own. I doubt he’d go to the gym. I doubt he’d make the effort. He’d just stay around. (Care Partner – FG 2)

Many persons with MCI/dementia agreed that if their partner wasn’t present, they would choose not to be active,

It's easy to decide [to not exercise], and if my wife's not around that type of thing, it's easy to decide to let it [exercise] go. (MCI/dementia – FG 2)

Care partners believed that their partner with MCI/dementia’s lack of intrinsic motivation to exercise may be part of their nature and not due to diminished initiative as result of disease progression. Care partners discussed their partner with MCI/dementia’s inability to overcome obstacles, such as injuries, in the past,

If he [spouse with MCI/dementia] didn’t have dementia, he’d probably be the same... he won’t go swimming, he won’t go to yoga. He’s got a real hesitation since he fell and injured his shoulder. (Care Partner – FG 2)

Care partners believed that the persons with MCI/dementia needed to assume a level of responsibility for health behaviours, of which exercise is one, since they (care partners) cannot assume total responsibility,

I can't make him better right? He has to have some initiative sometime. (Care Partner – FG 2)

However, the lack of initiative to exercise was also thought to be moderated by insecurity and fear, especially when partners with MCI/dementia had a history of injuries or falls.

Care partners also indicated that engagement in sedentary activities, such as the computer or TV, negatively influenced their partners' willingness to exercise,

It's very easy not to do it [exercise]. It's so easy for him to sit in a chair. The dictionary's there, Sudoku is here, something is there, and the TV's there. (Care Partner – FG 2)

Care partners generally believed that in order to sustain exercise behaviour, “you gotta have that mind to want to exercise”. Care partners expressed self-motivation deeply rooted in the meaningfulness of exercise in their lives,

Mine [exercise] is a commitment to myself. It's automatically there. (Care Partner – FG 2)

Care partners, however, also indicated that they sometimes experience lack of ambition, laziness and feelings of “just not wanting to do it” that stopped them from exercising. Care partners also explained that their partners with MCI/dementia's lack of initiative and reluctance to exercise sometimes reduced their own motivation,

It's nice to do together [exercise] but sometimes I find it hard to get out if he [spouse with MCI/dementia] doesn't feel like walking or doesn't want to. (Care Partner – FG 1)

In contrast, persons with MCI/dementia indicated that the diagnosis of MCI/dementia itself encouraged them to increase their exercise levels. When asked how their diagnoses



influenced their willingness or opportunities to exercise, one person with MCI/dementia responded,

Mine have increased 'cause I didn't exercise before [the diagnosis]... I do more exercise now than I ever did. (MCI/dementia – FG 1)

In addition, persons with MCI/dementia also described their interest and enjoyment in helping with research that was geared towards exercise. Results of published literature influenced some persons with MCI/dementia to increase their exercise based on positive findings of different types, durations and intensities of exercise,

Sometimes hearing results of different studies is motivating [to exercise]... they'll say you'll live a longer life. (MCI/dementia – FG 1)

#### *Space Apart as Motivation to Exercise*

Care partners professed that caring for their partner was a manageable, albeit non-stop “battle”, that was said to take a toll on care partners both physically and mentally. Daily life challenges were described as “difficult” and that “sometimes you feel you're in a box”. Some care partners were able to meet these challenges by spending time away from their partner, which was used to facilitate their own exercise needs and goals,

You want a place to go where your partner goes here and you go there cause you still both need your time on your own. (Care Partner – FG 1)

Time away from their partners was only described as a facilitator to care partners' own exercise where they would engage in independent activities. Time apart to “do your own thing” was also believed to benefit the overall health and mental wellness of each partner. This “trade-off” was described by one care partner as a motivator for their spouse to walk on a regular basis so that each partner had the opportunity to partake in activities they individually enjoyed,

He's [partner with MCI/dementia] only started walking this last five weeks and that's because it's a trade-off. (Care Partner – FG 2)

Care partners also acknowledge that their partners with MCI/dementia “need time away from us too”. In order to facilitate time away, some suggested that organized exercise for persons with dementia and care partners should be separated into classes for each group that run simultaneously.

Care partners also believed that their partners with MCI/dementia would support them by “going along with the exercise” or encouraging them to do so,

They care for us. I know if I haven't done my exercise and wait until later on, he [spouse] reminds me... He'll actually motivate me. He'll say oh come on it's a nice day. (Care Partner – FG 2)

#### *Boredom as a Barrier and Motivator to Exercise*

Boredom, with exercising as well as within daily life, was reported as a factor that influenced exercise behaviour. It acted both as a barrier and a motivator for exercise. Persons with MCI/dementia sometimes found exercise boring, which deterred them from exercising. This was especially true for some forms of exercise, such as exercising on a treadmill,

It's boring [walking for exercise]. I force myself to go [to rec centre to walk the track]. (MCI/dementia – FG 1)

However, in some cases, boredom coupled with the acknowledged perceived benefits of exercise enhanced their desire to exercise. In particular, boredom at home or in general daily life could be a motivator,

I do [exercise] a lot of times out of boredom... When I get frustrated with watching TV uh I go out and walk more. (MCI/dementia – FG 1)

#### *Perceived Abilities for Exercise*

Despite mental strategies to circumvent boredom, persons with MCI/dementia were sometimes not motivated to exercise because they believed they were physically incapable of

engaging in certain activities. Self-efficacy for exercise was sometimes related to the beliefs of persons with MCI/dementia before their diagnosis,

I sort of self-imposed my limits before I was diagnosed so, I knew I couldn't do certain things before. (MCI/dementia – FG 1)

#### *7.1.5 Experiencing Time Constraints*

Lack of time was a barrier to exercise. From the perspective of those with MCI/dementia, exercising was dependent on other things that were important to their lives,

It's been sort of sporadic [exercise behaviour] depending on what other things are happening in my life. Probably time, well time to fit it [exercise] in with all the things going on at home. (MCI/dementia – FG 2)

Time commitments were also expressed by care partners as a barrier to exercise, where opportunities to exercise were restricted as a result of not having enough time. Family life and “other things to do” could limit their opportunity to be active. Time constraints could further decrease their likelihood of encouraging their partners to exercise,

I may not do that [suggest to do more exercise to partner] because I've got other things that are going on. (Care Partner – FG 1)

#### *7.1.6 Individual Preferences for Exercise*

Persons with MCI/dementia and their care partners held a number of common preferences for exercise, which would be likely to increase participants' interest and motivation to participate if available (discussed under Community Level themes below). Characteristics for preferred exercise opportunities emerged as being tightly coupled to exercise history and past exercise experiences.

##### *Walking Outdoors*

Persons with MCI/dementia expressed a general preference for walking outdoors in nature (at a park or in the woods), which appeared to be the most preferred method of exercise.

Outdoor walks, where they could experience nature, was enjoyable and so motivated them to exercise,

From way back I'm just not interested [in the gym or using equipment] as long as I can walk, I can be outside... The oxygen outside is so much better... That's my first choice for sure, that's my preference. (MCI/dementia – FG 1)

It became evident that the preference for walking outdoors among persons with MCI/dementia was also sometime driven by a general dislike of, and sometimes poor access to, using exercise equipment and machines.

I don't really like using the [exercise] equipment... I'd rather walk the neighbourhood. The treadmills are usually busy everywhere and I can't do the bike. (MCI/dementia – FG 1)

Similarly, care partners also expressed a general preference for walking outside,

It's nice to be able to walk outside in the fresh air... I would really have to say walking [as preferential exercise opportunity]. I love to go to the local parks... or anything of the woods around. I prefer to do it outside again it's that oxygen and the air and just that interactive element. (Care Partner – FG 2)

### *Preferences for Exercise Programming*

Despite preferences for walking outdoors, participants had strong preferences for how programs and classes could increase their interest in group exercise. Both persons with MCI/dementia and care partners viewed music as a major facilitator of positive and enjoyable exercise experiences. Music was said to either “make or break” their interest and motivation to participate in a structured exercise program. “Bad” music strongly discouraged interest in group exercise,

That [music] is actually a barrier [to group exercise] because sometimes it's so loud and rattling. The music is what kills you. (MCI/dementia – FG 1)

There was a clear interest in a fun social environment, interacting with other people with whom persons with MCI/dementia could identify. People put forth programs such as Tai Chi classes and ballroom dancing as ideal exercise opportunities because,

They've got fantastic music and everybody's moving together. It's fun [dancing] and you're meeting lots of people, to me that's the best. (MCI/dementia – FG 1)

Care partners further expressed that a social atmosphere was necessary and indispensable as well as motivational. Appealing social atmospheres were also tied to class composition, where some care partners had experienced issues related to gender imbalances. In this case, care partners saw tailored exercise programming for older adults with MCI/dementia and their care partners as problematic, where individuals with MCI/dementia could be alienated in classes that were dominated by the opposite gender. Given the perception that persons with MCI/dementia who attend exercise programs are predominantly male and the care partners are female, care partners suggested that segregating exercise groups based on cognitive status may pose identification issues for persons with MCI/dementia or care partners of the minority gender, as classes were often composed of both genders,

If you're gonna be looking at [exercise] classes, there's gonna be these real gender differences, especially if you want care givers there too. I'm not sure you'd want it gendered like that... it is a problem. (Care Partner – FG 2)

Despite these concerns, care partners suggested that exercise programs which include persons with MCI/dementia and care partners (potentially separately to provide space away for each partner) are a fun and enjoyable activity that they could do together and with other people,

A good thing for planning, I would think, to not just have someone who's diagnosed with need, to have programs for them but actually make the programs for both the care giver and they go through it exactly the same. Gives us something to do together and then one is in the care giver, if it's a man especially, gets more invested in it. So he'll get the benefit even though he thinks he's doing it because of the support of his spouse. (Care Partner – FG 2)

Other important characteristics of exercise programming that were described by persons with MCI/dementia included having knowledgeable, understanding and personable exercise providers and having activities that were appropriate to their individual capabilities and physical limitations. Some persons with MCI/dementia indicated that it would not matter whether they were in a group program or being individually trained, as long as the exercise was “appropriate” for what they could physically do,

Wouldn't matter [whether exercising in a group or not]... as long as it was appropriate for what I could do. I think if I had an instructor who was right there saying come on, one more! (MCI/dementia – FG 1)

Care partners also suggested that variability in exercise modality was needed to maximize potential health benefits,

I would say if you had a choice I think you would need multiple different exercises so walking's really good, some kind of stretching exercises, balancing, breathing right. Somehow all types of exercises I think are necessary. (Care Partner – FG 2)

Preferences for ideal exercise opportunities were also bound to activities that could be sustained or engaged in on an on-going manner, especially if they were able to notice physical and mental benefits in their health.

#### *Lack of Interest in Home-Based Exercise*

Persons with MCI/dementia disliked tracking and reporting home-based exercise. They indicated that monitoring would have to be very simple, due to problems with memory and a general dislike for administrative work associated with exercise. The dislike for tracking exercise seemed to translate into a general dislike of organized home-based exercise, where they felt insufficient motivation or encouragement,

Any kind of recording we have to do has to be minimal or we either won't do it at all or we won't record it... Just doing them on your own um, you're at home and there are more distractions... There's nobody watching you. (MCI/dementia – FG 1)

Care partners corroborated their partners' challenges to engage in and adhere to home-based exercise saying that they "just won't do it" by themselves. They further stated that tracking exercise progress proved challenging,

Now he kind of did them [exercises at home]... he was supposed to be reporting back but uh there was a lot of empty pages. (Care Partner – FG 1)

## **7.2 Interpersonal Level**

Engagement in exercise was strongly influenced by a range of social factors and relationships. Specifically, the exercise behaviours of persons with MCI/dementia was influenced by social identification, and dependency on formal and informal support and encouragement to exercise, most notably from their care partner.

### *7.2.1 Social Identification*

Both persons with MCI/dementia and care partners suggested that social interaction with people that they identify with is a motivator to exercise, particularly for group exercise. They indicated that interaction with persons they identify with induces feelings of comfort and enjoyment and a sense of self-worth. Valuable social interactions during exercise were said to be facilitated by several aspects of identity including cognitive/caring status, gender, and age.

#### *Identification with Other Persons with MCI/Dementia and Care Partners*

Persons with MCI/dementia emphasise how much they enjoy being with others who understand and accept them and their condition they have,

To be able to be with others and speak a little bit and not have... [to] speak like you're speaking to someone who knows nothing about what's going on in your life... it's great... they can throw in their awareness and understanding of what's involved [with having dementia]. (MCI/dementia – FG 2)

Similarly, care partners viewed organized exercise programming as more enjoyable and positive when they felt they were surrounded with others who were undergoing similar experiences. One care partner explains,

Oh, good! Yea, yea. People are accepted for who they are, where they're at. Uh, get to know them, you get to know care givers. (Care Partner – FG 1)

They valued environments where they could identify with others and where others were accepting and understanding of both their situation and that of their partner,

That's what I find the best is the exercise group when it's the person with the Alzheimer's and the caregiver and everybody accepts everybody just the way they are. (Care Partner – FG 1)

Despite an inherent interest in being around other people who also had MCI/dementia, persons with MCI/dementia were concerned about the stigmatization and medicalization of dementia where they sometimes felt as though others perceived them as being a culmination of the disease they had,

Sort of feeling that in this stage, I'm identified by [the] disease I have. So that's something I've wrestled with and I guess the hesitation I have sometimes in telling others what my diagnosis is, how are they going to interpret that? Are they going to start looking for all kinds of this and that and the other, other thing? (MCI/dementia – FG 1)

### *Identification with Others of the Same Gender*

Care partners also indicated that gender imbalances in exercise programming had left their partners with MCI/dementia feeling alienated or out of place,

I know in our yoga class, the only classes he feels comfortable are the ones that are either taught by an older man or the ones that he's seeing there's a lot of men of similar ages go to those classes. (Care Partner – FG 2)

It was clear that persons with MCI/dementia often identified as much by their gender as with their diagnosis. Group dynamics appeared to influence program engagement and maintenance.



Gender imbalance, even among those with similar cognitive status could deter persons with MCI/dementia from exercising,

He [partner with MCI/dementia] went back to do the exercises to keep it up. He'd be right with the women... well he felt so out of place not enjoying it. (Care Partner – FG 2)

#### *Identification with Others of the Same Age*

Persons with MCI/dementia also expressed desire to exercise with those who were of the same age,

I did, uh, a program at one of the gyms a few years ago that was sort of geared to a younger crowd and I didn't particularly enjoy [it]... (MCI/dementia – FG 1)

From their own perspective, persons with MCI/dementia often identified at least as strongly by their age as by their cognitive status. Care partners similarly expressed disinterest in group exercise that was composed of individuals not similar in age. One participant explains,

...he never wanted to go back to the ones... where you get these young [people] who are talking about going through a mid-life crisis... You don't want to be in a class with twenty year olds! (Care Partner – FG 2)

#### *7.2.2 Social Support from Care Partners*

The care partner has a major influence on the exercise behaviour of the person with MCI/dementia because of the dependency of the person with MCI/dementia on the support they provide. Both persons with MCI/dementia and their care partners reported that the dynamic between the persons with MCI/dementia and the care partner was characterized by changing roles and shifting responsibilities, with increasing responsibility on the care partner as cognitive impairment progresses. However, care partner health status and time demands, alluded to above in the intrapersonal factors, can limit the care partners' ability to act in a supportive role.

#### *Encouraging Exercise by Care Partners*

Persons with MCI/dementia indicated that their care partner played a significant role in their exercise behaviour, usually to promote exercise. Care partners were the primary source of motivation and encouragement to exercise. The care partners' enthusiasm for exercise was a major source of motivation for persons with MCI/dementia,

Well my wife uh has always been pretty keen on uh doing exercises so that makes it easier for her and uh for me I guess. That spurring on I think this is, uh, from your mate, even if she doesn't walk. (MCI/dementia – FG 1)

Care partners' drive to get their partner with MCI/dementia to exercise were rooted in their belief that exercise was beneficial,

We're already on board and so, we're going to keep exercising and we're going to keep whoever in our lives [exercising]. We would just do that naturally. I don't know how you would be able to motivate them, someone with dementia if they had care givers who didn't have that lifelong connection with exercise. (Care Partner – FG 2)

Care partners further suggested that their partners with MCI/dementia's diagnoses increased the necessity for them to suggest purposeful activities to avoid inactive lifestyles and to prevent their partners from being "absorbed in their puttering". Care partners specifically believed that exercise could slow the rate of decline that their partner with MCI/dementia might experience,

It's not letting them [partners] sit there and deteriorate, just go down, down, down [health]. (Care Partner – FG 2)

In some cases, care partners acted as primary motivators for exercise among their partners with MCI/dementia,

It's easy for me to decide [to not exercise] unless my wife says let's go, you know, that kind of thing is enough. (MCI/dementia – FG 2)

Similarly, persons with MCI/dementia described their partners' motivation to exercise as opportunities to alleviate sedentary behaviours.

Despite the stronger reliance of the person with MCI/dementia on the care partner, most thought that they provided mutually beneficial support. In some cases, persons with MCI/dementia sometimes motivated and encouraged their care partners to exercise,

When she's not feeling very much like going for a walk, I'd say, well, I'm going for a walk and she'd say well, wait a minute, I'm coming too. We're mindful of each other's exercise. (MCI/dementia – FG 2)

#### *Facilitation of Exercise by Care Partners*

Among persons with MCI/dementia, exercise was facilitated by care partners driving them and acting as an exercise companion. Since many persons with MCI/dementia were unable to navigate well enough to walk alone, they specifically reported the need for care partners to facilitate walking activities.

Just uh, can't do it anymore [walk alone]... I usually need my wife to go with me cause sometimes I can't remember where to go.  
(MCI/dementia - FG 1)

Although the care partners usually motivated and facilitated exercise among persons with MCI/dementia, this was not always the case. The care partner's facilitation of exercise was sometimes hampered due to abilities or worries, preventing persons with MCI/dementia from exercising,

I used to do it [cross country ski] but, then again, my wife has to drive me and she doesn't cross country ski and, well, she's not so keen on me going by myself in case I fall.  
(MCI/dementia – FG 1)

Both the person with MCI/dementia and the care partner were aware that their roles were changing over time and that the person with MCI/dementia gradually relied on their care partner more. Sometimes, care partners expressed stress, worry, and uncertainty about the future and the growing reliance on them. Tied in with their expanding role as a carer, care partners expressed an increasing devotion in time towards their partner and, consequently, less time for themselves.

That's another stressor [constantly providing support]... Seven, twenty-four is very difficult, cause sometimes you feel you're in a box. It's a non-stop battle and it only gets harder... I barely have enough time to myself because we're always doing this, that and the other thing.

(Care Partner - FG 2)

Persons with MCI/dementia and care partners indicated that transportation could be a major barrier to the exercise where lack of transportation or inability to drive themselves was seen as a problem that limited their personal freedom and increased reliance on their care partner, both in the context of exercise and more generally. Even when a person with MCI/dementia was still driving, they foresaw downsides to not being able to drive, expecting that transportation would be problematic,

It would be [a barrier] for me if I couldn't drive. (MCI/dementia – FG 2)

Furthermore, among these few persons with MCI/dementia who still drove, sharing a car with their partner could still be an issue that created transportation problems as they were often “going in opposite directions.”

It was also apparent that the care partner's willingness to provide transportation was a major influence on persons' with MCI/dementia opportunities to exercise,

Fortunately, my wife is very supportive and um enjoys the exercises too [referring to driving him]. (MCI/dementia – FG 1)

It was understood by persons with MCI/dementia that accessibility to various opportunities to exercise would be limited if not for their care partner driving.

Managing driving was described by care partners as having a “full-time job” where they generally assumed full responsibility of this task, limiting personal opportunities to exercise due to lack of time,

That's pretty well all I do, between driving and from one... the one place or another place constantly, I never stop. (Care Partner – FG 2)

Conversely, for those persons with MCI/dementia who were still driving, care partners expressed feelings of uncertainty and worry for the future as they acknowledged that their partner with MCI/dementia would not always be able to drive,

My greatest fear or limitation is that what happens if ... he loses his license? (Care Partner – FG 2)

Their feelings were grounded in a support for their partner with MCI/dementia and concern for the loss of freedom and decreased self-esteem they may experience if they were unable to drive. In some instances, the person with MCI/dementia's loss of driving was particularly troublesome when care partners did not drive,

It wasn't until I became visually disabled and I didn't have the capacity to drive... he's [person with MCI/dementia] then become my driver. (Care Partner – FG 2)

In one circumstance, the reliance of the care partner on the person with MCI/dementia was beneficial, as the person with MCI/dementia then accompanied them for exercise,

Because he's driving me now, he's going with me [for walks in the park]. He's gotten into the habit of going for these long [walks]. (Care Partner – FG 2)

### *7.2.3 Social Support from Others*

Social support and encouragement from others more generally also influenced exercise behaviour of persons with MCI/dementia. This support and encouragement came from a wide range of formal and informal influences including care partners (as discussed above), family and friends, pets, exercise instructors and physicians.

#### *Encouragement and Support for and during Exercise from Others*

Persons with MCI/dementia indicated that the encouragement and support of others is a major determinant of their exercise behaviour, where the others need not be the care partner. It was unanimously agreed among persons with MCI/dementia that having a companion motivates and encourages them to exercise. As one participant describes,

It's a lot easier [to exercise] if you have somebody to do things [with]. Helps to have somebody with you. It's the other person that...is a good incentive [to exercise]. It's a very great help to have someone with you who's doing more or less the same thing... encouraging you to do it. (MCI/dementia – FG 1)

Persons with MCI/dementia also described needing help from a companion to exercise,

Well it's just, I need somebody to go with me... I can't go by myself. (MCI/dementia – FG 1)

Care partners also expressed a desire for having a companion to exercise with,

It's nice when you're with somebody else [exercising] helps, with your partner or your daughter or son or something like that. It motivates you to keep going. I like the companionship. (Care Partner – FG 1)

Both persons with MCI/dementia and care partners expressed a desire to exercise with their partner.

Conversely, lack of a companion or person to support and encourage them was a barrier to exercise and made them more reluctant to be active,

I wish I had somebody to kind of spur me on [to exercise]. I'm all by myself. (MCI/dementia – FG 1)

### *Pets as a Motivator for Walking*

Persons with MCI/dementia described pets, specifically dogs, as being an encouraging, “good incentive for walking” and also a “good incentive for older people” in general. They even mentioned prior pet ownership as a factor that positively influenced walking activity. Having a pet not only directly motivated exercise but also increased opportunities to interact socially during exercise, providing further motivation,

If you had a dog, get you out walking every day, couple times a day... If you have a dog you always stop and talk to people... Always conversations. (MCI/dementia – FG 1)

### *Support from Knowledgeable and Encouraging Exercise Providers*

Persons with MCI/dementia also described the importance of having knowledgeable, understanding, and friendly instructors or exercise providers during exercise programs. They expressed greater enjoyment and interest in exercise in the presence of friendly exercise providers, where instructors were motivational and encouraging,

I think that if I had an instructor or someone who was right there saying uh come on, one more! Or, six more! I seem to need something like that... somebody egging me on. Having a good teacher I think is vital... very encouraging. (MCI/dementia – FG 2)

Persons with MCI/dementia expressed a specific desire for “more trained people” to better understand the exercise needs of persons with dementia.

Care partners also considered that the exercise providers helped them exercise, but to a lesser extent. They viewed the positive aspects of encouragement for their partner if they had an instructor or trainer helping them, also suggesting that their partner may be more likely to exercise regularly. Persons with MCI/dementia also expressed that having a trainer present was important in preventing injuries and correcting improper form that could potentially lead to injury, while also maximizing the possible benefits of exercising,

I'm so bad at lunges, [the trainer] always came and set me straight, you know, so that I don't do myself more harm than good, encouragement. (MCI/dementia – FG 1)

### *Physician Encouragement and Recommendations*

Persons with MCI/dementia indicated that recommendations by their family physician motivated them to exercise, though it was unclear whether exercise was recommended for overall health or specifically for their condition. In some cases, it was apparent that advice from a physician induced a sense of urgency and fear, inciting participants to initiate and maintain their exercise habits,

He [doctor] says, you know you got a serious problem, although you're not sick, but that weight's gonna kill you. He motivates me. He's the one that said you're going to die. (MCI/dementia – FG 1)

Care partners also described health care providers being influential on their partner with MCI/dementia's exercise behaviours. In most cases, they suggested that individuals with MCI/dementia were more likely to listen and adhere to a voice of authority than to them (care partners). This issue was particularly emphasized for male persons with MCI/dementia,

From a male point, he needs that authoritative... I'm nothing. If I tell him something, my voice is not worth anything but if a doctor tells him, he's much more so [willing to do exercise]. (Care Partner – FG 2)

There was consensus that the delivery of the message from the physician influences the acceptance and use of beneficial health-related information more generally,

It would be better if the doctor tells the [person with MCI/dementia] directly with the care giver there listening to be able to say "well the doctor said". I don't know. That's my experience with a male spouse. (Care Partner – FG 2)

Relatedly, care partners also suggested that the gender of the care partners impacts the frequency of physician visits for the person with MCI/dementia, where male care partners are less likely to take their female partners for ongoing care.

#### *7.2.4 Social Engagement during Exercise*

Persons with MCI/dementia viewed exercise as a social activity and appreciated that you could acquire "double benefits, physically and socially." The social atmosphere of exercise was viewed as beneficial and motivated both persons with MCI/dementia and care partners to exercise. Some participants indicated that the two were inseparable from one another, which also improved their mood,

I think the two [exercise and social activity] are [together] and, I think, could be seen as an opportunity to socialize and improve your physical [health]. I also found that the uh social dimension of exercising, um, kind of brightens the day too. (MCI/dementia – FG 1)



The social dimension of exercise appeared to motivate and encourage exercise even more so than the prospects of achieving health benefits. Social engagement during exercise was an incentive to maintain their exercise behaviours due in part to the ability to socialize with others,

You meet some nice peoples too, you know, when you exercise. [Socializing] adds incentive to, uh, going back. (MCI/dementia – FG 1)

The importance of social activity that comes with exercising was also noted by care partners. Care partners felt that the coupling of social interaction with exercise was of great benefit,

He's happier when he's been doing something or talking to somebody or socially, social contact. He's happier. He talks more. (Care Partner – FG 2)

They also believed that the social engagement during exercise was beneficial to them where they were able to socialize and be around others,

That's the best part, exercise and the social. I think they're great together. That's the two main things. You cannot beat that. (Care Partner – FG 2)

### **7.3 Community Level**

Factors related to the external environment such as the physical environment, accessibility of exercise opportunities, and the availability of preferred exercise options were reported as factors that impacted exercise levels among persons with MCI/dementia. More specifically, weather, neighbourhood infrastructure, perceived safety, accessibility policies, and availability of preferred exercise programs.

#### *7.3.1 Physical Environment*

Persons with MCI/dementia and their care partners indicated that both the natural and built environment influenced the exercise levels of persons with MCI/dementia. The physical environment was a particularly important barrier to exercise to walking outdoors, which was the preferred exercise option for many persons with MCI/dementia and their care partners. One care

partner suggested that walking outside “where there’s nice greenery and there’s other stimulations” was preferred.

### *Weather as a Barrier and Facilitator of Exercise*

Weather was a dominant barrier to exercise, particularly to walking outdoors. One participant explains,

If it's too hot or too cold or wet, I just wouldn't go out [for a walk]. (MCI/dementia – FG 1)

However, some persons with MCI/dementia had identified alternative exercise opportunities that they could do without going outside. Several persons with MCI/dementia and care partners indicated that they would walk inside the halls of their buildings,

Walking inside on a blowy, blustery day, it's still better than not doing anything because you can use that as a crutch. (MCI/dementia – FG 1)

Alternatively, another care partner used mobility accessories and devices to overcome the weather so that they could still walk outside,

I wear Yak Tracks, those spikey things, on my boots [when walking]. I'll take a cane with me even though I don't need a cane but my vision is quite wonky at times... I'll just make sure I've got the cane and just maximize [supports for] my frailties. (Care Partner – FG 2)

### *Neighbourhood Infrastructure Limiting Walking*

Walking outdoors was further limited among persons with MCI/dementia when neighbourhood infrastructure was poor. Unfinished construction in streets and uneven sidewalks were considered potentially dangerous. Persons with MCI/dementia indicated that the surface that they walked on was “important”,

Some of the sidewalks they've been working on have been just too dangerous to walk on... sometimes they're not level. The surface you're walking on is important! (MCI/dementia – FG 1)

In contrast, access to pleasant locations to walk were facilitative to exercise among persons with MCI/dementia. Parks and forests were described as prime locations for walking, though cyclists, pets, and crowds sometimes hindered these walks,

The one thing that bothered me [about walking in park] when we did it a lot was the cyclists cause they don't always warn you they're coming. Sometimes people are just y'know, scoot by at such great speed about that far away and it just made me very anxious. (MCI/dementia – FG 1)

### *Perceived Safety*

Persons with MCI/dementia indicated that potential danger in the neighbourhood caused anxiety and paranoia and, ultimately, prevented them from going out, particularly by themselves,

I wouldn't go by myself [to the park]. There's all kinds of weird people there. Many stories [of potentially dangerous situations happening there]. I would never go on those trails by myself. (MCI/dementia – FG 1)

Having a companion (pet or person) improved their confidence for some in contrast to walking alone,

If I had two nice big dogs with me, well-trained I would feel much more secure [walking along in the woods]. (MCI/dementia – FG 1)

### *7.3.2 Accessibility to Exercise Facilities and Opportunities*

Opportunities to exercise for persons with MCI/dementia were also determined by accessibility to facilities and preferred exercise programs. Accessibility to preferred exercise opportunities was largely determined by issues of feasible transportation and policies and, to some degree, on social relationships.

#### *Access to Appropriate Exercise Settings*

Despite some challenges, persons with MCI/dementia generally felt that opportunities existed for them, whether it be a forest nearby to walk in, local parks, or nearby recreation centres. The type of infrastructure that persons with MCI/dementia wanted access to, however,

depended on the individuals' exercise preferences. Poor accessibility to walking paths and a far distance to exercise facilities were raised as barriers to exercise. Even when a park was nearby, having too few benches could limit using the park for exercise. One person with MCI/dementia elaborated,

The best shortcut to do it [walk to community centre]... they cut it off... they're times when I might go then but don't because of distance to the facility. I also won't walk through the park now... there's not enough benches. (MCI/dementia – FG 1)

If accessible exercise infrastructure did not match their preferences or abilities, it did not facilitate exercise. For example, some individuals did not use the exercise facilities even when they were in their buildings because they did not like exercising with machines. On the other hand, exercise equipment that was available was sometimes unsuitable due to physical impairments. Some individuals with balance and joint problems indicated they were “terrified” to use equipment such as Bosu balls without supervision,

I'm limited on the machines I can use too, locked in on the bike with my shoes or I'm on the rowing machine so I can't, it's cause I have a little bit of balance problem. (MCI/dementia – FG 1)

Participants reported that living in rural areas resulted in a poorer access to infrastructure and services that are needed for exercise and healthcare. Those living in rural communities, however saw increasing opportunities to be active, even if still somewhat limited.

#### *Access to Exercise Programs with Preferable Characteristics*

Accessibility to exercise programs and services that catered to their needs was also challenging at times. Participants brought up several program characteristics that would facilitate their participation in organized group exercise,

You know, having somebody working with you, if it's not hard to get there and if it's not too expensive and a whole bunch of other reasons, I think I would [participate in a program]. (MCI/dementia – FG 1)

Persons with MCI/dementia described money as a barrier to accessing exercise facilities and programs, and particularly in having a personal training, something they viewed as a facilitator and motivator for exercise. Care partners agreed that money was an issue when accessing programs. Care partners indicated that the cost of exercise programs further encouraged walking as the preferred exercise option as, “we can do it without money and it has all these benefits.”

Care partners expressed knowledge of dementia-specific exercise programs available to them,

Y'know if you can look at the Alzheimer's society website, they have uh a lot of things offered for caregivers and the uh person [persons with dementia]. (Care Partner – FG 1)

However, persons with MCI/dementia explained that there were barriers even to accessing these dementia-specific programs and classes, which were described as preferred social environments by some. Most of these programs require the person with dementia to have their care partner present. This was not possible for all persons with MCI/dementia,

As with all these programs [for persons with dementia], you have to have your care partner with you and I knew I wasn't going to get that so I didn't even look at it. [MCI/dementia – FG 1)

However, persons with MCI/dementia viewed this as a problem in program design rather than an issue of care partner availability.

#### *Unsupportive Policies Limiting Accessibility and Motivation to Exercise*

Policies could also restrict exercise among persons with MCI/dementia. Two policies mentioned related to transportation and restriction of pets in apartments or condos. First, for the purpose of local assistive transport for persons with disabilities, care partners raised concerns that persons with MCI/dementia were not considered disabled. These policies precluded persons with MCI/dementia from accessing transportation that could be a feasible option and, thus,

limited exercise opportunities when care partners could not provide rides. Care partners described active challenges to these rules,

There's a drive on to have people with dementia classified as disabled so they can use disabled transport, right now, dementia does not count as a disability. (Care Partner – FG 1)

The alternative of taking a taxi was simply too expensive to use on a regular basis. Lack of subsidized funding was seen as a barrier to travelling to nearby exercise facilities and programs.

Some care partners also indicated that apartment or condo rules against pets could be a barrier to exercise. Indirectly, limiting pet ownership eliminated a motivator for exercise (pets) and so may reduce exercise levels. It was also suggested that having a pet could also improve both partners' psychological health,

You'd think that apartments for seniors would be much more open [to having pets] and they're not though. If you could have a pet... [dogs] they're good prompters [for walking]. (Care Partner – FG 1)

### *7.3.3 Availability of Appropriate Exercise Opportunities*

Participants, particularly care partners, suggested several program characteristics that would entice them to exercise but were seldom available in the community. This included dementia-specific programs as well as particular program characteristics. Increasing the availability of exercise opportunities with preferred characteristics was likely to improve motivations to undertake exercise among both persons with MCI/dementia and care partners.

Care partners specifically indicated concerns about the limited availability of exercise programs that were appropriate for the physical and mental abilities of persons with MCI/dementia. It was suggested that generic exercise programs that did exist could result in

unfavorable circumstances such as injuries due to the unspecific design towards older adults with dementia and in general,

They definitely need more group exercise for those with dementia... it goes up and down [fluctuating behaviour], some days they need more help than others but I don't know... With their frailties... inadvertent bumping could be harmful. (Care Partner – FG 2)

Care partners suggested that dementia-specific programs were scarce. They suggested that motivation to undertake an exercise program would be enhanced with increased availability,

The problem that we've had is we've never found the kind of exercise program [that is appropriate that they like], we'd love to do it. I think there should be more group programs [for persons with MCI/dementia]. (Care Partner – FG 2)

Motivation to exercise could also be enhanced with increased availability of socially-oriented group activities that included other older adults that persons with MCI/dementia and care partners could identify closely with,

It would become fun [attending exercise program with older adults whom are similar], something you don't want [to] miss out on, meet some nice people and have a good time. (Care Partner – FG 2)

Care partners also offered detailed characteristics of exercise programming they would like to have available to them, but is not currently. For example, availability of relatable exercise providers who understand the needs of persons with MCI/dementia was limited. Availability of such knowledgeable and relatable exercise providers could enhance motivation to exercise as well as the opportunity for safe exercise. In addition, care partners valued program characteristics such as variety, social engagement, and good music,

Say if your kinesiology program developed a senior's exercise evening, aerobics where you're not doing stairs up and down for forty minutes but there's a whole variety of different motion movements and good music, I think people would flock to it. (Care Partner – FG 2)

Care partners expressed a strong desire for increasing the availability of preferred exercise opportunities, which they believed would also be valued by their partners. In contrast, however,

many persons with MCI/dementia considered exercise programs inessential or irrelevant. They preferred walking outdoors, as long as it was available.



## 8.0 Discussion

This study explored the barriers and facilitators to, as well as preferences for, exercise among community-dwelling older adults diagnosed with MCI/dementia from the perspective of persons with MCI/dementia and their care partners. Persons with dementia faced challenges to exercise participation, including low intrinsic motivation, physical and mental health challenges, and stigma against dementia. However, support at the level of the individual or community can help to over-come these barriers. Specifically, motivation to engage in exercise could be increased by care partner support through accompanying during exercise as well as increasing the availability of meaningful and enjoyable exercise opportunities that align with the individual preferences of persons with MCI/dementia and their care partners. Similarly, the limitations associated with physical and mental health problems could be reduced through external social influences such as exercise providers and particularly care partners. Findings extend the sparse literature by specifically highlighting key roles for the care partner, other external supports, and the community for enabling exercise among older adults with dementia.

Motivation for exercise was a major theme across our focus groups. Persons with MCI/dementia, the care partner, other people (health care professionals, exercise providers), and exercise opportunities, all influenced motivation for exercise among persons with MCI/dementia. Low intrinsic motivation for exercise among our participants with MCI/dementia significantly restricted exercise, in line with one prior study (Yu & Kolanowski, 2009). Participants suggested that low intrinsic motivation may be more impactful than actual health limitations among persons with MCI or mild dementia, discussed further below. Dementia may cause low intrinsic motivation, as apathy is a common neuropsychiatric symptom across all stages of dementia (David et al., 2012). However, care partners in this study also suggested that low intrinsic

motivation among their partners with MCI/dementia may be part of their personality, more generally, rather than a result of dementia. Indeed, lack of motivation is a common barrier to exercise among older adults more broadly (Lees et al., 2005).

The diagnosis of dementia itself was a strong motivator for exercise among persons with MCI/dementia. Persons with MCI/dementia indicated that their motivation to exercise increased after they were diagnosed, and did not believe that their ability to exercise had substantially changed. Another study similarly noted that the importance of physical activity increased after AD diagnosis, where persons with AD used physical activity as a strategy to achieve a sense of well-being and dignity as their symptoms of the disease progressed (Cedervall et al., 2015). Also, an Alzheimer's Association's (2008b) analysis of the dialogues and perspectives of over 300 persons living with early AD noted that having the disease taught them to value what was important to them, including physical activity, and motivated to stay physically active. It could be that persons with MCI/dementia who were active prior to their diagnosis were especially motivated to be physically active, employing exercise to achieve continuity in their lifestyle despite their dementia diagnosis as in prior work (Menne, Kinney, & Morhardt, 2002).

Despite the motivation associated with a diagnosis of MCI/dementia, persons with MCI/dementia's intrinsic motivation may be limited by low self-efficacy for exercise. Persons with MCI/dementia's actual and perceived capabilities to exercise may negatively influence their self-efficacy (belief that they are capable of exercising). Even among older adults with healthy cognition, self-efficacy for exercise is a strong determinant of the adoption and maintenance of exercise behaviours (McAuley et al., 2011, Schutzer & Graves, 2004). Persons with worse cognitive function report having lower self-efficacy for exercise than those with better cognitive function (Resnick et al., 2007). Self-efficacy for exercise may be an especially important

moderator of exercise as disease in the presence of the social and physical barriers to exercise, where greater self-efficacy helps overcome challenging circumstances (McNeill et al., 2006).

Low intrinsic motivation among persons with MCI/dementia could be mediated and counteracted by external motivation provided by a variety of individuals, particularly their care partners. Care partners held a strong, almost existential connection to exercise, where they perceived it as beneficial and meaningful activity for both their own health and wellness and that of their partners with MCI/dementia. A number of prior studies confirm the strong influence between care partner support, beliefs, and experience regarding exercise and their partner with MCI/dementia's motivation to exercise (Malthouse & Fox, 2014, Suttanon et al., 2012, Yu et al., 2011). Reasonably, care partners' belief in the benefits of exercise could drive them to encourage and support their partners with MCI/dementia to exercise, which may help their partners with MCI/dementia overcome wavering intrinsic motivation.

Other people, including health care providers and exercise providers, can also provide external motivation for persons with MCI/dementia to help them to overcome low intrinsic motivation. In this study, many care partners indicated that their partners with MCI/dementia (particularly men) were more likely to listen and follow the advice of an authority figure, especially health care providers. Previous studies have also highlighted the importance of support from health care professionals to encourage people to take part in exercise (Suttanon et al., 2012, Taylor et al., 2004a). In this study, persons with MCI/dementia seemed already convinced of the value of exercise; however, it is possible that prior advice from healthcare providers influenced this belief. Care partners believed that it was beneficial for healthcare providers to provide exercise advice to the person with MCI/dementia in their presence so they could specifically reiterate the healthcare professional's instructions as a strategy to motivate and

increase exercise. In this manner, both the care partner and the healthcare provider have roles in disseminating information to encourage exercise among persons with MCI/dementia, as has been suggested in prior work (Suttanon et al., 2012).

Knowledgeable, accepting, and understanding exercise providers could also be a major external motivator for exercise among persons with MCI/dementia. Older adults (in general) indicated that exercise providers provided important motivation to exercise and who incentivized adherence to exercise programs (Costello et al., 2011). Similarly, persons with dementia and their care partners reported that their motivation to adhere to an exercise program was facilitated by the presence of a professional and positive exercise provider in a prior study (Suttanon et al., 2012). In addition, encouragement from professionally trained staff has also been shown to increase motivation to adhere to exercise programs among adults with Parkinson's disease (O'Brien, Dodd, & Bilney, 2008), suggesting that it is important across adults with different conditions. Supervision and instruction from a qualified exercise provider is likely to play a critical role in increasing motivation and adherence to exercise among persons with MCI/dementia, and the absence of adequately trained exercise professionals is likely to restrict exercise.

Participants with MCI/dementia and care partners further believed that access to meaningful and enjoyable exercise opportunities provided further external motivation to exercise, and could help overcome low intrinsic motivation among persons with MCI/dementia. In this study, persons with MCI/dementia and care partners often preferred walking outdoors in nature as the most enjoyable and motivational method of exercise, in line with previous findings (Cedervall & Aberg, 2010, Cedervall et al., 2015). Outdoor walks may maintain a sense of selfhood by allowing continued engagement in valued activities they have always done

(Cedervall et al., 2015). Alternatively, walking may be preferred because accessibility to group exercise programs appropriate to, or specifically for, dementia was challenging, as reported by the current participants and in prior studies of MCI and AD (Chong et al., 2014). Unfortunately, weather mediated access to walking outdoors, as both a preferred and motivating exercise, as previously reported (Chong et al., 2014, Malthouse & Fox, 2014, Suttanon et al., 2012).

Despite an overall preference for walking outdoors, results from the current study indicate that persons with MCI/dementia and care partners also wanted exercise opportunities with social engagement, where social engagement was an important motivator to exercise. Exercising in a group setting was motivating for ongoing participation, particularly if exercise was with other people with whom they could identify. The value of meaningful social cohesion during exercise was previously acknowledged in a prior study, albeit in a study of home-based exercise (Suttanon et al., 2012).

Both persons with MCI/dementia and their care partners suggested that interaction with others who are on a “similar path” (that is, others with similar cognitive/carer status) was motivational for group exercise. Similarly, in prior studies, both care partners and persons with dementia expressed pleasure in having the opportunity to be accepted and to be with others “who have the same problem” (Dal Bello-Haas et al., 2014, Yu et al., 2011). However, both persons with MCI/dementia and care partners indicated that there was a lack of dementia-specific exercise opportunities in which to interact with their peers. Efforts to reduce barriers to social inclusive exercise may increase motivation for continued exercise participation.

Not noted in prior literature, persons with MCI/dementia clearly indicated a desire to engage with people they could identify with beyond cognitive/carer status. Persons with

MCI/dementia and care partners also enjoyed and were motivated by engaging with individuals of similar age and gender in exercise programs, which were important characteristics by which they identify. As such, gender imbalances in exercise programming, both in group exercise in general and that specifically targeted to persons with dementia and care partners could be a barrier to exercise, decreasing motivation. Programs for persons with MCI/dementia tended to have more male persons with MCI/dementia and female care partners, in line with research indicating that there are a greater number of female care partners than males (Brodaty & Donkin, 2009, Prince, 2004). Programs may be less enjoyable and motivational for persons of the opposite gender. Also, care partners described being unmotivated when exercising with others who were not similar to them in age, especially in groups predominantly composed of younger people. Thus, social inclusion at the level of the care partner is also an important factor to for exercise programming if care partners are to motivate and facilitate exercise for persons with MCI/dementia.

Perhaps due to the lack of external motivation from exercise providers or social engagement, home-based exercise was viewed as very challenging for persons with MCI/dementia and was associated with very low motivation to exercise. Persons with MCI/dementia often found it difficult to successfully engage in home-based exercise as memory problems could restrict independent exercise and tracking home-based exercise. As such, increasing group-based exercise opportunities that meet the needs of persons with MCI/dementia is important because of the challenging nature that home-based programs. Substantial interpersonal support from care partners and/or exercise providers may be required to make home-based exercise programs successful. In this case, external motivation and encouragement could potentially compensate for low intrinsic motivation experienced by persons with

MCI/dementia, as well as cognitive challenges. For example, in two home-based exercise intervention that achieved high compliance and completion rates, care partner involvement and support was marked in (Steinberg et al., 2009, Suttanon et al. 2012). In our study, however, some care partners indicated that their partner in MCI/dementia would not follow their exercise advice. Thus, care partner support may need to be supplemented by the advice of health care or exercise provider.

In addition to low intrinsic motivation, persons with MCI/dementia found that physical health, fatigue, and cognitive challenges were limiting factors to exercise. This finding is consistent with previous research exploring physical activity among older adults with MCI and AD where health problems, disability, and fatigue were prominent barriers (Chong et al., 2014, Malthouse & Fox, 2014, Cedervall & Aberg, 2010). Poor physical health has also been reported as a barrier to exercise more broadly among older adults (Schutzer & Graves, 2004), suggesting that age-related problems with physical health may moderate exercise participation at a more general level. Physical health issues are common among older adults (Nelson et al., 2007), as in this study, and may contribute to fatigue. Other symptoms associated with dementia such as disrupted executive functioning, poor quality sleep, and depression may further exacerbate fatigue (Goetz, 2007), and reduce exercise.

Cognitive challenges made exercise more difficult for persons with MCI/dementia. Memory problems were the most frequently cited cognitive problem. Prior studies have also noted emerging cognitive challenges among persons with MCI, such as impairments in attention and memory as barriers to exercise (Chong et al., 2014, Yu & Kolanowski, 2009). However, these studies did not note that cognitive problems were particularly restrictive to independent exercise (including home-based exercise), as reported by participants in the current study.

Support of the care partner in combination with appropriately designed exercise programs could be sufficient to help overcome both cognitive and physical challenges.

Care partners facilitated exercise among persons with MCI/dementia by providing continual support, which reduced the impact of physical and mental health challenges on exercise levels. For example, care partners accompanied their partners with MCI/dementia on walks and to exercise programs, especially when they could not or would not go alone. Previous research suggests that care partners are the primary facilitators for persons with MCI/dementia's exercise behaviours (Van Alphen et al., 2016a). This may not be surprising as persons with MCI/dementia rely on their care partners more so than older adults in general.

Care partners often facilitated exercise by providing transportation to exercise programs, where persons with MCI/dementia often lose their driver's license due to cognitive (and sometimes physical) challenges associated with dementia. Transportation has previously been noted in the literature as a barrier to exercise among both older adults with and without cognitive impairment (Boehm et al., 2013, Yu et al., 2011). Many older adults with dementia depend on private transportation, primarily by their care partners, for getting to all destinations (Taylor & Tripodes, 2001). However, reliance of persons with MCI/dementia on care partner transportation could also have a beneficial side-effect, where some persons with MCI/dementia accompany their care partners wherever they go, including exercise.

Unfortunately, some care partners found it difficult or stressful to facilitate exercise for their partners with MCI/dementia, due to physical or mental health problems. Care partner health status was previously noted as a barrier to persons with dementia's exercise behaviour, specifically to home-based exercise (Suttanon et al., 2012). Another study indicated care partner



health problems such as arthritis and low energy limited both their own exercise and that of their partner with AD (Malthouse & Fox, 2014). It could be postulated that poor health experienced by care partners may influence their own perceived and actual capacity for exercise, and thereby negatively influence their ability to accommodate and support the physical and mental needs for exercise of their partners with MCI/dementia. In addition, some care partners indicated that anxiety and worry about accidents, falls, or getting lost sometimes stopped them from supporting their partners to exercise. Due to care partner concern for safety, opportunities to exercise independently among persons with MCI/dementia could be reduced, leading to a sense of loss of perceived freedom by both parties. Indeed, Malthouse and Fox (2014) referred to care partners as “gate-keepers,” where care partners protect persons with dementia from potentially hazardous or stressful situations.

When care partners could not facilitate exercise, due to fears, stress, or their own health limitations, this often placed considerable restriction on the persons with MCI/dementia’s ability to exercise due to societal-level failure to broadly accommodate and support persons with dementia. For example, some dementia-specific exercise programs required the presence of a care partner, excluding the person with MCI/dementia if their care partner could not participate. In addition, challenges in accessing public transportation often left few options for persons with MCI/dementia if their care partners were not available. Concerns for safety based on physical and mental limitations may cause persons with MCI/dementia to avoid use of public transportation services, even when they lack other options (Taylor & Tripodes, 2001). Furthermore, a diagnosis of dementia may not qualify a person for using assistive public transportation, as in the region where the study was conducted. Several steps could improve transportation options for persons with MCI/dementia that would benefit both persons with

MCI/dementia and care partners. Such options could include access to assistive transit, expanded volunteer driving services, and greater training for public transit personnel to understand the accessibility needs of persons with dementia. Suggested modifications to transportation services may facilitate exercise behaviours among persons with MCI/dementia by improving the societal-level accommodation of physical and mental challenges common to dementia.

To enable exercise despite the physical and mental health limitations of persons with MCI/dementia, the real and perceived safety of the environment (natural or built) and exercise programming is also important. Although safety has not been noted as a barrier to exercise among persons with MCI/dementia, safety concerns are a well-documented as a barrier to exercise among healthy older adults (Schutzer & Graves, 2004). Perceived danger, due to poor and under-developed neighbourhood infrastructure and the presence of cyclists and animals (Schutzer & Graves, 2004, Van Alphen et al., 2016), may restrict exercise more so as physical and mental health declines among persons with MCI/dementia. Maneuvering more challenging environments may require facilitation by care partners, as reported by both persons with MCI/dementia and their care partners in this study.

The safety of exercise programs can also be of concern but can be enhanced by exercise providers who understand the physical and mental needs of persons with MCI/dementia, thereby facilitating exercise in this group. Persons with MCI/dementia and care partners indicated that exercise tailored to their individual needs and interests is strongly preferred, in line with previous research (Chong et al., 2014). Exercise literature among older adults, more generally, has concluded that a one-size-fits-all strategy cannot address their specific needs (Schutzer & Graves, 2004). This may be particularly true for persons with MCI/dementia, who are likely to have both lower cognitive function and greater functional decline (Black & Rush, 2002).

Accessibility to appropriate exercise programming may become more important as cognition declines (Chong et al., 2014).

The perception of dementia more broadly in society has a major influence on behavior, and specifically exercise behaviour, among persons with dementia. In this study, perceptions of dementia, which differed by the individual affected, the care partner, and society more broadly, seemed to play a role in facilitating or deterring exercise among persons with MCI/dementia. Persons with MCI/dementia remained optimistic for the future and did not feel that they had changed significantly as a person, or in their abilities to exercise. Despite this, some acknowledged that they struggled with “being identified by the disease [dementia]”. The cultural and societal perceptions of dementia may perpetuate the stigmatization that some persons with MCI/dementia experienced. Persons with early forms of dementia are aware of and internalize the negative perceptions that society holds regarding dementia, causing them to worry about how others may respond to their diagnoses (Reed & Bluethmann, 2008). One study suggested that worry about their diagnoses and fear of public embarrassment could result in persons with MCI/dementia withdrawing from social activities and situations, including exercise (Cedervall & Arberg, 2010, Husband, 2000). Indeed, stigma relating to dementia can result in loss of confidence and related withdrawal from activities such as exercise (Ashworth, 2017). Although little research has examined the degree to which the stigmatization of dementia impacts exercise, the current results suggests that greater public education and awareness could promote social participation in activities such as exercise.

Unlike persons with MCI/dementia, who focus on their abilities, care partners tended to focus on the negative of dementia including their partner with MCI/dementia’s physical and mental decline and increasing dependence, as in previous studies (Cedervall & Aberg, 2010) and

aligning with society's negative perception of dementia (Mitchell et al., 2013). Care partners' perceptions of dementia tended to align with the generalizations of society (one of tragic loss) rather than that of their partners with MCI/dementia (one of retained capacity). Positively, the negative perception of dementia motivated care partners to be proactive and help their partners exercise in order to achieve associated the physical and mental health benefits.

Societal level stigma against dementia may cause failure to plan and accommodate persons with dementia in exercise. Our participants indicated that exercise classes that accommodated the individual needs of persons with MCI/dementia existed were not widely available, restricting exercise. Persons with MCI/dementia are often discounted in social contexts and sometimes perceived by the broader community as lacking capacity (Alzheimer's Europe, 2013). Failure to provide exercise programs devoted to the needs of persons with dementia, more than simply 'day programs', suggests society's failure to acknowledge retained capacity of this population in lieu of societal stereotypes that dominate our cultural understandings of the disease. Furthermore, the perceived lack of availability may remain when exercise program offerings are targeted only to persons with moderate to severe stages of dementia. Successful exercise program planning needs to acknowledge and differentiate the individualized and variable progression of dementia.

Results from the current study indicate that the impact of barriers to exercise among persons with MCI/dementia (such as low motivation, poor physical or mental health, and stigma against dementia) could be reduced through social and community-level factors. First, external motivation provided by care partners, health care providers, and enjoyable social exercise opportunities may help overcome limited intrinsic motivation. Secondly, supports to increase the accessibility and availability of exercise opportunities that are enjoyable and designed to

accommodate their individual physical and cognitive needs appears to be of the utmost importance in mediating exercise participation. Access to such programs could increase motivation and reduce the negative impact of physical and mental challenges on exercise levels among persons with MCI/dementia. Lack of available and accessible exercise opportunities specifically targeted towards older adults with dementia may be linked to a societal-level failure to acknowledge retained capacity among this population. Such shortcoming in exercise program design not only contributes to the increasing stigmatization of persons with the disease but, ultimately, may negatively influence exercise engagement. Openly inclusive, available and accessible exercise opportunities/programs that encompass desirable characteristics and meet physical and mental needs should be developed for older adults with MCI/dementia.

## 9.0 Strengths and Limitations

This study was the first to explicitly explore the factors influencing exercise among community-dwelling older adults with MCI/dementia from the perspectives of persons with MCI/dementia and their care partners using focus group discussions, specifically probing on the SEM intrapersonal, interpersonal, and community levels. A recent systematic review of the barriers to physical activity among older adults with dementia classified factors within the SEM theoretical framework, but recognized that there were limited probes of the community (environment or policy) level in individual studies (Van Alphen et al., 2016a). Another strength of this study was the homogenous focus group dynamics, which allowed the thoughts, opinions and experiences of the persons with MCI/dementia and care partners to be relatively free from influence of their partner.

This study does have limitations. Inferring generalizability of the results should be approached cautiously due to the relatively small sample size and sampling from a single urban area. However, 10 persons with MCI/dementia and 7 care partners is appropriate for a qualitative framework. Focus group discussions and size enabled exploration of the individual experiences and opinions regarding exercise participation in a manner where data saturation could be met. By the end of the focus groups, new factors no longer emerged.

Participants were also highly educated and Caucasian, limiting generalizability of findings to very specific cultural and demographic perspective. This study could not depict specific cultural perceptions of exercise as well as the barriers and enablers that might be more prominent among sub-populations. A larger and more varied participant sample could have more variation and depth in response. However, findings are reflective of the views held of exercise among the current study's participants.

Possible selection bias may also have been introduced as through the sampling methods used as many participants had been previously engaged in community exercise programs or exercise research interventions, indicating that they were likely to be more active and possibly have fewer comorbidities than age-matched older adults with cognitive impairment not involved in social outreach. Furthermore, they may be more motivated to exercise as they volunteered to participate in research regarding exercise, which may not be representative of persons with MCI/dementia. Facilitative and inhibitory factors to exercise are likely to differ between those who are already more active compared to those who are sedentary. However, the sample did include two persons with MCI/dementia who said they currently completed no exercise per week.

Cognitive impairment among persons with MCI/dementia may have made it difficult to remember questions or express their opinions during focus groups. This was minimized by repeating questions several times to allow ample time to think and respond in any way. Furthermore, the nature of focus groups may be influenced by interviewer bias, reluctant participants, or avoidance due to dislike of group settings, all of which may be particularly prominent to persons with MCI/dementia (Morgan, 1996). However, there are many advantages to focus groups, which include encouraging and supportive group environments, clarifying views in a timely manner, and highlighting group dynamics and norms in a way interviews cannot (Morgan, 1996). Furthermore, heightened moderator awareness and enhancing facilitator techniques likely reduced discomfort in focus group discussions (Chong et al., 2014).

Efforts were made to increase the validity of this study's findings. Although findings may represent accurate depictions of how participants perceived exercise, there is always a tendency for participants to behave differently in a social context. For example, participants may withhold

opposing opinions in the face of group consensus. Future research could hold closing individual interviews with each person with MCI/dementia and care partner separately to ensure consistency between the thoughts expressed in focus groups and those they express in private.

Another limitation pertained to the timeline in which this study was completed. Focus groups occurred over a two-month period from January 2017 to March 2017. Seasonality could have influenced responses and preferred exercise options. It is possible that preferred activities for exercise such as walking outdoors is affected to a greater degree by the seasons in Canada, where winter is more severe.

Finally, social and behavioural phenomenon are suggested to be contextually bound (Guba, 1981), meaning that perspectives and opinions of exercise may be ever changing. This may be particularly true among persons with MCI/dementia with increasing reliance as cognitive function declines. Perspectives of exercise are likely to change over time due to health status, changing social relationships, and addition or exclusion of services or facilities.



## **10.0 Conclusion and Future Directions**

Thematic analysis of focus groups with community-dwelling older adults diagnosed with MCI/dementia and their care partners revealed a complex and dynamic interplay between factors across different levels of the SEM to moderate engagement in regular exercise. Discussions provide insight into how persons with MCI/dementia can be engaged in regular exercise and importantly acknowledge how social and environmental factors may reduce or accentuate the impact of individual-level challenges. Although barriers to exercise among persons with MCI/dementia exist at multiple levels of influence, exercise was held as both a meaningful and beneficial activity by both persons with MCI/dementia and their care partners, suggesting that pursuing strategies to facilitate exercise among this population is worthwhile.

Despite positive views towards exercise, physical impairments and memory problems often prevented exercise among persons with MCI/dementia. Lack of intrinsic motivation further restricted exercise. However, social support may moderate intrapersonal barriers to facilitate exercise among persons with MCI/dementia through encouragement, facilitation, and transportation. The care partner, in particular, was a dominant influence to persons with MCI/dementia. The physical environment also influenced exercise opportunities and, thus, exercise levels. Community-level factors such as safety, transportation support, and accessibility to preferred exercise opportunities could facilitate exercise among persons with MCI/dementia.

Availability of preferred and accommodating exercise programs might also motivate persons with MCI/dementia to exercise. Participants expressed a preference for walking outdoors but also for social exercise programs with others they could identify on the level of cognitive/carer status, age, gender, and/or exercise. Programs that could accommodate their individual physical and cognitive deficits were also important.

The current findings contribute to the sparse information regarding factors that influence older adults with dementia to exercise and improves the understanding of the persons with MCI/dementia and their care partner's perspectives of exercise. Our findings highlight how social and community-level factors may help overcome or accentuate the individual level barriers faced by persons with MCI/dementia. Future research should continue to probe and develop interventions focused on the social and community-level to enable exercise among persons with MCI/dementia. In addition, the influence of the social and physical environment should be further probed in diverse geographical and social communities. In the long-term, findings from this line of study could be translated into guidelines and practical strategies to increase exercise among older adults with dementia.

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## **Appendix A: Recruitment Materials**

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## **Telephone Recruitment Script for Recruitment of Persons with MCI and Early Dementia (and Care Partners)**

Hello [*name*], my name is Nic Hobson and I am a student research investigator at the University of Waterloo. The reason that I am calling is that you indicated that you may be interested in participating in a study looking at exercise for persons with mild cognitive impairment and early dementia. Are you still interested in hearing more about this study, and how you can be involved?

[IF NO] Thank you, good bye.

[IF YES] Participants in this study will be invited to participate in a focus group discussion held here at the University of Waterloo, if you live locally, OR online with a video call program, if you are if you do not live locally. As well, you will be asked to complete a very brief questionnaire about yourself and your current physical activity.

The focus group discussion along with questionnaires will take approximately 2 hours to complete if you choose to participate.

The first thing that you would do is come to University of Waterloo where you will sign a consent form for the study and will complete a short interview to answer the questionnaire. We will then have a group discussion.

You will only need to visit us once and upon conclusion of the discussion group your participation in this study will be complete!

Would you be interested in participating?

[IF NO] Thank you, good bye.

[IF YES] Thank you, we appreciate your interest in our research. I have a session open on [*date*] and [*time*]. Will you and your partner be available then?

[IF NO] Offer another date and time until one is found that is mutually convenient.

[IF YES] This is great. Let me give you some important details about the study. Have you got a pen so that you can write this down and keep it with you?

I would also like to let you know that this study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee.

## **VOLUNTEERS NEEDED FOR A RESEARCH STUDY ON IDENTIFYING WAYS TO GET PERSONS WITH MILD COGNITIVE IMPAIRMENT AND EARLY DEMENTIA ACTIVE**

We are currently looking for volunteers, who:

- Have a diagnosis of mild cognitive impairment (MCI) or early dementia, OR
- Are a care partner to a person with MCI or early dementia

This study is being conducted by Dr. Laura Middleton, a Professor of Kinesiology at the University of Waterloo and Nic Hobson, currently completing his master's degree in Kinesiology at the University of Waterloo. They are trying to identify barriers to physical activity among people diagnosed with mild cognitive impairment (MCI) and early dementia and strategies to overcome these barriers.

Eligible participants will be invited to participate in a group discussion and complete a short interview regarding current physical activity practices and barriers to physical activity.

You will be asked to meet at the University of Waterloo or at a convenient location in the Kitchener-Waterloo community for approximately 2 hours.

You will be compensated for parking or public transportation.

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee. However, the final decision about participation is yours

If you are interested in participating or would like more information regarding this study, please contact:

Nic Hobson

Student Investigator

University of Waterloo- Brain & Body Lab

by phone: 519-888-4567 ext. 38548

by email: nbhobson@uwaterloo.ca

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**If you:**

- Have a diagnosis of mild cognitive impairment (MCI) or early dementia, OR
- Are a care partner to a person with MCI or early dementia, OR  
... **then contact us to be involved!**

**Confidentiality**

All information collected from you will be kept strictly confidential and data resulting from your participation that may be published in scientific journals, texts, or other media will not reveal your identity.

**Ethics Clearance**

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee. If you have any comments or concerns about participation in this study, you may contact the Office of Research Ethics, 519-888-4567 ext 36005.

***Participate in a focus group discussion at no cost. Parking, participation costs are covered!***

**Background:**

- Recent studies show that physical activity may benefit people with MCI or early dementia
- However, it may be difficult for people with MCI or early dementia to become physically active

**What is this study about?**

- Identifying barriers to physical activity among people with MCI and early dementia.
- Identifying possible strategies to become more physically active.

**Our Team of Investigators**

Prof. Laura Middleton  
(University of Waterloo,  
Kinesiology)

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Kinesiology)

Dr. Suzanne Tyas  
(University of Waterloo, School of  
Public Health)

**What will I be asked to do?**

- Participate in a discussion held at the University of Waterloo or in the Kitchener-Waterloo community
- You will participate in a group discussion about physical activity and barriers to being active
- You can talk as much or as little as you like
- This study will take approximately 2 hours to complete

**GET ACTIVE!**

***Help us understand the barriers to physical activity among people with mild cognitive impairment and early dementia.***



**For more information, please contact:**

**Nic Hobson**

Tel: (519) 888-4567 ext. 38548  
Email: nbhobson@uwaterloo.ca

Or:

**Laura Middleton:**

Tel: (519) 888-4567 ext. 33045  
Email:  
laura.middleton@uwaterloo.ca

University of Waterloo  
Department of Kinesiology  
200 University Ave W  
Waterloo, ON

[DATE]

**Subject: Recruitment for a Research Study Called**

**Getting Older Adults with MCI and Dementia Active: What do we need?**

**Primary Investigator:** Laura Middleton, PhD, University of Waterloo, Kinesiology, 519-888-4567 ext. 33045

**Student Investigator:** Nic Hobson, MSc Candidate, University of Waterloo, Kinesiology, 519-888-4567 ext. 38548.

Dear friends of MAREP:

The Murray Alzheimer Research and Education Program (MAREP) is inviting you on behalf of researchers at the University of Waterloo to participate in a research study. The study is being conducted to help understand barriers get in the way of physical activity and exercise among persons with MCI and early dementia. Laura Middleton (Kinesiology Faculty) and her Master's student (Nic Hobson) are currently recruiting individuals with Mild Cognitive Impairment (MCI) OR early dementia and their care partners to participate in a focus group discussion held at the University of Waterloo.

***What will participation include?***

Participation will consist of a single session where you will be asked to take part in a discussion about physical activity and exercise. Additionally you will be asked some questions about yourself and your current physical activity habits. The session will take approximately 2 hours in total to complete. The focus group will be held at the University of Waterloo, OR at a convenient location in the Kitchener Waterloo Community, OR via an online video call program (called zoom). The online video call would consist of a video interview involving both you and your care partner.

If applicable, you will be reimbursed for costs of parking or public transportation.

If you agree to participate, then we will provide you with parking information and directions prior to your session.

***Eligibility for this study:***

You are eligible for this study if you have been diagnosed with MCI or early dementia by your doctor and are 50 years of age or older, or are a care partner to someone who meets these criteria.

Please be assured that the study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee.

If you are interested in participating in this study, then please contact the lead student investigator, Nic Hobson.

Nic Hobson, MSc Candidate

519-888-4567, ext. 38548

[nbhobson@uwaterloo.ca](mailto:nbhobson@uwaterloo.ca)

Kind regards,



Lisa Loiselle

Associate Director of Research

Murray Alzheimer Research and Education Program





## **INFORMED CONSENT TO PARTICIPATE IN A RESEARCH STUDY**

**Full Study Title: Getting Older Adults with MCI and Dementia Active: What Do We Need?**

### **Principal Investigator:**

Dr. Laura Middleton, PhD, University of Waterloo, Kinesiology, 519-888-4567 ext. 33045

### **Student Investigator:**

Nic Hobson, MSc Candidate, University of Waterloo, Kinesiology, 519-888-4567 ext. 38548

### **Co-Investigators:**

Dr. Lora Giangregorio, PhD, University of Waterloo

Dr. George Heckmann, MD, University of Waterloo

Dr. Colleen Maxwell, PhD, University of Waterloo

Kayla Regan, MSc, University of Waterloo

Dr. Suzanne Tyas, PhD, University of Waterloo

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## **INFORMED CONSENT**

You are being asked to consider participating in a research study as part of Nic Hobson's Master's thesis. This form explains the purpose of this research study and provides details about what you would be asked to do if you choose to participate. Please read this form carefully and ask any questions you may have. Please ask the study staff or one of the investigator(s) to clarify anything you do not understand or would like to know more about.

### **INTRODUCTION**

Physical activity may be beneficial for those with mild cognitive impairment or early dementia. However, there may be barriers that get in the way of being physically active. To better understand how to best develop physical activity programming for persons with mild cognitive impairment (MCI) or early dementia, we are talking to: 1) persons diagnosed with MCI or early dementia; 2) their care partners. You are being asked to participate in this study because you belong to one of these four groups.

### **WHO IS ELIGIBLE FOR THE STUDY?**

To be eligible for this study you will need to be able to affiliate with one of the following groups:

- 1) Adults diagnosed with MCI or early dementia who are at least 50 years of age.
- 2) Care partners of persons with MCI or early dementia.

### **WHAT WILL HAPPEN DURING THIS STUDY?**

If you choose to participate, you will be invited to participate in a focus group discussion held either at the University of Waterloo, or a convenient location in the Kitchener-Waterloo community, or online using a video call program. Focus group discussions will be audio recorded in person and online in order to be analyzed by our research team.

You will answer some demographic questions about yourself (such as age, gender, type of residence, any current health problems you are experiencing) and your physical activity experience to help to characterize our participants. You will then participate in a discussion related to barriers and facilitators for physical activity among persons with MCI and early dementia. The entire session will take approximately 2 hours.

Participation in this study is voluntary and you may discontinue the study at any time.

The entire study is expected to take approximately 8 months to complete and results are expected to be available in 1 year.

### **WHAT ARE THE RISKS OR HARMS OF PARTICIPATING IN THIS STUDY?**

There are no anticipated risks in participating in this study. However, if you experience any feelings of discomfort, please contact the primary investigator, Laura Middleton, at 519-888-4567x33045 about any side effects that you experience.

### **WHAT ARE THE BENEFITS OF PARTICIPATING IN THIS STUDY?**

You may or may not benefit directly from participating in this study. Your participation may help develop strategies for referral, prescription, and programming of physical activity for persons with MCI and early dementia.

### **WHAT ARE THE COSTS OF PARTICIPATING IN THIS STUDY?**

Participation in this study will not involve any additional costs to you. Any parking or public transportation costs will be reimbursed.

### **WHAT ARE THE RIGHTS OF PARTICIPANTS IN A RESEARCH STUDY?**

1. You have the right to have this form and all information about this study explained to you.

2. Participating in this study is your choice (voluntary). You have the right to choose not to participate, or to stop participating in this study at any time without having to provide a reason. Even if your substitute decision maker consents on your behalf, we will seek your assent as well at all times. You have the right to skip or not answer any questions you may choose not to answer during the questionnaire/interview or during the focus group. If you are uncomfortable or unhappy about participating, you have the right to refuse participation in this study. Should you choose to withdraw from the study you are encouraged to contact Laura Middleton, 519-888-4567 ext. 33045 or Nic Hobson, 519-888-4567 ext. 38548.
  
3. You have the right to receive all significant information that could help you make a decision about participating in this study. You also have the right to ask questions about this study and your rights as a research participant, and to have them answered, before you make any decision. If you have any questions about this study, you may contact the person in charge of this study (Principal Investigator), Laura Middleton, University of Waterloo, 519-888-4567x33045. If you have questions about your rights as a research participant or any ethical issues related to this study that you wish to discuss with someone not directly involved with the study, you may call **Dr. Maureen Nummelin, Director of University of Waterloo Office of Research Ethics at (519) 888-4567 x36005.**
  
4. You have the right to have any information about you that is collected, used or disclosed for this research study to be handled in a confidential manner.

The investigator(s), study staff and the other people listed above will keep the information they see or receive about you confidential, to the extent permitted by applicable laws. Even though the risk of identifying you from the study data is very small, it can never be completely eliminated.

When the results of this study are published, your identity will not be disclosed.

The Principal Investigator will keep any personal information about you in a secure and confidential location for the minimum retention period of 7 years and then destroyed when appropriate as required by University of Waterloo policy.

5. You have the right to be informed of the results of this study once the entire study is complete. If you would like to be informed of the results of this study, please provide your name, address and telephone number to Dr. Laura Middleton, University of Waterloo, 519-888-4567x33045.

## **CONFIDENTIALITY AND SECURITY OF INFORMATION**

Your identity will be kept confidential and will not be passed to a third party. Only the researchers associated with the study (Drs. Middleton, Heckmann, Maxwell, Giongregorio, Heckman, Tyas, and associated students and research assistants) will have access to the data. The collected data will be coded with participant numbers (not names) and will be kept in a locked file cabinet in the researcher's office, or on a password-protected computer for a minimum of seven years after publication. After this time, all paper copies will be shredded and computer disks erased.

Given the group format of this session, we will ask you to keep in confidence information that identifies or could potentially identify a participant and/or his/her comments.

## **QUESTIONS**

Any questions with regard to this research should be directed to student investigator, Nic Hobson at 519-888-4567 ext. 38548 or via email: [nbhobson@uwaterloo.ca](mailto:nbhobson@uwaterloo.ca)

## **ETHICS CLEARANCE**

This project has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee. However, the final decision about participation is yours. Participants who have concerns or questions about their involvement in the project may contact the Chief Ethics Officer, Office of Research Ethics at 519-888-4567, Ext. 36005 or [maureen.nummelin@uwaterloo.ca](mailto:maureen.nummelin@uwaterloo.ca)



## DOCUMENTATION OF INFORMED CONSENT

Full Study Title: Getting Older Adults with MCI and Dementia Active: What do we need?

Name of Participant: \_\_\_\_\_

You have the right to receive a copy of this signed and dated informed consent form before participating in this study.

### Participant

By signing this form, I confirm that:

- This research study has been fully explained to me and all of my questions answered to my satisfaction
- I understand the requirements of participating in this research study
- I have been informed of the risks and benefits, if any, of participating in this research study
- I have been informed of the rights of research participants
- I have read each page of this form
- I authorize the recording of my voice during focus group/online video call discussions

\_\_\_\_\_  
Name of participant

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

### Person obtaining consent

By signing this form, I confirm that:

- This study and its purpose has been explained to the participant named above
- All questions asked by the participant have been answered
- I will give a copy of this signed and dated document to the participant

\_\_\_\_\_  
Name of Person obtaining  
consent (print)

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

Statement of Investigator

I acknowledge my responsibility for the care and well-being of the above participant, to respect the rights and wishes of the participant as described in this document, and to conduct this study according to all applicable laws, regulations and guidelines relating to the ethical and legal conduct of research. By signing this consent form, you do not give up any of your legal rights.

\_\_\_\_\_  
Name of Investigator (print)

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

**ASSISTANCE DECLARATION**  (check here if not applicable)

The participant/substitute decision-maker was assisted during the consent process as follows:

- The consent form was read to the participant/substitute decision-maker, and the person signing below attests that the study was accurately explained to, and apparently understood by, the participant/substitute decision-maker.

\_\_\_\_\_  
Name of Person Assisting (Print)

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

**Appendix B: Data Collection Materials**

Demographic Questionnaire ..... 141

Focus Group Discussion Guides ..... 146





INFORMATION (PERSON WITH DEMENTIA/MCI)

- Diagnosis:             MCI             Dementia
- Time of Diagnosis:    This year     <5 years ago         > 5 years ago
- Marital Status:                             Never married
- Married
- Partner/significant other
- Widowed
- Separated
- Divorced
- Usual living arrangement:                 Alone
- With spouse / partner only
- With spouse / partner and other(s)
- With child (not spouse / partner)
- With other(s), please specify \_\_\_\_\_
- Location of usual residence:                Rural (small town, country)
- Urban (large city, higher population)
- Type of usual residence:                     Private home / apartment / room
- Seniors residence
- Other \_\_\_\_\_
- Do you use a mobility aid?                 No                 Yes, if yes what kind? \_\_\_\_\_
- In the past 2 months, have you fallen (ended up on the ground or floor)?    No     Yes
- If yes:
- a) Have you fallen more than once?                             No     Yes
- b) Were you injured as a result of the fall(s)                    No     Yes
- c) Did you have trouble getting up?                             No     Yes

Please indicate which health conditions you have experienced:

- d) Heart Attack or Operation  No  Yes
- e) Heart Disease  No  Yes
- f) High Cholesterol  No  Yes
- g) Diabetes  No  Yes
- h) High Blood Pressure  No  Yes
- i) Chronic Back Pain  No  Yes
- j) Knee Injury  No  Yes
- k) Hip Injury  No  Yes
- l) Other condition:  No  Yes, please specify \_\_\_\_\_

INFORMATION (CARE PARTNER)

Relationship to Person with Mild Cognitive Impairment or Dementia:

Spouse / partner

Child

Other, please specify: \_\_\_\_\_

Do you live with this person:            Yes            No

If NO, how often do you visit? \_\_\_\_\_ times per week **OR** \_\_\_\_\_ times per month

Location of usual residence:            Rural (small town, country)

Urban (large city, higher population)

Type of usual residence:            Private home / apartment / room

Seniors residence

Other \_\_\_\_\_

Do you use a mobility aid?            No            Yes, if yes what kind? \_\_\_\_\_

In the past 2 months, have you fallen (ended up on the ground or floor)?  No    Yes

If yes:

a) Have you fallen more than once?            No    Yes

b) Were you injured as a result of the fall(s)            No    Yes

c) Did you have trouble getting up?            No    Yes

Please indicate which health conditions you have experienced:

a) Heart Attack or Operation            No    Yes

b) Heart Disease            No    Yes

c) High Cholesterol            No    Yes

d) Diabetes            No    Yes

e) High Blood Pressure            No    Yes

f) Chronic Back Pain            No    Yes

g) Knee Injury            No    Yes

h) Hip Injury

No  Yes

i) Other condition:

No  Yes, please specify \_\_\_\_\_

## PERSONS WITH MCI/DEMENTIA

1. What would you like people to know/understand about dementia?
2. What does exercise mean to you or how does exercise impact you (positively or negatively)?
  - a. Potential prompts:
    - i. For your health?
    - ii. For your brain/thinking ability?
    - iii. For your relationships and social functioning?
3. How has your condition (diagnosis) affected exercise opportunities?
4. What gets in the way of you doing exercise?
5. What helps/motivates you to exercise?
6. What would the (your) ideal exercise opportunity look like?
  - a. Potential prompts:
    - i. Where would you like to exercise?
    - ii. Who would you like to exercise with?
    - iii. What would you like to do for exercise?
    - iv. (If group program suggested) How long should each session be? How often should each session run? What costs should be associated?
7. How would better exercise opportunities change your exercise habits/behaviours?

## CARE PARTNERS

1. What would you like people to know/understand about dementia?
2. What does exercise mean to you or how does exercise impact you (positively or negatively)?
  - a. Potential prompts:
    - i. For your health?
    - ii. For your brain/thinking ability?
    - iii. For your relationships and social functioning?
3. How has your partner's condition (diagnosis) affected exercise opportunities?
4. What gets in the way of your partner doing exercise?
5. What helps/motivates your partner to exercise?
6. What would the (your) ideal exercise opportunity look like?
  - a. Potential prompts:
    - i. Where would you like to exercise?
    - ii. Who would you like to exercise with?
    - iii. What would you like to do for exercise?
    - iv. (If group program suggested) How long should each session be? How often should each session run? What costs should be associated?
7. How would better exercise opportunities change your exercise habits/behaviours?

## Appendix C: Cross-level Thematic Analysis

Intrapersonal	Interpersonal	Community
<b>Motivation to Exercise</b>		
Low intrinsic motivation Low self-efficacy for exercise Diagnosis as motivational Motivated by enjoyable exercise: walking outdoors, social engagement (with others of similar age, sex, diagnosis)	Encouragement by care partners Recommendations from healthcare provider Encouraging exercise provider	Infrastructure to support walking, as preferred activity Availability of exercise programs suitable to preferences
<b>Physical and Mental Challenges</b>		
Declining physical health Cognitive challenges	Company of and facilitation by care partners Transportation by care partners	Real and perceived safety of environment Neighbourhood infrastructure Exercise that accommodates individual needs Assistive transportation
<b>Perceptions of Dementia</b>		
Retained capacity Optimism for future Ongoing identification by age, sex as well as diagnosis	Care partner perception of loss	Failure to consider persons with dementia in exercise program planning