Investigating and promoting lifestyle factors to improve sleep in people at risk for and with dementia

by

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

Introduction: Sleep disturbance is not only associated with increased risk of dementia but is common after dementia onset and is a noted stressor for care partners. Physical activity may reduce dementia risk, as well as promote sleep for people with dementia. However, it is unclear whether physical activity and sleep interact to mitigate dementia risk or promote quality of life in people with dementia. This thesis aims to: 1A) understand the relationship between sleep, physical activity and cognitive function in people without dementia, and 1B) understand how sleep and physical activity relate to cognitive function and functional abilities among people with dementia, and 2) adapt a lifestyle-focused sleep intervention for Canadians with dementia.

Aim 1: Data from the Rush Memory and Aging Project —which utilized accelerometers, a cognitive battery, and clinical expertise— was used to examine: how sleep and physical activity were associated with cognitive decline and dementia risk in people without cognitive impairment (Study 1); and how sleep and physical activity were associated with cognitive and physical function in people with dementia (Study 2). In Study 1, greater physical activity was associated with slower cognitive decline and reduced dementia risk. Additionally, more fragmented sleep was associated with worse baseline global cognition, but not cognitive trajectory or dementia incidence. In Study 2, physical activity was associated with better functional abilities, but not with cognitive trajectory or sleep fragmentation in people with dementia. Sleep fragmentation was not associated with global cognition or functional abilities among people with dementia.

Aim 2: A lifestyle intervention for sleep (NITE-AD) that included sleep education, physical activity, and light therapy was adapted to be s appropriate for use in Canada (NITE-CAD). Based on the *Knowledge to Action* cycle, we approached this program adaptation in three steps. Step 1: identify the knowledge gap and determine availability of sleep programs for people with dementia in Canada. Step 2: assess the barriers and facilitators to knowledge use (Study 3) and determine which aspects of the program required requires modification. Using a qualitative descriptive design, semi-structured interviews were carried out with people with dementia and their care partners. Interviews were coded with a deductive content analysis, using the Behaviour Change Wheel as the guiding framework. Findings indicated winter conditions exacerbated previous challenging circumstances for people with dementia and winter physical activity participation was facilitated when people with dementia had appropriate equipment, access to facilities or cleared trails, and had their preferences met (e.g. indoor vs. outdoor activities, risk tolerance). Step 3 (Study 4) tailored the NITE-AD program with an advisory team using the results from Study 3 to create the NITE-CAD program. Changes included flexible physical activity options to support participation of people with dementia with diverse needs, contexts, and preferences, and minor wording and formatting changes.

Conclusion: Sleep and physical activity were independently associated with cognitive functioning, with physical activity reducing cognitive decline and dementia risk in adults without dementia. However, the positive effect to cognitive function was not evident after dementia onset, although physical activity benefited functional abilities. Several barriers and facilitators for engaging in winter physical activity were identified for people with dementia,

which should be kept in mind for future dementia interventions utilizing physical activity. Flexible options may be needed to accommodate the diverse preferences, abilities, and resources of people with dementia and care partners.

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List of abbreviations

ADL	Activities of Daily Living
Aß	Amyloid-Beta
BMI	Body Mass Index
CESD	Center for Epidemiological Studies-Depression
EEG	Electroencephalography
HR	Hazard Ratio
IADL	Instrumental Activities of Daily Living
MCI	Mild Cognitive Impairment
NITE-AD	Nighttime Insomnia Treatment and Education for Alzheimer's Disease
NITE-CAD	Nighttime Insomnia Treatment and Education for Canadians with Alzheimer's Disease
NREM	Non-Rapid Eye Movement
RCT	Randomized Control Trial
REM	Rapid Eye Movement
SCN	Suprachiasmatic Nucleus
SWS	Slow-Wave Sleep
VLPO	Ventrolateral Preoptic Area

Chapter 1: Introduction

1.1 Overview

Dementia is an umbrella term for a condition where one experiences significant cognitive decline in one or more cognitive domains that is sufficient to interfere with activities of daily living (ADLs). The prevalence of dementia is rapidly increasing and it is projected nearly 75 million older adults will be living with dementia worldwide by 2030 (Prince et al., 2015). In Canada, 8.4% of Canadian adults over 65 are living with dementia, and this is expected to increase to 13.2% by 2050 (Alzheimer Society of Canada, 2022). The prevalence of dementia is anticipated to increase the greatest in people over 85 years of age – around 30% faster than the overall number of cases (Alzheimer Society of Canada, 2022).

Alzheimer's disease is a progressive neurodegenerative disease most known for significant loss of memory and other cognitive processes and is the most common cause of dementia. Although this thesis will focus primarily on Alzheimer's disease caused dementia (commonly referred to as Alzheimer's disease, as will be done in this thesis), all-cause dementia will also be discussed because many studies do not differentiate the cause of dementia in participants. However, one less commonly discussed factor related to dementia, and Alzheimer's disease in particular, is sleep disturbance.

Although the nature of the relationship is still uncertain, there appears to be a link between sleep and developing Alzheimer's disease and other dementias (Bubu et al., 2017; Lysen et al., 2020; Shi et al., 2018; Xu et al., 2020). In recent years, researchers have speculated the relationship between sleep and dementia may be bi-directional (Carroll & Benca, 2024; Ju et al., 2014; Lucey, 2020; Mander et al., 2016; C. Wang & Holtzman, 2020),

in that poor sleep increases Alzheimer's disease pathology in the brain while Alzheimer's disease pathology causes degradation to sleep circuitry and consequently sleep quality.

In those who develop dementia, sleep disturbance is quite common. It is estimated up to 66% of people with Alzheimer's disease experience some sort of sleep disturbance (Guarnieri et al., 2012), which includes difficulty falling or staying asleep, early awakenings, and excessive daytime sleepiness (Cipriani et al., 2015). Nighttime wandering and incontinence are other significant manifestations of sleep disturbance (McCurry et al., 2003).

There are major consequences to sleep disturbances in people with dementia. Sleep disturbances are associated with poorer functional abilities, mood, and cognitive status (Moe et al., 1995; Sinforiani et al., 2007; Tractenberg et al., 2003, 2005). In addition, sleep disturbances can impact care partners. Care partners to people with dementia with sleep disturbances report having poor sleep themselves (Donaldson et al., 1998; Gao et al., 2019; Montgomery et al., 2018; Okuda et al., 2019). This can result in greater psychological and physical distress for the care partner and reduced quality of life (Benca et al., 2022; Donaldson et al., 1998; Montgomery et al., 2018; Okuda et al., 2019; Terum et al., 2017). Sleep disturbance is a major reason for deciding to institutionalize people with dementia (R. Gibson & Gander, 2021; Hope et al., 1998; Pollak & Perlick, 1998).

Understanding what factors contribute to sleep and finding ways to promote sleep in people with dementia may reduce care partner stress and delay institutionalization of people with dementia. However, improving sleep in people with dementia is challenging. The cause of sleep disturbance is likely multifaceted — potentially a combination of disease severity and lifestyle. Sleep changes are more common with increasing dementia severity and mood

disturbance, as well as physical inactivity (McCurry et al., 1999). There are also a number of changes in the sleep circuitry of the brain, making it difficult to initiate and maintain sleep (Mander et al., 2017).

There have been many attempts and approaches to improve sleep in people with dementia, but few have been effective. Pharmacological interventions are often used to improve sleep. However, the efficacy of pharmaceuticals is undetermined in people with dementia and comes with negative side-effects (e.g., increased risk of hip fractures, cognitive impairment, dizziness, loss of balance) which are arguably more harmful than beneficial (Berry et al., 2013; Glass et al., 2005; McCleery & Sharpley, 2020). Instead, non-pharmaceutical options are an attractive alternative as they often have little risk. Non-pharmaceutical lifestyle interventions studied to date include education on proper sleep habits, exposure to bright lights, physical activity, or a combination of these. Although preliminary evidence suggests individual and multicomponent lifestyle interventions are effective at improving sleep in people with dementia (O'Caoimh et al., 2019). Most multicomponent interventions tested to date include physical activity as one component. However, as winter weather, particularly cold, snow, and ice which is common in Canada, impedes physical activity (Chan et al., 2006; Chan & Ryan, 2009; Ermagun et al., 2018), there is a critical need to refine interventions to ensure they are regionally appropriate. Thus, this thesis aims to understand and promote lifestyle factors to improve sleep in people with, and at risk for, dementia. This thesis will examine the impacts of physical activity on sleep among people with, or at risk for, dementia.

1.2 Sleep

Sleep is a dynamic and necessary life process; however, there is a lack of consensus on the function of sleep. Various hypotheses have been proposed, which can broadly be divided into those who suggest that: 1) sleep supports higher cognitive processes, and 2) sleep is a restorative process (Frank & Heller, 2018; Smith & Mong, 2019).

Sleep quantity and quality are two important aspects of sleep. Sleep *quantity* refers to the amount or duration of sleep, whereas sleep *quality* refers to how well one sleeps. Sleep duration is assessed using time and, thus, it is relatively easy to measure and determine if someone is getting the recommended amount of sleep each night (7 to 9 hours for adults aged 18 to 65 years, 7 to 8 hours for adults aged over 65 years (Hirshkowitz et al., 2015)). There are several indicators of sleep quality. Broadly, a person can sense if they have poor sleep quality if they feel tired (Harvey et al., 2008), have difficulty concentrating, are hungrier than usual or have food cravings (and subsequent weight gain), and/or experience emotional dysregulation (feeling extremely stressed, angry, emotionally exhausted, etc. (Medic et al., 2017).

Markers of sleep quality can be illustrated using a hypothetical case, “Marion”. Marion gets into bed at midnight (12:00 A.M.) and it takes 30 minutes for her to fall asleep. Marion sleeps relatively peacefully throughout the night, except for waking up three times in the night for 10 minutes each (or 30 minutes awake in total). Marion wakes up and gets out of bed at 08:00 A.M., feeling refreshed and ready to start the day. In this example, the 30 minutes taken to fall asleep is referred to as s*leep latency*. Taking less than 30 minutes to fall asleep may be an indicator of good sleep quality. Longer sleep latencies are a sign of

insomnia, though falling asleep too quickly may indicate sleep deprivation. The *number of nighttime awakenings* would be three, as Marion woke up three times in the night. Her *wake after sleep onset*, or the total time awake (three times, each for a duration of 10-minutes), would be 30 minutes. *Sleep efficiency* is the amount of time spent in bed asleep compared to the amount of time in bed. In this example, Marion's sleep efficiency would be 87.5% (7 hours asleep ÷ 8 hours in bed) ×100% = 87.5%). Higher sleep efficiency, lower wake after sleep onset, and decreased number of awakenings are relative markers of better sleep quality. Although there are no universally accepted criteria, 85% sleep efficiency, ≤ 20 minutes of wake after sleep onset, ≤ 2 awakenings, and sleep latency ≤ 30 minutes have been considered markers of good sleep quality (Nelson et al., 2022; Ohayon et al., 2017).

The Rush Memory and Aging project uses a less common measure of sleep quality, referred to as the k_{RA} index. The k_{RA} index is a measure of sleep fragmentation and is the probability of transitioning into a state of activity following a period of rest (Lim et al., 2011, 2013). Unlike sleep efficiency and wake after sleep onset, the k_{RA} index factors in both the frequency and duration of periods of movement. For example, if Marion only wakes up three times throughout the night for a long period of time, the k_{RA} value would be low, indicating her sleep was not very fragmented. In contrast, if Marion woke up ten times throughout the night for three minutes each time, their wake after sleep onset and sleep efficiency would be the same but their k_{RA} value would be higher, as her sleep was more fragmented.

1.2.1 Stages of sleep

Sleep occurs in several different stages, which are broadly separated into two categories, *rapid eye movement* (REM) sleep and *non-rapid eye movement* sleep (NREM). NREM and

REM sleep are primarily differentiated by the presence or absence of rapid eye movements (as the names imply), but there are also stark differences in autonomic processes (i.e., involuntary physiological processes, such as breathing and heart rate), brain activity, and muscle activity. During REM sleep, the eyes dart rapidly back and forth, the brain shows activity resembling wakefulness, and autonomic processes are variable. In contrast, there is minimal/slower eye movement during NREM sleep and autonomic processes are more tightly regulated (e.g., heart rate and breathing rate slows down, decreases in body temperature). NREM is further divided into three stages (NREM 1, NREM 2, NREM 3), with each stage reflecting greater sleep depth and synchrony of brain activity (Pace-Schott & Spencer, 2011; Smith & Mong, 2019). During sleep, humans spend about with 75% in NREM sleep, and 25% of their total sleep time in NREM 3 sleep (Patel et al., 2025). For this thesis, I will focus on NREM 3 sleep as this is when slow-wave sleep (SWS) occurs, which plays a critical role in the relationship between sleep and Alzheimer's disease. During SWS, brain activity shows the most synchrony (recorded using electroencephalography (EEG)), as evident by the presence of low-frequency, high-amplitude. SWS is the deepest and most restorative aspect of sleep (Luppi & Fort, 2019), playing a critical role in metabolite clearance from the brain (discussed in Section 1.3.3.2.3).

During the first few iterations of the sleep cycle, NREM sleep dominates. However, as the night progresses, the time spent in REM sleep increases and time spent in NREM 3 subsequently decreases. See Figure 1 (top image) for visualization of REM and NREM stages throughout the night.

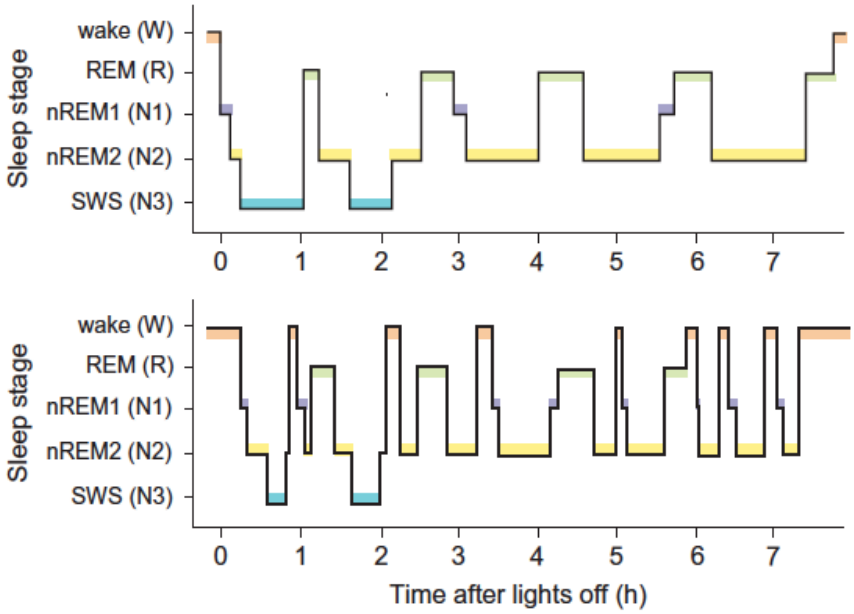


Figure 1. Hypnograms showing the stages of sleep. The top image shows the stages of sleep in young adults. The bottom image shows the stages of sleep in older adults.
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1.2.2 Assessing sleep

There are three primary ways to assess sleep: polysomnography, actigraphy, and self-report.

1.2.2.1 Polysomnography

Polysomnography is considered the "gold standard" of sleep research. Polysomnography uses several methods to measure sleep, including EEG to measure brain activity, electrooculography to measure eye activity, and electromyograms to measure muscle activity. SWS is the deepest stage of sleep and reflects a high degree of brain synchrony (i.e., the greatest correlation of brain activity) recorded by EEG as shown by high-amplitude, low-frequency waves which roll throughout the cortex. Polysomnography uses

these three measures to infer the different stages of sleep and is the only method which can do so. Polysomnography also captures the markers of sleep quality and quantity discussed above. Polysomnography is traditionally completed in polysomnography to be to be used outside of a lab setting.

1.2.2.2 Actigraphy

Actigraphy is another objective method to evaluate sleep. Actigraphs are body-worn devices (typically placed on the wrist or hip) which use accelerometers to measure acceleration of that body part across one or more dimensions. The presence or absence of acceleration is used to infer periods of wakefulness and sleep, as well as physical activity levels. Actigraphy can be used to measure sleep quality and quantity; however, a major limitation is it cannot distinguish the stages of sleep like polysomnography. Nonetheless, actigraphy can be advantageous over polysomnography as it is cheaper, easier to use, and allows for examination of habitual sleep patterns over days or weeks (Cole et al., 1992). For these reasons, actigraphy is often used in large, longitudinal studies (e.g., the *Rush Memory and Aging Project* (Bennett et al., 2005), the *Osteoporotic Fractures in Men* study (Orwoll et al., 2005)).

1.2.2.3 Self- or proxy-reported sleep

Self- or proxy-reported sleep can be in the form of a sleep diary where participants record their sleep quality and habits daily or questionnaires asking participants to reflect on their sleep over a period of time. Self-report measures are convenient and can be done quickly. However, they are based on participants' recollection and perception of sleep, which can introduce bias. Often, there are discrepancies between self-reported sleep measures and

their objective counterparts, both in healthy populations and people with dementia (Most et al., 2012).

1.2.3 Sleep regulation

Sleep is regulated through two processes: the circadian rhythm and the homeostatic drive for sleep. These processes work both independently and together to promote sleep or wakefulness (Figure 2). One important brain region for sleep regulation is the ventrolateral preoptic area (VLPO). The VLPO is a sleep-promoting brain region located in the hypothalamus of rodents and is thought to be in the intermediate nucleus in humans. Briefly, the VLPO sends inhibitory signals to the wake-promoting regions of the brain to induce sleep; conversely, the wake-promoting regions inhibit the VLPO to promote wakefulness.

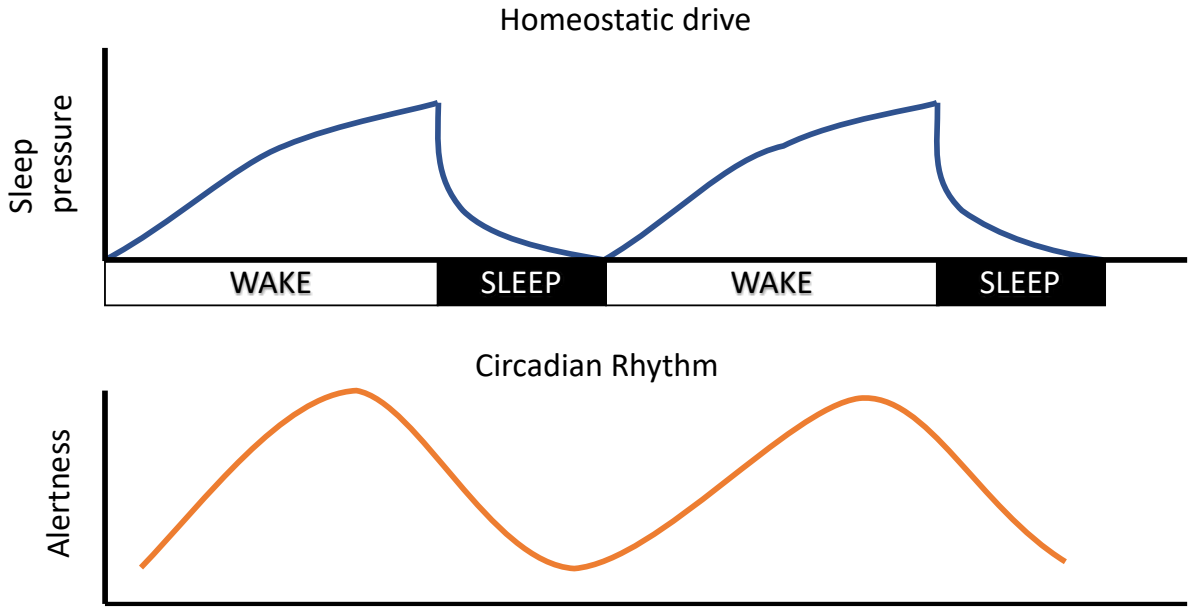


Figure 2. Visualizations of the interaction between the homeostatic drive to sleep (top) and the circadian rhythm (bottom).

1.2.3.1 The circadian rhythm

Circadian rhythms come from the Latin words circa ("around") and diem ("day"). Circadian rhythms follow a roughly 24-hour period in which endocrine and other bodily processes experience predictable fluctuations (Dibner et al., 2010). Circadian timing is determined from both endogenous processes (i.e., internal regulation) and exogenous (external) cues. Exogenous cues include signals such as light, exercise, and temperature. Light cues are the strongest, as the circadian processes orient themselves to the light and dark periods of a day (LeGates et al., 2014). The role of light for circadian rhythms is critical, and will become increasingly relevant throughout this thesis, as light therapies are a common approach to address disordered sleep.

Although many cells in the human body have their own endogenous cycle, the suprachiasmatic nucleus (SCN) located in the hypothalamus is referred to as the "master clock". The SCN is also where exogenous cues are processed and relayed to various parts of the body (Dibner et al., 2010). The SCN transmits the information from oscillating gene expressions and environmental cues to synchronize to the rest of the body via neurological and hormonal pathways (Dibner et al., 2010). Notably, the SCN has projections to the pineal gland in response to light, controlling the secretion of the "night hormone" melatonin, which plays a role in promoting sleep.

1.2.3.2 Homeostatic drive for sleep

The homeostatic drive for sleep is essentially the body's need for sleep after a period of wakefulness to maintain homeostasis (i.e., keeping the body in a state of balance) (Allada et al., 2017). The homeostatic drive for sleep is sometimes referred to as "sleep pressure", as

with increased time spent awake there is a build-up of "pressure" which makes an individual need to sleep. Homeostatic sleep pressure rises during wakefulness, potentially reflecting adenosine build up (Scharf et al., 2008). Adenosine is a by-product of cellular metabolism and accumulates extracellularly, which may support sleep by inhibiting the wake-promoting centers of the brain and activating the VLPO (Saper et al., 2010; Scharf et al., 2008). However, drugs such as caffeine are adenosine antagonists, preventing the VLPO from responding to rising adenosine concentrations.

1.2.3.3 The integration of the circadian rhythm and the homeostatic drive for sleep

The homeostatic drive for sleep interacts with the circadian rhythm, where they work together or in opposition to promote wakefulness and sleep (Figure 2). Later in the day, sleep pressure is high; however, the circadian drive for wakefulness is at its peak and overrides the need for sleep (known as the wake maintenance zone (Strogatz et al., 1987)). Later in the evening, as it becomes increasingly dark, the circadian-wake drive wanes. Now, the high homeostatic sleep pressure initiates the onset of sleep. During sleep, the homeostatic drive for sleep diminishes, but the maximum circadian drive to sleep peaks in the early morning, helping to maintain sleep. Eventually, the circadian drive for wakefulness would begin to rise and surpass the homeostatic drive for sleep, resulting in wakefulness.

1.3 Sleep, aging, and dementia

1.3.1 How sleep changes with aging

Sleep changes dramatically with aging. Nearly half of older adults report regular difficulties falling asleep or maintaining sleep (Chaput et al., 2017; Foley et al., 1995; National Sleep Foundation, 2003), and experience excessive daytime sleepiness (Foley et al.,

1995; National Sleep Foundation, 2003). Moreover, older adults are at higher risk of developing sleep disorders, including insomnia (Kocevska et al., 2021), sleep-disordered breathing (Glasser et al., 2011), or restless-leg syndrome (Allen et al., 2005).

Sleep quality decreases with aging by a number of measures, where older adults have less efficient sleep, increased sleep latency, and spend more time awake throughout the night (Boulos et al., 2019; Evans et al., 2021; Moraes et al., 2014; Ohayon et al., 2004). Sleep duration also decreases with aging (Boulos et al., 2019; Evans et al., 2021; Moraes et al., 2014), which is accompanied by shifts in sleep phases where older adults have earlier bed-times and wake-times (Evans et al., 2021). Changes in sleep timing may be driven by shifts in the circadian rhythm in older adults (Duffy et al., 2015). Although the circadian period does not change with age, older adults may have greater difficulty maintaining sleep in the early morning (Duffy et al., 1998). This results in older adults waking and going to bed earlier, shifting their circadian phase to be earlier in the day. There are also phase shifts and reduced amplitudes to circadian markers such as melatonin levels and core body temperature (Dijk et al., 1999; Duffy et al., 1998, 2015; J. Li et al., 2018; Musiek et al., 2018). Finally, older adults also experience reduced sensitivity to light cues (Duffy et al., 2007) and greater difficulty re-adjusting their circadian rhythm (*think resetting after being jet-lagged*) (Duffy et al., 2015; J. Li et al., 2018). See Figure 3 for visualization.

When examining objective sleep, older adults experience reductions in NREM 3 sleep (i.e., spending less time in SWS which is the deepest and most restorative part of sleep) and instead have much lighter sleep (i.e., spend more time NREM 2 and NREM 1). The amplitude and density of slow waves decrease, particularly in the frontal lobes of the brain

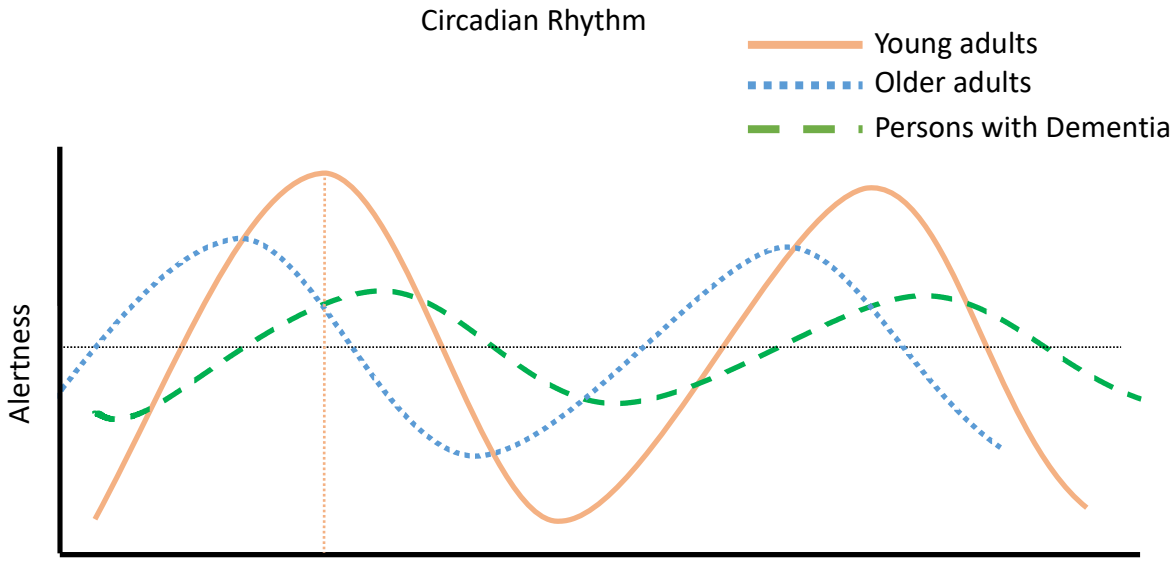


Figure 3. Depictions to changes in the circadian rhythm with aging (blue) and in dementia (green).

(Carrier et al., 2011; Dubé et al., 2015). Additionally, the total time spent in REM sleep decreases, as do the overall number of REM cycles (Moraes et al., 2014; Ohayon et al., 2004). See Figure 1 (bottom) for the changes to sleep stages in aging.

There are several limitations or critiques to assessing SWS in aging (including among people with Alzheimer's disease and other dementias). Although older adults might still have a similar proportion of SWS, their slow wave amplitude is reduced and does not meet the criteria used for young adults, potentially creating bias in detecting SWS (Muehlroth & Werkle-Bergner, 2020). This may result in SWS being erroneously recorded as NREM 2 sleep. This may also be part of the reason decreases in SWS and REM sleep are not consistent across studies (Boulos et al., 2019).

1.3.1.1 Causes and mechanisms for sleep-related changes in aging

There are likely many causes for the observed changes in sleep, each of which is complex and may work independently or in conjunction with each other. However, methodological limitations make it challenging to understand the true nature of aging-related changes to sleep. Many studies use a cross-sectional design, which prevents determination of the directionality of the relationships. Additionally, some studies rely on animal models, which are informative but need to be verified in humans. Within these limitations, some of the potential mechanisms will be described here in brief.

With aging, there may be degeneration of many regions of the brain, including sleep- and wake-promoting brain regions such as the VLPO (or intermediate nucleus in humans) (Garcia-Falgueras et al., 2011). Additionally, degeneration of SCN neurons may contribute to circadian dysfunction (J. Wang et al., 2015; J. N. Zhou et al., 1995). Finally, older adults may experience degeneration in the prefrontal cortex, which has been associated with sleep fragmentation (Lim et al., 2016) and decreased SWS (Mander et al., 2015). Degeneration of the medial prefrontal cortex and poor sleep is associated with amyloid beta (Aß) burden (Mander et al., 2015), which will be further expanded on in Section 1.3.3.2.1. Overall, degeneration in these brain regions may make it difficult to initiate sleep and obtain deep sleep, as well as synchronize the circadian rhythm, contributing to the changes in sleep discussed above.

Additionally, older adults may have a reduced homeostatic drive for sleep (i.e., sleep pressure, recall Section 1.2.3.2) (Mander et al., 2017). In older rodents, there are high levels of adenosine (Murillo-Rodriguez et al., 2004), which suggests high sleep pressure. However,

older rodents also have reduced adenosine receptors (Cheng et al., 2000; Ekonomou et al., 2000), and these receptors have decreased sensitivity to adenosine (Murillo-Rodriguez et al., 2004). Thus, while the higher levels of extracellular adenosine would normally increase the homeostatic sleep drive, the reduced numbers of adenosine receptors lessen the functional effect of adenosine, diminishing sleep drive.

In addition to the pathological mechanisms discussed above, other factors may contribute to the changes in sleep observed with aging. Chronic diseases, such as depression or pain, may also influence sleep as those with greater numbers of comorbidities report worse sleep (Foley et al., 2004). The nature of the chronic disease may influence sleep directly, as factors like pain make sleep initiation and maintenance challenging (Haack et al., 2020), or it may indirectly influence sleep by increasing health-related anxiety (Barczi & Teodorescu, 2017). Changes in psychosocial factors and mobility may also contribute to sleep disturbances in older adults (Miner & Kryger, 2017). Psychosocial factors include caregiving, social isolation, and bereavement (Miner & Kryger, 2017). These psychosocial factors are often associated with physical or psychological distress, which can worsen sleep (Miner & Kryger, 2017). In addition, decline in physical function may result in reduced social engagement and increased social isolation (Miner & Kryger, 2017). Further, reduced physical function can restrict physical activity levels (which can promote sleep), and social isolation reduces one's chance to be physically active (Miner & Kryger, 2017). Together, these factors can result in less opportunities to be exposed to circadian cues, resulting in worsening sleep. In short, the factors contributing to sleep in aging are complex and likely multifactorial.

1.3.2 Alzheimer's disease and dementia

Dementia refers to cognitive decline in one or more cognitive domains sufficient to interfere with ADLs. Alzheimer's disease is the most common form of dementia. Alzheimer's disease is a progressive neurodegenerative disease where one experiences significant memory loss, accompanied by declines in other cognitive processes, behavioral changes, and loss in ability to perform ADLs. In addition to Alzheimer's disease, dementia can be caused by other conditions such as Parkinson's disease, stroke or cerebrovascular disease, and head trauma (Tripathi & Vibha, 2009).

It is expected that 1.7 million Canadians will have dementia by 2050, triple that of the current number (Alzheimer Society of Canada, 2022). With mild cognitive impairment (MCI), people experience cognitive impairment, but the impairment is not sufficient to affect independence in ADLs (Alzheimer's Association, 2021). MCI is sometimes framed as a precursor to dementia and Alzheimer's disease, as ~19% of people with MCI develop dementia within one year and this number increases to 33% in 5 years (Ward et al., 2013).

Unfortunately, there is no cure for Alzheimer's disease, and the cause of Alzheimer's disease is still not fully understood. However, Alzheimer's disease has two notable pathologies: Aß plaques and phosphorylated tau proteins. Aß is a protein which aggregates to form insoluble plaques on the outside of neurons. These insoluble plaques are neurotoxic, damaging dendrites and reducing synaptic function (Palop & Mucke, 2010). It has been speculated that people with Alzheimer's disease may have impairments in clearing Aß, leading to the accumulation of these neurotoxic plaques. Under normal circumstance tau plays a role in supporting neuronal structure and shape (Knopman et al., 2021; Scheltens et

al., 2021). However, when tau becomes hyperphosphorylated—as seen in Alzheimer's disease—it aggregates into neurofibrillary tangles, losing its ability to support neuronal structure and disrupting cellular functions. Both Aß and tau pathology are dependent on synaptic activity (Cirrito et al., 2005; Yamada et al., 2014) and are potentially modified by physical activity (De la Rosa et al., 2020) and sleep (see Section 1.3.3.2 for further discussion).

1.3.2.1 Risk factors for Alzheimer's disease and dementia

There are a variety of non-modifiable and modifiable risk factors for developing Alzheimer's disease. Briefly, non-modifiable risk factors include demographics (e.g., age, sex) and genetics (Armstrong, 2019). A recent Lancet Report identified 14 modifiable risk factors for dementia, which have effects at different times throughout the life course (Livingston et al., 2024). Although all modifiable risk factors are important, this thesis will focus primarily on physical (in)activity and sleep disturbance.

Physical inactivity was identified to be a mid-life risk factor for dementia (Livingston et al., 2024). Estimates of the portion of Alzheimer's disease or dementia cases attributed to physical inactivity are around 13% (Livingston et al., 2017; Norton et al., 2014), likely because the prevalence of physical inactivity varies considerably worldwide. In Canada, physical inactivity is the largest contributing factor, with estimates suggesting it contributes around 10.2% of dementia cases (Son et al., 2024). Systematic reviews and meta-analyses show people who are more physically active have lower risk of cognitive decline or dementia (Blondell et al., 2014; Iso-Markku et al., 2022; Sofi et al., 2011). Critically, a 25% reduction

in physical inactivity could potentially prevent one million Alzheimer's disease cases globally (Barnes & Yaffe, 2011).

Of note, the Lancet report proposed sleep might be a modifiable risk factor but did not include it as the evidence is relatively weak (Livingston et al., 2024). Currently, certain sleep disorders, such as sleep apnea, are associated with an increased risk of Alzheimer's disease and all-cause dementia (Bubu et al., 2017; Emamian et al., 2016; Shi et al., 2018) while insomnia shows mixed results (Almondes et al., 2016; Shi et al., 2018). Poor sleep quality has been found to be a risk factor for Alzheimer's disease (Bubu et al., 2017; Lysen et al., 2020) and all-cause dementia (Shi et al., 2018; Xu et al., 2020). For sleep duration, there is a U-shaped relationship for the risk of developing Alzheimer's disease (Bubu et al., 2017; Wu et al., 2018; Xu et al., 2020), as well as all-cause dementia (Benito-León et al., 2009; Xiong et al., 2024; Xu et al., 2020). The U-shaped association suggests too little or too much sleep is associated with an increased risk of Alzheimer's disease and dementia and is speculated to reflect different underlying processes, in that short sleep durations may be a risk factor for dementia whereas long sleep durations might be an early indicator (Bokenberger et al., 2017; Westwood et al., 2017). Finally, weakening circadian rhythms are associated with cognitive decline and increased risk of dementia (P. Li et al., 2020; Rogers-Soeder et al., 2018; Tranah et al., 2011).

One of the challenges in establishing sleep as a risk factor is the observational nature and the time course of the available studies. As Alzheimer's disease pathology starts occurring nearly 20 years before symptoms emerge (Jansen et al., 2015; Rodriguez-Vieitez et al., 2016), longitudinal studies examining adults who are older (e.g., 60+) may have

participants who already have Alzheimer's disease pathology. Mendelian randomization is one method that can help to explore causal effects, as it uses genetic variations as instrumental variables (Davies et al., 2018). Recent Mendelian randomization studies have found little evidence to link sleep as a causal factor to Alzheimer's disease (Anderson et al., 2021; Huang et al., 2020; Xiong et al., 2024). However, Huang et al. (2020) did find evidence suggesting those at higher risk of developing Alzheimer's disease had poorer sleep, suggesting Alzheimer's disease may impact sleep patterns. Further research is required.

1.3.3 Sleep and Alzheimer's disease

Sleep disturbance is common in Alzheimer's disease, although the prevalence of sleep disturbance is difficult to estimate. The estimated prevalence is 24-66% for people with Alzheimer's disease living in the community and 20-70% in those who are institutionalized (Guarnieri et al., 2012; Koren et al., 2023; McCurry et al., 1999; Webster et al., 2020; G. Zhou et al., 2019). Common sleep complaints include insomnia, sleep-disordered breathing, and excessive daytime sleepiness (Guarnieri et al., 2012). Additionally sleep complaints reported by care partners included nighttime wandering, waking the care partner up at night, and other behaviors such as incontinence and hallucinations (McCurry et al., 2003). People with Alzheimer's disease tend to have reductions in their sleep duration, sleep efficiency, and time spent in REM and NREM 3/SWS, with increases in their sleep latency and time spent in light sleep (NREM 1) (Casagrande et al., 2022; Kent et al., 2021). Critically, sleep disturbance has been associated with lower quality of life in people with dementia (Leng et al., 2020; Petrovsky et al., 2018).

Another common behavior is described as sundown syndrome or "sundowning", which is a phenomenon where people with dementia are more likely to show confusion, agitation, or anger/aggression during the late afternoon to early evening. Sundowning is a controversial phenomenon, and its existence and the appropriateness of the term has been questioned (Bliwise et al., 1993; Cohen-Mansfield, 2007). This thesis will use the term "evening restlessness" as a person-centered term to describe the behavior, upholding their personhood and dignity (Alzheimer Society of Canada, 2017).

The circadian rhythm also experiences considerable changes with Alzheimer's disease. As discussed, with aging the circadian rhythm shifts to be phased advanced (i.e. earlier wake and sleep times), has reduced amplitude, and reduced sensitivity to light cues (Duffy et al., 2007, 2015; J. Li et al., 2018; Musiek et al., 2018). However, with Alzheimer's disease, these circadian changes are either intensified or markedly different. As with aging, in Alzheimer's disease, there are significant reductions in circadian amplitude, but the circadian rhythm is significantly phased *delayed* (i.e. it is later, rather than earlier as is typical with aging), (Harper et al., 2005, 2008; P. Li et al., 2020; Musiek et al., 2018; Satlin et al., 1995; Volicer et al., 2001; J. Wang et al., 2015). Additionally, people with Alzheimer's disease tend to have increased nocturnal activity with reduced daytime activity (Harper et al., 2008; Musiek et al., 2018; Volicer et al., 2001). More severe Alzheimer's disease pathology has been associated with greater circadian dysfunction in both post-mortem studies (Harper et al., 2008; Stopa et al., 1999; J. Wang et al., 2015; J. N. Zhou et al., 1995) and in living adults (Musiek et al., 2018).

1.3.3.1 Effects of sleep disturbance for care partners

Being a care partner for a person with dementia can be stressful, and sleep disturbance can be a major contributor. Care partners often indicate being woken up is the most stressful complaint and increased frequency and duration of sleep disturbance in people with dementia worsens care-related stress (Ali & Bokharey, 2015; McCurry et al., 1999; Pollak & Perlick, 1998; Terum et al., 2017). Sleep problems of the person with dementia can cause care partners to have poor sleep themselves (Donaldson et al., 1998; Gao et al., 2019; Montgomery et al., 2018; Okuda et al., 2019), leading to psychological and physical distress as well as reductions in quality of life (Donaldson et al., 1998; Gehrman et al., 2018; Isik et al., 2019; Okuda et al., 2019). Care partners for people with dementia had shorter sleep durations, equivalent to losing 2.4 to 3.5 hours of sleep per week compared to carers for other older adults (Gao et al., 2019). Ultimately, these sleep disturbances are often a determining factor for the institutionalization of people with dementia (Hope et al., 1998; Pollak & Perlick, 1998), with longitudinal data showing an increased odds of institutionalization with greater sleep disturbance (Spira et al., 2012).

1.3.3.2 Potential mechanisms for the relationship between sleep and Alzheimer's disease

There are several potential underlying mechanisms for the causes of sleep changes in Alzheimer's disease. Here, we will discuss the relationship between sleep changes and the major pathological hallmarks of Alzheimer's disease (Aß and tau) and explore other factors such as the glymphatic system and neurodegeneration.

1.3.3.2.1 Amyloid-beta

As discussed, Aß is a peptide produced with synaptic activity (Cirrito et al., 2005) and aggregates extracellularly to form neurotoxic plaques (Palop & Mucke, 2010). A bi-directional relationship between Aß aggregation and sleep has been proposed (Carroll & Benca, 2024; Ju et al., 2014; Lucey, 2020; Mander et al., 2016; C. Wang & Holtzman, 2020). In short, poor sleep (e.g., short sleep duration, fragmented sleep, and/or decreased time in SWS) increases the concentration of Aß and prevents the clearance of Aß. Conversely, the accumulation of Aß results in more fragmented sleep and reductions in SWS, which result in more wakefulness and less Aß clearance. In sum, there may be a perpetual cycle of poor sleep increasing Alzheimer's disease pathology (i.e., Aß burden), while Aß burden worsens sleep and accelerates Alzheimer's disease pathology.

1.3.3.2.2 Tau pathology

Sleep deprivation has been shown to dramatically change tau pathology. In In rodents, sleep deprivation or sleep restriction accelerates the development and spread of tau pathology (Holth et al., 2019; Zhu et al., 2018). In humans, experimental sleep deprivation has been shown to increase cerebral spinal fluid levels of tau (Holth et al., 2019). Observational studies show greater levels of tau are associated with poorer sleep in humans (Ju et al., 2017; Liguori et al., 2014; Lucey et al., 2019; Sprecher et al., 2017) and in rodents (Holth et al., 2017). While the relationship between sleep and tau is still not well understood, some have speculated the tau-sleep relationship is similar to the Aß -sleep relationship—that is, it is bi-directional (C. Wang & Holtzman, 2020).

1.3.3.2.3 Glymphatic system

The glymphatic system acts as the "garbage truck" of the brain, responsible for clearance of metabolites and wastes (including Aß) from the brain (Nedergaard, 2013). Sleep plays an important role in glymphatic clearance (Hauglund et al., 2020; Jessen et al., 2015). With sleep, cerebral spinal fluid penetrates deep into the brain to promote the clearance of Aß (Xie et al., 2013), which is thought to be related to SWS (Hablitz et al., 2019). However, disruption of SWS or total sleep deprivation can prevent the removal of wastes including Aß (Ju et al., 2017; Kang et al., 2009; Lucey et al., 2018; Ooms et al., 2014) and lead to accumulation of Aß in brain regions such as the hippocampus (Shokri-Kojori et al., 2018). However, this proposed mechanism has been called into question, as study methodologies (e.g., using anesthesia to simulate sleep, dye used) may impact the rate of clearance (Miao et al., 2024) and this proposed mechanism requires further investigation.

1.3.3.2.4 Neurodegeneration

Like with aging, in Alzheimer's disease there is neurodegeneration of brain regions related to sleep-wakefulness regulation and the circadian rhythm. In Alzheimer's disease, there is significant degeneration of the sleep-wake regulation cells in the brainstem and thalamus, which can be associated with sleep dysfunction (Kent et al., 2021). There is also an imbalance of several neurotransmitters and hormones responsible for wakefulness or sleep (Kent et al., 2021; Van Erum et al., 2019). Finally, there may be an indirect effect from changes to circadian rhythm circuitry. As discussed in Section 1.2.3.1, the SCN (the master circadian pacemaker) has indirect connections to the wake-sleep promoting regions of the brain (such as the VLPO/intermediate nucleus). With Alzheimer's disease, there is

significant degeneration of SCN neurons which has been associated with circadian dysfunction (Harper et al., 2005; Stopa et al., 1999; J. Wang et al., 2015; J. N. Zhou et al., 1995). There is also significant loss of melanopsin-containing retinal ganglion cells (Uddin et al., 2020). These retinal cells detect incoming light and are critical for synchronizing the circadian rhythm, potentially contributing to circadian dysfunction (La Morgia et al., 2017).

In sum, degeneration of the retinal areas may diminish the strength of light-cues from reaching the SCN. This may contribute to the degeneration of the SCN and result in downstream effects, such as dysregulation of sleep-wake brain regions. The combined loss of the circadian input and Alzheimer's disease pathology may contribute to the degeneration of these sleep-wake brain regions and the diminished capacity of neurotransmitters, contributing to the changes in sleep seen in Alzheimer's disease.

1.4 Physical activity

Physical activity refers to any bodily movement produced by skeletal muscles resulting in energy expenditure (Caspersen et al., 1985). Exercise is a sub-component of physical activity and refers to structured movement with the intention of increasing physical fitness (Caspersen et al., 1985). A physically active lifestyle is generally associated with better sleep (Alnawwar et al., 2023; Kredlow et al., 2015; Kubitz et al., 1996), though the benefits may decrease with age (X. Zhou et al., 2025). Recent evidence suggests 70 minutes of low to moderate intensity activity per week is the minimum amount required to experience benefits to sleep quality in older adults, while 160 minutes of low-moderate intensity activity may be optimal (Xue et al., 2024).

1.4.1 Physical activity and sleep

There is scant evidence regarding the impact of habitual physical activity on sleep in people with dementia. Preliminary evidence suggests higher physical activity levels are associated with better care partner reported sleep quality, reduced evening restlessness, and lower levels of sleep disturbance (Christofoletti et al., 2011; Shih et al., 2017). Exercise interventions also show promise for improving sleep and will be discussed in Section 1.5.1.

The mechanism behind how physical activity may improve sleep is still unknown, but several hypotheses have been proposed. The two prominent hypotheses relate to body temperature and restoration. Body temperature fluctuates throughout the day and is lowest at night. It is hypothesized increased body temperature during physical activity enhances thermal downregulation at night, deepening sleep (McGinty & Szymusiak, 1990; Van Someren, 2000). Alternatively, the increased energy expenditure and metabolic demands of exercise may improve sleep. Exercising increases adenosine concentration, a molecule thought to promote sleep pressure, which would increase the homeostatic drive for sleep (Roig et al., 2022). By increasing the need for and depth of sleep, physical activity may better enable the body to repair itself and replenish consumed resources (Buman & King, 2010; Driver & Taylor, 2000). There are other proposed mechanisms, including exercise-induced improvements in mental health, hormone and neurotransmitter release, improved glymphatic or circadian functioning, reductions in inflammation, and overall improvements in health (Buman & King, 2010; Memon et al., 2020; Roig et al., 2022; Varrasse et al., 2015).

1.4.2 Barriers to physical activity

Although physical activity provides many benefits to sleep (Christofoletti et al., 2011; Shih et al., 2017) and diverse aspects of health (Garcia et al., 2023), there are many recognized barriers to regular engagement in physical activity. One notable factor relevant to this thesis is weather, and particularly, changes with seasons. People tend to be less active in the winter than in the summer (McCormack et al., 2010; Moschny et al., 2011; Tucker & Gilliland, 2007; Welch et al., 2018). During the winter, snow and ice significantly impede physical activity (Chan et al., 2006; Chan & Ryan, 2009; Ermagun et al., 2018). One study of a physical activity intervention found adherence varied with temperature and daylight hours (Welch et al., 2018). As temperature, daylight, and weather conditions vary between seasons, countries, and even regions within countries, the impact of weather on physical activity is nuanced. As Canada has relatively extreme winters conditions (Health Canada, 2018), it is critical to plan for weather variance when designing physical activity-based interventions. These barriers to physical activity in the winter have not been explored in people with dementia. The barriers to physical activity caused by weather may be compounded in people living with dementia due to interaction with established barriers in this population (e.g., cognitive impairment, risks of falling, reliance on others for transportation, wayfinding issues (Allan et al., 2009; Hobson et al., 2020; Sheehan et al., 2006)). As a result, understanding the barriers, facilitators, and supports needed for winter physical activity among people with dementia is a necessary focus for future research.

1.5 Interventions to improve sleep in people with Alzheimer's disease and dementia

Given the relationship between sleep and dementia, finding ways to improve sleep has the potential to improve the well-being of people with Alzheimer's disease and other dementias. Pharmaceuticals are a common treatment approach and can include the use of sedative-hypnotic agents (benzodiazepines and nonbenzodiazepines), antidepressants, or antihistamines (Deschenes & McCurry, 2009). Pharmaceuticals have small or weak benefits for sleep in older adults (Glass et al., 2005; Wilt et al., 2016), and have weak evidence for benefits among people with dementia (McCleery et al., 2014; McCleery & Sharpley, 2020). Additionally, many pharmaceutical sleep treatments have negative side effects (Berry et al., 2013; Glass et al., 2005), and pharmacological interventions should be used judiciously (Deschenes & McCurry, 2009) or as a short-term solution (Guarnieri et al., 2014). Instead, researchers recommend individualized, non-pharmacological interventions as the first-line treatment to improve sleep.

A variety of non-pharmaceutical interventions have been shown to improve sleep in people with dementia. These interventions can be completed alone or used in combination with each other. The different types of interventions will be explored in the following sections with emphasis on physical activity, bright light therapy, education, and multi-modal interventions as these are particularly relevant to Studies 3 and 4 (Chapters 4 and 5). A summary of studies identified, and their findings can be found in Table 1 (multi-component interventions) and Appendix A (other interventions, Table A1-Table A4).

1.5.1 Physical activity

A recent meta-analysis suggests exercise significantly improves objectively measured sleep duration and efficiency in people with dementia (Páez et al., 2024). However, this meta-analysis did not examine results by place of residence. In the present thesis, eight studies examining physical activity to promote sleep in people with dementia were identified (three in community-dwelling and five people with dementia living in institutional settings) (Appendix A (Table A1)). Several patterns were identified. Community-dwelling people with dementia were more likely to show improvements in sleep, whereas results were inconsistent in people with dementia living in institutional settings. Some of the differences reported between community-dwelling people with dementia and those in institutional settings may be related to activity intensity and environmental constraints. The physical activities in people with dementia living in institutional settings, such as self-directed walking, were likely less intense and shorter in duration, possibly insufficient to improve sleep (Callisaya et al., 2017). In addition, walking outdoors may be more feasible for community-dwelling people with dementia, and may provide the added benefit of increased light exposure (discussed in Section 1.5.2).

Multi-modal exercise interventions (combining two or more types of exercise, most often aerobic and strength training) consistently demonstrated improvements in sleep (Namazi et al., 1995; Nascimento, Ayan, et al., 2014; Richards et al., 2011). In addition, exercise interventions that met or surpassed the recommended 150 minutes of physical activity per week (Ross et al., 2020) were more likely to show benefits in sleep; nearly all

interventions observing improvements met this threshold (Buysse et al., 2008; McCurry et al., 2011; Namazi et al., 1995; Richards et al., 2011).

Though the benefits of physical activity, especially multi-modal interventions meeting the activity guidelines, are consistent, there are many barriers to exercise for people with dementia. Poor walkability and weather, including winter precipitation, were reasons for low adherence or for dropping out of a sleep intervention (McCurry et al., 2011). These weather-related factors also act as barriers to physical activity in the general population (Y. Li et al., 2012). There has been little in-depth exploration of how weather, particularly winter weather, impacts physical activity in people with dementia. Understanding these unexplored barriers and facilitators to winter physical activity is the motivating factor for Study 3.

1.5.2 Bright light therapy

Several meta-analyses have been conducted to look at the effectiveness of light therapy on people with dementia. These meta-analyses provide inconsistent results, as some found improvements in sleep (Van Maanen et al., 2016), while others did not (Forbes et al., 2014; He et al., 2023; Wilfling et al., 2023). One critical difference between these meta-analyses is that the Van Maanen et al. (2016) analysis included non-randomized control studies, while the other reviews only included randomized control trials (RCTs) (Forbes et al., 2014; He et al., 2023; Wilfling et al., 2023).

There are several other methodological considerations which might contribute to the effectiveness of light interventions in people with dementia. One is the residential status of the participant. Studies which take place in long-term care homes may be more effective than for those living in the community. This may be because light levels in long-term care homes

tend to be too low, allowing for more contrast between the intervention and control group (De Lepeleire et al., 2007; Kolberg et al., 2022; Konis, 2018). People with mild dementia living in institutional settings may only get ~10 minutes per day of sufficiently bright lighting, but that amount is even worse for those with severe dementia (only ~1 minute per day (Ancoli-Israel et al., 1997; Shochat et al., 2000)). In contrast, community-dwelling people with dementia tend to be more mobile, allowing for more opportunities to engage in outside activities for increased light exposure (Figueiro et al., 2015). A second consideration is if the intervention used environmental restructuring (installing lights into the built environment) or using light boxes (a device which emits lights). Environmental restructuring may be more effective than light boxes as it allows participants to engage in normal day-to-day activities and requires less staff support. In contrast, light boxes require the person to sit for an extended period of time, often with supervision to ensure compliance (Fetveit et al., 2003), and prevent engagement in physically stimulating activities which also improve sleep.

1.5.3 Sleep hygiene education

Some modifiable risk factors for sleep may be improved by making simple lifestyle, behavioral, and environmental changes. Thus, education on sleep promoting practices, known as sleep hygiene, may be one way to improve sleep (Baranwal et al., 2023; Irish et al., 2015). Good sleep hygiene includes exercise, having a consistent bedtime routine, and keeping bedrooms cool and quiet. Poor sleep hygiene practices include consuming caffeine, nicotine, or alcohol too close to bedtime; eating too heavy of a meal close to bedtime; and watching television in bed before sleeping. Educational sessions informing participants about sleep hygiene have been found to improve sleep in university students (Kloss et al., 2016).

Results for studies using sleep hygiene education as the only intervention modality can be seen in Appendix A (Table A4). Using an RCT design, McCurry et al. (2012) did not find any significant improvements in sleep immediately following an education intervention. But, at the 6-month follow-up, they found significant improvements for actigraph-measured sleep duration and sleep efficiency. Further, McCurry et al. (2003) found the intervention group was more likely to implement sleep hygiene practices including a consistent in-bed/rise time and reduced daytime napping; however, they did not look at other measures of sleep. In contrast, Naismith et al. (2019) found significant improvements in self-reported sleep but not objective sleep following a randomized control pilot study in people with MCI.

McCurry et al. (1998) also examined sleep of care partners of people with dementia and found an educational intervention was effective at improving subjective sleep of care partners. This is important, as care partner stress is linked to sleep disturbance and psychological or physical distress (Montgomery et al., 2018; Okuda et al., 2019). By improving sleep in care partners of people with dementia, this can help alleviate some of their stress and better equip them to cope throughout the dementia journey.

Of note, there are relatively few studies using sleep hygiene education alone (McCurry et al., 1998, 2003, 2012; Naismith et al., 2019). More often sleep hygiene education is used as part of a multicomponent intervention. For example, many sleep hygiene practices, such as engaging in exercise or bright light exposure, are integrated into the intervention design, rather than being only being included as recommendations within education (e.g., Livingston et al., 2019; McCurry et al., 2005, 2011).

1.5.4 Other interventions

There are several other approaches for improving sleep in people with dementia, including robotic pets and music. Although other interventions were identified (e.g., cognitive behavioral therapy, massage therapy, aromatherapy, non-invasive brain stimulation), they will not be discussed as there are less than three articles for each approach in people with dementia, or the evidence is in older adults without cognitive impairment.

Therapeutic robotic pets involve having a soft, furry robotic animal that is physically and verbally responsive to being petted. Robotic pets are used as an alternative to live-animal pet therapies. These robotic pet therapies have been found to reduce depression and agitation in people with dementia living in institutional settings (Jøranson et al., 2015). There are mixed results regarding sleep where some studies find improvements in nighttime sleep and reductions in daytime napping (Jøranson et al., 2021; Pu et al., 2021), while other studies found reductions in nighttime motor activity but not sleep (Moyle et al., 2018). Of note, these interventions were highly controlled where participants were restricted to designated periods where they could interact with the robotic pet. Future interventions should examine a flexible approach, where individuals have more freedom interacting with the robotic pet.

Music therapy for sleep can be active or passive. Active music therapy involves engaging in a music activity (singing), whereas passive involves listening to music. Both show promise for improving sleep. Six months of singing training (active music therapy) was shown to improve sleep in people with Alzheimer's disease, as reported by their care partners (Satoh et al., 2015). Passive music therapy was found to improve sleep in community-dwelling people with subjective memory decline (Innes et al., 2016) and in people with

dementia living in institutional settings (as reported by nursing home staff (Lindenmuth et al., 1992)). However, one study in people with dementia living in institutional settings showed minimal improvements in sleep quality when compared to baseline ($d = 0.40$, $p = .06$), but the intervention group showed improvements in sleep over the control ($d = 0.52$, $p = .04$) (Weise et al., 2020). Due to the limited number of studies using small sample sizes, further investigation is required.

1.5.5 Multi-component interventions

Combining several individual interventions may have additive benefits to sleep. Often, multi-component interventions include sleep education and/or behavioral management, light therapy, and physical activity or other stimulating activities. Table 1 summarizes the results of multi-component interventions. Every study was an RCT, and most used objective measures of sleep. Most multi-component interventions observed improvements in nighttime sleep in community-dwelling people with dementia and those in institutional settings (Dowling et al., 2008; Falck et al., 2020; McCurry et al., 2005, 2011; Richards et al., 2011; Riemersma-van der Lek, 2008). Two studies failed to find significant improvements in sleep, potentially due to the intervention not being intensive enough (e.g., too short light therapy exposure (Friedman et al., 2012), or the exercise was not intensive enough (Ouslander et al., 2006)).

Using a multicomponent intervention approach may provide superior benefits over single-component interventions. The *Nighttime Insomnia Treatment and Education for Alzheimer's disease* (NITE-AD) program is an eight-week program consisting of weekly sleep education sessions, 30 minutes of daily self-directed walking, and one hour of evening

light exposure (McCurry et al., 2005). McCurry et al. (2011) compared the multi-component NITE-AD program to its subcomponents (one hour of daily light exposure or 30 minutes of self-directed daily walking), as well as a control group that received the educational materials but did not receive additional support (e.g., goal setting, problem solving). All three intervention modalities decreased time awake at night, but only the NITE-AD program had significant improvements in sleep efficiency. Additionally, the NITE-AD program had the largest effect sizes across the sleep outcomes.

1.5.6 Summary and final remarks of lifestyle interventions to improve sleep in people with dementia

Most studies of sleep interventions showed an improvement in at least one indicator of sleep, whether the intervention was unimodal or multi-modal. However, using a multi-modal approach may yield superior benefits (O'Caoimh et al., 2019), as intervention modalities may have additive benefits. Tailoring multi-modal interventions to the individual's sleep needs and challenges may accentuate benefits. For example, light therapy could be used to make one's bedtime earlier or later depending on when the exposure occurs; thus, understanding a person's ideal nighttime schedule is necessary.

One main challenge of sleep intervention literature is a lack of cohesion between studies (Brown et al., 2013). Seldom did researchers build their study design from previous literature, and instead research groups stayed within their own protocols or approaches, even if previously shown to be ineffective. This line of research could be bolstered through communication and collaboration. The present thesis aims to do so by building on the

protocol and structure of the NITE-AD program, which will be adapted to make it more appropriate for use in Canada and adapted in line with the most recent best evidence.

Table 1. Multicomponent interventions to improve sleep in community-dwelling people with dementia and people with dementia living in institutional settings

Authors	Dementia type	Sample	Study Design	Duration	Intervention	Control treatment	Outcome
Community-Dwelling							
(Falck et al., 2020)	MCI	INT *n* = 48 CON *n* = 48	RCT	24 weeks	Education: 4 1-weekly sleep education classes BLT: 20 weeks of individualized BLT (for 1 hour, twice daily) PA: 20 weeks of tailored PA promotion (150 min/week)	4 1-weekly health enrichment lectures and follow-up phone calls to check in. Asked to continue monthly activities.	*Objective sleep* – Actigraphy ↔ SE, TST, fragmentation, latency, WASO *Subjective sleep* – self-report ↓ PSQI (i.e., better subjective sleep)
(Friedman et al., 2012)	Not specified	INT *n* = 31 CON *n* = 23	RCT	2 weeks	Education: 1x 50-minute phone call + follow up call BLT: 30-minutes of light exposure (4200 lux) for 30-minutes within 30-minutes of waking up	Same as intervention, but 90 lux dim red light	*Objective sleep* – Actigraphy PwD (in INT) ↓ TIB ↔ WASO, SE
(McCurry et al., 2005)	AD	INT *n* = 17 CON *n* = 10	RCT	8 Weeks	NITE –AD Education: 6 1-weekly in-home sleep education and developing individualized sleep plans. PA: Encouragement to partake in 30-minutes of self-directed walking daily. BLT: exposure to 2,500 lux for 1 hour/day within 2 hours of bed Other: Behavior management, problem solving and troubleshooting for these plans	Non-directive dementia care education and support, but with no training or homework	*Objective sleep* – Actigraphy *2-months follow up* ↓ total wake time, # of nighttime awakenings ↔ SE, TST, duration of night awakenings *6-months follow up* ↓ total wake time, # of awakenings, duration of night awakenings ↔ TST, SE, daytime sleep *Subjective sleep* - proxy SDI (by care partner) ↔ SDI

(McCurry et al., 2011)	AD	INT *n* = 27 CON *n* = 29	RCT	8 Weeks	NITE –AD Education: 6 1-weekly in-home sleep education and developing individualized sleep plans. PA: Encouragement to partake in 30-minutes of self-directed walking daily. BLT: exposure to 2,500 lux for 1 hour/day within 2 hours of bed Other: Behavior management, problem solving and troubleshooting for these plans	Non-directive dementia care education and support, but with no training or homework	*Objective sleep* – Actigraphy *After 2 months* ↑ SE & ↓ total wake time *After 2 months and 6 months* ↔ # of awakenings, TST, daytime sleep, SE, total wake time *Subjective sleep* - proxy SDI (by care partner) *After 2 months and 6 months* ↔ SDI
People with dementia living in institutional settings							
(Dowling et al., 2008)	AD	INT *n* = 15 CON *n* = 17	RCT	10 weeks	BLT: 1 hour of morning light exposure (2500lux) (930am-1030am) from Monday to Friday Melatonin: 5mg of melatonin 2-3 prior to bed	TAU	*Objective sleep* – Actigraphy ↓ Daytime sleep, number of sleep day bouts
(Ouslander et al., 2006)	Not specified†	INT *n* = 77 Delayed intervention CON *n* = 96	Cluster controlled clinical trial	17 days	PA: FIT training 4-5 times a day (for 5-10 minutes total) Environmental: Noise reduction Other: Behavioral management, keeping participants out of bed during the day, having a consistent bedtime routine, modified nighttime continence care	TAU	*Objective sleep* – Actigraphy ↓ daytime napping ↔ TST, nighttime awakenings *Objective sleep* – PSG ↔ TST, NREM, REM, latency, WASO, SE
(Richards et al., 2011)	Not specified	INT *n* = 41 CON *n* = 47	RCT	7 weeks	PA: High intensity resistance strength training 3x per week + 45 minutes of walking 2x/week Social Activity: 1 hour of individualized social activities	TAU	*Objective sleep* – PSG ↑ NREM Sleep, TST (> control) ↑TST, SE, NREM sleep (overall)

(Riemersma-van der Lek, 2008)	AD, VD, LBD, PD†	INT *n* = 26 CON *n* = 24	RCT	Mean of 15 months (up to three years)	BLT: Environmental restructuring, BLT installed into ceilings of common areas (1000 lux) and were on from 9am-6pm Melatonin: 3.5mg of melatonin 1-hour before bedtime	TAU, lights installed but not as bright	*Objective sleep* – Actigraphy ↓ nocturnal restlessness, duration of awakenings ↑ SE ↔TST, SOL

† Sample includes cognitively intact participants

AD = Alzheimer's disease, BLT = Bright light therapy, CON = Control group, CP= Care partner, DREAM:START = Dementia RElAted Manual for Sleep; STrAtegies for Relatives, INT = Intervention group, LBD = Lexy body dementia, MCI = Mild cognitive impairment, NITE – AD = Nighttime Insomnia Treatment and Education for Alzheimer's Disease, NREM = Non-rapid eye movement, RCT = Randomized control trial, REM = Rapid eye movement, PA = Physical activity, PD = Parkinson's' disease, PSG = Polysomnography, PSQI = Pittsburgh sleep quality index, PwD = Person with dementia, SCI = Sleep condition indicator, SE = Sleep efficiency, SOL = Sleep onset latency, TAU = Treatment as usual, TIB = Time in bed, TST = Total sleep time (sleep duration), VD = Vascular dementia, WASO = Wake after sleep onset

1.6 Rationale and research questions

The relationship between sleep and dementia is complex. Poor sleep may act as both an early indicator and a potential risk factor for developing dementia (Bokenberger et al., 2017; Shi et al., 2018; Xu et al., 2020). In those with dementia, poor sleep is common, with rates differing with dementia type and severity (Guarnieri et al., 2012; Koren et al., 2023; McCurry et al., 1999; Webster et al., 2020; G. Zhou et al., 2019). These sleep disturbances can manifest in different ways, but when these disturbances are frequent and disrupt the sleep of care partners, it increases care partner burden and the odds of institutionalization (Hope et al., 1998; Pollak & Perlick, 1991; Spira et al., 2012).

Lifestyle, and specifically physical activity, may play a role in sleep disruption and dementia risk. Physical activity is associated with reduced risk of dementia and cognitive decline (Blondell et al., 2014; Iso-Markku et al., 2022; Sofi et al., 2011), as well as better sleep in healthy older adults (Alnawwar et al., 2023; Kredlow et al., 2015; Kubitz et al., 1996), and people with dementia (Páez et al., 2024). However, it is unclear whether and how physical activity and sleep may interact to mitigate dementia risk.

Lifestyle interventions to improve sleep in people with dementia show promise, especially when multiple modalities are utilized (O'Caoimh et al., 2019). However, a major limitation to lifestyle interventions is they seldom build upon existing studies, and intervention modalities may need to be adapted to be acceptable and feasible across different geographies, as well as cultures.

Thus, the present thesis aims to investigate, understand, and promote lifestyle factors (with emphasis on physical activity) to help improve sleep in people with, or at risk for, dementia. This thesis will be broken down into two parts:

Part 1 includes Studies 1 and 2 (Chapters 2 and 3), which use longitudinal observational data to understand how sleep and physical activity influence cognition in healthy older adults and people with dementia independently and interactively. Although poor sleep and lower physical activity are associated with increased dementia risk, it is unclear how or whether they interact in their effects on dementia risk and cognition. T**he objectives of Studies 1 and 2 are to understand the relationship between sleep, physical activity, and cognition before and after the onset of dementia.** Using data from the *Rush Memory and Aging Project*, I aimed to address the following research questions:

Study 1:

1. In healthy older adults, how do physical activity and sleep, independently and in interaction, impact cognitive trajectory and incidence of dementia?

Study 2:

2. In people with dementia, how does physical activity relate to sleep over time?
3. In people with dementia, how do physical activity and sleep interact to impact cognition over time?
4. *Secondary*: In people with dementia, how do physical activity and sleep interact to impact ADLs (inclusive of ADLs and instrumental activities of daily living (IADLs) over time?

Part two of this thesis (Studies 3 and 4) will focus on adapting and understanding the acceptability and feasibility of the adapted NITE-AD program. The NITE-AD program is a multi-modal program to improve sleep among people with Alzheimer's disease (McCurry et

al., 2005, 2011). The creators of the NITE-AD program noted that climate and weather impacted adherence to the physical activity component (McCurry et al., 2011). Given the NITE-AD program was tested in Seattle, Washington, a region with very mild weather and winters, adoption of this program in much colder regions likely requires modifications. People are often less active in the winter, which has been attributed to factors such as reduced daylight, temperature, and precipitation (Chan et al., 2006; Jones et al., 2017; Welch et al., 2018). However, the impact of winter on physical activity specifically in people with dementia and their care partners has not been investigated. **Thus, the overarching aim of Study 3 (Chapter 4) is to understand the barriers and facilitators to physical activity during the wintertime in people with dementia and their care partners.** Study 3 will answer the following research questions:

1. What are barriers to physical activity among people with dementia during winters?
2. What facilitates physical activity among people with dementia during winters?

Study 4 aims to adapt the NITE-AD program to make it more appropriate for use in Canada. This new program, NITE-CAD (Nighttime Insomnia Treatment and Education for Canadians with Alzheimer's Disease), was be adapted based on information from **Study 3,** best evidence, and the input of a small advisory team. I aim to answer the following question:

1. How should the NITE-AD program be adapted for the Canadian context and emerging best evidence?

Chapter 2: Study 1 – Investigating the interaction between physical activity and sleep on cognition and dementia risk

2.1 Introduction

World-wide, the number of people with dementia is expected to increase from 57 million in 2019 to 153 million people by 2050 (Nichols et al., 2022). Understanding the contributing factors for developing dementia is critical as it can allow for early intervention and risk reduction. Delaying dementia onset by even one year could result in 500,000 fewer new dementia cases in Canada by 2050 (Alzheimer Society of Canada, 2022).

Physical activity can reduce the risk of cognitive decline or dementia by approximately 18 to 38% (Blondell et al., 2014; Iso-Markku et al., 2022; Sofi et al., 2011), while physical inactivity increases dementia risk (Livingston et al., 2024). Physical inactivity may independently contribute to 2% of dementia cases world-wide and 10.2% of cases in Canada (Livingston et al., 2024; Son et al., 2024). A 25% reduction in physical inactivity may prevent one million dementia cases (Barnes & Yaffe, 2011). A recent meta-analysis found a dose-dependent relationship between physical activity and dementia, suggesting more intense physical activity had a greater effect in reducing dementia risk (Iso-Markku et al., 2022).

In recent years, there is growing evidence that sleep is associated with dementia risk. Poor sleep may be both a risk factor for dementia (Shi et al., 2018; Xu et al., 2020), as well as an early symptom of dementia (Bokenberger et al., 2017). Longitudinal data suggest poorer sleep is associated with a 1.5-fold increase of developing dementia, when compared to better sleep (Lim et al., 2013). However, dementia pathology can start forming 20 years before symptom onset (Jansen et al., 2015; Rodriguez-Vieitez et al., 2016). Thus, it is difficult to determine the time course or causality of dementia pathology and sleep

disturbance. Thus, the evidence for sleep as a modifiable risk factor for dementia is still considered low quality (Livingston et al., 2024).

Physical activity plays an important role in promoting sleep (Kredlow et al., 2015; Kubitz et al., 1996; H. Zhao et al., 2023). Although physical (in)activity and sleep are related and are both associated with dementia risk, few studies have looked at how these two factors may interact. In healthy older adults, there is preliminary evidence for physical activity protecting cognition from the deleterious effects of poor sleep. In a cross-sectional study, Lambiase et al. (2014) found that older women who were highly active did not experience executive function impairment with poor sleep. Conversely, among individuals who had lower levels of physical activity, executive functioning performance was directly related to their sleep quality, whereby those who had the lowest sleep efficiency had the worst executive functioning (Lambiase et al., 2014). Similar results from cross-sectional studies were found for physical activity, sleep, and episodic memory (Kuhn & Heisz, 2022; Sewell et al., 2023). There is also emerging evidence from longitudinal studies that physical activity is protective against short sleep duration and cognitive decline over 10 years (Bloomberg et al., 2023). Further investigation is needed to fully understand how sleep, and sleep quality specifically, interacts with physical activity to influence dementia risk.

The objectives of this study were to understand how sleep and physical activity independently and interactively predict cognitive trajectory and dementia risk among older adults without dementia. It was hypothesized that physical activity would moderate the relationship between sleep and cognition, given preliminary research in older adults (Kuhn & Heisz, 2022; Lambiase et al., 2014; Nakakubo et al., 2017; Sewell et al., 2023). Specifically,

it was expected that in people who engage in lower levels of physical activity, sleep quality would be predictive of cognitive trajectory, but that there would not be a relationship between sleep and cognition in those who engaged in higher levels of physical activity.

2.2 Methods

2.2.1 Study sample

Participants were individuals from the Rush Memory and Ageing Project, which has collected data since September 1997 (ongoing) with 2297 people enrolled to date. Participants were eligible to enroll if they were above the age of 65 without known dementia; agreed to undergo clinical evaluation, cognitive testing, and blood draws; and agreed to organ donation. Participants were recruited primarily from retirement communities throughout north east Illinois (Bennett et al., 2005). Follow-ups visits were conducted annually, with actigraphy and cognitive data collected at all assessments (though participants could choose not to complete). This study was approved by the Institutional Review Board of Rush University Medical Center. Written informed consent was obtained from all participants. This study also received ethics clearance from the University of Waterloo Research Ethics Board (ORE #46680).

Participants were included in the current analytic sample if they had their sleep and movement tracked with an Actical in 15-second time intervals (i.e., epochs) for at least two days with cogntive assessments collected at the same assessment as when the Actical was collected (adjusted baseline), as well as at least one follow-up visit. The adjusted baseline reflects the first eligible year when participants had complete actigraphy (for at least two days) and cognitive data. At the time of analysis, there were 1343 participants with

appropriate data. Of the 1343 participants with valid actigraphy data, 99 were removed for screening positive for clinical dementia at adjusted baseline and a further 73 were removed for not having at least one follow-up visit, for a final sample of 1171.

2.2.2 Primary assessments

2.2.2.1 Actigraphy

Actigraphy was collected using the Actical activity monitor (Actical, Philips Respironics; Bend, OR) from 2005-2018. The Actical activity monitor is a wrist-worn device which uses an omnidirectional accelerometer. Participants were instructed to wear the Actical device on their non-dominant wrist for 24 hours per day for 10 consecutive days. The device records acceleration in one-second samples, describes as activity counts. These activity counts are then summated within 15-second epochs, with 0 to 3000 activity counts in each epoch. High counts indicate higher levels of activity. From these data, measures of sleep fragmentation and physical activity can be extracted. Other actigraph models were introduced to the Rush cohort in 2018 but variables using these devices will not be included in this analysis due to potential differences across models.

2.2.2.1.1 Sleep fragmentation

Sleep fragmentation was estimated using the k_{RA} index (Lim et al., 2011). The k_{RA} index is the probability that someone will transition into a state of activity following approximately five minutes of rest. The k_{RA} index is calculated over the entire day and includes periods of rest at night and during the day (i.e., naps). A high k_{RA} indicates a greater probability of going from rest to activity and suggests disrupted periods of rest or fragmented sleep. Methods which look at state-transition properties are a less common approach to measuring

sleep quality but have the advantage of factoring in both the frequency and duration of sleep disturbances. To calculate the k_{RA} index (Lim et al., 2011), each epoch was categorized to rest (0 activity count) or active (>0 activity counts). Using nonparametric local regressions, regions of rising, falling, and (relatively) constant activity were identified. The weighted average value of epochs (0,1) within the constant regions of rest were used to calculate k_{RA}. In this analysis, the k_{RA} index was calculated from 621 participants in the Rush Memory and Aging project. The k_{RA} index is not correlated with other actigraph metrics such as intradaily variability and interdaily stability.

2.2.2.1.2 Physical activity

Daily physical activity was calculated by first identifying the most active 14-hour window in each 24-hour day (00:00 to 23:59), which was selected in an effort to exclude sleep time and nighttime movement. Periods that did not have data for a full 24 hours were not included. A daily physical activity average was calculated by averaging daily physical activity counts over the most active 14 hours for each day, then averaging across all the days the participant wore the actigraph. Twelve-hour and 16-hour windows were also calculated for exploratory purposes, to ensure the results were not influenced by the selected timeframe. Only total activity counts, rather than time spent in moderate-vigorous physical activity, were used as a variable as algorithms to calculate time in moderate-vigorous physical activity intensity have not been validated for the Actical among older adults.

2.2.2.2 Global cognitive function

Global cognitive function was assessed using 19 different cognitive tests and scored by a computer. Details are provided elsewhere (Bennett et al., 2005, 2012). Cognitive assessments

were collected at every follow-up visit when possible. In the present sample, out of 9446 participant-visits, 209 (2.2%) were missing a global cognition score. In brief, global cognitive performance was calculated across five domains: episodic memory, semantic memory, working memory, perceptual speed, and visuospatial abilities. Composite scores were calculated for each domain by converting each test score into a z-score and taking the average across tests in that domain. A final global cognitive score was calculated by taking the global average of z-scores across the 19 tests (Bennett et al., 2005, 2012), creating a global cognition z-score. This global cognitive function score was used as the outcome of interest.

2.2.2.3 Cognitive diagnosis

Dementia was diagnosed using a combination of computer scoring (using a decision tree which simulates clinical judgment and a rating of severity of impairment) and clinician evaluation. A clinician examined the participants and reviewed all cognitive and clinical information (e.g., history of stroke, presence of Parkinson's disease, depression severity) to make a final diagnosis based on the National Institute of Neurological and Communicative Disorders and Stroke–Alzheimer's Disease and Related Disorders Association criteria (see Bennett et al., (2006) for details about this process). Participants were placed into one of six categories: no cognitive impairment, MCI (with or without other contributing conditions), Alzheimer's dementia (with or without other contributing conditions), or other dementia. Participants without clinical dementia at the adjusted baseline were included in this study, while those with clinical dementia were excluded.

2.2.3 Descriptive characteristics and covariates

Participants reported age, sex, and years of education, presence of vascular diseases (myocardial infarction, congestive heart failure, claudication, stroke), vascular risk factors (hypertension, diabetes, smoking history), and the presence of other comorbidities (thyroid disease, cancer). Depressive symptoms were assessed using the Center for Epidemiological Studies-Depression (CESD) 10 scale (Andresen et al., 1994; Radloff, 1977). Participant height and weight were measured to calculate body mass index (BMI, kg/m^2). A clinician screened for the possible presence of Parkinson's disease. These covariates were selected for their established influence on sleep, physical activity, or cognitive function.

2.2.4 Statistical analysis

Participant characteristics were described as mean (standard deviation) or number (percent), as appropriate. For ease of interpretation, sleep and physical activity variables were centred at the mean and scaled according to standard deviation from the mean to create a z-score for each variable. All data analysis was carried out using R software (R Core Team, 2023).

We examined the longitudinal relationship between baseline physical activity and sleep fragmentation in relation to cognitive change over time using multilevel linear equations. The adjusted baseline (first year with Actical and cognitive assessments) was considered year 0 for the purpose of these analyses. The multilevel linear models included subject-specific random terms for slope and intercept. Fixed effects included physical activity, sleep fragmentation, and other covariates. A continuous autoregressive covariance structure was selected, which uses an autocorrelation structure with a continuous time covariate (Pinheiro

et al., 2023). Finally, to examine the effect of physical activity and sleep fragmentation on risk of all-cause dementia, we used proportional Cox hazard ratios.

For all analyses, the base model included include age at adjusted baseline, sex, and education. Model 1 looked at the independent effect of sleep fragmentation on the outcome. Model 2 looked at the independent effect of physical activity on the outcome. Model 3 looked at the independent effects of sleep fragmentation and physical activity on the outcome. Model 4 then added an interaction term between sleep fragmetnation and physical activity. Additional covariates were explored in two clusters. Model 5 included vascular factors, such as the presence of vascular disease (the sum of yes (1) or no (0) to having: myocardial infarction, congestive heart failure, claudication, stroke), and vascular risk factors (the sum of answering yes (1) or no (0) to questions about hypertension, diabetes, smoking history). Model 6 included other comorbidities, such as the presence of cancer, Parkinson's disease, thyroid disease (yes (1) or no (0)) and depressive symptoms (as assessed with the CESD-10).

To ensure the results were not the result of the activity period used, sensitivity analyses were done using the most active 12 or 16 hours of physical activity. Analysis of Variance (ANOVAs) was used to compare the model fit of the most active 14 hours to 12 and 16 hours.

2.3 Results

2.3.1 Participant characteristics

Participants had an average age of 80.9 (standard deviation (SD) 7.9 years) and 77.1% were female. Participants had an average of 7.5 follow up visits (SD 4.1, range 1 – 17, 424

missing visits). See Table 2 for detailed participant characteristics. Nine hundred twenty-nine participants experienced a negative change in their cognitive score between their baseline and last global cognitive score (mean cognitive change in z-score: -0.64, SD 0.85, range -4.29 – 1.4). On average, actigraphy data was recorded for 7.9 days (SD 0.4, range 6-11 days). The average physical activity for the most active 14 hours was 282.6 counts*min^{-1} (SD 163.5, range 15.6 – 1350.5) and the average k_{RA} was 0.028 (SD 0.007).

2.3.2 Sleep, physical activity and cognitive decline

When analyzing the effects of physical activity and sleep fragmentation (k_{RA}) on cognitive decline in separate models, both the main effect of physical activity (Estimate = 0.07, 95% CI = 0.04 – 0.10, $p < .001$) and its interaction with time were significant (Estimate = 0.01, 95% CI = 0.002 – 0.02, $p = .01$), indicating that physical activity was associated with

Table 2. Participant characteristics (*n* = 1171)

Clinical Characteristics	**Mean (SD) or N (%)**
Age (year)	80.9 (7.3)
Sex, female	902 (77.1%)
Education (years)	15.1 (3.0)
BMI, kg/m^2	27.3 (5.4)
MMSE, /30	28.1 (1.9)
Depressive Symptoms (CESD-10), /10	1.0 (1.5)
Vascular risk factors	
Hypertension	680 (58.1%)
Diabetes Mellitus	119 (10.2%)
Smoking	477 (40.8%)
Vascular disease	
Myocardial infarction	108 (9.2%)
Congestive Heart Failure	53 (4.5%)
Claudication	122 (10.4%)
Stroke	119 (10.2%)

BMI = Body Mass Index, MMSE = Mini-mental state examination; CES-D 10 = Center for Epidemiological Studies-Depression 10-item

higher baseline cognition and a slower rate of cognitive decline over time. Only the main effect of sleep fragmentation was significantly associated with cognition (Estimate = -0.03, 95% CI = -0.06 – -0.01, p = .02) but not its interaction with time (Estimate = -0.003, 95% CI = -0.01 – -0.004, p = .46), indicating that fragmented sleep was associated with worse cognition, but not the rate of cognitive decline. In addition, the main effect of sleep fragmentation disappeared when considering other comorbidities (Estimate = -0.02, 95% CI = -0.05 – 0.01, p = .12). See Table 3 for a summary of results.

When considering both physical activity and sleep fragmentation in the same model, relationships remained similar. Both the main effect of physical activity (Estimate = 0.08, 95% CI = 0.05 – 0.11, p <.001) and its interaction with time (Estimate = 0.01, 95% CI = 0.001 – 0.02, p = .01) remained associated with cognitive function (see Figure 4 (left)). Again, the main effect of sleep fragmentation was associated with worse cognitive performance (Estimate = -0.05, 95% CI = -0.07 – -0.01, p <.01) but its interaction with time was not (Estimate = -0.005, 95% CI = -0.01 – -0.004, p = .21; see Figure 4 (right)). There was no significant interaction between physical activity and sleep fragmentation (Estimate = -0.02, 95% CI = -0.05 – 0.01, p = .16), nor was there for the three-way interaction between time, physical activity, and sleep fragmentation (Estimate = 0.007, 95% CI = -0.0002 – -0.01, p = .06). ANOVAs confirmed that these models did not significantly change when considering different physical activity intervals (i.e., 12-, 14-, or 16-hour daily activity windows), nor the introduction of vascular risk factors and vascular disease and other comorbidities into the models.

Table 3. Regression coefficients for the longitudinal association between baseline sleep fragmentation, baseline physical activity, and cognitive trajectory

	Sleep fragmentation (at baseline)		Physical activity (as baseline)		Time		Time × sleep fragmentation		Time × physical activity		Sleep fragmentation × physical activity		Sleep fragmentation × physical activity × time		R^2
	b (95% CI)	*p*	*b* (95% CI)	*p*	*b* (95% CI)	*p*	*b* (95% CI)	*p*	*b* (95% CI)	*p*	*b* (95% CI)	*p*	*b* (95% CI)	*p*	.86
Model 1	-0.03 (-0.06 – -0.003)	.03			-0.09 (-0.10 – -0.09)	<.001									.86
Model 2			0.07 (0.04 – 0.10)	<.001	-0.09 (-0.10 – -0.09)	<.001									.86
Model 3	-0.03 (-0.06 – -0.01)	.02			-0.09 (-0.10 – -0.09)	<.001	-0.003 (-0.01 – 0.004)	.46							.86
Model 4			0.07 (0.04 – 0.10)	<.001	-0.10 (-0.10 – -0.09)	<.001			0.01 (0.002 – 0.02)	.01					.86
Model 5	-0.05 (-0.07 – -0.01)	<.01	0.08 (0.05 – 0.11)	<.001	-0.10 (-0.10 – -0.09)	<.001	-0.005 (-0.01 – 0.003)	.20	0.01 (0.001 – 0.02)	.01	-0.02 (-0.05 – 0.01)	.16	0.007 (-.0002 – 0.01)	.06	.86

Model 1 = baseline k_{RA} + time + base covariates (age, sex, education); Model 2 = baseline physical activity + time + base covariates; Model 3 = baseline k_{RA} × time + base covariates; Model 4 = baseline physical activity× time + base covariates; Model 5 = baseline physical activity× baseline k_{RA}×time + base covariates

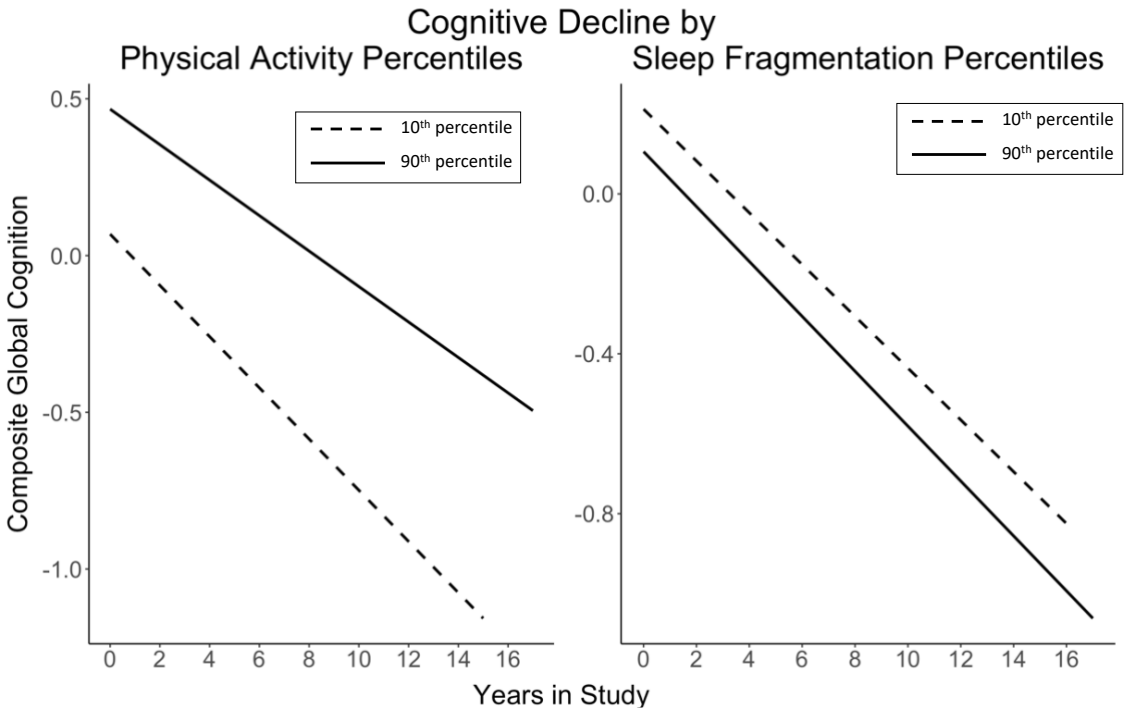


Figure 4. Cognitive change over time by physical activity (left) and sleep fragmentation (right). The figures show models of predicted rates of cognitive decline for the 90th percentile and 10th percentile of physical activity and sleep fragmentation (k_{RA}), respectively

2.3.3 Sleep, physical activity, and incident dementia risk

See Table 4 for results regarding dementia risk. Over a mean follow-up year of 6.9 years (SD 4.1), 357 (30.5%) persons developed dementia (2 participants without a follow-up cognitive status assessment were not included). When considered independent of sleep fragmentation, physical activity was associated with a reduced risk of developing dementia (HR = 0.84, 95% CI = 0.74 – 0.96, p <.01). In contrast, sleep fragmentation was not significantly associated with dementia risk (HR = 1.08, 95% CI = 0.92 – 0.98, p = .11). When both factors were in the model, physical activity continued to be associated with a reduced risk of developing dementia (HR = 0.84, 95% CI = 0.57 – 0.95, p <.01), while sleep fragmentation was not associated with dementia risk (HR = 1.09, 95% CI = 0.99 –1.20, p =

Table 4. Hazard ratios for developing all-cause dementia.

	Physical activity (at baseline)		Sleep fragmentation (at baseline)		Sleep fragmentation × physical activity	
	HR (95% CI)	p	HR (95% CI)	p	HR (95% CI)	p
Model 1	0.84 (0.74 – 0.96)	<.01				
Model 2			1.08 (0.99 – 1.19)	.10		
Model 3	0.83 (0.73 – 0.95)	<.01	1.10 (0.99 – 1.20)	.06		
Model 4	0.84 (0.74 – 0.95)	<.01	1.09 (0.99 – 1.20)	.06	0.97 (0.86 – 1.08)	0.56
Model 5	0.84 (0.74 – 0.96)	.01	1.09 (0.99 – 1.21)	.06	0.97 (0.87 – 1.09)	0.62
Model 6	0.87 (0.76 – 0.99)	.03	1.05 (0.95 – 1.17)	.06	1.00 (0.88 – 1.13)	0.98

Model 1 = baseline physical activity + base covariates (age, sex, education); Model 2 = baseline k_{RA} + base covariates; Model 3 = baseline physical activity + baseline k_{RA} + base covariates; Model 4 = baseline physical activity × baseline k_{RA} + base covariates; Model 5 = baseline physical activity × baseline k_{RA} + base covariates + vascular risk factors + vascular disease; Model 6 = baseline physical activity × baseline k_{RA} + base covariates + other comorbidites (cancer, Parkinson's disease, thyroid disease, BMI**,** and depression severity)

.06). When adding an interaction between physical activity levels and sleep fragmentation, the interaction was not significant (HR = 0.94, 95% CI = 0.77 – 1.14, p = .51). These results did not change when controlling for vascular health and other comorbidities.

2.4 Discussion

This study sought to understand how physical activity and sleep independently and interactively relate to cognitive functioning and dementia risk in older adults without dementia. Greater physical activity was associated with a slower cognitive decline, while sleep fragmentation was associated with worse baseline cognitive function but not with cognitive decline over time. Finally, physical activity, but not sleep, was associated with a reduced dementia risk. These results highlight that sleep and physical activity may have different and independent relationships with cognitive function, as well as may act on separate time scales.

Looking at the independent effects of sleep and physical activity, physical activity was associated with a slower rate of cognitive decline and reduced dementia risk, aligning with previous literature (Blondell et al., 2014; Iso-Markku et al., 2022; Sofi et al., 2011). In contrast, sleep fragmentation was not associated with cognition nor dementia risk, contradicting previous research from the same cohort (Lim et al., 2013). One critical difference between the present study and the prior study is that the follow-up period is longer. The present study had up to 17 follow-up visits, whereas Lim et al. (2013) had a maximum of six years of follow-up data. Thus, it is possible the predictive power of sleep fragmentation is time sensitive. In other words, a relationship between sleep and dementia risk may only exist when sleep fragmentation is measured close to the time of dementia onset. Given the pathological changes associated with dementia may precede clinical onset by decades, these results suggest sleep fragmentation may be an early indicator of dementia pathology rather than a risk factor. Future research should continue to investigate sleep as a biomarker for dementia (Blackman et al., 2022; Carpi et al., 2024; Winer et al., 2019, 2020).

We did not find an interaction between sleep and physical activity for cognitive function, neither longitudinally nor in relation to dementia risk, conflicting with prior cross-sectional studies (Kuhn & Heisz, 2022; Lambiase et al., 2014; Nakakubo et al., 2017; Sewell et al., 2023) and longitudinal studies (Bloomberg et al., 2023). Even when we explored cross-sectional associations (not included here), there was no interaction between sleep and physical activity on cognition. These conflicting results may be due to differences in assessments for cognitive function, sleep, or physical activity. For example, this study examined how physical activity and sleep related to decline in global cognition. In prior

studies, those looking at associations with global cognition (measured with the Mini-Mental State Exam) found no interaction (Lambiase et al., 2014; Nakakubo et al., 2017). In contrast, a significant interaction was observed for executive functioning (Lambiase et al., 2014; Nakakubo et al., 2017) and episodic memory (Kuhn & Heisz, 2022; Sewell et al., 2023), but not for verbal fluency (Lambiase et al., 2014; Nakakubo et al., 2017). Thus, the interactive effects of physical activity on sleep might be specific to certain cognitive domains and may not be observed in global cognition. These studies also used different metrics of sleep (sleep duration, sleep efficiency, number of nighttime awakenings, or subjective sleep quality) whereas the present study used the sleep fragmentation (k_{RA}). Sleep fragmentation factors in the temporal distribution of wakefulness following sleep, a consideration not captured by traditional actigraphy variables like sleep efficiency. Thus, differences cognitive measures, sleep metrics, or both may contribute to the inconsistencies in results.

An additional reason for conflicting results may be due to sample characteristics. Previous research has often been in community-dwelling older adults approximately 60 to 70 years of age, whereas the present study included older adults who were around 80 years of age who lived in retirement communities. Recent evidence shows that effects of physical activity and sleep duration on cognitive trajectory may vary with age (e.g., 50, 60, and 70 years of age (Bloomberg et al., 2023)). With this in mind, it is possible these differences may continue to change beyond 80 years of age. Further, the inclusion criteria for the present study were less restrictive than prior work, as the only eligibility criteria was consenting to tissue donation at the time of death and exclusion of those with known dementia at baseline. As much of the testing was done in-home, rather than in the lab, this may reduce the chances

of a “healthy volunteer” effect (Bennett et al., 2012; Lindsted et al., 1996). Thus, the combination of the advanced age and more variable health status of participants in the present study may explain why we did not find an interactive effect.

There are several strengths and limitations to this study. A strength of this sample is that the recruitment methods and in-home assessments capture more variability in health status (Bennett et al., 2012; Lindsted et al., 1996), as discussed above. However, one limitation is the sample was a volunteer-based, retirement community sample, composed mostly of women, which may limit the generalizability of the findings. A second limitation is the observational nature of this study makes it difficult to determine causality. A third limitation is that actigraphy is an ambulatory measure of sleep but does not directly measure sleep. It is possible long periods of non-sleep rest may erroneously be recorded as sleep. However, actigraphy has been shown to have good concordance with polysomnography (Cole et al., 1992), including the sleep fragmentation metric used in this study (Lim et al., 2013). Another strength is the physical activity metric looked at the most active 14 hours in a 24-hour period (from midnight to midnight), rather than total volume in a 24-hour period. This allowed us to capture activity during waking hours which would be less biased by any motor activity occurring during nighttime sleep. However, one limitation to this metric is that physical activity scores may be underestimated for individuals who were extremely phase-delayed and had their most active bout of activity after midnight. However, the relationships did not differ significantly when we used 12-hour or 16-hour windows.

2.5 Conclusion

Physical activity was associated with a slower rate of cognitive decline and decreased risk of developing dementia. In contrast, sleep fragmentation was associated with worse cognition but was not associated with cognitive trajectory. To better understand physical activity and sleep as risk factors for and biomarkers of dementia, future research should carefully try to disentangle how sleep and physical activity relate different cognitive domains, and whether these associations depend on time prior to dementia diagnosis.

Chapter 3: Study 2 – Investigating the role of habitual physical activity on sleep and cognition in people with dementia

3.1 Foreword

The results from Study 1 highlight that physical activity is associated with better cognitive function and may help to ward off dementia. However, better sleep quality was associated with better cognition at baseline but was not associated with cognitive change over time. It seems reasonable that physical activity should continue to provide benefits to cognition even after a dementia diagnosis. Yet, there has been relatively little investigation into the relationship between physical activity and cognitive trajectory over years after a diagnosis of dementia, as well as how physical activity relates to sleep during this time.

In addition, people with dementia, care partners, and health care professionals consistently rank functional independence as one of the most important outcomes for people with dementia (Wehrmann et al., 2021). As a result, the following study also investigates how physical activity and sleep are related to change in functional abilities as a secondary outcome. Thus, the goal of this chapter is to understand how habitual physical activity is associated with sleep, as well as how sleep and physical activity relate to cognition and functional abilities in people with dementia.

3.2 Introduction

Dementia is characterized as the presence of significant cognitive decline in one or more cognitive domains that is sufficient to interfere with daily functioning. It is important to support cognition and functional capabilities of people with dementia throughout their dementia journey. Although pharmaceuticals are a common approach to managing dementia

symptoms, their efficacy is mixed and comes with many adverse effects (Dyer et al., 2018). Promoting a healthy lifestyle might be one way to help support people with dementia. Two lifestyle factors worth further investigation are physical activity and sleep.

Growing evidence suggests physical activity interventions slow the rate of cognitive decline among people with and without dementia (Law et al., 2020) and improve ADLs (S. Zhou et al., 2022). In addition, physical activity interventions show promise in improving sleep in community-dwelling people with dementia (McCurry et al., 2011; Nascimento, Pereira, et al., 2014; Shih et al., 2020), although not all studies show benefits (Stella et al., 2011). Although physical activity is a promising tool to support the sleep and cognition of people with dementia, interventions have limited follow up times, often only a few months. The longitudinal effects of physical activity over multiple years remains relatively unexplored.

Similarly, sleep is critical for people with dementia. Sleep quality is associated with better functional abilities (Moe et al., 1995; Sinforiani et al., 2007; Tractenberg et al., 2003, 2005), greater quality of life (Petrovsky et al., 2018), and cognitive trajectory (Santacruz Escudero et al., 2019) in people with dementia. However, sleep disturbances are common in people with dementia (Guarnieri et al., 2012; Koren et al., 2023; McCurry et al., 1999; G. Zhou et al., 2019), which is associated with care partner stress (Ali & Bokharey, 2015; McCurry et al., 1999; Pollak & Perlick, 1998; Terum et al., 2017) and higher rates of institutionalization (Hope et al., 1998; Pollak & Perlick, 1998; Spira et al., 2012).

The present study sought to understand how physical activity is associated with change in sleep, cognition, and functional abilities in people with dementia. Further, we examined if

physical activity and sleep interact to modify the rate of cognitive decline. As a secondary outcome, we also examined the impact of physical activity and sleep on functional abilities (i.e., ADL/IADLs). There is emerging evidence that sleep and physical activity interact to support cognition in older adults without cognitive impairment (Kuhn & Heisz, 2022; Lambiase et al., 2014; Nakakubo et al., 2017; Sewell et al., 2023). However, these benefits are inconsistent, as they are observed for some cognitive domains such as executive functioning (Lambiase et al., 2014; Nakakubo et al., 2017) and episodic memory (Kuhn & Heisz, 2022; Sewell et al., 2023)), but not all (verbal fluency (Lambiase et al., 2014; Nakakubo et al., 2017)). In studies using data from the Rush Memory and Aging project, there were no interactions between physical activity and sleep in relation to global cognition in adults without dementia (see Study 1). It was hypothesized that people with dementia who were more physically active would have better sleep, cognitive functioning, and functional abilities over time. Additionally, fragmented sleep was hypothesized to be associated with worse cognitive functioning and functional abilities over time, with this effect being attenuated with greater physical activity.

3.3 Methods

3.3.1 Study sample

This is an analysis of secondary data from the Rush Memory and Ageing Project. The Rush Memory and Aging project is a longitudinal clinical-pathologic cohort study that has been ongoing since September 1997 (Bennett et al., 2005). Participants were recruited from retirement communities through northeast Illinois and were eligible if they were over 65 years of age without known dementia. Detailed methods are published elsewhere (Bennett et

al., 2005). Participants were included in the study if they agreed to undergo clinical evaluation, blood draws, and cognitive testing, as well as agreeing to organ donation upon death. Additionally, they had to be over the age of 65 without known dementia. Follow-ups visits were conducted annually. This study was approved by the Institutional Review Board of Rush University Medical Center, and from the University of Waterloo Research Ethics Board (ORE #46680). Written informed consent was provided by all participants.

To be eligible for the current analysis, participants must have been free of (known or unknown) dementia at baseline but be classified as having dementia at subsequent assessments, according to the diagnostic criteria of the study. A total of 357 participants developed dementia (including Alzheimer's disease and other dementias) during their participation in the Rush Memory and Aging Project. The year when they screened positive for dementia was considered their baseline for these analyses. Participants were included in the current analysis if they also had their sleep and movement tracked with an Actical in 15-second time intervals (i.e., epochs) and cogntion assessed at either adjusted baseline or the year prior. A final sample of 127 were included in the study.

3.3.2 Primary measures

3.3.2.1 Actigraphy

From 2005 to 2018, the Actical activity monitor was used for actigraphy recordings (Actical, Philips Respironics; Bend, OR). The Actical uses omnidirectional accelerometers to track the degree of acceleration. Participants wore the Actical device on their non-dominant wrist for 24 hours per day for 10 consecutive days. The device records movement in one second samples and then summates these samples into 15-second epochs, with higher counts

representing greater levels of activity. As other actigraph models were introduced in 2018, measurements using these devices were not included in this analysis due to probable differences across models. Data from the Actical was used to create objective measures of sleep fragmentation and physical activity. 'Baseline' Actical could be collected at the adjusted baseline (year when the participant was classified with dementia) or the year before, in order to increase sample size but still have reasonable windows for data collection.

3.3.2.1.1 Sleep fragmentation

Sleep fragmentation was estimated using the k_{RA} index, which is the probability of transitioning into a state of activity following a period of rest (Lim et al., 2011). The k_{RA} index is calculated over the entire 24-hour day. A high k_{RA} indicates highly fragmented sleep, as this means the participant has a greater probability of transitioning from a period of rest to activity. See Study 1 for further details.

3.3.2.1.2 Physical activity

The most active 14 hours in a 24-hour period (00:00 to 23:59) was used as a marker of daily physical activity. Participants were required to wear the device for at least two full days, and periods that did not have data for the full 24-hour window were not included. Average daily physical activity was calculated by taking the average activity counts within the most active 14-hour window for each day and averaging it across all days the Actical was worn. Physical activity intensity bouts were not calculated, due to lack of validation studies people with dementia using an Actical device.

3.3.2.2 Global cognition

Cognition was assessed using 19 different cognitive tests across five cognitive domains (episodic memory, semantic memory, working memory, perceptual speed, and visuospatial abilities) and scored by a computer. Composite scores for each domain were calculated by converting each test into a z-score and taking the average. The average across the 19 tests were used to calculate a global cognitive z-score, which correspond to the average of the entire cohort at baseline. For details, see Bennett et al. (2005). In the present sample, out of 591 participant visits, 78 (13.2%) were missing a global cognition score.

3.3.2.3 Dementia diagnosis

Dementia was diagnosed according to the National Institute of Neurological and Communicative Disorders and Stroke–Alzheimer's Disease and Related Disorders Association criteria using a combination of computer scoring and clinician evaluation (Bennett et al. 2006). The computer scoring was the outcome of a decision tree which simulates clinical judgment and a rating of severity of impairment. The cognitive and clinical information was reviewed by a clinician who made a final diagnosis. Participants were either diagnosed as no cognitive impairment, MCI, Alzheimer's dementia (with or without other contributing conditions), or other dementia.

3.3.2.4 Functional abilities

Basic ADLs were measured using the Katz Activities of Daily Living Scale (Katz & Akpom, 1976). This scale measures six basic physical abilities (walking across a small room, bathing, dressing, eating, getting from bed to chair, and toileting). Participants reported their need for help or assistance in performing these tasks, with responses categorized and coded

into no help (0) and requires some help or unable to do (1). A composite score was calculated by taking the sum of their responses, with scores ranging from 0 to 6. A higher score indicates poorer functional ability.

IADLs were assessed using the Lawton and Brody IADL scale (Lawton & Brody, 1969). This scale measures eight IADLs required for independent living (telephone use, meal preparation, light housekeeping, heavy housekeeping, handling medications, handling finances, traveling within the community, and shopping). Participants reported their need for help or assistance in performing these tasks, with responses categorized into no help (0) or requires some help or unable to do (1). A composite score was calculated by taking the sum of their responses, with scores ranging from 0 to 8. A higher score indicates poorer functional abilities.

3.3.3 Descriptive characteristics and covariates

Participants self-reported their age, sex, years of education, presence of vascular risk factors (hypertension, diabetes, smoking history), presence of vascular diseases (myocardial infarction, congestive heart failure, claudication, stroke), and presence of other comorbidities (thyroid disease, cancer). A clinician screened for Parkinson's disease by reviewing participant self-reported questions, neurological exams (if available), cognitive testing, and interviewing the participant. Depressive symptoms were assessed using the CESD-10 scale (Radloff, 1977). A trained technician measured weight and height to determine BMI.

3.3.4 Statistical analysis

Participant characteristics were described as mean (standard deviation) or number (percent), as appropriate. Physical activity and sleep fragmentation (k_{RA}) were normalized by

centring at the mean and scaled according to standard deviation from the mean to create a z-score for each variable.

The adjusted baseline for the purpose of these analyses was the year when the participant was classified as having dementia. 'Baseline' actigraphy for the purpose of physical activity and sleep measures could be collected at adjusted baseline or the year before. Multilevel linear equations were used to examine how: 1) baseline physical activity levels were related to change in sleep fragmentation over time, 2) baseline physical activity and sleep fragmentation were associated with change in cognitive function over time, and 3) adjusted baseline physical activity and sleep fragmentation were associated with change in ADLs and IADLs over time among people with dementia. These models included subject-specific random effects for slope and intercept. Adjusted baseline physical activity, sleep, and other covariates were included as fixed effects. A continuous autoregressive covariance structure was selected, as it uses a autocorrelation structure with a continuous time covariate (Pinheiro et al., 2023).

For all analyses, the base model included age at adjusted baseline, sex, and education as covariates. Model 1 looked at the independent effect of sleep fragmentation., while Model 2 looked at the independent effect of physical activity. Model 3 looked at the independent effects of sleep fragmentation and physical activity, with Model 4 adding an interaction term between sleep fragmetnation and physical activity. Additional covariates were added in two clusters independent of each other. The first cluster included variables relating to vascular health at adjusted baseline and was composed of vascular risk factors (sum of yes (1) or no (0) to having hypertension, diabetes, smoking history) and the presence of vascular disease

(sum of yes (1) or no (0) to having myocardial infarction, congestive heart failure, claudication, stroke). The second cluster included the presence of additional comorbidities (yes (1) or no (0) to having cancer, Parkinson's disease, thyroid disease), BMI, and depressive symptoms at adjusted baseline.

3.4 Results

3.4.1 Participant characteristics

Characteristics of the 127 participants are displayed in Table 5. Participants were followed for an average of 3.57 years (SD 2.23, range 1 – 11, 29 with missing follow up visits) after diagnosis. The majority of participants were women and had Alzheimer's dementia with no other contributing conditions. Additionally, 115 (90.6%) of participants had died since their diagnosis.

114 participants had a negative change in their cognitive score between the time of their dementia diagnosis and last global cognitive score (mean change in global cognition z-scores: -0.79, SD 0.75, range -2.60 – 0.95). Participants had on average 8.08 days of actigraphy recording (SD 0.60). During the most active 14 hours, the daily average activity count was 150.1 counts*min^{-1} (SD 108.0, range 7.47 – 446.2) during their most active 14 hours. Participants had a k_{RA} index (sleep fragmentation) of 0.026 (SD = 0.008; range = 0.014 – 0.068).

Table 5. Characteristics of study participants at year of dementia diagnosis (*n* = 127)

Characteristics	Mean (SD) or N (%)
Age, years	88.7 (6.27)
Sex, female	98 (77.2%)
Education, years	14.9 (3.2)
Katz ADL Scale, /6	1.2 (1.7)
IADL Scale, /8	3.9 (2.6)
Dementia diagnosis	
Alzheimer's dementia, no other conditions contributing to CI	111 (87.4%)
Alzheimer's dementia, with other conditions contributing to CI	6 (4.7%)
Other dementias	10 (7.9%)
Body mass index (kg/m^2, at baseline)	25.3 (4.2)
MMSE Score, /30	21.2 (3.7)
Composite global cognition, z-score	-1.2 (0.5)
Depressive Symptoms (CESD-10), /10	1.6 (2.1)
Vascular risk factors	
Hypertension	75 (59.1%)
Diabetes Mellitus	13 (10.2%)
Smoking	42 (33.1%)
Vascular disease	
Myocardial infarction	16 (12.6%)
Congestive Heart Failure	6 (4.7%)
Claudication	35 (27.6%)
Stroke	18 (14.2 %)

ADL = activities of daily living, IADL = instrumental activities of daily living; CI = cognitive impairment; MMSE = mini mental state examination; CESD-10= Center for Epidemiological Studies-Depression 10-item

3.4.2 The associations between sleep fragmentation and physical activity

Physical activity was not significantly associated with sleep fragmentation (k_{RA}) as a main effect (Beta Estimate = 0.01; 95% CI = 0.11 – 0.42; p = .87). There was no significant interaction between physical activity and time (Estimate = -0.03; 95% CI = -0.15 – 0.03; p = .20). Of note, sleep fragmentation was significantly associated with time (Estimate = -0.28; 95% CI = -0.32– -0.24; p <.001), suggesting sleep became less fragmented with time. Statistical significance of these associations did not change when adding vascular factors or other comorbidities, and the magnitude of the relationship did not change by more than 20%.

3.4.3 The associations between physical activity, sleep fragmentation and global cognition

Without physical activity in the model, sleep fragmentation alone was not associated with global cognition as a main effect (Estimate = -0.05; 95% CI = -0.14 – 0.04; p = .27), nor was its interaction with time (Estimate = -0.02; 95% CI = -0.06 – 0.03; p = .49). Without sleep fragmentation in the model, physical activity was not associated cognitive function as a main effect (Estimate = 0.01; 95% CI = -0.09 – 0.10; p = .87) or in interaction with time (Estimate: -0.03; 95% CI = -0.07 – 0.01; p =.20).

When both physical activity and sleep fragmentation were included in the model, the main effect of sleep fragmentation was not associated with cognition (Main effect: Estimate = -0.06; 95% CI = -0.15 – 0.04; p = .23), nor was the interaction with time (Interaction: Estimate = -0.01; 95% CI = -0.05 – 0.04; p = .75). Neither the main effect of physical activity nor its interaction with time were associated with cognition (Main effect: Estimate = 0.02; 95% CI = -0.074 – 0.12; p = .64; Interaction: Estimate = -0.03; 95% CI = 0.07 – 0.02; p = .25).

In a final model with an interaction term between sleep fragmentation and physical activity, the interaction between sleep and physical activity was not significant (Estimate = -0.002; 95% CI = -0.08 – 0.08; p = .70), nor was the three-way interaction with time (Estimate = -0.01; 95% CI = -0.05 – 0.03; p = .68). Neither the statistical significance of these relationships nor the magnitude of the relationships changed when factoring in vascular health and other comorbidities. See Table 6 for a summary of the results.

Table 6. Sleep fragmentation, physical activity, and the rate of cognitive decline in people with dementia.

	Model 1			Model 2			Model 3			Model 4		
	b (95% CI)	p	R^2	b (95% CI)	p	R^2	b (95% CI)	p	R^2	b (95% CI)	p	R^2
			.77			.77			.77			.77
Time	-0.28 (-0.33 – -0.24)	<.001		-0.28 (-0.33 – -0.24)	<.0001		-0.28 (-0.33 – -0.24)	<.001		-0.28 (-0.33 – -0.24)	<.001	
Sleep fragmentation	-0.05 -0.14 – 0.04)	.27					-0.05 (-0.15 – 0.04)	.23		-0.06 (-0.15 – -0.04)	.63	
Time × sleep fragmentation	-0.02 (-0.06 – 0.03)	.49					-0.01 (-0.05– 0.04)	.75		-0.004 (-0.06 – 0.04)	.85	
Physical activity				-0.01 (-0.09 – 0.10)	.87		0.02 (-0.07 – 0.12)	.64		0.02 (-0.06 – 0.04)	.65	
Time × physical activity				-0.03 (-0.07 – 0.01)	.20		-0.03 (-0.07 – 0.032)	.25		-0.02 (-0.08 – 0.12)	.28	
Sleep fragmentation × physical activity										-0.002 (-0.08 – 0.08)	.96	
Time × sleep fragmentation × physical activity										-0.01 (-0.05 – 0.03)	.68	

All models control for age at diagnosis, sex, and education.

3.4.4 The associations between physical activity, sleep fragmentation and ADLs

Sleep fragmentation alone was not associated with ADLs either as a main effect nor in interaction with time (Main effect: Estimate = 0.15; 95% CI = -0.13 – 0.43; p = .30; Interaction: Estimate = -0.46; 95% CI = -0.14 – 0.05; p = .32). In contrast, physical activity was associated with better ADLs as a main effect (Estimate: -0.41; 95% CI = -0.69 – -0.12; p = .01) but its interaction with time was not (Estimate: -0.02 95% CI = -0.10 – 0.074; p = .75), when sleep fragmentation was excluded in the model.

When both were included independently in the same model, the main effect of physical activity continued to be associated with ADLs, but not its interaction with time (Main effect: Estimate: -0.48; 95% CI = -0.78 – -0.19; p =.002; Interaction: Estimate: 0.001; 95% CI = -0.091 – 0.09; p =.98). In contrast, sleep fragmentation was not associated with ADLs either as a main effect or in interaction with time (Main effect: Estimate = 0.27; 95% CI = -0.02 – 0.55; p =.07; Interaction: Estimate = -0.05; 95% CI = -0.14 – 0.04; p = .29).

In a final model with an interaction term between sleep fragmentation and physical activity, there was no significant interaction between sleep fragmentation and physical activity (Estimate = -0.03; 95% CI = -0.28 – 0.22; p = .81), nor was there a three-way interaction with time (Estimate = -0.05; 95% CI = -0.12 – 0.03; p = .26). Neither the statistical significance of these relationships nor the magnitude of the relationships changed when factoring in vascular health and other comorbidities. See Table 7 for a summary of the results.

Table 7. Sleep fragmentation, physical activity, and ADL trajectory in people with dementia.

	Model 1			Model 2			Model 3			Model 4		
	b (95% CI)	p	R^2	b (95% CI)	p	R^2	b (95% CI)	p	R^2	b (95% CI)	p	R^2
			.62			.64			.64			.64
Time	0.56 (0.46 – 0.66)	<.001		0.58 (0.48 – 0.68)	<.001		0.58 (0.47 – 0.68)	<.001		0.58 (0.48 – 0.69)	<.001	
k_{RA}	0.15 (-0.13 – 0.43)	.65					0.27 (-0.02 – 0.55)	.07		0.26 (-0.03 – 0.55)	.08	
Time × sleep fragmentation	-0.43 (-0.14 – 0.05)	.33					-0.05 (-0.14 – 0.04)	.29		-0.04 (-0.14 – 0.05)	.96	
Physical activity				-0.41 (-0.69 – -0.12)	.01		-0.48 (-0.78 – -0.19)	.001		-0.47 (-0.77 – -0.17)	.002	
Time × physical activity				-0.02 (-0.10 – 0.074)	.75		-0.001 (-0.091 – 0.09)	.98		-0.003 (-0.09 – 0.09)	.37	
Sleep fragmentation × physical activity										-0.03 (-0.28 – 0.22)	.81	
Time × sleep fragmentation × physical activity										-0.04 (-0.12– 0.03)	.26	

All models control for age at diagnosis, sex, and education.

3.4.5 The associations between physical activity, sleep fragmentation and IADLs

When excluding physical activity from the model, sleep fragmentation was not significantly associated with IADLs as main effect or as an interaction with time (Main effect: Estimate = 0.17; 95% CI = -0.21 – 0.54; p = .38; Interaction: Estimate = -0.02; 95% CI = -0.09 – 0.12; p = .74). Similar to ADLs, physical activity was associated with better IADLs as a main effect but its interaction with time was not (Estimate: -0.53; 95% CI = -0.91 – -0.15; p = .01; Estimate: 0.07; 95% CI = -0.03 – 0.17; p = .18), when sleep fragmentation in the model was excluded. When both were included independently in the model, the main effect of physical activity continued to be associated with IADLs but not its interaction with time (Main effect: Estimate: -0.62; 95% CI = -1.01 – -0.23; p =.002; Interaction: Estimate: 0.07; 95% CI = -0.03 – 0.17; p =.17). Sleep fragmentation was not associated with IADLs as main effect nor as an interaction with time (Main effect: Estimate = 0.32; 95% CI = -0.05 – 0.70; p =.09; Interaction: Estimate = -0.03; 95% CI = -0.11 – 0.10; p = .17). In a final model with an interaction term between sleep fragmentation, physical activity, and time, there was no significant interaction between sleep fragmentation and physical activity (Estimate = -0.10; 95% CI = -0.43 – 0.22; p = .54), or in a three-way interaction with time (Estimate = -0.03; 95% CI = -0.06 – 0.12; p = .55). The statistical significance nor the magnitude of the relationships did not change when factoring vascular health and other comorbidities. See Table 8 for a summary of results.

Table 8. Sleep fragmentation, physical activity, and IADL trajectory in people with dementia.

	Model 1			Model 2			Model 3			Model 4		
	b (95% CI)	p	R^2	b (95% CI)	p	R^2	b (95% CI)	p	R^2	b (95% CI)	p	R^2
			.66			.66			.66			.66
Time	0.62 (0.51 – 0.73)	<.001		0.62 (0.52 – 0.75)	<.001		0.63 (0.52 – 0.75)	<.001		0.62 (0.51 – 0.74)	<.001	
Sleep fragmentation	0.17 (-0.21 – 0.54)	.38					0.32 (-0.05 – 0.70)	.09		0.34 (-0.04 – 0.72)	.08	
Time × sleep fragmentation	-0.02 (-0.09 – 0.12)	.74					-0.03 (-0.11 – 0.10)	.96		-0.01 (-0.1w – 0.10)	.87	
Physical activity				-0.53 (-0.91 – -0.15)	.01		-0.62 (-1.01 – -0.23)	.002		-0.60 (-0.99 – -0.20)	.003	
Time × physical activity				0.07 (-0.03 – 0.17)	.19		0.07 (-0.03 – 0.17)	.17		0.07 (-0.03 – 0.10)	.18	
Sleep fragmentation × physical activity										-0.10 (-0.43 – 0.22)	.54	
Time × sleep fragmentation × physical activity										-0.03 (-0.06 – 0.12)	.55	

All models control for age at diagnosis, sex, and education.

3.5 Discussion

We examined how physical activity and sleep were associated with cognitive and functional abilities among people with dementia. In this sample, physical activity was not associated with fragmented sleep. Neither sleep fragmentation nor physical activity were associated with cognition and cognitive trajectory. However, physical activity was associated with better functional abilities (ADLs, IADLs) but not change in functional abilities over time. Although nearing significance, sleep fragmentation was not associated with functional abilities. These results suggest physical activity may support functional abilities in people with dementia, but neither sleep nor physical activity seems to impact cognitive functioning.

In this study, physical activity was not associated with sleep at dementia onset. This contradicts previous studies in cognitively healthy adults that suggests physical activity is associated with better sleep quality (Alnawwar et al., 2023; Kredlow et al., 2015; Kubitz et al., 1996), and intervention studies which find that physical activity improves sleep in people with dementia (McCurry et al., 2011; Nascimento, Pereira, et al., 2014; Shih et al., 2020). Similarly, our results with sleep fragmentation contradict previous studies showing sleep is associated with cognitive trajectory (Santacruz Escudero et al., 2019) and functional abilities (Moe et al., 1995; Tractenberg et al., 2005), although the latter neared significance.

In this study, actigraphy was used to measure both sleep fragmentation and physical activity, which may partially explain the lack of association between physical activity and sleep. Although actigraphy has high sensitivity in detecting periods of sleep (Cole et al., 1992), it has low specificity to detecting periods of wakefulness (Slater et al., 2015), especially in older adults with insomnia (Sivertsen et al., 2006). The sleep fragmentation metric used in this study (k_{RA}) relies on actigraphy and represents the probability of

transitioning from sleep to waking (Lim et al., 2011), but people with dementia in long-term care homes spend much of their day being sedentary (Alphen et al., 2016). Thus, it is possible the actigraphs erroneously measured sedentary periods of wakefulness with little movement as sleep, confounding the relationship between physical activity and sleep.

Further, physical activity was not associated with slower cognitive decline or the trajectory of functional abilities, contradicting intervention studies which find improved cognitive and functional outcomes with exercise interventions (Balbim et al., 2022; Law et al., 2020; S. Zhou et al., 2022), but aligning with the results found in Study 1. Why physical activity was not associated with cognition or functional abilities here is unclear but there are several possible reasons. It is possible that participants were not engaging in enough physical activity to confer benefits. People with dementia in this sample were significantly less active than the participants in Study 1 (calculated post hoc using Welch's T-test, $t(191) = 13.1$, $p < .001$), whereas exercise interventions are usually close to meeting the physical activity guidelines for older adults (Balbim et al., 2022; Ross et al., 2020). Additionally, the older adults in the present sample tended to be older than most epidemiological studies (e.g., the *Canadian Longitudinal Study on Aging* (Raina et al., 2009), the *Osteoporotic Fractures in Men* study (Orwoll et al., 2005)). As aging is associated with decreased neuroplasticity and physiological adaptability in older adults without cognitive impairment (Marzola et al., 2023; Strasser et al., 2021), their brains may be less capable of neuroplasticity to benefit from exercise.

3.5.1 Strength and limitations

There are several strengths and limitations to this study. A strength of this sample is the inclusion criteria for this cohort is relatively less restrictive than other studies. Since participants were in retirement communities and assessments were completed in-home, this may reduce the chances of a "healthy volunteer" effect and may capture more variability in health status (Bennett et al., 2012; Lindsted et al., 1996). One limitation was that a considerable number of participants did not have actigraphy data at the time of diagnosis, which resulted in a small sample size and reduced power for these analyses. As several *p*-values hovered around significance, a larger sample size would allow for greater confidence in whether sleep or physical activity are truly related to cognition or functional abilities. Another limitation is that the residential status of the participants was unknown, which could impact the physical activity and sleep opportunities available across individuals. Although all participants were living in retirement communities, the level of care varied from independent living to skilled nursing care (Bennett et al., 2005). People in long-term care often have lower physical activity (Alphen et al., 2016) and different environmental determinants of sleep (Ye & Richards, 2018). Finally, the study design limits causality and generalizability, as this was an observational study conducted in a volunteer-based, predominately women sample.

The use of actigraphy has several strengths and limitations to use. One strength of activity metric is that it is more likely to capture daytime, waking activity than measures which cover an entire 24-hour period. To confirm our results weren't a reflection of the 14-hour window we chose, we verified the results using 12- and 16-hour windows, yielding similar results. One major limitation is that there has been a lack of validation studies in

persons with dementia. Some recent trials have elected to remove actigraphy from their outcome measure due to low compliance and lack of validity (Livingston et al., 2019; Rapaport et al., 2024). Additionally, the physical activity metric looked at the most active 14 hours between midnight and midnight, which may underestimate physical activity in extremely phase-delayed individuals who have their activity bouts continue past midnight. Finally, actigraphy infers sleep through bodily movements, and may erroneously infer period of rest and stillness as sleep. However, actigraphy tends to have good concordance with the gold-standard measure of sleep, polysomnography (Cole et al., 1992), as does the sleep fragmentation metric used (Lim et al., 2013).

3.6 Conclusion

We sought to understand how physical activity and sleep were associated with cognitive function and functional ability over the dementia journey. We found that physical activity was associated with better physical functioning but not with sleep nor cognition. Sleep fragmentation was not associated with either cognition or physical functioning. Although these results contradict previous literature, it highlights the need for further research to understand how physical activity may influence sleep, cognition, and functional abilities, probing issues of age and dose.

Chapter 4: Study 3 – Barriers and facilitators to physical activity participation in people with dementia and their care partners during Canadian winters

4.1 Foreword

Despite the results above and the need for further exploration, physical activity is generally considered important for the health and well-being of people with dementia and for sleep promotion. Interventions using exercise show improvements in sleep (Páez et al., 2024), as do multi-modal lifestyle interventions using exercise (O'Caoimh et al., 2019). One such sleep intervention is the NITE-AD program (McCurry et al., 2005, 2011), which used physical activity (preferably outdoors) in combination with light therapy and education and observed improvements in sleep quality. However, interventions advocating for exercise outdoors can be challenging in climates with cold, icy, and/or snowy weather, which includes much of Canada for a large portion of the year. Researchers designing interventions that are feasible and acceptable in practice need to understand and accommodate seasonal variance.

While physical activity declines in the winter (McCormack et al., 2010; Moschny et al., 2011; Tucker & Gilliland, 2007; Welch et al., 2018), especially in geographies with ice and snow, there is little research to understand the barriers, facilitators, and experiences of winter physical activity, especially among people with dementia and their care partners. Study 3 will examine the lived experiences of people with dementia and their care partners when trying to engage in physical activity during the wintertime. The focus will be on what the barriers are preventing them from being active, and which facilitators support their ability to engage in winter exercise.

After understanding the winter needs of people with dementia, we then sought to tailor the NITE-AD program for the Canadian context. This process is outlined in Study 4. To tailor the intervention, we formed an advisory team to provide insights from lived expertise of dementia and dementia program delivery. Using the results of Study 3 and the expertise of the advisory team, we made several changes to the NITE-AD program.

4.2 Introduction

Physical activity has broad benefits for people with dementia. Benefits include increased independence in ADLs and better cognitive functioning in people with dementia and MCI (Farina et al., 2014; Forbes et al., 2015; Groot et al., 2016; Law et al., 2020; S. Zhou et al., 2022). Additionally, physical activity reduces the risk of falls, the number of falls, depressive symptoms, and personal expressions (Demurtas et al., 2020) of people with dementia.

Outdoor walking is a form of physical activity that is enjoyable and meaningful to people with dementia (Cedervall et al., 2015; Cedervall & Åberg, 2010; Hobson et al., 2020; McDuff & Phinney, 2015). Preliminary research suggests that outdoor physical activity may have greater benefits to mood and stress than indoor physical activity (Brito et al., 2022). However, walking and physical activity can be supported or hindered by the physical environment. Good weather has been identified as a facilitator to physical activity (Karssemeijer et al., 2020) and poor weather (e.g., rain, snow or cold) as a barrier to physical activity among people with dementia (Chong et al., 2014; Malthouse & Fox, 2014; McDuff & Phinney, 2015; Suttanon et al., 2012).

There is limited research exploring the nuances of weather and its impact on physical activity among people with dementia, particularly in climates with cold and harsh winters. In general adult populations, people tend to be more physically active during the summers compared to the winters (McCormack et al., 2010; Moschny et al., 2011; Tucker & Gilliland, 2007; Welch et al., 2018), likely due to longer day light hours and warmer temperatures (Klenk et al., 2012; Tucker & Gilliland, 2007; Welch et al., 2018). However, there is a parabolic association between temperature and physical activity. People increase physical activity with increasing temperature, but only to a point where it eventually becomes "too hot" and physical activity subsequently decreases (Ermagun et al., 2018; Tucker & Gilliland, 2007; Watanabe et al., 2005).

When examining specific weather conditions, people often cite rain and wind as factors that can restrict physical activity (Chan et al., 2006; Chan & Ryan, 2009; Ermagun et al., 2018). Some studies in southern Ontario and Michigan suggest snow or ice may be more detrimental than cold weather for impeding physical activity (Jones et al., 2017; Y. Li et al., 2012; Wagner et al., 2019). In Toronto, Li et al. (2012) found poor walking conditions on sidewalks—particularly ramped sidewalks where water can pool to form ice sheets—making it difficult for people to walk, especially for older adults. In contrast, another Canadian study found that snowfall increased physical activity among lean, middle-aged men, likely due to engaging in snow removal activities (Chan et al., 2006). Importantly, these studies involved the general population and did not focus on older adults or people with dementia.

Winter weather does not always have to be a barrier to physical activity. In a naturalistic experiment in Manitoba, Canada, a local, frozen waterway was converted into a 10

kilometer, multi-use winter trail system (McGavock et al., 2019). Over two winters, an estimated 200,000-250,000 visitors walked along the frozen network. A subset of trail users agreed to wear a waist-mounted pedometer (N = 218; n = 13 were 65+ year of age, n = 77 were 45-64 years of age). Of this sub-sample, 90% used this trail for over 30 minutes per use, and nearly one-third were engaging in enough moderate-to-vigorous physical activity to achieve health benefits (McGavock et al., 2019). Critically, the daily temperatures averaged -13˚C to -17˚C, demonstrating that cold temperatures do not necessarily prevent engagement in physical activity and that environmental restructuring can help facilitate physical activity.

Little research has explored the experiences and perceptions of winter physical activity in people with dementia. It is possible that people with dementia may experience additional challenges to physical activity in the winter, as they are more likely to fall (Allan et al., 2009). Therefore, icy or uneven sidewalks due to packed snow may make it challenging to walk around the community. In addition, navigational challenges may be accentuated in a winter landscape as familiar landmarks, a navigational tool used by people with dementia (Sheehan et al., 2006), may look different or be obscured in the snow.

The relationship between winter weather and physical activity is likely complex, region specific, and dependent on age and ability. The specific barriers and facilitators to physical activity among people with dementia during the winter remain unexplored. Understanding how people with dementia adapt to winter conditions is important to promoting physical activity both alone and as a component within broader lifestyle interventions. Additionally, as care partners are major facilitators and motivators for people with dementia to engage in physical activity (Hobson et al., 2020), it is important to understand the perspectives of care

partners as well. This study investigated the barriers and facilitators to physical activity in people with dementia and care partners during Canadian winters.

4.3 Methods

4.3.1 Study design

This study used a qualitative descriptive design to examine the barriers and facilitators to engaging in physical activity during the winter in both people with dementia and care partners. A qualitative descriptive design was chosen to deepen and advance our understanding of this topic, while providing straightforward descriptions of the experiences and perceptions of people with dementia and their care partners (Doyle et al., 2020; Sandelowski, 2000).

4.3.2 Participants

Participants were recruited from throughout Canada, excluding areas that rarely experience snow or ice during the winter months (e.g., Vancouver, Abbotsford and Victoria, British Columbia). People with dementia and care partners were eligible to participate together or on their own. Eligibility criteria for people with dementia included: 1) self-identified as a person with dementia or MCI; 2) community-dwelling; 3) above the age of 55; 4) sufficient cognitive capacity to read and understand the consent process and consent on their own behalf; and 5) able to speak and understand English. Eligibility criteria for care partners included: 1) self-identifying as a primary care partner for a person with dementia or MCI; 2) community-dwelling; 3) do not identify as someone with dementia; and 4) able to speak and understand English.

We aimed to recruit a convenience sample of 6 to 10 participants, with a roughly equal distribution of participants in each group (i.e., people with dementia and care partners), as Braun and Clarke (2013) suggest that a sample size of 6 to 10 is sufficient for a small project or dissertation. Participants were recruited through various channels including social media platforms (such as Facebook, Instagram, and Twitter), word of mouth, and advertisements in memory and aging groups, such as the Alzheimer's Society of Canada, Dementia Connections, and memory clinics. All participants gave verbal consent prior to their participation. This study received ethics clearance from the University of Waterloo Research Ethics Board (ORE #44166).

4.3.3 Procedure

Participants were asked to complete a demographic survey followed by a semi-structured interview (Appendices B & C for people with dementia; Appendices D & E for care partners). The demographic survey and interview were completed during a single session, which took place in the mid to late winter or early spring of 2022 and 2023. Data collection was deliberately done at those times so participants could reflect on their current or recent experiences with winter physical activity without having to recall too far in the past.

The demographic survey was used to gather information on age, gender, residential status (private home/apartment/room, seniors residence, other), marital status (single/never married, married/common law, widowed, divorced, separated, other), education (high school, university or college degree, trade certificate or diploma, post-graduate degree), presence of health conditions which may impact physical activity participation (heart disease, chronic back pain, knee injury, hip injury, arthritis, other), use of mobility aides (no, yes, if yes what

kind), and type of dementia. The survey was administered by the student investigator (TK) to the participants.

The semi-structured interview immediately followed the demographic survey and explored the participants' experiences engaging in physical activity in the winter, focusing on the barriers and facilitators to being active. Interviews took place over Zoom. While participants could video call or phone into a Zoom meeting, all participants chose to participate via video call. For participants who enrolled as dyads, interviews were done either individually or with both members of the dyad, based on participants' preferences.

4.3.4 Analyses

Deductive content analysis was used to examine the barriers and facilitators to winter physical activity (Hsieh & Shannon, 2005). Deductive content analyses are used to extend the application of a theoretical framework (Elo & Kyngäs, 2008; Hsieh & Shannon, 2005) — in this case, the COM-B model for behavior change (Michie et al., 2011). The COM-B model is a framework for classifying the determinants of behaviour to inform interventions and includes factors that influence behaviour within three categories: capability (physical and psychological), opportunity (social and physical), and motivation (automatic and reflective).

The interviews were transcribed from the audio recordings, first using *OtterAI* software (mean interview length (42.5 ± 27min)). The student investigator then listened to the audio recordings and confirmed that the transcripts were accurate, correcting as needed. The student investigator then read the transcribed interview data several times to immerse themselves in the raw data and develop familiarity with responses.

With the COM-B model in mind, the data were highlighted and coded in meaningful units (word, phrase, or a sentence or two) using *NVivo* software. A second coder (LM) coded two transcripts and met with TK to discuss the codes. There was general agreement between the coders, so TK coded the remaining manuscripts independently. Codes were iteratively reviewed and refined with the research team (LM and CM). The final codes were categorized within the COM-B framework (Michie et al., 2011). After developing the codes, they were reviewed and sorted into categories to help with organization and interpretation. Categories were iteratively evolved by the research team until all members agreed that the categories were distinct and coherent representation of the data.

A variety of processes were taken to ensure the rigor and trustworthiness of the study (Graneheim & Lundman, 2004; Shenton, 2004; Stahl & King, 2020). Member checks were completed during the interviews by paraphrasing the interviewee's responses to confirm the interpretation was accurate. Additionally, opportunities for peer/mentor scrutiny were pursued by seeking feedback from research team members. Further, an audit trail was established by preserving the verbatim transcriptions of the interviews. Finally, all stages of the study were clearly documented, including information regarding the study setting, research methods, data collected, and a comprehensive account of decision-making and research findings.

4.4 Findings

4.4.1 Participant characteristics

Four people with dementia and five care partners completed the interviews. Of these participants, there were two dyads who completed the interviews together, while two people

with dementia and three care partners participated alone. Participant characteristics are detailed in Table 9.

4.4.2 Barriers and facilitators to winter physical activity

One core category, *individual attitudes shape the impact of winter on physical activity*, and two categories *winter conditions exacerbate barriers to physical activity* and *resources and social support influence winter physical activity for people with dementia* describe the barriers and facilitators to physical activity among people with dementia and care partners during the winter (Figure 5). The following text provides a narrative of the concepts within each category and how they are connected.

Table 9. Participant characteristics (mean ± standard deviation or *n*)

Characteristics	People with dementia	Care partners
N	4	5
Age in years (Mean ± SD)	79 ± 2.8	64.4 ± 9.0
Women (*n*)	1	5
Relationship to person with dementia (*n*)		
Spouse	-	3
Adult child	-	2
Education (*n*)		
High-school or lower	1	0
University or college degree	1	1
Trade certificate	1	1
Post-graduate degree	1	3
Province of Residence (*n*)		
Alberta	0	1
New Brunswick	1	1
Ontario	2	1
Saskatchewan	1	2
Urban area (*n*)	3	3
Dementia type (*n*)		
Young-onset dementia	1	1
Alzheimer's dementia	1	2
Mixed (Vascular and Alzheimer's)	1	2
Not specified	1	0

In addition, the role of care partners is interwoven throughout all the categories. Care partners were the primary supporters of the person with dementia to engage in physical activity. Care partners were often the person who provided support for and adapted physical activity, managed schedules, and assisted with clothing, gear or equipment for the person

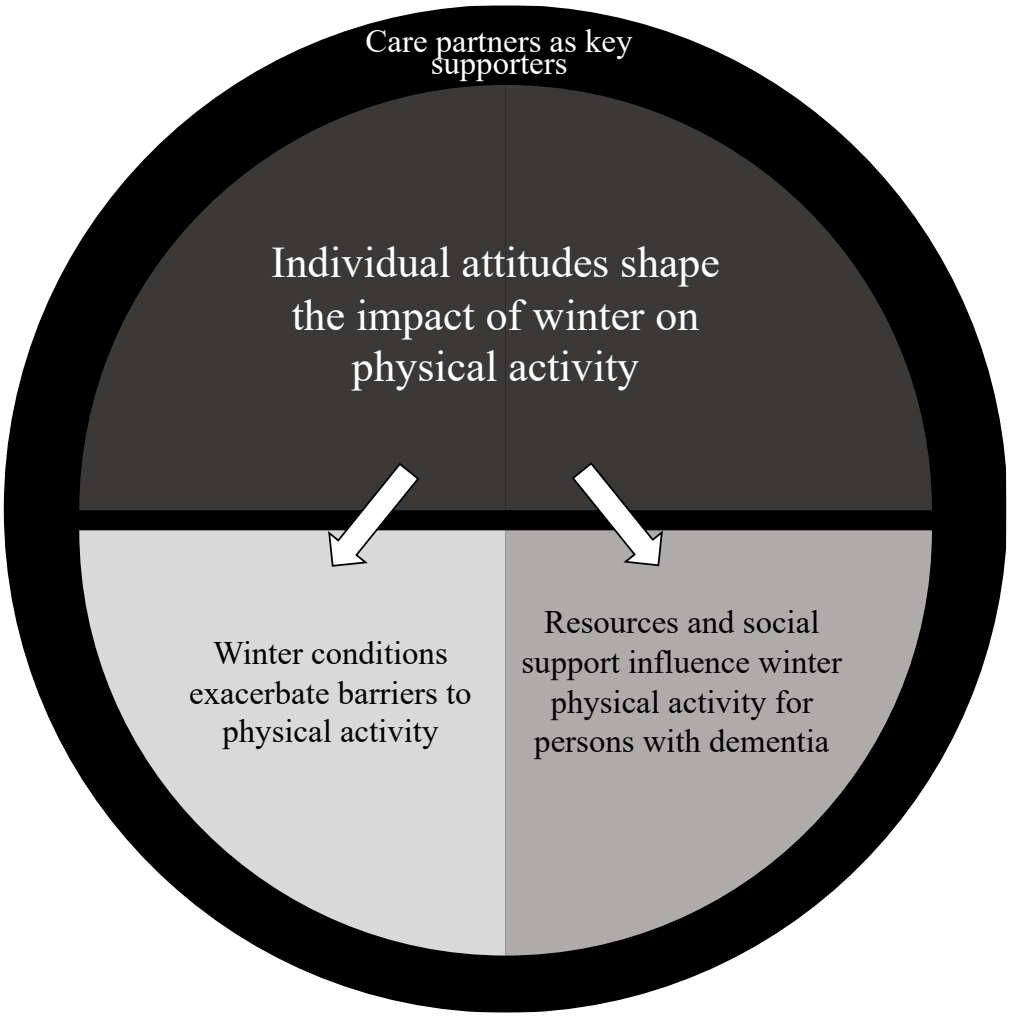


Figure 5. Model of the barriers and facilitators to winter physical activity for persons with dementia and their care partners.

with dementia to be active. See Appendix F (Tables A5-7) for an overview of categories, relevant concepts within each, and how they related to the COM-B framework.

4.4.2.1 Individual attitudes shape the impact of winter on physical activity

This core category explores how the varying attitudes influenced participants' reactions to winter weather, how they would like to be active, and the supports needed to be active. Some participants *enjoyed outdoor activities* as they liked being outside and experiencing nature, even if they preferred summer weather to winter weather. The cold made it more difficult to enjoy the outdoors at a leisurely pace. Participants described pushing themselves to stay outside until they were too cold to bear it.

Some people who enjoyed being outdoors were *willing to take on risk* so that they could continue to be active even during snowy and icy weather. Ground conditions in the winter, such as ice or snow, increase risk of slipping and falling. However, some described being willing to take this risk because they enjoyed outdoor activities and were sufficiently mobile. Some enjoyed solo winter activities, which were often perceived as less safe. One participant, an avid snowshoer, indicated their enjoyment of their hobby outweighed their concern of the associated risks.

> *"But in all honesty, I don't mind snowshoeing on my own. I know I've got different people saying to me, you know, 'if you're half a mile back in a bush and something happens to you at your age, you know, you're gonna freeze to death.' Well, yeah." [Participant (P)01, 81-year-old male with dementia]*

To lessen the risks, other people identified supports (e.g., specialized winter equipment – discussed further below) that allowed them to continue to be active outdoors.

For other participants, their dislike of winter weather was sufficient to drive them towards indoor activities, as they could be done in more comfortable and warm environments. Even so, indoor activities were often not considered as fun or stimulating as outdoor summer activities. For example, several participants mentioned that boredom stopped them from walking at an indoor track or going to a nearby exercise facility.

> *… "there are walking programs, [in town] in the rink they have a circuit set up so you can walk around and around... but what was missing for both of us is… nothing to see, nothing is stimulating" [P08 – 75-year-old female spousal care partner]*

Other people described an overarching decrease in motivation to be active in the winter. Some care partners indicated that the person with dementia was significantly less motivated to be active during the winter, as leaving the house was perceived as being too much of a chore (whether for indoor or outdoor activity). Getting dressed took more time and they needed extra emotional fortitude to endure the cold. However, there was a decline in interest for indoor activities as well. Some care partners felt the declining motivation was a recent development that only happened in the winter.

Although people experienced a number of challenges to be active, they were still determined to incorporate physical activity throughout their day. Several participants described being *motivated to integrate daily physical activity into their routine*. One example

mentioned by two separate participants was using grocery shopping as their physical activity. Grocery shopping was done regularly and could be adapted to be comfortable and stimulating for the person with dementia. By combining two tasks, it was also perceived as easy to set aside the time to do these activities, making it easier for care partners to balance their responsibilities.

4.4.2.2 Winter conditions exacerbate barriers to physical activity

Although many participants experienced a number of non-winter related barriers to physical activity, wintery conditions exacerbated these barriers and caused new barriers to arise. Wintery conditions impacted participants in several ways.

Weather conditions were a barrier to physical activity expressed by all participants. Many participants indicated cold, ice, snow, wind, and fluctuations in weather made physical activity more difficult in the winter. For people with dementia and care partners who preferred indoor activity options during the winter, unpleasant cold or windy air could still deter them from leaving the home to go to a recreation facility.

Even those who enjoyed being active outdoors in the winter experienced challenges as *many outdoor physical activity options are weather dependent.* Fluctuations in weather and temperature make it difficult to anticipate whether the conditions will be favorable for outdoor activities. For example, the freeze-thaw-freeze cycle of snow and ice made it difficult to know if outdoor trails will be safe to use, or if extra gear would be needed.

" Who knows on a trail. If it's going to be icy or something, they do clear them but clear today and tomorrow, it could be ice you know type thing–" [P02, 71-year-old female spousal care partner]

Additionally, *fewer hours of sunlight* during the winter months restricted physical activity, especially among those keen to be active outdoors. Fewer hours of daylight narrowed the window of time for physical activity, as the darkness acted as a cue that the day was done. For example, one participant shared that their summer ritual was to go for a walk following dinner, but they stopped in the winter as the person with dementia would rather "hunker down" and stay indoors most winter evenings.

"…the walks tend to be the end of the day. So, a lot harder to motivate her, she doesn't want to go out if it's dark. But in the summer, we could go out for a walk after supper, so… to get her out during the day, I have to be quick in the winter […] I think it's just feeling like the day is done…" [P09, 58-year-old female adult-child care partner]

In the wintertime, pre-existing challenges became harder to manage, especially among those who prefer to be active outdoors but even among those who need to get to a car to travel to indoor opportunities. *Health issues and safety concerns were accentuated in the wintertime.* For example, the presence of ice may elevate any previously existing fears around falling. While people with dementia and care partners expressed a general concern of the person with dementia falling (in any weather), the icy or snowy conditions worsened these fears. In addition, people with dementia may use walkers due to limited mobility, but

walkers are less effective on the uneven surfaces created by packed snow or ice on a sidewalk, which often occurs if sidewalks or trails are not properly maintained.

> *"…we have the walking trail right across the road from us. So, we should be able to go out on the walking trail… But it has been blocked a lot of this winter, there has been so much snow… And he can't take his walker in the snow." [P08, 75-year-old female spousal care partner]*

Some care partners also felt the impact of dementia symptoms on physical activity was more profound in the winter, as *preparation for going outdoors and outdoor activities took more time and support.* The person with dementia may have difficulty choosing appropriate clothing independently. As a result, the care partner must dedicate more time for support to prepare for the activity.

> *" I very, very seldom leave [person with dementia] here alone at home where he has this issue with falling because I'm scared to death he'll go down sometime. ....it takes [person with dementia] a while to get himself organized and ready to go. So, [I] ... might look and say "ohh well we should go for a walk", well by the time we got ready and went, it would be time that … I should be thinking about being back to get dinner ready or whatever.... [this is more of an issue in the winter] because you need your boots, you need all these things." [P02, 71-year-old female spousal care partner]*

Among those choosing outdoor physical activity options, people with dementia were more likely to need support for safety during winter weather as the risk of falling is greater on snow or ice. Some would shorten the duration of the activity to make it easier for the person with dementia.

Finally, variability in *comfort with winter driving* impacted activity participation, particularly for those choosing indoor physical activity not at home. Although all care partners were capable of driving, they expressed varying degrees of comfort driving in the winter. Older, spousal care partners also were often less comfortable driving when it was snowing out. Younger, adult children were more likely to be comfortable driving in any weather condition. Consequently, driving was less of a barrier for people with dementia who had adult children care partners in comparison to those whose care partner was their spouse.

4.4.2.3 Resources and social support influence winter physical activity for people with dementia

Having access to adequate *resources and infrastructure* was critical in supporting winter physical activity. Helpful resources and infrastructure differed between those who preferred being active outdoors versus those who preferred to be active indoors in the winter.

Many of those who enjoyed being active outdoors used *specialized winter gear* to facilitate safety during the winter. Specialized gear such as ice cleats, walking poles, and winter boots could give security, stability, and warmth, allowing people with dementia to be safer when active outdoors. However, using this gear could be challenging. Some winter gear cannot be used in all settings. For example, ice cleats prevent slipping on icy surfaces but are

slippery when going into a store or coffee shop. Further, winter gear might not be as comfortable as clothing worn during the warmer months as it can be heavy and bulky.

> *"If it's icy out, she has boots that are really nice, roomy boots and Manitoba Mukluks, and then she's got boots that have clickers on them, which are good on the ice. And those feel more secure on the ice, but they kind of squish her feet. Like she usually complains about her feet being sore because the clickers squish on her boots" [P09, 58-year-old female adult-child care partner]*

For those who choose indoor options during the winter, *indoor gear and equipment* could facilitate physical activity at home. However, purchasing expensive equipment such as a treadmill or rowing machine may not be an option to all. Even then, many did not consider stationary indoor exercise equipment as engaging as outdoor activities. After purchasing the equipment, some additional modifications were required to make the activities more appealing. For example, one dyad considered using an iPad with nature videos to make treadmill walking more engaging.

4.5 Discussion

This was the first study, to our knowledge, that explored the experiences of winter physical activity in people with dementia and highlights several key barriers and facilitators. While winter influenced the opportunity to be active, participants' attitudes guided how they responded and adapted. Although nearly all participants felt that winter weather reduced opportunities to be active, many were able to overcome winter conditions. Some employed adaptive strategies, such as buying specialized gear to be active at home or outside and were

able to maintain their motivation throughout the cold winter months. Others were less successful in being active during the winter. Care partners play a pivotal role in supporting the person with dementia to be active, helping them overcome barriers related to weather, access to facilities, and changes to abilities. Although many challenges experienced by people with dementia may also be experienced by older adults generally (e.g., mobility concerns, challenges with transportation (Finlay, 2018; Hjorthol, 2013)), the physical and psychological changes associated with dementia added another degree of magnitude in how the winter made physical activity more challenging to do.

Not surprisingly, winter weather was a significant barrier to physical activity. Previous research shows that Canadians are less active in the winter for many reasons, including snowfall, fewer hours of daylight, and colder temperatures (Chan et al., 2006; Jones et al., 2017; Welch et al., 2018). This paralleled the findings of the present study where participants indicated the cold was demotivating for physical activity. Additionally, reduced daylight hours created a limited window for when people with dementia were willing to be active.

Winter weather also exacerbated other barriers to physical activity. For example, time is a common barrier to physical activity among people in general (Felicia Cavallini et al., 2020) and people with dementia and care partners (Cedervall & Åberg, 2010; Hobson et al., 2020). In the winter, leaving the house often takes more time to dress appropriately. In the case of people with dementia, support from care partners is more likely to be needed in the winter as the amount of clothing and the steps to getting ready are more significant for the person with dementia. This means that care partners would need to dedicate extra time for leaving the house, which can be stressful and challenging.

There was great diversity in people's attitudes and enthusiasm for outdoor winter activities. Some participants enjoyed winter activities, particularly winter walking in their neighborhood or through nature trails. For these participants, they balanced their decision to engage in activity against the potential risks of falling or injury and ultimately were willing to accept the risks associated with these activities.

Walking was also recognized as an enjoyable and meaningful activity for people with dementia in prior studies (Cedervall et al., 2015; Cedervall & Åberg, 2010; Hobson et al., 2020; McDuff & Phinney, 2015). However, being active outdoors often relies on maintenance of infrastructure, especially in the winter. Sidewalk design and accessibility is a critical barrier to physical activity for people with dementia (Chaudhury et al., 2021; Hobson et al., 2020; McDuff & Phinney, 2015). In the winter, poorly maintained pathways pose a significant challenge to people with dementia, as well as to the general population (Y. Li et al., 2012). In fact, 18% of fall-related injuries in Canadian adults 65+ were the result of slipping on snow or ice while walking (Public Health Agency of Canada, 2022). Additionally, people with dementia experience more significant mobility problems, and are at higher risks of falling (Allan et al., 2009) compared to adults without cognitive impairment. Understandably, icy conditions worsen fears of falling in older adults (Mehrabi et al., 2024), as observed in the present study among the people with dementia who experienced balance challenges.

In contrast, there were other people who preferred not to go outdoors during the winter and, instead, found ways to be active indoors. Some were active in their homes as this allowed for more flexibility in the timing of exercise. However, this often required a

significant investment to acquire exercise equipment. We also had participants note that space limitations impacted their ability to be active, aligning with previous literature (Mehrabi et al., 2024).

For those who enjoyed indoor physical activity at a separate facility, there were challenges to utilizing these spaces. First, care partners were often responsible for transporting the person with dementia to facilities, as described in other studies (Hobson et al., 2020). However, if care partners did not feel comfortable driving in certain winter conditions (particularly older spousal care partners), this limited transportation options. Second, indoor walking activities were not considered as fun or stimulating as walking outdoors. Finding ways to make indoor activity spaces fun and engaging, particularly walking tracks, could help encourage more use among people with dementia.

Regardless of the adaptations used, the motivations of people with dementia were a critical factor for physical activity. Motivation has already been a noted barrier to physical activity in people with dementia (Hobson et al., 2020), and several care partners noted their person with dementia's motivation plummeted in the winter. Although the rate of seasonal affective disorder is not known in dementia, it is possible that it may exacerbate the changes in mood that people with dementia experience (Q.-F. Zhao et al., 2016). Thus, an additional challenge care partners may need to address are seasonal fluctuations in mood and motivation. Although bright light therapy has been found to be beneficial for treating seasonal affective disorder (Chen et al., 2024), more research is required to understand the benefits of light therapy in people with dementia (Forbes et al., 2014).

The results of this study have several implications for exercise researchers and providers. First, if wanting people with dementia to come to a facility, they may need to help provide transportation options as care partners may not be comfortable driving during the winter. Exercise providers could consider having at-home exercise options for people with dementia, either as the primary intervention option or as a back-up option depending on winter weather. The exercises used need to be fun and engaging, as activities may feel boring and thus people with dementia may be less willing to participate.

There are several strengths and limitations to this study, including the use of video calling during data collection. By using Zoom, we were able to connect with participants from a variety of geographical regions in Canada. Although participants did have the option to call in, all interviews took place over Zoom. However, it is possible our sample was biased by having people who had access to a computer and internet, who were more technologically savvy, and thus may not be representative of people with dementia more generally. Further, people who enjoy being physically active were probably more likely to participate in this study and may not represent the experiences of those who are less physically active and potentially those with greater variability in their seasonal activity levels.

4.6 Conclusion

Engaging in physical activity during the winter months is a challenge to many people in cold climates, particularly people with dementia. Critically, many people with dementia and care partners showed willingness and enthusiasm to be active in the winter but need support. Many barriers stemmed from the weather, as winter weather was often associated with decreased motivation, stability, and comfort to exercise, as well as difficulties for driving.

However, most people were still able to be active by accessing indoor and outdoor opportunities using safety measures. Future physical activity interventions for people with dementia and care partners should consider and integrate specific planning for the winter months.

Chapter 5: Study 4 – The co-development of the Nighttime Insomnia Treatment and Education for Canadians with Alzheimer's Disease (NITE – CAD) program

5.1 Foreword

The results from Study 3 demonstrate that people with dementia have varying abilities and opportunities for winter physical activity. Physical activity opportunities need to be flexible to accommodate the diverse needs of people with dementia. Informed by these results, we sought to modify the Seattle-based NITE-AD program to be more applicable to the Canadian context, creating the *Nighttime Insomnia Treatment and Education for Canadians with Alzheimer's Disease* (*NITE-CAD)* program. To ensure the program is appropriate for participants, an advisory team was formed to evaluate, critique, and adapt the original program and materials for Canadians. The following chapter details the co-adaptation process for the NITE-CAD program, finishing with a planned program pilot.

5.2 Introduction

Sleep disturbance is a common consequence of Alzheimer's disease, where 24 to 66% of community-dwelling people with Alzheimer's disease report disturbed sleep (Guarnieri et al., 2012; Koren et al., 2023; McCurry et al., 1999). Sleep disturbances can manifest differently and with varied intensities across individuals. Some people with dementia may have insomnia and sleep-disordered breathing (Guarnieri et al., 2012), whereas others may engage in nighttime walking or have nighttime incontinence (McCurry et al., 2003). These sleep disturbances can be very stressful, especially when the care partner is also frequently woken (Ali & Bokharey, 2015; McCurry et al., 1999; Pollak & Perlick, 1998; Terum et al., 2017).

Critically, sleep disturbances increase the risk of institutionalization of the person with dementia (Hope et al., 1998; Pollak & Perlick, 1998; Spira et al., 2012).

Finding ways to improve sleep in people with dementia is necessary for reducing care-related stress and improving the well-being of care partners, allowing people with dementia to age in place at home for longer. Although pharmaceutical interventions are the most common approach to treat sleep problems, efficacy of pharmaceutical approaches are uncertain among people with dementia and come with a myriad of negative side effects (Glass et al., 2005; McCleery & Sharpley, 2020). For these reasons, non-pharmacological interventions are an attractive and preferred alternative (Deschenes & McCurry, 2009; Dzierzewski et al., 2018).

A meta-analysis showed that multi-modal lifestyle interventions significantly improved sleep quality among people with MCI or dementia (O'Caoimh et al., 2019). Many multi-modal lifestyle interventions for sleep in people with MCI or dementia use a combination of education, physical activity, and light therapy (Falck et al., 2018; R. H. Gibson et al., 2017; Livingston et al., 2019; McCurry et al., 2005, 2011; Tewary et al., 2018). One example of a multi-modal lifestyle intervention is the NITE-AD program, developed by McCurry *et al.* (2005). NITE-AD is an eight-week program for care partners composed of six one-hour one-on-one sessions with a program leader. During these sessions, participants go over sleep education and problem-solving behavioural management. Care partners are also given a light box to help increase light exposure of the person with dementia that they care for. Care partners are encouraged to have the person with dementia walk for 30 minutes daily, preferably outdoors. Evaluation of the NITE-AD program found improvements in objective

sleep quality in people with dementia (McCurry et al., 2005, 2011). The NITE-AD program was viewed favorably by care partners, who felt they benefited from participating and expressed higher confidence in managing sleep disturbances in people with dementia (McCurry et al., 2005, 2011).

The NITE-AD program was adapted into a shorter, group format by Tewary et al. (2018). This study showed promising evidence that the NITE-AD program was feasible when delivered in a group setting (Tewary et al., 2018). McCurry et al. (2011) noted inclement weather was a barrier to engaging in the recommended 30 minutes of outdoor daily walking, even though the study took place in Seattle (USA) which has moderate temperatures and little to no ice or snow (McCurry et al., 2011). This suggests the NITE-AD program, and particularly the physical activity recommendations, would likely need adaptations to accommodate the more severe winter climate common in Canada.

Best practice for program design (or adaptation) is to include those who will be affected by the program within the design process (i.e., co-design). Co-design is an approach of designing *with* people instead of *for* them (McKercher, 2020). The role of co-design is to elevate the voices of people with lived experience to improve something the collective cares about (McKercher, 2020). In the case of NITE-AD including the voices and experiences of care partners and people with dementia (future program participants) and providers who may deliver the program (i.e., Alzheimer Society staff or others who provide dementia-related services) may improve the relevance and feasibility of the program (Dupuis et al., 2012). The objective of this study is to describe the co-adaptation of the NITE-CAD program, an adapted version of the NITE-AD program appropriate for the Canadian context.

5.3 Development of NITE-CAD

The NITE-CAD development process (Figure 6) is described over three steps: 1) Identification of the knowledge gap; 2) Assessment of barriers to knowledge use; and 3) Tailoring of the intervention. These steps loosely follow the Canadian Institutes of Health Research's *Knowledge to Action cycle.* The *Knowledge to Action cycle* is a dynamic and iterative process from knowledge creation to application (Graham et al., 2006).

5.3.1 Step 1: Identifying knowledge gap - sleep interventions in dementia in Canada

A literature search was conducted to understand suitable sleep interventions ready for implementation that improve sleep among people with dementia in Canada. Despite preliminary evidence supporting multi-modal interventions to improve sleep among people with dementia (O'Caoimh et al., 2019), it was our perception that there were no widely available programs targeting sleep in Canada. A review of the Alzheimer Society of Canada website confirmed this notion. Although the Alzheimer Society of Canada had information regarding sleep on their website, the website did not mention any programs specifically targeting sleep. In addition, an informal review of literature identified only one study of a lifestyle intervention among people with cognitive impairment in Canada, which was in people with MCI (Falck et al., 2020). Like the NITE-AD study, Falck et al. (2020) used physical activity, light therapy and education as the intervention modalities, which was found to improve subjective sleep quality but not objective measures of sleep among people with MCI. Thus, there appeared to be a gap in the implementation of multi-modal lifestyle interventions for sleep among people with dementia in Canada.

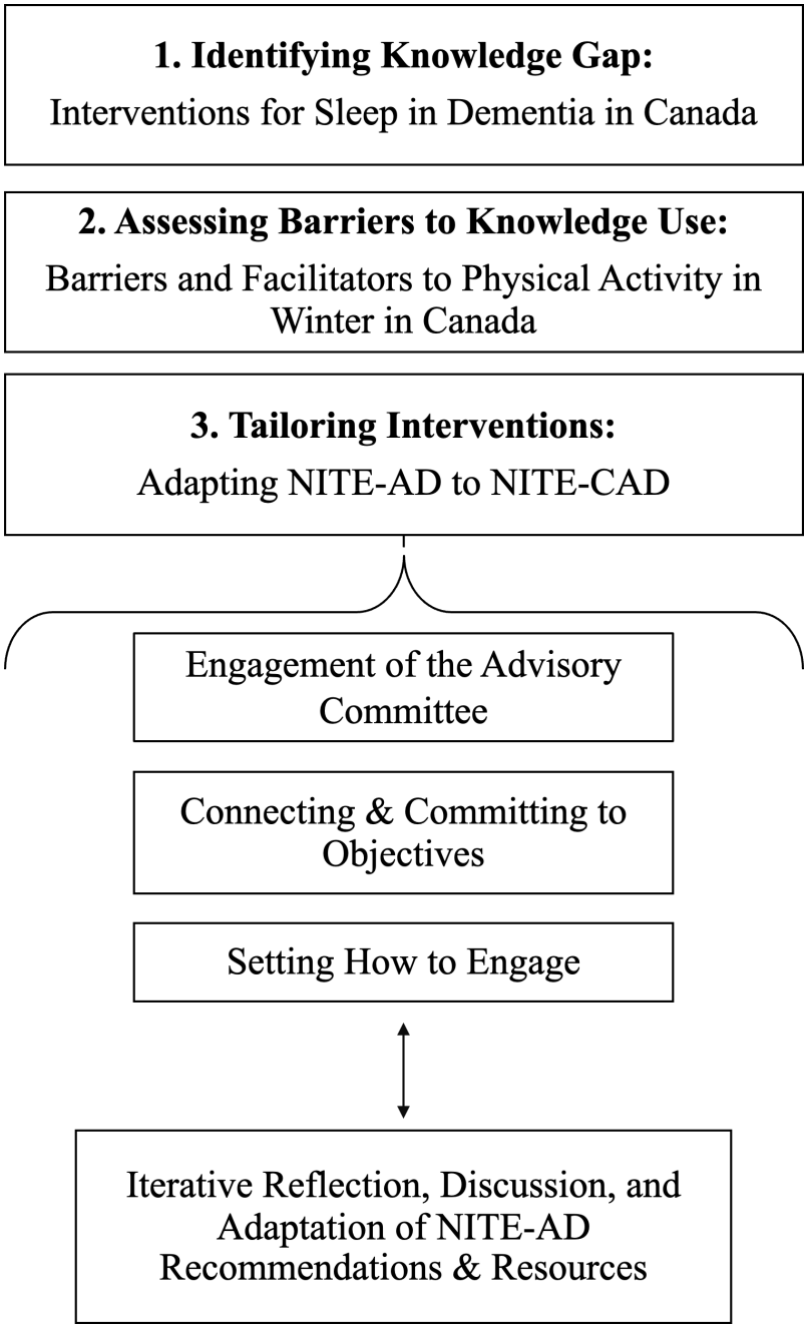


Figure 6. The NITE-CAD co-design process.

5.3.2 Step 2: Assessing barriers and facilitators to knowledge use - barriers and facilitators to winter physical activity

Assessing barriers is an integral step when promoting the uptake of knowledge to develop effective implementation strategies (Graham et al., 2006). The authors of the original NITE-AD program noted weather was a barrier to adhering to the physical activity recommendations (30 minutes of outdoor walking). As this study took place in Seattle, Washington, a region with mild winters, it seemed reasonable to presume the NITE-AD program would need modification to be feasible and acceptable among care partners (and people with dementia) who experienced cold, snow, and ice during Canadian winters.

To understand the barriers and facilitators to winter physical activity in Canada and make the necessary modifications to the NITE-AD program, we conducted interviews with people with dementia and their care partners. The detailed results of these interviews are described elsewhere (i.e., Study 3). In brief, there are several notable results that are relevant to the adaptation of the NITE-AD program. First, in line with the reports from the NITE-AD study, participants in the interviews found that snow, ice, and cold were barriers to outdoor physical activity during the winter. Furthermore, dressing for outdoor physical activity took people with dementia more time and required more care partner support in the winter. However, the preferred types of physical activity during the winter were diverse, varying with attitudes towards winter weather and outdoor physical activity during winter, local indoor and outdoor physical activity opportunities, and supporters for physical activity. Some people with dementia reported they were able and confident with engaging in physical activity outdoors, even in the winter. Others felt the risk of falls was too high. In this case, alternative programs and facilities were important but varied depending on geographical

location. Furthermore, even when alternates were available, some care partners were not comfortable driving to exercise facilities during snowy and icy conditions. These points were kept in mind when considering modifications to the NITE-CAD program in order to identify physical activity options that could be effective and safe across diverse attitudes, abilities, opportunities, and supports for physical activity.

5.3.3 Step 3: Tailoring the intervention

Modification of NITE-AD to create NITE-CAD was accomplished across several steps, starting with engagement of the advisory team for the purpose of co-adapting the NITE-AD program and program resources through a series of co-adaptation meetings. All members of the advisory team provided verbal, informed consent to participate in the co-design process.

5.3.3.1 Engagement of the advisory team

The goal was to include future participants for NITE-CAD (i.e., care partners and, potentially, people with dementia), persons who would offer NITE-CAD (Alzheimer Society staff), and people with expertise relevant to necessary adaptations (exercise professionals) on the advisory team, in addition to researchers (the student researcher and supervisor). The goal was to recruit care partners and people with dementia who had experience with sleep disturbances and/or exercise programming.

To recruit care partners and/or people with dementia, recruitment material was posted on the Alzheimer's Society of Canada participant recruitment portal. In addition, we reached out to people who had previously participated in research or programming through the Brain and Body Lab or at the Research Institute for Aging (both in Waterloo, Ontario). While four

people reached out about the study from the Alzheimer Society website, two did not respond to follow-up emails (potentially wanting to be part of the program itself, not an advisory team), one was located outside of Canada, and one was not fluent in English (they only spoke French).

Through the Brain and Body lab network, two care partners expressed interest in being part of the advisory team. Both had experience with exercise programming for their person with dementia but neither provided care for someone with sleep problems. One care partner dropped out before providing consent due to increased caring demands. The remaining care partner joined the advisory team. This care partner had valuable experience with supporting a person with dementia in participating in physical activity year-round but limited experience in caring for someone with sleep disturbances.

In addition, a registered kinesiologist, with about three years of experience in providing exercise and wellness programming for people with dementia, was recruited through their affiliation with the Brain and Body Lab. Finally, a representative from the Alzheimer's Society of Ontario who had 29 years of experience in dementia programming, with the last eight years at the Alzheimer Society, was recruited to the advisory team. Thus, the final advisory team included one care partner, one registered kinesiologist, and one Alzheimer Society staff member alongside the researchers.

5.3.3.2 Setting ways of engagement

In engaging the advisory team, we sought to take an *Authentic Partnership* approach (Dupuis et al., 2012), which was developed over a decade of participatory research with people with dementia. There are three guiding principles for the Authentic Partnership

approach: 1) a genuine regard for self and others; 2) synergistic relationships; and 3) focusing on the process (rather than just project outcomes). There are also five enablers to the Authentic Partnership approach, which we implemented in our adaptation process. These enablers are discussed throughout the following section (highlighted with *italics*).

Advisory sessions took place between November 2023 to January 2024. During the first meeting, our goal was to *connect* team members and have them *commit* to the project objectives. All team members introduced themselves and their connection to the project and its objectives. Next, the student researcher provided an overview of the NITE-AD program, the previous program variations, the limitations of the program in the Canadian context (particularly related to weather), and the proposed goals of the NITE-CAD project.

During the first meeting, the student researcher proposed four to six meetings for meaningful discussion and decisions for program adaptations. The initial meeting also allowed for the dates and times for Sessions 2-4 to be scheduled accordingly for late 2023. Sessions 5 and 6 were later scheduled using a meeting poll and took place in January 2024. Given the relatively small size of the committee, finding a time that worked for everyone was not too challenging.

We next sought to *establish open communication* during the advisory meetings. We discussed the best way for everyone to participate. All members were comfortable meeting by Zoom and found the platform appropriate as it allowed the committee to participate from a location that was convenient to them. The use of Zoom also allowed for easier scheduling as travel time was eliminated. The student investigator made clear that the codesign process was flexible to the needs of individuals and to the group. The student investigator continued

to check in with committee members at the end of each meeting to ensure the process was still working for them. They encouraged members to give feedback or reach out via email if they were not comfortable voicing their concerns in front of other members.

As agreed by the group, approximately one week before each session, participants were sent prompting questions and relevant materials to prepare them for the upcoming meeting. Sessions were recorded and transcribed using the Zoom transcription option (reliant on Otter AI software). This allowed adequate time for team members to *reflect* on materials and changes needed prior to *dialogue* during team meetings.

The first few minutes of each meeting were dedicated to casual conversation and check-ins to build relationships among the team and to foster *connection* among team members. Next, the student researcher shared any progress related to discussion and decisions from the prior meeting, with follow-up discussion if necessary. The meetings then went on to discuss the topic and related materials for that session, with discussion facilitated by the student researcher. The student researcher would ask open-ended questions to the advisory team. The student researcher sought to ensure the *diverse perspectives* of the team members were valued, respected, and included in the decision-making. There was active facilitation by the student investigator to ensure everyone had the opportunity to share their thoughts for each discussion item. Fortunately, due to the small group size and the pre-existing relationships between some of the team members, there was already a sense of trust which *created a safe space* for open discussion. At the end of the sessions, the student researcher provided a summary of what was discussed, and the objectives or goals for the next session were introduced.

5.3.3.3 Iterative review, reflection, discussion, and adaptation of NITE-AD program

Sessions 2 to 6 were dedicated to co-adapting the NITE-AD into the NITE-CAD program. The goal was to create a program that was feasible, acceptable, and effective in the Canadian context, while maintaining the core components of the original NITE-AD program. Areas where changes were potentially needed were usually introduced by the researcher, reflected upon by the team, and discussed as a group prior to finalizing adaptations.

The core components of the NITE-CAD program were constrained to align with the fundamentals of the NITE-AD program. These core components included: 1) educational materials; 2) one hour of daily exposure to light therapy, 3) recommended 30 minutes of daily physical activity. While these components were considered fixed, the content and format of the education materials and the modality of physical activity was considered flexible. The structure and timing of the program were also considered flexible, as long as it was a minimum of six weeks and covered the content of the NITE-AD program. The topic of each advisory meeting and guiding questions are shown in Table 10.

5.3.3.3.1 Adaptation of physical activity recommendations

Discussions of the physical activity component of NITE-AD started with a summary of the original NITE-AD protocol and the results of the qualitative study of barriers to physical activity in the winter (i.e., Study 3). In particular, two points were highlighted: the variability in preferences across individuals, plus the advantages and disadvantages of indoor versus outdoor winter activities (e.g., safety, enjoyment, gear needed, time). The advisory team agreed the 30 minutes of daily outdoor walking recommended in NITE-AD was not feasible year-round for many people with dementia and care partners in Canada. As a result, a goal of

Table 10. Discussion topics of advisory team meetings

Date and session	Topic	Guiding questions
Meeting 1 November 24th, 2023	Physical activity options	- What are some alternative physical activity options that could be offered in the NITE-CAD?
Meeting 2 November 30th, 2023	Physical activity options (continued from Meeting 1)	- What are some alternative activity options that could be offered in the NITE-CAD? - What concerns (e.g., barriers) would we need to consider for these activities? - What is the best way to track compliance?
Meeting 3 December 8th, 2023	Discussion of study materials (part 1)→ Tewary 2018 manual	- What are things you like about the handouts that you think are necessary to keep in? Why? - What are things you dislike about the handouts that we should consider removing or modifying? Why? ***Sub-categories of discussion:*** - Topics covered/content: Do you like the topics presented? Do they resonate with you? Is anything missing that you would want to learn more about? - Language: Does the language used make sense? Could it be simplified? - Formatting: Is the spacing, font size, font type, etc. appropriate? Can you read it with ease? How could the formatting be improved?
Meeting 4 December 15th, 2023	Discussion of study materials (part 2) → McCurry et al. manual	
Meeting 5 January 11th, 2024	Discussion of program structure and layout	- Should the educational sessions be 60 or 90 minutes, as previous iterations suggested a longer time might be preferred (Tewary et al., 2018)? - How involved are people with dementia and the care partner? Is this just for the care partner or should both be involved?
Session 6 January 18th, 2024	Review of the final NITE-CAD manual	- Looking at the new NITE-CAD manual, what is your feedback?

the co-adaptation process was to identify alternative physical activity recommendations or programming.

Next, the advisory team brainstormed alternative physical activity formats. Ideas for meeting the 30 minutes of physical activity included creating physical activity stations around the house (e.g., marching while brushing teeth), purchasing exercise equipment, virtual exercise programming, and providing participants with a home-circuit routine. Many of these options could be done by both the people with dementia and care partner, which was considered a benefit. Alternatively, care partners who could not engage in the activity could still provide encouragement for the person with dementia. There was also a consensus that the physical activity options should be enjoyable.

The supervising faculty member suggested it may be reasonable to provide a few physical activity options, such as walking (indoors or outdoors) or attending an exercise class (in-person or virtual), with the consistent goal being to get 30 minutes of daily physical activity. This suggestion was relayed to the advisory team, and everyone agreed that providing a selection of exercise options would be ideal. It was suggested that participants could be provided with a detailed list of exercises, programs, or exercise equipment that participants could use as a reference to develop an activity plan.

Finally, there was discussion about tracking compliance to physical activity recommendations, for the purpose of supporting future iterations. Team members agreed a tracking system should be as simple as possible. Suggestions included a standardized calendar with check marks or stickers to indicate whether the 30 minutes of physical activity was completed each day. The student investigator then created a custom calendar checklist

(Appendix G). Team members provided iterative feedback until consensus was reached that the final calendar checklist was acceptable. The approved calendar had check boxes where people answered questions about whether they engaged in physical activity or light therapy that day ("Yes" or "No"), the duration of that activity (light therapy: <30 min, 30–60 min, 60+ min; physical activity: >15 min, 15–30 min, 30–45 min, 45+ min), and the type of physical activity (walking indoors, walking outdoors, home circuit, exercise class, other).

5.3.3.3.2 Educational material content and format

The advisory team reviewed the educational materials used in previous iterations of NITE-AD for content, formatting, and language (McCurry et al., 2005, 2011; Tewary et al., 2018). The original NITE-AD (McCurry et al., 2005, 2011) provided participants with several documents, which included education materials (discussing sleep and circadian rhythms, sleep hygiene, and behavioral management) and forms to make sleep hygiene and walking plans. The Tewary et al. (2018) NITE-AD version provided participants with two documents, one which provided information regarding sleep hygiene and the other an action planning form.

Overall, the group preferred the materials used by McCurry (2005; 2011) over those used by Tewary et al (2018) due to the depth of content, as well as for formatting and wording. The McCurry et al. action planning materials were preferred because they were more detailed and specific to each intervention modality (i.e., sleep hygiene, light box use, physical activity engagement) and allowed for precise goals setting and planning.

Overall, minor content changes were needed for the educational materials, while all resources had changes in formatting with the exception of the behavioral management resource. We used all content from both the McCurry et al. (2005) and Tewary et al. (2018) resources. We presented the sleep hygiene information by dividing content into three topics: 1) behaviors to do during the day, 2) behaviors to do at night, and 3) how to make an optimal bedroom environment. There were further changes to the wording, focusing on actionable behaviors they *should do* (e.g., DO keep the bedroom cool, DO use a fan) instead of vague, non-actionable things they *shouldn't do* (e.g., "DON'T let the bedroom get too warm").

Other minor changes to the McCurry et al. materials included simplification of language, adding images to the documents, and using text boxes for participants to write down their responses or make notes. There were further minor revisions to grammar, spelling errors, and formatting in response to suggestions from the advisory team. The student investigator made these revisions. Revised materials were reviewed again at a later session prior to final approval. The advisory team was satisfied with each adapted resource after the first round of revisions. See Appendix G for the final NITE-CAD participant manual.

5.3.3.3.3 Program structure

The advisory team then discussed the program structure. Previous iterations of the NITE-AD program ran for either six or eight weeks and consisted of weekly one-hour group sessions and individual check-in phone calls to help manage their action plan. The advisory team reflected on the session length and the program duration. Tewary et al. (2018) had 60-minute sessions but commented longer sessions may be needed for more meaningful discussions. Despite these researcher reflections, the advisory team felt 60-minute sessions

were best for ease of scheduling and to constrain demands on participants. In addition, 60 minutes is the average length of the programs offered by the Alzheimer Society of Canada.

Next, the advisory team discussed program participants and session structure. Facilitation skills of the program leader would be critical to ensure productive discussions where all program participants felt confident to contribute. The advisory team discussed whether people with dementia should be participants in the program given its impact on the person with dementia's schedule and activities. From a rights-based approach, the advisory team felt the person with dementia should be part of the discussions. Furthermore, the insights of people with dementia may be valuable to other participants. Still, there would need to be opportunities for people with dementia to have discussions separate from care partners so both could speak freely and comfortably about their experiences and concerns. The advisory team believed the program guidelines created by Tewary et al. (2018) would provide ample opportunities for separate group discussions, as the program had group discussions built in. The advisory team felt it would be reasonable to have two separate spaces for discussion during those times.

Advisory team members also discussed whether the program should remain in-person or whether it could be virtual. Team members felt virtual programming would be easier and more time efficient, working well if the care partner attended alone. However, the advisory team believed an in-person program would be more accessible for people with dementia, enabling people with dementia to make more meaningful contributions to discussion.

The advisory team discussed what the appropriate group size should be. For in-person programs, the Alzheimer Society staff member suggested the ideal group size to be about 8-

15 people, in line with their experience in dementia programming. This amount was perceived as ample for meaningful discussion, even if some participants were unable to attend a session and mirrored the Alzheimer Society's typical program sizes. The care partner advisory member agreed with a narrower range, indicating that 10-12 people was reasonable.

A summary of the changes made in comparison to previous NITE-AD iterations can be seen in Table 11.

Table 11. Comparison variations of the NITE-AD program and the adapted NITE-CAD program.

	Original NITE-AD (McCurry et al. 2005, 2011)	**Group adapted NITE-AD (Tewary et al., 2018)**	**Adapted NITE-CAD**
Physical activity	• 30 minutes of daily walking, preferably outdoors. • Indoor walking alternatives were permitted for poor weather. • Action planning document to create a walking plan.	• 30 minutes of outdoor daily walking. • Discussions about the importance of walking and how to set a routine. • No action planning documents related to physical activity.	• 30 minutes of daily physical activity. • Provides a variety of Canadian physical activity resources with physical activity strategies and examples, including: o *It's Time to Get Active* (*Ontario Brain Institute*) o *Being Active at Home* (The *Dementia Inclusive Choices for Exercise* (DICE) project (Middleton, Pelletier, et al., 2023)) o *Assess Physical Activity Safety* (The *Dementia Resources for Eating, Activity, and Meaningful Inclusion* (DREAM) projects (Middleton, Freeman, et al., 2023)) o *Home Support Exercise Program* (*Alberta Centre for Active Living*) • Action planning document so participants can select and plan for at least two types of physical activity that accommodate different weather conditions.
Researcher and participant manual	• Researcher developed user manual for participants. • Provided facilitator with an outline and discussion points for topics to cover. • Daily logs to report sleep patterns, physical activity, and light box compliance.	• Researcher developed user manual, adapted from McCurry et al. (2005). • Created a standardized script for the facilitator to follow throughout the session. • No daily logs.	• Advisory team adapted user manual mostly from McCurry et al. (2005) with minor wording and formatting changes. • Facilitator guide from Tewary et al., with minor wording changes. • Simplified daily log with checkboxes to record the duration and frequency of physical activity and light box use.

			• No log of sleep patterns.
Program structure	• Program designed for care partners. • Unclear whether people with dementia participated in education sessions. • Offered in person, one-on-one.	• Program designed for care partners. • Unclear whether people with dementia participated in education sessions. • Offered in person, in a group setting.	• Program designed for care partners, with optional participation of people with dementia in education sessions if interested. • Offered in a group setting, either in-person or virtually depending on demand.

5.4 Discussion and reflection

The aim of this study was to describe the co-adaption of a lifestyle intervention to improve sleep in people with dementia in Canada. With the co-adaptation advisory team, several changes were made to create the NITE-CAD program, including modifications to the physical activity options, program content, and program structure. Future research is required to further test the feasibility and acceptability of the NITE-CAD program, to give directing for future refinement or to guide implementation of the program.

The *Canadian Institutes of Health Research* argues that people with lived experience of a health condition have a right to engage in research that impacts their care (Canadian Institutes of Health Research, 2020). Often, there is a disconnect between what researchers and what care partners and people with dementia view as important (Byrne-Davis et al., 2006; Thorgrimsen et al., 2003). The advisory team for the present study involved a person with lived experience (a care partner) as well as community service and exercise providers to help adapt a sleep intervention (NITE-AD) for the Canadian context (NITE-CAD). We additionally gained valuable insight from people with dementia and their care partners about their experiences with winter physical activity through interviews. Together, these interviews and the advisory team informed the co-adaptation process to create the NITE-CAD program, which was tailored to be accessible in the Canadian context. Although we were unable to pilot the interventions, our process provides insights and guidance for future co-adaptation processes.

Engaging care partners and people with dementia who experienced sleep difficulties was a major challenge for the co-adaptation of this sleep-focused program. Even though one care

partner was on the advisory team, the care partner brought expertise related to exercise and did not provide care for people with dementia who had sleep problems. Our difficulty recruiting care partners who cared for people with dementia with sleep difficulties may be because such care partners often experience high levels of stress (Ali & Bokharey, 2015; McCurry et al., 1999; Pollak & Perlick, 1998; Terum et al., 2017). The insights of people with dementia and care partners experiencing sleep difficulties are necessary to inform an advisory process that could work for them. For example, one potential advisory member (a care partner) had initially shown interest in participation but struggled to find the time to commit due to evolving and increasing caring demands. Although we tried to find ways to accommodate for their caring responsibilities, it was mutually decided this was not the best time for the care partner. Unfortunately, time constraints made it infeasible to recruit another care partner out of respect to other people who had committed to the advisory team and due to the time constraints of the PhD thesis.

Co-designed processes are time intensive as creating trust and comfort among advisory team members cannot be rushed. Embedding co-design as a single part of a graduate thesis can, thus, be challenging. Furthermore, the study examining the barriers and facilitators to winter activities (Study 3) was necessary to inform the present program. For graduate student researchers wishing to use co-design in their thesis, it may be necessary to engage with an advisory team at the thesis inception and throughout their graduate studies. Forming an advisory team early on may allow for insightful feedback throughout the entire thesis process and prevent constrictions at critical points towards the end of the thesis.

5.5 Conclusion

This NITE-CAD study aimed to promote lifestyle factors to improve sleep in Canadians with dementia, while considering their winter physical activity needs. Using an Authentic Partnership approach, the voices of people with lived experience were heard, valued, and integrated into improving the NITE-CAD program with the goal of making the program more acceptable. Taking time to pause and reflect if engagement procedures are feasible for the specific target population (i.e., people with dementia with sleep disturbances and their care partners) may be critical, even when timelines are demanding. This will help ensure the wisdom of the advisory team can be fully realized and implemented to avoid overlooking critical aspects of practical research design. Although co-designing processes with people with dementia are being increasingly adopted, there is still much progress to be made.

Chapter 6: General discussion

This thesis had two overarching goals. The first was to understand how sleep and physical activity relate to cognition in persons at risk for or with dementia. The second was to adapt a multi-modal lifestyle intervention to improve sleep in Canadians with dementia. Epidemiological data was used to examine how sleep and physical activity related to cognitive function and dementia risk in healthy older adults (Study 1). Those who developed dementia in Study 1 were followed to see how physical activity and sleep influenced the dementia journey (Study 2). Although physical activity was associated with better cognitive function at baseline and over time in people without cognitive impairment, there was no significant benefit from physical activity on the cognition of people with dementia. Despite our findings, many sleep interventions for people with and without dementia include physical activity (O'Caoimh et al., 2019; Páez et al., 2024; Xue et al., 2024). Therefore, to inform the adaptation of a multi-modal sleep intervention for people with dementia which includes physical activity for the Canadian context, the barriers to engaging in physical activity during the wintertime were explored (Study 3). It was clear the impact of winter weather varied depending on the person with dementia and care partner's abilities, enjoyment of being outdoors in the winter, and tolerance of risk associated with being active in winter weather conditions. With this information, as well as the insight of an advisory team consisting of a care partner, a community service provider, and an exercise provider, an American program was adapted to be more suitable for use in Canada (Study 4).

6.1 Highlights and contributions

This thesis has improved our understanding of physical activity and sleep quality in relation to cognitive function and dementia risk in several ways. Though sleep was associated with baseline cognitive function, only physical activity was associated with a slower cognitive decline and reduced dementia risk among people with no cognitive impairment. This is in contrast to other studies that identified sleep quality as a risk for cognitive decline and dementia (Shi et al., 2018; Xu et al., 2020). For a very good comparison study, Lim et al. (2013) used the same Rush Aging and Memory Study data and found sleep fragmentation was associated with an increased risk of developing dementia over six years whereas Study 1 found no relationship over a 17-year follow-up period. It is possible sleep is predictive of dementia risk for a limited period of time. Given that neurodegeneration starts decades before changes in cognition (Jansen et al., 2015; Rodriguez-Vieitez et al., 2016), poor sleep may instead be an early symptom of dementia (Bokenberger et al., 2017).

There was no interaction between sleep and physical activity in relation to cognitive function, cognitive decline, or dementia risk. In relation to cognitive function, there is conflicting evidence whether or not there is an interactive relationship between sleep and physical activity as some studies find such an interaction (Kuhn & Heisz, 2022; Lambiase et al., 2014; Nakakubo et al., 2017; Sewell et al., 2023) while others do not (Falck et al., 2018). Why the observed relationship varies across studies is unclear. It is possible only specific cognitive domains (e.g., processing speed, executive functioning, or episodic memory) are impacted by sleep quality and physical activity (Kuhn & Heisz, 2022; Lambiase et al., 2014; Nakakubo et al., 2017), while other domains (verbal fluency) are not (Lambiase et al., 2014;

Nakakubo et al., 2017). Further, sleep is a complex behavior with many methods of assessment; thus, the different aspects of sleep quality or sleep duration may impact health differently. At this time, there are no notable trends indicating the features of sleep or specific measures which are more likely to be associated with better cognitive outcomes.

When following people with dementia, different results emerge. We found sleep fragmentation was not associated with cognition or cognitive trajectory. Additionally, physical activity was not associated with cognition after the onset of dementia. It is unclear why these associations are different before and after the onset of dementia. The difference may be related to physical activity dose and intensity. The average activity in Study 1 was 70.6 counts, but only 34.3 counts in Study 2. It is possible the people with dementia in this study did not engage in sufficient physical activity to experience cognitive benefits. Exercise interventions that find improvements in cognition among people with dementia also use interventions that are moderate intensity done three or four times per week (Balbim et al., 2022; Law et al., 2020), which is likely more intensive physical activity than that of our present sample. Moreover, as dementia pathology starts forming up to 20 years before a dementia diagnosis (Jansen et al., 2015; Rodriguez-Vieitez et al., 2016), it is possible that the year of (or the year prior to) a dementia diagnosis is not a meaningful starting point for this longitudinal analysis. Future work should examine the relationship between physical activity on cognitive trajectory spanning a time from before to after dementia diagnosis. Finally, there may also be unmeasured confounding factors, like care partner support or residential status, that could influence the dementia journey (including both physical activity and cognition).

We did not find an association between physical activity and sleep in people with dementia. Again, physical activity intensity and duration may also play a role as previous research finds these characteristics impact sleep and suggests the minimum amount of physical activity required to receive benefits is 70 minutes of low-to-moderate exercise per week (Xue et al., 2024). Further, it is possible physical activity alone may not promote sleep, but rather physical activity in combination with other sleep-promoting factors may be needed to realize any benefits. For example, McCurry et al. (2011) found that when breaking down an intervention into individual components (sleep versus light versus NITE-AD versus the control), the full NITE-AD program conferred the most benefits.

One theme throughout Part 2 of this thesis (Studies 3 & 4) was the challenge of time. Winter activity participation required more time to prepare and extra supervision due to elevated fears of falling. Time has been noted as a barrier to physical activity in previous studies (Cedervall & Åberg, 2010; Hobson et al., 2020), as well as participation rates in co-design (Waite et al., 2019). We experienced significant challenges in recruitment to the advisory team, which may have been partly related to time as caring for a person with dementia experience sleep difficulties can be challenging. Providing some financial support (e.g., funding to hire a personal support worker) may have helped free up time so care partners could participate in the advisory team. In particular, the financial stressors around caring for a person living with dementia, on top of their other expenses, can exacerbate care partner burden for those with low socioeconomic status (Mahomed & Pretorius, 2022) so financial and other support may be particularly important for participation.

Time and willingness to participate in research may be particularly restricted among care partners of people with dementia who have sleep disturbances. Previous studies trying to recruit care partners for sleep interventions noted many care partners already felt stretched thin and did not believe they had the capacity to participate (Dowling & Wiener, 1997). Though not specifically explored, the combination of caring for a person with dementia with sleep challenges, participating in research, and making physical activity changes in addition to winter barriers may have a compounded impact on care partner stress.

6.2 Future directions

From Studies 1 and 2, there are several avenues for future investigations. First, these results need to be replicated, as this was the first time the interaction between sleep and physical activity has been investigated in the context of dementia risk. These studies should include several sleep characteristics and cognitive assessments across different domains to understand if results vary depending on the measures used. Furthermore, exploring the different dosages of physical activity should be considered, which can provide meaningful interpretations of the results (e.g., those who meet the physical activity guidelines to those who do not). Additionally, future studies should investigate the underlying physiological mechanisms contributing to either the independent or interactive relationship between sleep, physical activity, and cognitive function. Finally, researchers could explore the time course of the relationship between physical activity or sleep and cognitive function. This would allow us to understand if there are times before or after a dementia diagnosis that may be more sensitive to the impacts of sleep or physical activity.

From Studies 3 and 4, future research should continue to explore the unique needs for care partners of people with dementia who experience sleep difficulties. As with physical activity, there may potentially be seasonal impacts of providing care. Understanding the intersection between seasonality and providing care may uncover additional considerations needed to support care partners year-round.

Future research should also continue to focus on the inclusion of people with dementia and their care partners. Although we should continue to use co-design to create acceptable interventions, there needs to be a focus on how to make this form of participation accessible. It is critical to understand how to engage care partners who experience high levels of stress and demands, as these people are likely the ones who need support the most. Engaging with those caring for someone experiencing sleep difficulties can help create research priorities and inform better programming in the future. Finally, future research should also test the adapted NITE-CAD program to assess its feasibility and acceptability.

6.3 Conclusion

We sought to understand how physical activity was related to sleep in people with and at risk for dementia. We found that sleep and physical activity had independent effects on cognition in older adults without cognitive impairment but may be less impactful during the dementia journey. We sought to adapt a lifestyle intervention to improve sleep in people with dementia by ensuring it was appropriate for the Canadian context (including icy and snowy winters). Our process highlights the need to remain flexible and provide different ways to engage so the diverse attitudes, abilities, and resources of people with dementia and care partners are supported.

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Appendix A: Introduction – Tables of interventions to improve sleep in people with dementia

Note: Many studies used subjective sleep measures, with the two most common being the Pittsburgh Sleep Quality Index (PSQI) and the Sleep Disorders Inventory (SDI). For both cases, a higher score is indicative of poorer sleep. Thus, when a study outcome in the tables reads as "↓ PSQI", this indicates their subjective sleep is improving.

Table A 1. Physical activity interventions to improve sleep in community-dwelling people with dementia and people with dementia living in institutional settings

Authors	Dementia type	Sample	Study Design	Duration	Intervention	Control treatment	Outcomes
Community-dwelling people with dementia							
(McCurry et al., 2011)	AD	INT *n* = 27 CON *n* = 29	RCT	8 weeks	30-minutes of continuous, self-paced walking 7x/week	Non-directive dementia care education and support, but with no training or homework	*Objective sleep* – Actigraphy ↓ total wake time ↔ SE, nighttime awakenings, TST, TIB, daytime sleep *Subjective sleep* – Proxy SDI (by care partner) ↔ SDI
(Nascimento, Ayan, et al., 2014)	PD AD	INT *n* = 31 (PD =17, AD =14) CON *n* = 33 (PD = 17, AD = 16)	Matched pairs design?	6 months	1-hour multi-modal exercise program (resistance, balance/motor coordination, aerobic) 3x per week	TAU	*Subjective sleep* – Proxy report (by psychiatrist) ↓ sleep disturbance
(Shih et al., 2020)	AD	INT (Morning) *n* = 15	Quasi Experimental	6 months	30-minutes of continuous walking, 4x/week Morning group = before noon	Normal daily activities, CP encouraged to engaged in 30-minutes for interactive time to mimic intervention	*Subjective sleep* – Proxy reports (by care partner)

		INT (Afternoon) *n* = 15 CON *n* = 16			Afternoon Group = after lunch but before 6pm		↓ evening restlessness in morning walking group (across intervention) ↓ evening restlessness in morning and evening at 16&24 weeks
(Stella et al., 2011)	AD	INT *n* = 16 CON *n* = 16	Controlled trial	6 months	60 minutes of aerobic exercise, 3x per week	TAU	*Subjective sleep* – Proxy reports (by staff) ↔ sleep disturbances
People with dementia living in institutional settings							
(Alessi et al., 1995)	Not specified	INT *n* = 33 CON *n* = 32	Secondary analyses of controlled trials	9 weeks	Lighter exercises: Functional Incidental training (FIT) 4x/day sets FIT exercises, 5x/week More intense exercises: Row/Walk/Wheel 10 minutes of rowing + walking OR 30-minutes of wheelchair propulsion, 3x/week	TAU	*Objective sleep* – Actigraphy ↔ TST, SE, sleep episodes, peak sleep duration *Subjective sleep* – Proxy reports (by research staff) ↔ Daytime sleep
(Eggermont et al., 2010)	Not specified	INT *n* =41 CON *n* = 38	RCT	6 weeks	30-minutes of walking at a self-selected speed, accompanied by a student, in the nursing home 5 days/week	Social visit by a student in the nursing home	*Objective sleep* – Actigraphy ↔ Night-time restlessness, SE, # of wake bouts
(Lee & Kim, 2008)	Not specified	*n* = 23	Pre-post (Pilot)	4 Weeks	1 hour of Indoor Gardening 2x/day, 7x/week	N/A	*Subjective sleep* – Proxy sleep diaries (by registered nurses or nurses' aides)

							↑ SE, TST ↓ WASO, naps
(Namazi et al., 1995)	Mild AD	INT *n* = 11 CON *n* = 11	Voluntary enrollment?	4 weeks	45 minutes of guided "light" exercise (walking and mobility/balance) 7x/week	"placebo" social activity (reading and poetry)	*Subjective sleep* – Proxy reports (by staff) ↑ "sleep soundly' episodes ↓ "restlessness" episodes
(Richards et al., 2011)	Not specified	INT *n* = 55 CONT *n* = 47	RCT	7 weeks	30-minutes of high intensity resistance strength training 3x per week + 45 minutes of walking 2x/week	TAU	*Objective sleep* – PSG ↑ SE ↔ TST, NREM, REM, SOL

AD = Alzheimer's disease, CON = Control group, INT = Intervention group, RCT = Randomized control trial, PD = Parkinson's disease, PSG = Polysomnography, SDI = Sleep disorders inventory, SE = Sleep efficiency, SOL = Sleep onset latency, TAU = Treatment as usual, TIB = Time in bed, TST = Total sleep time (sleep duration), WASO = Wake after sleep onset

Table A 2. Light interventions in community-dwelling people with dementia

Authors	Dementia type	Sample	Study Design	Duration of exposure	Intervention	Control treatment	Outcomes
Environmental restructuring							
(Figueiro et al., 2015)	Not specified	INT (PwD) *n* = 35 CON (CP) *n* = 34	Pre-post	4 weeks	Environmental restructuring: Luminaries installed into the house and would stay on from wake to sleep. Minimum 350-400 lux (reaching the eye), 9325K	Co-habituating care partners were the control group, had the same exposure to the light	*Objective sleep* – Actigraphy ↑ SE for PwD ↔ TST for PwD
(Sloane et al., 2015)	Not specified	*n* = 17 (Dyads with care partners)	Randomized crossover	6 weeks (per condition)	Environmental restructuring: Fluorescent lights placed in tables/floor lamps + LED Lightbox at breakfast/lunch eating area Lights on from wake to 18:00 13,000 K (blue-white) lights	Same as intervention but with 2700K (yellow-white) florescent bulb + Red LED lightbox	*Objective sleep* – Actigraphy ↔ TST, SOL, SE *Subjective sleep* – Self-reported or proxy-report (by care partner) PSQI ↔ PSQI ↑ SE (PSQI sub-component)
Light boxes							
(Kim et al., 2021)	AD	INT *n* = 14 CON *n* = 11	RCT	2 weeks	Light box(es): 1 hours of morning light exposure, 9am-10am 30 lux at eyes	Same as intervention, but wore blue attenuating glasses	*Objective sleep* – Actigraphy ↔ SOL, TST, SE, WASO, fragmentation *Subjective sleep* – Self-report ↓ PSQI global
(McCurry et al., 2011)	AD	INT *n* = 29 CON *n* = 29	RCT	8 weeks	Light box(es): 1 hours of evening light exposure, 2-hours before bedtime 2,500 lux	Non-directive dementia care education and support, but with no training or homework	*Objective sleep* – Actigraphy ↓ total wake time ↔ SE, nighttime awakenings, TST, TIB, daytime sleep *Subjective sleep* – Proxy SDI (by care partner)

							↔ SDI

AD = Alzheimer's disease, CON = Control group, CP = Care partner, FTD = Frontotemporal dementia, INT = Intervention group, LBD = Lewy body dementia, PSQI = Pittsburgh sleep quality index, PwD = People with dementia, RCT = Randomized control trial, SDI = Sleep disorders inventory, SE = Sleep efficiency, SOL = Sleep onset latency, TAU = Treatment as usual, TIB = Time in bed, TST = Total sleep time (sleep duration), VD = Vascular dementia, WASO = Wake after sleep onset

Note: The unit for measuring light brightness (or luminosity) is lux. Daytime light can range from 32,000-100,000 lux on a sunny day and drop to 1000 lux on a cloudy day. While older adults tend to like lighting of at least 1000 lux when performing tasks (Davis & Garza, 2002), some people with dementia living in institutional settings are only receiving ~10 minutes a day in such lighting (Ancoli-Israel et al., 1997; Shochat et al., 2000). Another characteristic of light is colour temperature, measured in Kelvin (K). "Warm light" is about 2700-3000K and has a yellow-orange appearance (similar to a sunset). "Cool light" is about 5000K and is crisper and more blueish (think of midday sunlight or a bright LED light). Colour temperature is important as cool colours suppress melatonin secretion (think of midday light, an individual needs to be awake), much more so than warm colors (think of sunset as a cue for sleep) (Morita & Tokura, 1996). In some of the interventions discussed below, cool light temperatures are used as the intervention condition whereas warm colors are used as the control.

Table A 3. Light interventions in people with dementia living in institutional settings

Authors	Dementia type	Sample	Study Design	Duration of exposure	Intervention	Control treatment	Outcomes
Environmental restructuring							
(Figueiro et al., 2014)	Not specified	*n* = 10	Pre-post	4 weeks	Luminaries installed into the house Lights on from wake to sleep (6 or 8am-6pm). 300-400 lux (at eye), 9325K	NA	*Objective sleep* – Daysimeter, ↑ SE, TST ↔ SOL *Subjective sleep* – Proxy PSQI (by nursing staff) ↓ Global PSQI
(Figueiro et al., 2019)	Not specified	*n* = 46	Randomized crossover	4 weeks	Luminaries and light boxes installed in bedrooms or in common areas Lights on from wake to sleep (6 or 8am-6pm). Luminaries = 550 lux, 5000K Light boxes = 350-400 lux, 9325K	100 lux (2700K)	*Objective sleep* – Actigraphy ↔ SE, SOL, TST, naps *Subjective sleep* – Self-report PSQI ↓ PSQI Scores
(Hjetland et al., 2021)	AD, VD, LBD, and unknown	INT *n* = 32 CON *n* = 34	Cluster randomized	24 weeks	Ceiling fans installed into common rooms to increase ambient lighting Lights on from 10am – 3pm 1000-6000	Same as intervention but with lights were 150-300lux	*Objective sleep* – Actigraphy ↔ TST, SE, WASO *Subjective sleep* - proxy SDI (by nursing staff) ↔ SDI at 8 weeks ↑ SDI at 16 & 24 weeks
(Riemersma-van der Lek, 2008)	AD, VD, LBD, PD (and cognitively normal)	*Baseline* INT *n* = 49 CON *n* = 45 *@ 1.5 years*	RCT	Mean of 15 months (up to three years)	Fluorescent tubes installed into ceiling in common areas, and were on from 9am-6pm 1000 lux	TAU, lights installed but not as bright	*Objective sleep* – Actigraphy ↑ TST ↔ nocturnal restlessness, duration of awakenings, SE, latency

		INT *n* = 23 CON *n* = 18					
(Sloane et al., 2007)	Not specified	*n* = 66	Cluster-unit crossover	3 weeks (per condition; morning, evening, and all-day light exposure)	Ambient bight light installed into common areas Goal of exposure to be 1-2 hours Morning = 7am-11am Afternoon = 4pm-8pm All day = 7am - 8 pm (2500lux, 6500K)	500 lux	*Objective sleep* – Actigraphy ↑ TST (Morning & All-day groups) (↑↑ in severe dementia) ↔ # of sleep bouts
Light boxes							
(Ancoli-Israel et al., 2003)	Probable AD	INT (Morning) *n* = 30 INT (Evening) *n* = 31 CON *n* =31	RCT	10 days	2 hours of morning (9:30am-11:30am) or evening (5:30pm-7:30pm) light exposure, 2500 lux	Same but with <300 lux red light	*Objective sleep* – Actigraphy ↔ TST, SE, WASO
(Ancoli-Israel et al., 2002)	Not specified	INT (Morning) *n* = 10 INT (Evening) *n* = 11 CON *n* = 13	RCT	10 days	2 hours of morning (9:30am-11:30am) OR evening (5:30pm-7:30pm), 2500 lux	Exposed to less than 50 lux red light from 530-730pm	*Objective sleep* – Actigraphy ↔ nighttime sleep
(Burns et al., 2009)	AD, VD, LBD, & mixed	INT *n* = 22 CON *n* = 26	RCT	2 weeks	2 hours of morning light exposure (10am-12pm), 10000 lux	Same as BLT but 100 lux	*Objective sleep* – Actigraphy ↔ TST *Subjective sleep* – proxy report (by nursing staff) ↔ TST
(Dowling et al., 2005A)	AD	INT *n* = 29 CON *n* = 17	RCT	10 weeks	1 hour of morning light exposure (930am-1030am) from Monday to Friday, 2500 lux	TAU (150-200 lux)	*Objective sleep* – Actigraphy ↔ SE, TST, # of awakenings, duration of awakenings, wake time
(Dowling et al., 2005B)	AD	INT (Morning) *n* = 29 INT (Evening) *n* = 24	RCT	10 weeks	1 hour of morning (9:30am-10:30am) or evening (3:30-4:30) light exposure from Monday to Friday,	TAU (150-200 lux)	*Objective sleep* – Actigraphy ↔ SE, TST, Wake time, # number of awakenings

		CON *n* = 17			2500 lux+		
(Dowling et al., 2008)	AD	INT *n* = 18 CON *n* = 17	RCT	10 weeks	1 hour of morning light exposure (930am-1030am) from Monday to Friday, 2500 lux	TAU (150-200 lux)	*Objective sleep* – Actigraphy ↔ TST, # of nighttime awakenings, naps
(Fetveit et al., 2003; Fetveit & Bjorvatn, 2004, 2005)	Not specified	*n* = 11	Pre-post (Pilot)	2 weeks	2 hours of morning light exposure (8am-11am), 6000-8000	NA	*Objective sleep* – Actigraphy ↓ Total wake time, TIB, WASO immediately post treatment ↑ SE. up to 4 weeks post treatment ↓ SOL for up to 12 weeks post treatment *Subjective sleep* – Proxy report (by nursing staff) ↓ decreased nighttime activity ↓ average and total nap duration
(Lyketsos et al., 1999)	AD, VD	*n* = 15 8 completed though?	Randomized crossover	4 weeks	1 hour of morning light exposure, 10,000 lux	Blinking light in the box, bright light turned off	*Subjective sleep* – Proxy reports (by nursing staff) ↑ TST
(Mishima et al., 1994)	Not specified	INT *n* = 14 CON *n* = 10	Pre-post	4 weeks	Light box(es): 2 hours of morning light exposure (9am-11am), 3000-5000 lux	Not described, assume TAU	*Subjective sleep* – Proxy reports (by nursing staff) ↓ behaviors ↑ TST, Night ST ↓ napping
(Mishima et al., 1998)	AD & VD	*n* = 22 (AD *n* =10 VD *n* = 12)	Randomized crossover	2 weeks	2 hours of morning light exposure (9am-11am), 5000-8000 lux	Same as intervention but with dim light (300 lux)	*Objective sleep* – Actigraphy VD had significant reductions in night activity and percentage of night activity, and these were greater when compared to dim light ↔ for AD

(Onega et al., 2018)	Not specified	INT *n* = 30 CON *n* = 30	RCT	8 weeks	30-minutes of light exposure twice a day (mornings (8am-12pm) and evenings (2pm-8pm)) for five days per week, 10,000 lux	Same as intervention but with 250 lux light	*Subjective sleep* – Proxy report (by nursing staff) ↓ sleep impairment in participants with severe dementia (not observed in placebo or mild dementia)
(Satlin et al., 1992)	AD	*n* = 10	Pre-post	1 week	2 hours of light exposure per day (7pm – 9pm) 1500-2000 lux	NA	*Objective sleep* – Actigraphy ↓ nocturnal activity *Subjective sleep* - Proxy reports (by nursing staff) ↓ evening restlessness
(Skjerve et al., 2004)	Severe dementia (not specified)	*n* = 9	Pre-post	4 weeks	45 minutes of morning light exposure (8am-10am), 5000-8000 lux	NA	*Objective sleep* – Actigraphy ↔ SE
(Yamadera et al., 2000)	AD	*n* = 27	Pre-post	4 weeks	2 hours of morning light exposure (9am-11am), 3000 lux	NA	*Objective sleep* – Actigraphy ↓ % naps (in all groups) ↑ SE (in all + questionable demented) ↑ #of awakenings (total, mod, demented)

AD = Alzheimer's disease, CON = Control group, INT = Intervention group, LBD = Lewy body dementia, PSQI = Pittsburgh sleep quality index, RCT = Randomized control trial, SDI = sleep disorders inventory, SE = Sleep efficiency, SOL = Sleep onset latency, TAU = Treatment as usual, TIB = Time in bed, TST = Total sleep time (sleep duration), VD = Vascular dementia, WASO = Wake after sleep onset

Table A 4. Education interventions to improve sleep in people with dementia

Authors	Population	Sample	Study Design	Duration	Intervention	Control treatment	Sleep measure
(McCurry et al., 2003)	Community-dwelling people with AD (+ Care partners)	INT *n* = 10 CON *n* = 12	RCT (Feasibility)	8 Weeks	6 1-hour in-home sessions with a geropsychologist, where they received education booklets with principles of sleep hygiene, changes of sleep with aging, and strategies for modifying sleep problems in people with dementia. Participants were then guided on how to make goals based on their baseline sleep diary. Weekly follow ups to help ensure compliance and support in creating plans and training to implement them	Similar to INT, but were not provided with specific recommendations, suggestions, or homework. Only offered general encouragement and support, questions were answered about dementia care and community resources.	*Subjective sleep* – proxy reported (care partners) CP in intervention group were more likely to implement sleep hygiene practices (consistent bedtime, consistent rise times, reduced napping)
(McCurry et al., 2012)	Institutionalized people with AD	INT *n* = 31 CON *n* = 16	RCT	4 weeks	Staff underwent four ~45-minute tailored sessions and were provided homework for before sessions. A trainer would help with creating sleep plans and problem solving.	TAU	*Objective sleep* – Actigraphy ↑ TST, SE (at 6 months) ↔ WASO, naps (after 1 & 6 months)
(Naismith et al., 2019)	Community-dwelling people with MCI	INT *n* = 20 CON *n* = 15	RCT (Pilot)	8 weeks	Provided with several booklets with education materials relating to sleep and aging and strategies to improve sleep + 4 1hour face-to-face sessions which used principle from cognitive behavioral therapy and interviewing, interactive components. Participants were guided on how to create a sleep program, and modifications were created made if necessary	Provided with same booklets are the intervention condition, but were not given any directive, specific support to improve sleep.	*Objective sleep* – Actigraphy ↔ in TST, WASO, SE *Subjective sleep* - self-report ↓ PSQI

AD = Alzheimer's disease, CON = Control group, CP = Care partner, INT = Intervention group, MCI = Mild cognitive impairment, RCT = Randomized control trial, PD = Parkinson's' disease, PSQI = Pittsburgh sleep quality index, PwD = Person with dementia, SE = Sleep efficiency, SOL = Sleep onset latency, TAU = Treatment as usual, TST = Total sleep time (sleep duration), VD = Vascular dementia, WASO = Wake after sleep onset

Appendix B: Study 3 – Demographic survey questions for people with dementia

1. How old are you?
2. Residence
    a. What city/region are you currently living in?
    b. Do you live in a rural or urban area?
    c. What kind of residence do you live in?
        i. Private home/apartment/room
        ii. Seniors' residence
        iii. Other [textbox]
3. What gender do you identify with?
    a. Male
    b. Female
    c. Other
    d. Prefer not to say
4. What is your marital status?
    a. Single, never married, never lived with a partner
    b. Married/Living with a partner in a common-law relationship
    c. Widowed
    d. Divorced
    e. Separated
5. What is the highest level of education you have received?
    a. High-school or lower
    b. University or college degree
    c. Trade certificate or diploma
    d. Post-graduate degree
6. Do you have any current health conditions?
    a. Heart Disease □ No □ Yes
    b. Chronic Back Pain □ No □ Yes
    c. Knee Injury □ No □ Yes
    d. Hip Injury □ No □ Yes
    e. Arthritis □ No □ Yes
    f. Other condition: □ No □ Yes, please specify _____
7. DO you use any mobility aide?
    a. No
    b. Yes, if yes what kind? [text box]
8. Diagnosis of dementia or MCI
    a. When did you receive your diagnoses of dementia?
    b. What type of dementia were you diagnosed with?
9. Exercise (Stages of change short form)
    a. Regular Exercise is any planned physical activity (e.g., brisk walking, aerobics, jogging, bicycling, swimming, rowing, etc.) performed to increase physical fitness. Such activity should be performed 3 to 5 times per week for 20-60 minutes per session. Exercise does not have to be painful to be effective but should be done at a level that increases your breathing rate and causes you to break a sweat.
    b. Do you exercise regularly according to that definition?

        Yes, I have been for MORE than 6 months.

Yes, I have been for LESS than 6 months.
No, but I intend to in the next 30 days.
No, but I intend to in the next 6 months.
No, and I do NOT intend to in the next 6 months.

Appendix C: Study 3 – Semi-structured interview questions for people with dementia

1. Can you tell me how you feel about physical activity?
    - What do you enjoy about physical activity? What do you dislike?
    - What physical activities do you enjoy? Which of these activities do you do regularly?

2. In general, how do you feel about wintertime? (Do you like this winter?)

3. During the winter, what physical activity do you like to do?
    - Why do you enjoy this physical activity?
    - What motivates you to do this activity?

4. What makes it challenging to be physically active during the winter?
    - Prompts: Weather
        - Weather (Snow, Other winter precipitation)
        - Cold, ice, Reduced daylight
    - Built environment (i.e., infrastructure, city design/layout?)
        - Road or sidewalk conditions
        - Pathways
        - Difficulties wayfinding (how easy it is to navigate?)
    - Social support
        - partners ability to accompany (difficult to drive, walk outside, etc.)
    - Personal abilities
        - Need for help and support
        - joint pain, joint stiffness, etc.

5. During the winter, what helps you stay physically active?
    - Prompts:
        - Support from other people
        - Motivation
        - Transportation, driving
        - Access to facilities or programs
        - Equipment at home

6. What supports would you need to be more active in the winter?
    - People
    - Programs
    - Transportation
    - Safety
    - What would the ideal physical activity opportunity look like?

7. How would these supports change your physical activity during the winter?

Appendix D: Study 3 – Demographic survey questions for care partners

1. How old are you?
2. What is your relationship with [PLWD]?
    a. Spouse/Partner
    b. Child (Daughter/son/in-law)
    c. Extended family member
    d. Other
3. Do you reside with [PLWD]?
    a. Yes
    b. No
    c. If NO, how often do you visit? ____ time per week OR ____ times per month
4. Residence
    a. What city/region are you currently living in?
    b. Do you live in a rural or urban area?
    c. What kind of residence do you live in?
        i. Private home/apartment/room
        ii. Seniors' residence
        iii. Other [textbox]
5. What gender do you identify with?
    a. Male
    b. Female
    c. Other
    d. Prefer not to say
6. What is your marital status?
    a. Single, never married, never lived with a partner
    b. Married/Living with a partner in a common-law relationship
    c. Widowed
    d. Divorced
    e. Separated
7. What is the highest level of education you have received?
    a. High-school or lower
    b. University or college degree
    c. Trade certificate or diploma
    d. Post-graduate degree
8. Do you have any current health conditions?
    a. Heart Disease □ No □ Yes
    b. Chronic Back Pain □ No □ Yes
    c. Knee Injury □ No □ Yes
    d. Hip Injury □ No □ Yes
    e. Arthritis □ No □ Yes
    f. Other condition: □ No □ Yes, please specify _____
9. DO you use any mobility aide?
    a. No
    b. Yes, if yes what kind? [text box]
10. For you people with dementia:

a. When did you receive your diagnoses of dementia?
b. What type of dementia were you diagnosed with?

11. Exercise (Stages of change short form)
    a. Regular Exercise is any planned physical activity (e.g., brisk walking, aerobics, jogging, bicycling, swimming, rowing, etc.) performed to increase physical fitness. Such activity should be performed 3 to 5 times per week for 20-60 minutes per session. Exercise does not have to be painful to be effective but should be done at a level that increases your breathing rate and causes you to break a sweat.
    b. Do you exercise regularly according to that definition?

Yes, I have been for MORE than 6 months.
Yes, I have been for LESS than 6 months.
No, but I intend to in the next 30 days.
No, but I intend to in the next 6 months.
No, and I do NOT intend to in the next 6 months.

Appendix E: Study 3 – Semi-structured interview questions for care partners

Care Partners

1. Can you tell me how you feel about physical activity?
    - What do you enjoy about physical activity? What do you dislike?
        i. What do you think [PLWD] likes or dislikes about physical activity.
    - What physical activities do you enjoy? Which of these activities do you do regularly?
        i. What physical activities does [PLWD] enjoy? Which of these activities do they engage in regularly?

2. In general, how do you feel about wintertime? (Do you like this winter?)
    a. What do you think [PLWD] feels about the winter? Do they enjoy the winter?

3. During the winter, what physical activity do you like to do?
    - Why do you enjoy this physical activity?
    - What motivates you to do this activity?
        i. Does [PLWD] also engage in these activities, or what do they participate in? how often do they participate in these activities?

4. What makes it challenging for you and [PLWD] to be physically active during the winter?
    - Prompts: Weather
        - Weather (Snow, Other winter precipitation)
        - Cold, ice, Reduced daylight
        - Road or sidewalk conditions
    - Built environment (i.e., infrastructure, city design/layout)
        - Road or sidewalk conditions
        - Pathways
        - Difficulties wayfinding (how easy it is to navigate?)
    - Social support
        - partners ability to accompany (difficult to drive, walk outside, etc.)
    - Personal abilities
        - Need for help and support
        - joint pain, joint stiffness, etc.
        -
5. During the winter, what helps you and [PLWD] stay physically active?
    - Prompts:
        - Support from other people
        - Motivation
        - Transportation, driving
        - Access to facilities or programs
        - Equipment at home

6. What supports would you and [PLWD] need to be more active in the winter?
    - People
    - Programs

- Transportation
- Safety
- What would the ideal physical activity opportunity look like?

7. How would these supports change your physical activity during the winter?

Appendix F: Study 3 – Tables of findings

Table A 5. Barriers and facilitators relating to the varying attitudes towards physical activity and the winter.

Sub-category	Barriers	Facilitators	Quotes
Enjoyment of outdoor activities	Outdoor activities can't be done at leisurely pace	Enjoys winter and winter activities	"Snowshoeing is big in the winter, well, we have so much snow… And it's the quiet, I think it's the quiet of being in the bush in the winter. It's unbelievable." [P01, 81-year-old male person with dementia]
Willingness to take on risk	None identified	Enjoyment of their hobby outweighed their concern of the associated risks.	"But I in all honesty, I don't mind snowshoeing on my own. I know I've got different people saying to me, you know, 'if you're half a mile back in a bush and something happens to you at your age, you're gonna freeze to death.' Well, yeah." [P01, 81-year-old male person with dementia]
Enjoyment of indoor activities	Indoor activities boring	Making modifications to enjoy the activity more Flexibility in timing of activity	"There are walking programs, [in town] in the rink they have a circuit set up so you can walk around and around... but what was missing for both of us is… nothing to see, nothing is stimulating" [P08, 75-year-old female spousal care partner]
Integrating physical activity into their routine	None identified	Viewing grocery shopping as a chance to be active and do something fun	"What has helped us the most… has been going for groceries… I'm using that as an exercise program because you have to walk from the car to the store and then, whether we need something in each aisle or not, I make sure we run it up and down each aisle. […] There are walking programs…. But [there is] nothing to see… Whereas when you're walking in Costco there's plenty to see!" [P08, 75-year-old female spousal care partner]

Red = opportunity; Purple = motivation, blue = capability

Table A 6. Barriers and facilitators to winter physical activity relating to wintery conditions and their exacerbation of previous challenging circumstances.

Sub-category	Barriers	Facilitators	Quotes
Weather conditions negatively impact the opportunities and capabilities to be active	Cold, ice, snow, wind, and fluctuations in weather restricted opportunities to be active. Discomfort in cold weather made physical activity outdoors less likely.	None identified	"So winter is basically an inside, the choice to be is inside. Going out is a challenge. In the summer, going out is not a challenge. It's a pleasure… [In the winter] you force yourself to put on warm clothes and stay out there until your fingers and toes start getting cold." [P07, 79-year-old male person with dementia]
Many outdoor physical activity options are weather dependent.	Fluctuations in temperature caused freeze-thaw conditions, made it difficult to anticipate trail conditions or participate in activities that require ice or snow	Consistent weather Adequate snow fall	"And, again, when you get down to winter who knows on a trail. If, you know, it's going to be icy or something, they do clear them but clear today and tomorrow, it could be ice you know type thing–" [P02, 71-year-old female spousal care partner]
Fewer hours of daylight	Fewer hours of daylight narrowed the window of time for physical activity.	None identified	"…the walks tend to be the end of the day. So, a lot harder to motivate her, she doesn't want to go out if it's dark. But in the summer, we could go out for a walk after supper, so… to get her out during the day, I have to be quick in the winter […] I think it's just feeling like the day is done… [P09, 58-year-old female adult-child care partner]
Health issues and safety concerns accentuated in the wintertime	Can't use mobility devices on snowy icy surfaces	None identified	"…we have the walking trail right across the road from us. So, we should be able to go out on the walking trail… But it has been blocked a lot

	Fears of falling were elevated with ice and snow.		of this winter, there has been so much snow… And he can't take his walker in the snow." [P08, 75-year-old female spousal care partner]
Preparation for going outdoors and outdoor activities in winter took more time and support.	Greater difficulty in choosing appropriate attire to be active in the winter Requires a care partner to dedicate more time to help the person with dementia get ready to go outside	None identified	"....it takes [person with dementia] a while to get himself organized and ready to go. So, [I] ... might look and say "ohh well we should go for a walk", well by the time we got ready and went… I should be thinking about being back to get dinner ready or whatever.... [this is more of an issue in the winter] because you need your boots, you need all these things." [P02, 71-year-old female spousal care partner]
Comfort with winter driving	Being less comfortable with driving in snowy conditions	Being comfortable driving in any weather condition	"It's not harder per se to go to the gym in the winter, unless it's just had a snowstorm or something, you know, and then the roads are icy, then I wouldn't. I would wait till they're plowed." [P05] [P05, 53-year-old female spousal care partner]

Red = opportunity; Purple = motivation, blue = capability

Table A 7. The barriers and facilitators relating to people with dementia resources and social support

Sub-category	Barriers	Facilitators	Quotes
Resources and infrastructure	Space inside the home was too small to be active or to have exercise equipment. Lack of access to well-maintained trails	Having adequate space at home to be active Having access to indoor facilities, structured exercise programming, or maintained trails	"The infrastructure in the city really helps. Like we've got choices when it comes to walking… means that you can change it up and walk different places at different times" [P09, 58-year-old female adult-child care partner]
Specialized winter gear	Need to purchase new gear if they did not already have it or due to physical changes (e.g., needing larger shoes). Winter gear can be uncomfortable or not usable in all settings (e.g., shoe spikes indoors at a café)	Gear which gives security, stability, and warmth (e.g., ice cleats, winter boots, walking poles)	"If it's icy out, she has, so she has boots that are really nice, roomy boots and Manitoba Mukluks, and then she's got boots that have clickers on them, which are good on the ice. And those feel more secure on the ice, but they kind of squish her feet. Like she usually complains about her foot feet being sore because the clickers squish on her boots" [P09, 58-year-old female adult-child care partner]
Indoor activity gear or equipment (e.g., treadmill)	Requires purchasing gear if do not already have	Enhancing the activity to make it more engaging	"If we put the iPad on the treadmill and it was animals… maybe something like that will create some interest for him so that, that walking could be easier" [P08, 75-year-old female spousal care partner]

Red = opportunity; Purple = motivation, blue = capability

Appendix G: Study 4 – NITE-CAD Module

Available upon request.