The relationship between moderate physical activities and sleep quality and quantity among persons with dementia

by

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Abstract

Aims and Significance: The prevalence of dementia is rapidly increasing worldwide due to an aging population. Sleep disorders are a common characteristic of dementia, and pose a significant threat to the quality of life of persons with the condition and their families. This study compared the sleep quantity and quality between active and inactive persons with dementia.

Methods: This study used a cross-sectional design. Telephone questionnaires were administered to 40 caregivers of a person with dementia. The caregivers answered the questions as proxies on behalf of their care recipient.

Results: Active persons with dementia experienced significantly better sleep quantity than their inactive counterparts (*P*=.000). Furthermore, the active group obtained significantly better overall sleep quality scores (*P*=.003). Specifically, sleep onset latency (*P*=.021) as well as daytime napping (*P*=.000) and drowsiness (*P*=.015) were significantly correlated with activity level.

Conclusion: The preliminary evidence from this study suggests that physical activity may be an important method of improving sleep in this population. This study will aid in the promotion of safe and effective ways for managing aspects of dementia that impact quality of life and encourage future research in this area.

Keywords: dementia, physical activity, sleep quality, sleep quantity

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List of Abbreviations Used

ADLs	Activities of Daily Living
AD	Alzheimer's disease
ASDR	Alzheimer Society of Durham Region
BMI	Body Mass Index
BPSD	Behavioural and Psychological Symptoms of Dementia
CESP	Canadian Society for Exercise Physiology
CCHS	Canadian Community Health Survey
LTM	Long-Term Memory
LTPAEE	Leisure-time Physical Activity Energy Expenditure
MET	Metabolic Equivalent of Task
MOS-SS	Medical Outcomes Study Sleep Scale
NPI	Non-pharmacological intervention
NREM	Non-Rapid Eye Movement sleep
OTC	Over-the-counter
PA	Physical Activity
PD	Parkinson's dementia
PWD	Persons with dementia
REM	Rapid eye movement
SCN	Suprachiasmatic nucleus
SOL	Sleep onset latency
STM	Short-term memory
SWS	Slow wave sleep
WASO	Wake after sleep onset

Table of Contents

Chapter 1: Introduction

The world is experiencing a shift in demographics that disproportionately represents an aging population. Advancements in health care technologies and treatment options have resulted in people achieving longer lives than ever before. Statistics Canada projected that the average life expectancy in 2017 will be 79 for men and 83 for women in Canada [1]. This increase in life expectancy has resulted in a shift of focus from acute care treatment to chronic care management, as more people are living with non-communicable, chronic conditions [2].

The prevalence of dementia in society is rapidly increasing globally. In 2010, it was estimated that 35.6 million people worldwide had dementia, and the number is expected to double every 20 years at an average rate of one new case every four seconds [2]. Dementia now affects 14.9% of Canadians over the age of 65 [3]. After 65, the rates of incidence double for every five-year increment in age [2]. Dementia is characterized by the World Health Organization as a syndrome due to condition of the brain; usually of a chronic or progressive nature; in which there is a disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement [2]. Ontario had 228,000 residents living with dementia in 2016, 12,300 of which resided in the Central East LHIN [4, 5]. With a rapidly aging population, these numbers pose a serious threat to the sustainability of healthcare systems worldwide.

The economic repercussions of managing this condition are severe. The estimated total worldwide costs associated with dementia care in 2010 were $604 billion USD [2]. In Canada alone, these costs reached $33 billion in 2012 [3]. These expenses are mainly derived from a combination of informal care (45%) and formal care (40%), while only 15% are from direct medical expenditures. Far from being solely a medical concern, dementia has the ability to affect all areas of an individual's life as well as their family's life, representing the leading cause of dependency and disability among older persons [2].

Despite the growing demand for treatment, there is no known cure for dementia to-date. Currently, treatment options focus on maintaining the quality of life for persons with dementia (PWD) and their caregivers. In addition, various interventions exist to maintain physical and cognitive health as well as to manage the behavioural and psychological symptoms of dementia (BPSD) that can contribute to caregiver burden [2]. These symptoms are common and distressing for both the PWD and their caregiver. Symptoms such as depressed mood, anxiety, hallucinations, verbal and physical aggression, restlessness, wandering, and sleep disturbances are common [6, 7]. Current methods of care attempt to minimize the effects of these symptoms through early diagnosis, proper detection and treatment of BPSD, and providing education and support to caregivers [2].

1.1 Literature Review Strategy

A literature review search strategy was devised to determine the current peer-reviewed research available on sleep disturbances and physical activity (PA) in the dementia population. Multiple electronic search engines were used, including PubMed, ProQuest Nursing and Allied Health Source, and Medline. Specific keywords were used in a variety of combinations to maximize the number of articles found. This included sleep, sleep patterns, sleep quality, sleep disturbance, sleep duration, sleep improvement, PA, exercises, dementia, Alzheimer's disease (AD), and older adults. These studies were logged to avoid repeated examination.

A study matched the inclusion criteria if it was published between 2004 and September 2016, written in English, available in full-text, peer reviewed and scholarly. Studies performed in Canada were preferred, however studies from other countries were included if they met the inclusion criteria. The selected articles were thoroughly reviewed to ensure that they would provide strong insight into the issue being examined and contribute to this research in a significant way. The referenced section of relevant articles were also reviewed to take full advantage of findings. A study was excluded if it was published prior to January 2004, not available in English or full-text, and a non-peer-reviewed publication. Letters to editors, case reports, editorials, and qualitative studies were omitted.

1.2 Sleep

Sleep is an essential component for the physical processes and mental well-being of an individual [8]. It is defined as “a natural and reversible state of reduced responsiveness to external stimuli and relative inactivity, accompanied by loss of consciousness” [9]. During the sleep process, the body passes through two different states and four stages. The first state is non-rapid eye movement (NREM) sleep. NREM sleep consists of four stages where sleep becomes progressively deeper as you move from stage one to stage four. Stage one and two occur as sleep is being initiated and the individual is becoming disengaged from their surroundings. Stage three and four, known as slow-wave sleep (SWS), consist of deep sleep. It is here that restorative processes such as increased blood flow to the muscles, tissue growth and repair, memory consolidation, and energy restoration occur [9, 10]. Once this cycle has been performed, approximately 90 minutes after falling asleep, the body enters rapid eye movement (REM) sleep. During this state the body undergoes processes to support daytime performance such as providing energy to the body and the brain as well as memory stabilization [9, 10]. These states and stages recur through the night in intervals [10].

Sleep patterns are regulated by the body’s homeostatic drive and circadian rhythm. Sleep/wake homeostasis tells an individual when to sleep and aids in sleep maintenance during the night. This system is paired with the circadian rhythm, which regulates feelings of sleepiness and wakefulness during the day and is controlled by an area in the brain called the Suprachiasmatic Nucleus (SCN) [11]. The SCN is composed of cells that react to photic and non-photic external time cues sent through the optic nerve. These cues are referred to as zeitgebers. Light represents the most influential zeitgeber [12, 13]. When the SCN receives external cues it prompts the body to undergo various processes such as releasing cortisol, a hormone that promotes alertness, and increasing body temperature in order to prepare for wakefulness. The SCN also responds to darkness by releasing melatonin, a hormone responsible for regulating sleep-wake cycles and initiating sleep [11, 14]

Despite the overwhelming evidence surrounding the importance of sleep, it is estimated that 50 percent of adults over 55 years of age experience some symptoms of sleep disturbances weekly [15]. A sleep disturbance can manifest itself in many ways. Cormier defines sleep disturbances as a term that encompasses disorders of initiating and maintaining sleep, disorders of excessive somnolence, disorders of sleep-wake schedule, and dysfunctions associated with sleep, sleep stages, or partial arousals [16]. Typically, sleep disturbances interfere with the normal sleep process by leading to inadequate amounts of sleep. As a result, these disturbances may cause an individual to sleep at the wrong time of day, or decrease sleep quality [17]. A decrease in total sleep duration, an increase in sleep fragmentation, and less time spent in REM sleep and slow-wave sleep are all hallmarks of aging that harm sleep quantity and quality [12]. These changes can impair social functioning and increase an individual’s risk of cognitive errors and physical accidents [12, 17]. Although the rate of sleep disturbances typically increase with age [18], these issues affect people of all ages at some point in their lives [19].

Sleep disturbances can take a significant toll on the individual, their family, and the economy. Lower quality-of-life ratings have frequently been cited in chronically sleep-deprived individuals [20]. The experience of decreased enjoyment in social interactions, and an impairment in the capacity to carry out daily tasks among these individuals have been reported. Measures of cognitive processes and physical functioning have repeatedly shown that sleep deficiency can lead to performance deficits [20]. These deficits include decreased response time, increased cognitive errors, limited ability to learn new information, and a decreased ability to carry out critical-thinking skills. All of which have been shown to have a direct causal link to motor vehicle accidents (MVA), work-related injuries, and falls in older persons [20].

The effects of sleep disturbances are not limited to the affected individual. Those who share a bed with an individual who experiences sleep disturbances may also have lower quality of life measures, poorer health, increased rates of depression, and increased rates of marital and/or partner unhappiness [21]. This can impact their ability to earn an income, carry out daily tasks, and care for other family members. As a result, an increase in sick-days and higher rates of institutionalization of the individuals they care for have been observed, which results in economic loss for the community [20].

The economic impact of sleep disturbances can be categorized as direct costs, indirect costs, and related costs [22]. Direct costs comprise the medical and nonmedical expenses, such as diagnostic tests, treatment costs in the form of prescription drugs or over-the-counter (OTC) medications, and institutionalization [22]. Indirect costs consist of related expenditures that result from morbidity and mortality associated with sleep disturbances. They include workplace accidents, loss of productivity, absenteeism, falls resulting from sleepiness, motor vehicle accidents, and depression [20, 22]. Related costs are the non-financial implications of sleep disturbances that include pain, suffering, and inconveniences in both seeking treatment and in the inability to carry out daily tasks [22]. Findings from a study performed in Québec [23] found that the annual direct and indirect economic costs of individuals who report to having insomnia were $5,010, compared to only $421 in those who do not report to this sleep disorder. These costs consist of medications and other sleep aids, consultations with sleep professionals, and transportation to appointments. The authors also found that the total annual cost of insomnia in Québec was $6.6 billion. Health care appointments addressing sleep concerns made up $191.2 million of this amount, as well as $16.5 million in prescription medications, $1.8 million in OTC medications, and $339.8 million in alcohol being purchased for sleep purposes. Indirect costs consisted of $970.6 million from workplace absenteeism, and $5.0 million in loss of productivity [23]. The specific costs associated with dementia will be discussed below in section 1.3.1. Due to their high prevalence and numerous associated complications, the direct, indirect, and related costs of sleep disturbances have a significant impact on the individual, their family, and the community [20].

Age-related changes place older adults at an increased risk of experiencing a sleep disturbance [18]. The underlying causes may be external, such as retirement or experiencing a loss [24], or internal such as degeneration of the SCN [12]. As the SCN deteriorates its ability to absorb photic and non-photic time cues is reduced, therefore impairing the regulation process. An individual’s ability to regulate their homeostatic drive is also reduced with age [18]. This results in more awakenings during the night and less time spent in SWS and REM sleep, which limits the restorative effects that these stages have, and harms the individual’s ability to function in the daytime [14, 18]. This may lead to daytime napping which compounds the problem of inadequate amounts of light being received by the SCN and impairs the absorption process [12].

Nocturnal melatonin production also decreases with age. This reduction often leads to an increase in sleep disturbances and reduced sleep efficiency due to an impairment in the body's ability to regulate sleep-wake cycles [12].

A subgroup of the older adult population who is at an increased risk of experiencing excessive age-related changes to their sleep patterns is PWD. The neurodegenerative aspects of dementia both contribute to and compound the normal changes in sleep quality and quantity that typically occur with age [25]. As a result, risk to the quality of life due to sleep disturbances is much greater in this group, and makes them a particularly important population to target sleep interventions towards.

1.3 Sleep disturbances

Chronic sleep disturbances represent a debilitating characteristic of dementia, affecting up to 70 percent of PWD [26]. These disturbances are frequently manifested as difficulty sleeping at night, excessive daytime sleepiness, and an increase in sundowning behaviours [26, 27]. For this study daytime sleepiness or drowsiness was described as "an increased propensity to doze off or fall asleep" [28]. This is distinct from fatigue, which is "a feeling of strain or exhaustion" [28].

People in the late stages of dementia spend approximately 40 percent of their time in bed at night awake [26]. As a result, these individuals may experience excessive daytime sleepiness to the extent that no daytime hour passes without an unintentional sleep episode [27]. Sundowning occurs in approximately 12%-25% of individuals with AD [27]. It is defined as a common clinical phenomenon manifested by the emergent or increment of neuropsychiatric symptoms in the late afternoon, evening, or at night [29]. Frequent sundowning behaviours include vocalizations, wandering, disorientation, and extreme restlessness or agitation [26, 27].

These behaviours can be very disruptive and harmful to an individual and their family, and often require a combination of pharmacological, behavioural, and/or environmental interventions [27].

The pathophysiological correlation of dementia with sleep disturbances is not completely understood [27]. Previous studies have identified excessive damage that results from dementia in the neuronal pathways located in the SCN as a potential cause [25]. Postmortem examinations have also found a decreased cell-count in this particular area, suggesting impaired functioning of the SCN regulatory processes [27]. As a result, this impairment greatly impacts an individual's ability to maintain proper sleep-wake patterns. In severe cases, a complete flip in the normal nocturnal-sleepiness and daytime-wakefulness cycle has also been observed [26]. Another factor may be contributed by the markedly decreased melatonin levels in PWD. Evidence suggests that melatonin levels in PWD are 80% less than the levels in age-matched individuals without dementia [27]. These changes may increase the severity of sleep disturbances that typically occur with aging, leading to a decrease in sleep quality and quantity for PWD and their primary caregivers.

Memory loss is an established characteristic of dementia. Short-term memory (STM) loss is often one of the first symptoms that become apparent in the early stage of the disease. STM is essential for creating new memories made from information obtained within the past hours, days, or months [30]. Long-term memory (LTM) remains largely unaffected until the condition has progressed significantly [30]. There is a growing body of evidence confirming the importance of sleep in the consolidation of new memories [9]. The memory-forming process essentially consists of three stages: encoding, consolidation, and retrieval. During the encoding process the memory is at an increased risk of interference due to subsequent incoming stimuli therefore impairing the consolidation process [31]. Sleep diminishes this risk by reducing the amount of external noise that an individual experiences thus creating an environment more suitable for consolidating memories [32]. The role of sleep in this population is therefore of pivotal importance to both maintaining quality of life and decreasing the symptoms associated with dementia [9].

The consequences associated with sleep disturbances in PWD can be devastating for the individual, their family, and society. Caregivers in particular are disproportionately affected by dementia-related behaviours regarding sleep [27]. The unpredictable nature of nocturnal sleep disruption requires constant monitoring which can result in sleep loss and stress over caregiving duties as well as over the sleep loss itself [27]. Recent studies have found that two-thirds of caregivers report a loss in total sleep time by being awaken earlier than anticipated due to their partner's disruptive behaviours. Nocturnal awakenings were also a frequently cited problem [33]. The majority of caregivers have had their sleep interrupted by the confused awakenings of their partner as well as other dementia related behaviours that occurred in their partner's sleep. The latter is often the result of a nightmare which includes yelling, kicking, or knocking their partner. After occurrences like these, caregivers often have difficulty getting back to sleep. This further contributes to a decrease in total sleep time as well as an inability to progress to SWS. Caregivers recognize the importance of a good night's sleep, and feel the implications that these disturbances have on their functional ability [33]. These disturbances often become too much for the caregiver to handle and are a major cause of institutionalization of PWD [27].

1.3.1 Economic Costs of Sleep Disturbances in PWD

The economic costs of sleep disturbances in PWD are significant. Institutionalization places a heavy monetary burden on the healthcare system, costing up to CAD $3000 monthly per resident [34]. The costs of prescription medications to help control sleep disturbances are another important issue. Sedative, anxiolytic, antipsychotic, and antidepressant medications are used by up to 36% of PWD to address severe sleep concerns, behavioural disturbances, and cognitive impairments [25]. These drugs are expensive. Sedative medication alone costs approximately $240 per patient, per month in Canada [35]. Making matters worse, the excess use of these medications has been shown to increase a person's risk of falls, adverse cognitive effects, mood disorders, and morbidity [25, 36]. The increase use of health care in turn drives up costs [25]. Further exploration of alternative methods to manage sleep disturbances in the dementia population is needed to help contain rising healthcare costs and to ensure a safer and more efficient method of managing dementia behaviours.

1.4 Current Methods of Addressing Sleep Disturbances in the Dementia Population

Pharmacotherapy for the management of sleep disturbances in PWD is in the form of anti-depressants, anti-psychotics, or sleeping pills. Although it is the most common intervention currently used [37], the evidence regarding its effectiveness to treat sleep disturbances is inconclusive. Furthermore, these drugs can have serious side-effects for the individual such as an increased risk of falls or disorientation. As a result of these concerns, non-pharmacological interventions (NPIs) are beginning to become recommended as a first-time approach to managing sleep disturbances [25]. The NPIs most frequently cited in the literature include light therapy, sleep hygiene, and physical activity [25]. Melatonin supplementation will also be discussed due to its popularity, however in this study it was not considered non-pharmacological.

1.4.1 Light Therapy

Light therapy is a widely studied NPI for sleep disturbances in PWD [25]. This therapy instructs individuals to sit in front of a full-spectrum sun-ray light box at a certain distance for a set duration of time [23, 24]. Previous studies that have incorporated this approach as a component of their intervention have shown positive results such as decreased frequency and duration of night-time awakenings [38], and clinically significant reductions in daytime sleep [39]. Although seemingly effective, the up-front cost of purchasing this intervention is high. Small lamps generally retail for around $130 whereas larger ones can cost upwards of $300. Furthermore, a caregiver is often needed to ensure that the individual is using the device correctly [25].

1.4.2 Sleep Hygiene

The sleep hygiene approach refers to managing an individual's behaviours with regards to sleep habits and routines, as well as creating an environment that is suitable for sleep [25]. This includes making changes to their bedtime, rising time, and frequency and duration of daytime napping. Common changes consist of limiting the length of daytime naps to 30 minutes or less, and ensuring that napping does not occur after 1 p.m. The caregiver is also encouraged to identify triggers to night-time awakenings and to devise strategies to help minimize or eliminate these triggers [25]. This is often used as a first-line treatment for insomnia, and has shown positive effects for improving sleep disturbances in PWD [27]. McCurry and colleagues found that utilizing sleep hygiene techniques lead to improvements in sleep quantity and efficiency, as well as a reduction in the number of night-time awakenings and daytime sleep [40]. The major barrier to this intervention method is the extensive amount of time and effort that it requires from the caregiver. Caregivers are instructed to review sleep hygiene educational materials regarding sleep habits as well as diet, general health, and environmental factors that can affect sleep. An individualized sleep hygiene program is then developed with the caregiver as well as strategies to troubleshoot problems that may arise with regards to adherence [25, 38, 40].

1.4.3 Melatonin Supplementation

Melatonin is a key hormone in the regulation of bodily rhythms including sleep initiation and regulation [41]. Jet lag is a physiological condition that commonly affects travelers who fly across several time zones. It occurs when the body’s circadian rhythm is out of sync with the day-night cycle at the destination location. Melatonin supplements have shown positive results for regulating the sleep-wake cycles of travelers, thereby increasing sleep duration and efficiency [42]. Sleep efficiency is the ratio of the total sleep time to the time in bed at night awake, indicating how much of an intended sleep episode is actually spent sleeping [10].

Although these results have been observed among travelers, further consideration of this method for addressing the disturbed sleep cycles of PWD is warranted. Deschenes & McCurry investigated the utility of melatonin supplementation among the dementia population. They reported that the two largest placebo-controlled trials to date that investigated the direct impact of melatonin supplements on insomnia yielded nonsignificant findings [41].

Although it may not be useful as a stand-alone treatment, previous research has suggested that melatonin may be beneficial for sleep when used in conjunction with light therapy. Deschenes & McCurry reported findings from studies that investigated this relationship, which found that significant improvements in total sleep time and sleep efficiency were observed when using this combined method. Improvements in sleep onset latency were also reported, which refers to the length of time between bedtime and the onset of sleep [10]. Reported side effects of melatonin supplementation includes dysphoric mood, and future research is required to determine whether the benefits are significant enough to encourage usage [41].

1.4.4 Physical Activity

Physical activity is beginning to gain recognition as a potential NPI for sleep disturbances [37]. The Canadian Society for Exercise Physiology (CSEP) states that physical activity is: "any bodily movement produced by skeletal muscles that requires energy expenditure which increases heart rate and breathing" [43]. Exercise represents a component of physical activity, differing in the fact that it is "planned, structured, and defined by its frequency, intensity, and duration" [44]. Clinical trials for persons without dementia that have explored this method to date have included various physical activity protocols as components of interventions to explore their effect on sleep disturbances. This includes walking, aerobic and endurance activities, strength training, balance, and flexibility [25]. Of the limited evidence available, studies have demonstrated that frequent physical activity may be effective in regulating sleep cycles to increase the quality and quantity of sleep [13, 37-39]. The evidence surrounding the effectiveness of this intervention in persons without dementia suggest a strong potential for this method to be effective in the PWD population.

1.5 Physical Activity as a Sleep Aid

As the previous section indicated, physical activity is beginning to gain recognition for the positive effects it can have on sleep [37]. Physical activity may include all the activities in day-to-day living, whether professional, domestic, or leisure-time. The benefits of physical activity are well-known and widely accepted. They include improvements in body composition, metabolism, cardiac function, glucose control, mood, and immune function. Physical activity may also aid in regulating the hormone levels that are typically disrupted from a lack of sleep [44]. Previous research has suggested that sleep disturbances are associated with elevated levels of cortisol, which is a key hormone in the regulation of stress. Poor sleep can also lead to a decrease in glucose tolerance and insulin resistance, which are risk factors for weight gain. Physical activity can aid in the regulation of these hormones, which are important for physical and mental well-being [44]. Taken together, these benefits may contribute to positive changes in the sleeping patterns of individuals with sleep disturbances.

Despite the large body of evidence supporting an active lifestyle, 48% of Canadians were classified as inactive in their leisure time in 2005 [45]. The economic costs of inactivity are severe. In 2001, inactivity cost the Canadian government CAD $5.3 billion dollars in direct and indirect costs, representing 2.6% of total health care costs [46]. These inactivity levels have also shown to increase with age. Survey responses from the 2005 Canadian Community Health Survey (CCHS) found that 14% of Canadians aged 65+ reported no, or very little physical activity compared to only 4% of those aged 12-17 [45]. PA is extremely effective in reducing older adults' risk of chronic diseases such as heart disease and high blood pressure. It has also consistently demonstrated its effectiveness at maintaining an individual's functional independence and mobility, maintaining bone health, and improving mood and mental health [43]. The wide array of health conditions caused by physical inactivity show that it has the potential to affect multiple bodily functions that may interact and harm sleep.

The benefits of physical activities are well-documented in younger populations and those who do not report to having frequent sleep disturbances. In adolescents, regular, moderate-intensity physical activity has been associated with improvements in sleep duration and efficiency. These benefits were translated into enhanced mood and concentration during the day as well as improved subjective sleep quality ratings [44].

Similar results have been observed in adults who report to having chronic primary insomnia. Moderate aerobic physical activity, defined as any activity that increases heart rate and breathing but where it is still possible to speak comfortably [43, 44], as an intervention has been found to decrease sleep onset latency and increase total sleep time. As a result, increased feelings of being well-rested and quality of life measures were observed as well as a decrease in ratings of tension-anxiety, depression, and total mood disturbances. Surprisingly, these results were not observed in interventions that used high-intensity aerobic physical activity and resistance physical activity [37, 47]. This suggested that the mode of physical activity may have a strong effect on the success of the treatment and that it is important to consider the characteristics of the participants before recommending a method of physical activity.

Older adults with mild to moderate sleep complaints have also been the target of interventions to reduce sleep disturbances. Moderate-intensity endurance physical activity, described as 35-40 minutes of aerobic movements along with stretching, strength, and balance exercise, has been found to decrease awakenings during the night, increase slow wave sleep, decrease sleep-onset latency, and increase feelings of being well-rested throughout the day [48].

It is clear that physical activity may work as a sleep aid through intricate and reciprocal systems. Nevertheless, it is difficult to understand the direct mechanism linking physical activity and sleeping patterns. Although various studies explore the effectiveness of this treatment in younger cohorts or those with minimal sleep disturbances, literature on the elderly and those reporting sleep disturbances is scarce [44]. The following section will analyze existing studies and research on the effectiveness of physical activity specifically in the dementia population.

1.6 Physical Activity as an Intervention in the Dementia Population

Although sparse, existing research has suggested positive results for the use of physical activity as an intervention to improve sleep disturbances for PWD [6]. There are many mechanisms by which this may occur. For example, physical activity may decrease the psychological symptoms of dementia that impair sleep, such as anxiety and depression. It may also promote relaxation which can benefit sleep initiation [49]. Furthermore, regular physical activity is associated with an increase in core body temperature that aids in sleep initiation and decreases night-time awakenings [6, 50]. During the day, physical activity can decrease daytime napping by keeping PWD occupied and out of bed, therefore maintaining the sleep-wake cycle and encouraging nocturnal sleep [6]. Despite these benefits, current evidence lacks homogeneity therefore making it difficult to determine what mechanism of physical activity is effective in improving sleep. Studies investigating this relationship used mixed inclusion criteria, implemented various methods of physical activity, and used different outcome measures [6]. Further research is required to determine if a definite relationship exists, and, if so, what modality and dose of physical activity shows the greatest potential in ensuring that this benefit occurs.

Physical activity has been interpreted with a great degree of variability amongst existing studies. Prior research that has shown positive results with regards to sleeping patterns have implemented various regimens. This included low-level physical activities, regular moderate-intensity physical activity programs, indoor gardening, daily walking, a combination of physical resistance strength training and walking, “meaningful activities” that were geared towards the interests of the subjects, and unspecified daily physical activity [13, 38, 39, 51-56]. Only a few studies examined physical activity as the only intervention [51, 52]. For the majority of studies, the physical activity component was often used in combination with other treatments such as sleep hygiene therapy, increased daytime bright-light exposure, social activities, and reducing environmental stimulants that may disrupt night-time sleep [13, 38, 39, 53, 54, 56]. As a result, it was difficult to tease out the benefits of physical activities alone.

The outcome measures used to indicate the effect of the intervention on sleep also varied extensively. Specifically, total nocturnal sleep time, frequency and duration of night-time awakenings, sleep efficiency, and daytime napping frequency and duration were common measures used [13, 38, 39, 52-54]. Nonetheless, physical activity was observed to have a positive impact on most of these measures in the majority of studies.

Another outcome measure that is indirectly associated with sleep is BPSD. Behavioural disturbances such as wandering and restlessness may significantly contribute to inadequate levels of sleep. Furthermore, the psychological symptoms, namely anxiety and depressed mood, can impact sleep [6]. Current knowledge suggested a bi-directional relationship between sleep and mood. Chronic insomnia has been associated with an increase in the development of mood disorders such as anxiety and depression. Disturbed sleeping patterns also impair an individual's ability to respond to psychotherapy to treat mood disorders [36]. This further decreases an individual's quality of life. Previous studies have found that interventions such as walking, moderate-intensity chair-based physical activities, and moderate-intensity combination physical activity programs have been successful at reducing behavioural disturbances, as well as at reducing anxiety and depression levels [38, 51, 55, 57]. Similar to the previous studies discussed, these interventions often included other components in the intervention, making it difficult to distinguish if physical activity directly impacted these outcome measures.

There is clearly a lack of evidence that supports physical activity as an effective intervention to alleviate sleep disturbances in PWD. Despite the fact that physical activity is cost-effective, easily accessible [37], and has shown positive results in the non-dementia population, no published studies that I am aware of have determined the isolated effects of physical activities on sleep for community-dwelling PWD. Studies are needed to determine which aspects of physical activity lead to the positive outcomes found in the studies discussed above, specifically from the Canadian context.

1.7 Current Knowledge on Physical Activities Included in this Study

1.7.1 Walking

Walking was defined as a form of aerobic physical activity that involves rhythmic or repetitive activity using several large muscle groups of the lower extremities [58]. Previous studies have typically used a 30-minute intervention length of walking at a speed that is either of the individual's preference, or that meets a set target heart rate [53, 59, 60].

A population that tested the effects of walking on sleep outside of the dementia community included women diagnosed with early-stage breast cancer. A six-week walking program that included 30-minutes of walking per session showed positive results compared to controls in reducing sleep disturbances for participants [59].

Amongst PWD, walking has been shown to result in a decreased number and duration of nighttime awakenings, and improvements in sleep efficiency [53]. Furthermore, improvements in nighttime restlessness and increased daytime activity levels were also observed which, although not statistically significant, had clinical significance [60]. While walking may be a valuable aspect of a larger intervention, there is inconclusive evidence that walking, by itself, is an effective form of physical activity to reduce sleep disturbances in various populations.

1.7.2 Gardening

Gardening is a potentially positive intervention for PWD. It is believed to be an enjoyable activity that provides a sense of accomplishment while requiring minimal supervision by a caregiver [52]. There are a few studies that examined the effects of gardening on sleep in PWD. In a study performed by Connell and colleagues [61], the effects of indoor gardening were compared to those of outdoor gardening. Both indoor and outdoor gardening showed positive results for the individual's sleep. Nocturnal sleep duration significantly increased for both groups despite the outdoor group being exposed to significantly greater amounts of sunlight, which was expected to skew results. Additional findings from a study by Lee & Kim [52] found that indoor gardening produced effects such as improvements in wake after sleep onset (WASO), or time spent awake at night not including sleep onset [62], decreased napping, increased nocturnal sleep time, and greater nocturnal sleep efficiency. Significant decreases in agitation was also observed, which may aid in the sleep process.

1.7.3 Swimming

There is a very limited amount of scientific evidence available which demonstrates that swimming is an effective intervention to reduce sleep disturbances. Swimming is a form of aerobic physical activity performed in water that uses the body's large muscles to move in a rhythmic manner for a sustained period of time. Activities like swimming help improve cardiorespiratory fitness [43]. In a study that compared the quality and quantity of sleep amongst adolescent athletes compared to their non-athletic counterparts, sleep quality and quantity were significantly higher in the athletic group. Findings included shortened sleep onset latency, a smaller number of nighttime awakenings, increased daytime concentration levels, and decreased fatigue during the day. A limitation to these findings was that amongst the athletes, only 6.4% of female athletes and 8.4% of male athletes included identified swimming as their only sport [63]. Therefore it was difficult to draw conclusions regarding the impact of swimming on the observed results.

Swimming may be an effective intervention for older adults with insomnia as well as PWD. An intervention that included swimming as a component lead to significant reductions in daytime sleep as well as improvements in daytime dysfunction. Additional findings were significant improvements in subjective sleep quality, sleep efficiency, and sleep duration [64]. These results are beginning to be recognized in the dementia community. A water-based physical activity program currently exists that is evidence-informed and specifically developed for PWD. The program recognizes the potential benefits of this form of physical activity to reduce sleep disturbances and improve quality of life for this population [65].

1.7.4 Dance Therapy

Despite having positive impacts on the sleep patterns of individuals without dementia, dance-based physical activity has insufficient evidence to support itself as an effective intervention for PWD. Previous studies that have used dance as an intervention characterized it as a form of moderate-intensity physical activity that involved movement of the head and trunk and the shifting of the center of gravity in every direction from the axis of support [43, 66]. There have been significant improvements in sleep quality and quantity observed in individuals who have participated in programs that use dance-based physical activity as the intervention. These results have been observed in adults and older adults aged 58-68 [66, 67].

Popular or social dance has been implemented in various nursing homes that direct this intervention to PWD. Nevertheless, sleep is not a common outcome measure used. Previous studies often used psychological outcome measures while not considering the potential positive impact on sleep [68].

1.7.5 Weight Training

Weight training may improve sleeping patterns in the dementia population. It is defined as a form of physical activity that involves muscles contracting against a type of resistance greater than normally experienced to increase skeletal muscle strength, power, endurance, and mass [58]. Various studies have explored the effects of strength training on sleep amongst older individuals [54, 69, 70]. These studies also acknowledged that weight training has yet to be explored adequately [69].

Weight training is a form of physical activity that must be implemented progressively to avoid injury and other negative adverse events from occurring. The studies examined used resistance training in the form of bench press, leg press, leg extensions, rowing, shoulder press, arm curls, hip, and arm extensions. These physical activities were often implemented with the minimum amount of weight to begin with and then increased progressively [54, 69, 70]. The outcomes observed were generally positive with regards to sleeping patterns. An improvement in total nocturnal sleep time and sleep efficiency, increases in REM sleep, increased subjective sleep quality, and a lower rate of awakenings during the night were observed [54, 69, 70]. The participants in these studies ranged from older adults aged 65-80 in nursing home and assisted living residences. These programs should be replicated in the dementia population to determine if similar results would occur.

1.7.6 Exercise Class

Exercise classes have shown to be very effective at improving sleep quality and quantity amongst various populations [48, 51, 71-73]. Based on the characteristics of previous studies that have used exercise classes as an intervention, it is defined as a physical activity program run by a professional outside of an individual’s home that consists of more than one form of physical activity. The programs utilized various forms of physical activities such as strength, flexibility, aerobic, and balance activities that were performed successively to make a program. Although the results were typically positive, the high level of variation amongst the programs’ level of intensity made it difficult to tease out what components of the program were responsible for the observed results.

Adherence to physical activity programs has shown mixed, albeit generally positive results. King and colleagues found that 74% of older adults with sleep complaints adhered to the prescribed physical activity program. Participants attended an average of 3.7 of 5 prescribed sessions per week [48]. Classes that implemented yoga also had good adherence. Of the 67 assigned to the intervention, only 3 participants did not complete the sessions, whereas 6 of the 76 control group participants withdrew. A program that consisted of tai-chi and low-impact activities showed that 93% of the tai-chi participants, and 81% of the individuals in the low-impact exercise program attended 50 or more of the 72 sessions. The median compliance was 60 sessions. This study noted that of the drop-outs that occurred, 66% of them withdrew within the first 3-months [72]. This observation may be important to consider when implementing future programs. An adherence rate of 70% or more was observed in 14 of the 17 PWD involved in a 1-hour exercise session conducted 3 times a week in a program that used a multimodal approach to physical activity [73]. Additional studies that have focused on the dementia population have found that adherence rates are maintained following the intervention. McCurry and colleagues found adherence rates were maintained after the exercise program ended. Findings demonstrated that 62% of participants in the active treatment group continued to perform the activities from the intervention. This study also demonstrated high adherence during treatment, with a mean of 80.4% ± 24.6%. The reported findings from the studies discussed above suggest a strong potential for exercise programs to be a sustainable intervention for PWD and persons without dementia [53].

The effects of exercise classes on the sleeping patterns of older adults have been explored to some extent. Exercise classes have been in the form of yoga and stretching, balance exercises, endurance exercises, strength training, and tai chi [73]. These classes consist of multiple combinations of the exercises stated above, often performed for one hour per day for up to three days a week. The findings are typically positive, and consist of significant improvements in sleep such as reduced sleep onset latency, more time spent in stage two sleep and less in stage one, and decreased daytime dysfunction [48, 71]. Furthermore, improvements in subjective sleep quality, increased sleep duration, and fewer sleep disturbances were also reported [71, 72].

Similar findings exist within the dementia population. When PWD were exposed to exercise classes that consisted of combinations of aerobic or endurance activities, strength training, and balance and flexibility activities, significant improvements in their sleeping patterns were observed. This included reductions in reported sleep disturbances, improved subjective sleep quality, reduced nocturnal wandering, and reductions in hypnotic medications used by participants [51, 73]. Although the evidence available showed that there is a positive association between exercise classes and improved sleep, further investigation is warranted to determine what components of an exercise class are necessary to ensure these results.

1.8 Barriers to Physical Activity in the Dementia Population

The physical activity levels of an individual are heavily dependent on the barriers that they have to overcome, and the resources that are available to them. Stubbs and colleagues demonstrated that only 30.7% of PWD involved in a physical activity intervention achieved the level of physical activity that the study prescribed [74]. Reasons for this involvement rate are widespread across the individual’s life. They can be categorized as demographic, biological, behavioural, psychological, social, and environmental factors.

1.8.1 Demographic Factors

Stubbs and colleagues found that age has a negative effect on physical activity levels. Specifically, age was shown to have a greater impact on the physical activity levels than the stage or duration of the dementia, gender, ethnicity, and socio-economic status [74]. Accordingly, the age of the PWD must be considered when determining the appropriateness of physical activity as an intervention to improve sleep.

1.8.2 Biological Factors

Biological factors look at the influence of genetics on physical activity levels. Common biological factors that serve as barriers to physical activity participation for PWD include decreased gait and walking ability, high body mass index (BMI), recurrent dizziness, and pre-existing health conditions [74, 75]. A negative association between amount of comorbidities and motivation to participate in PA has been identified in a previous study. Reasons cited for this association may involve having to miss physical activity sessions to attend appointments as well as possible hospitalizations and a physical inability to complete activities [74, 75]. Physical activity may in fact help reduce some of these biological factors, and should therefore be implemented as early as possible [75].

1.8.3 Behavioural Factors

Behavioural factors that decrease physical activity involvement consist of taking four or more medications daily, being prone to falls, and experiencing difficulty in carrying out activities of daily living (ADLs). Physical activity has been shown to increase the ability of an individual to perform ADLs, as well as prolong frailty, and therefore should be implemented as early as possible to ensure that these barriers are minimized [74].

1.8.4 Psychological Factors

Fewer waking hours during the day as well as a negative attitude towards physical activity are the psychological factors that act as barriers to physical activity [74, 75]. These were found to be more impactful on activity levels than global cognition and depression [74]. As previously stated, physical activity may decrease daytime napping and therefore increase waking hours during the day by keeping individuals occupied [6]. Therefore this intervention may, in itself, help decrease the psychological barriers that currently exist.

1.8.5 Social Factors

Social factors can refer to the characteristics and presence of a caregiver who can help the PWD with daily tasks. Due to a decreased ability to carry out ADLs, PWD often require the assistance of a caregiver to accomplish numerous tasks [2]. Physical activity is one of these tasks. The caregiver's health and availability determines the level of support that they are able to provide. If the caregiver has other commitments or is in ill-health, this may act as a barrier because the PWD cannot participate in these activities unsupervised. Social capital can also refer to having other people to exercise with. Findings from previous studies indicated that some individuals prefer to exercise in groups and to make it a social event in order to facilitate adherence and compliance. Furthermore, social functioning in general was related to physical activity participation. It has been found that if the individual has low social functioning, the amount of physical activity that they engaged in was less than that of someone who had higher social functioning. [75].

1.8.6 Environmental Factors

Environmental factors are another set of potential barriers to physical activity. Poor weather as well as having to be away from home were cited as reasons that prevented engagement in activities [75]. Bauman and colleagues [76] identified perceived access to recreational facilities as the most consistent predictor of physical activity engagement. This study also found that socioeconomic class had a role in PA engagement, specifically the fact that individuals in a higher social class reported increased levels of PA. Access to economic resources are necessary to ensure that an individual is able to purchase appropriate memberships and equipment to partake in activities [76]. Future programs should take this into consideration when designing physical activity programs for PWD by focusing on home-based exercises, or providing transportation to those who need it.

1.9 Rationale and Significance

Despite the growing body of evidence indicating the severity and frequency of sleep disturbances in the dementia population, research on whether physical activity decreases these disturbances is sparse. Previous studies have focused on the effects of an intervention that included various components such as physical activity, sleep hygiene, social activity, and bright light exposure in a variety of combinations. Although these have typically shown a positive impact, it is impossible to draw a clear relationship from physical activity alone. Furthermore the physical activity component of these interventions often include a small variety of activities that were typically limited to one intensity level. As a result, these studies excluded other forms of physical activity that could have potentially improved sleep quality.

Evidence has also indicated that persons over 65, specifically PWD, are at a higher risk of sleep disturbances due to the additional neurodegenerative damage that is characteristic of dementia [26, 27]. Although various studies have shown a strong potential for physical activity as an intervention in young, good-sleepers, there is a lack of evidence in the elderly, poor-sleeper group, particularly PWD [44]. This research targeted the dementia population who have the greatest room for improvement. In particular, this study sought to elucidate the positive impact of physical activity on sleep quality and quantity in the Canadian dementia population.

Moreover, previous research has mainly focused on people who have already been institutionalized. Finding effective interventions to address sleep disturbances in the community population is crucial to improve the quality of life for the individual and their caregiver, and to possibly delay institutionalization which can be extremely expensive [20, 22, 27] . This study helped compensate for the lack of data regarding community-dwelling PWD and identified an intervention that is effective at improving sleep for these individuals.

1.10 Aim and Objectives

The main objective of this study was to explore the relationship between moderate physical activities and sleep quality and quantity in the dementia population in the Durham Region of Ontario, Canada. A wide range of activities were included to provide a comprehensive understanding about the types of activities PWD participate in and how they relate to their sleep quality and quantity.

1.11 Research Questions

The research questions for this study were as follows:

1) What are the types and levels of engagement in physical activities in the dementia population in the Durham Region of Ontario, Canada?
2) What is the relationship between moderate physical activities and self-reported sleep quantity (i.e. nocturnal duration) in the dementia population in the Durham Region of Ontario, Canada?

3) What is the relationship between moderate physical activities and the self-reported quality of sleep that PWD experience in the Durham Region of Ontario, Canada?

1.12 Hypotheses

It was hypothesize that:

1) PWD who engage in moderate physical activities are more likely to have an appropriate number of sleep hours defined as achieving 6-9 hours per night [77].

2) PWD who engage in moderate physical activities will report better sleep quality compared to those who do not engage in PA.

Chapter 2: Methods and Materials

2.1 Research Design

This proposed study included PWD and their primary caregivers living in the Durham Region. The caregivers acted as the proxy participants for this study, providing information about the PWD. The study was designed to compare sleep quality and quantity experienced by PWD according to the activity levels that were reported. The cross-sectional method was selected due to its ability to determine the relationship between an exposure and an outcome at a fixed point in time [78].

There were several advantages and disadvantages of the cross-sectional design. In terms of disadvantages, temporality was difficult to determine considering the exposure and outcome were measured simultaneously. As a result, it was difficult to draw conclusions about causality [78-80]. Moreover, the cross-sectional study design only provided a snapshot of the population. The results observed may be altered if a different time-frame was used, decreasing the generalizability of this design [80]. The study design also had limited ability to observe trends over-time [78].

An important advantage of the cross-sectional design was that it was relatively easy and economical to perform [78, 80]. Cross-sectional designs are often used as a first step for determining possible associations between variables when there is a limited amount of existing research on the topic [79, 80]. This allowed for the generation of hypotheses for future research in this area. In addition, data from this study were very timely which made it an attractive method to use. Loss to follow-up was eliminated considering the data were collected only once per participant. It was also easy to identify whether an association existed between the independent and dependent variable with the cross-sectional design [80, 81].

2.2 Measures

All surveys were administered as telephone interviews (Appendix 9). The caregiver completed the questionnaire verbally and the PWD was invited to participate alongside the caregiver if they desired. In situations like this, verbal assent or agreement from the PWD was obtained prior to the commencement of the phone interview. The survey took approximately 5-10 minutes to administer, and the conversation was approximately 10 minutes in total. This included the assent process for the PWD, completing the survey, and debriefing information.

The questionnaire inquired about the demographics, physical activity engagement, and sleep quality and quantity of the person with dementia whom they cared for. Resources used to aid in the design of this survey included the CCHS (2014), and the Sleep Scale from the RAND Medical Outcomes Study (MOS-SS). All surveys from RAND Health are public documents that are available without charge [80]. The CCHS physical activity component was adopted to determine an individual's activity level, and the MOS-SS was used to help measure sleep quality and quantity.

Sleep was evaluated using a modified version of the MOS-SS. The MOS-SS is a 12-item questionnaire that has consistently demonstrated validity and reliability for assessing the impact of disease on sleep [82]. Cronbach's alpha scores for this questionnaire range from 0.71 to 0.81, which is adequate established reliability [83]. Furthermore, sufficient construct validity has been reported for this questionnaire, namely that scores on the MOS-SS are moderately correlated with other health related quality of life surveys [83]. The key constructs of sleep that it evaluated included sleep disturbances, quality of sleep, snoring, awakening short of breath or with a headache, sleep adequacy, and somnolence [84]. Considering this study used proxy participants in the form of caregivers, questions that inquired about the feelings or emotions of the PWD were removed or re-worded to assess observable traits.

Physical activity levels were calculated by assessing the frequency and duration of participation in various physical activities for each PWD. The physical activities that were included were adopted from the physical activity list in the 2014 CCHS (2014) (Appendix 15). The activity list in the CCHS was adapted to reflect the appropriateness and presence in the literature of these activities for older persons. For example, downhill skiing was excluded. Participants were asked about how many times in a typical week the PWD that they care for engaged in these activities. They were asked how much time they generally spent performing these activities on each occasion. These numbers were used to determine if the PWD was active or inactive.

2.2.1 Dependent Variables

Two dependent variables were investigated in this study: sleep quality and nocturnal sleep quantity. Based on the information provided by the MOS-SS, sleep quality was measured by latency until sleep onset, nighttime awakenings, and daytime sleepiness. The specific questions that were used to evaluate sleep quality were 1, and 13a-13e on the sleep component of the questionnaire. The questionnaire is located in the appendix section of this thesis (Appendix 12).

Sleep quantity was the other dependent variable that was evaluated for its relationship with physical activity. Sleep quantity is the length of time (in hours) that the PWD sleeps on average per night. The National Sleep Foundation considers 6-9 hours of sleep per night as a good sleep quantity for individuals 65 and older [77]. This value was used to determine if an individual was experiencing inappropriate or appropriate sleep quantity.

2.2.2 Independent Variables

The primary independent variable was physical activity level. The activities included in this study's questionnaire were modelled after those asked about in the CCHS. Physical activity level was calculated for each respondent by using a formula identified in a previous study that used the CCHS as the data source. This formula combined the number of times an individual engaged in an activity over the past three months as well as the duration of the activity on each occasion, with an assigned metabolic expenditure of task (MET) value. This number was then divided by the length of time that the survey inquired about (three months) to determine the individual's total leisure-time physical activity energy expenditure (LTPAEE), expressed as kilocalories per kilogram of body weight per day (kkd). For this study, the length of time was adjusted to one week instead of three months to ease recall. A MET value represented the metabolic energy cost of an activity [85]. This study assigned appropriate MET values to the physical activity variables covered in the CCHS (Appendix 15). These MET values were adopted from the Canadian Fitness and Lifestyle Research Institute. Using this formula allowed for the creation of a new variable, which gave a clearer understanding of the relationship between the frequency and duration of physical activity with sleep. The formula was as follows: LTPAEE (kkd) = $\Sigma\ [(N_i \text{ x } D_i \text{ x } \mathrm{MET}_i)/7]$ where i represented the individual activity being considered.

Secondary independent variables were also examined. This included basic demographic factors, and other lifestyle habits that the literature has suggested may have an impact on sleep. The basic demographic questions that were examined included sex, education level, and marital status. These values were used to determine the characteristics of the subjects.

Regarding the factors that may impact sleep based on the literature, age, type of dementia, length of time since diagnosis, medication usage, and use of home care services were examined. Age was an important variable to examine considering increased age is a risk factor for sleep disturbances [11]. The type of dementia the subject had was inquired about, given that research has suggested that certain types of dementia are associated with more significant disruptions of the circadian rhythm [41, 86]. Length of time since diagnosis was also one of these questions, considering sleep tends to decline as the disease progresses [26]. Medication use was asked, specifically medication for the symptoms of dementia and sleep; any medication that passes through the blood-brain barrier has the potential to impact sleep. Sedative medication in particular is well-known for its ability to disrupt normal sleep architecture. Benzodiazepines are a commonly-used class of agents for the treatment of sleep disturbances; however the use of these drugs leads to a decrease in the deeper, restorative stages of sleep [87]. Whether a PWD received home care services was a final component to evaluate, considering home care services may reduce stress, which may contribute to poor sleep.

2.3 Participants

The participants were recruited via the caregiver support groups run through the Alzheimer Society of Durham Region (ASDR). There were eight locations where the support groups took place: Ajax-Pickering day group at Pickering Village United Church, Ajax-Pickering evening group at Orchard Villa Retirement Residence, East Durham at the Community Care Durham office in Bowmanville, North Durham at Trinity United Church in Uxbridge, Whitby at the ASDR office, Port Perry at the Port Perry United Church, Saturday Oshawa group at the Oshawa Senior Citizen Centre, and the Men’s breakfast support group, which was held at Denny’s Restaurant in Whitby. The support groups were attended by caregivers of someone with a form of memory impairment. A diagnosis of dementia did not necessarily have to be made for a caregiver to participate in the support group. The Alzheimer Society of Durham Region also allowed participation recruitment to occur at public education events run through the Society.

Participant recruitment occurred in-person. At the end of the support group, attendees were introduced to the study background and procedures by the research student (Appendix 11). Letters of Invitations with attached consent forms were distributed (Appendix 5). All interested caregivers completed a form that included a statement of consent and a sign-up section where they left a name, telephone number, and preferred call time. Regarding the public education events, participants were introduced to the study procedures at the beginning of the session. If they wanted to participate, they approached the research student at the end of the program and provided written consent and contact information on the letter of invitation. Participants were subsequently contacted at the time they indicated, in order to gain assent from the PWD if they were capable, and to complete the survey.

Recruitment criteria included primary caregivers of someone with a diagnosis of dementia who is community-dwelling. A formal diagnosis of dementia by a health care provider was required. Primary caregiver was defined as a family member who took primary responsibility for the care of a loved one. They did not necessarily have to live with the PWD. Community-dwelling referred to living at a home which is not a Long-Term Care facility.

Caregivers were excluded if they were not the primary caregiver of someone who had a formal diagnosis of dementia, and if their loved one lived in an institutional setting. This exclusion criteria was applied because the caregivers were asked to evaluate the ability of the PWD to provide assent. It was crucial that the caregiver was the closest person to the individual with dementia in order for them to provide an accurate evaluation of assent capacity. The PWD provided verbal assent over the phone prior to the commencement of the telephone interview; see Appendix 7.

2.4 Statistical Analysis

Statistical Package for Social Science (SPSS™) version 24 (SPSS Inc., Chicago, IL) was employed for statistical data analysis. The purpose of this research was to determine if a relationship existed between physical activity levels and sleep quality and quantity.

Descriptive statistics were performed to summarize and describe the data. This included mean and standard deviation (SD). Moderate physical activities were defined as those with a MET value of 3.0-5.99, as identified in a previous study that used the same activity list as those presented in this study [85]. By using the equation discussed previously to determine an individual's LTPAEE, respondents were classified as active if they engaged in $\geq$ 1.5 kkd of moderate physical activity [45, 85]. This was equivalent to walking for 30 minutes or more per day. Central tendency was calculated for all of the continuous secondary independent and dependent variables. The standard deviation for each variable was also calculated as a measure of dispersion to display how the frequencies were spread around the mean.

A chi-square test was used to determine whether the differences among groups with respect to PA level and sleep quality and quantity were independent. The categorical variables evaluated with this method were sex, education, marital status, type of dementia, medication usage, and use of homecare services.

An independent samples t-test and a Kruskal-Wallis *H*-test test were used to test the hypotheses with regards to continuous secondary independent variables. The t-test examined the continuous variables of age and months since diagnosis for the dependent variables PA level and sleep quantity considering they only had two possible categories. Sleep quality had three categories that subjects were grouped into, so the non-parametric ANOVA test, Kruskal-Wallis *H*-test, was employed.

To test for the possible effects of co-variates, ANCOVA was used for sleep quality. Sleep quantity was a dichotomous variable so the analysis of co-variates was not be performed. The raw sleep quality scores were evaluated against the possible covariates of age, months since diagnosis, and the numeric amount of medication and homecare service usage.

Finally, Spearman's rank test, was used to generate a matrix comparing the various aspects of sleep quality and how they were correlated with PA level. This included restlessness, sleep onset latency (SOL), frequency and duration of nighttime awakenings, daytime drowsiness, and daytime napping. This matrix evaluated how these aspects of sleep quality were correlated with one another as well as with PA level and overall sleep quality. A P-value of ≤ 0.05 was deemed significant a priori for all statistical procedures.

2.5 Ethical Considerations

Ethics approval was attained at the University of Ontario Institute of Technology Research Ethics Board (Appendix 2). Agency approval was also obtained from the Alzheimer Society of Durham Region (Appendix 4).

Persons with dementia are a particularly vulnerable population to conduct research on. The nature of dementia impairs an individual's ability to comprehend and relay information. Due to this, primary caregivers were used as proxy respondents to answer the questionnaire and provide informed consent to participate in research.

Assent was required from the PWD if the caregiver believed they were capable of understanding study procedures. There was no research conducted if the PWD dissented even if the caregiver had signed the letter of consent.

This study met TCPSII 2.1 guidelines for research involving live human participants, and received REB approval file #15-060 (see Appendix 2).

Chapter 3: Results

This chapter presented the results with regards to the three research questions, which inquired about the relationship between physical activity and sleep quality and quantity in the dementia population. The descriptive statistics included means and standard deviations. The inferential statistics included the independent samples t-test, chi-square test, Kruskal-Wallis *H*-test, ANCOVA, and Spearman's correlations.

3.1 Sample Characteristics

Out of the eight caregiver support groups and three public education sessions that were attended, 40 primary caregivers in the Durham Region agreed to participate as proxies on behalf of the PWD they cared for. Approximately 60% of all possible participants from the caregiver support groups and public education sessions signed-up for this study. This number was considered adequate given that the inclusion criteria of being community-dwelling prevented many caregivers from participating. The caregivers answered questions about the PWD's age, length of time since dementia diagnosis, type of dementia, sex, marital status, education level, use of home care supports, and medication use.

Regarding age, there were 3 participants (8%) in the 65-69 year old category, 8 (20%) in the 70-74 category, 11 (28%) the 75-79 category, 11 (28%) in the 80-84 category, 4 (10%) in the 85-89 group (10%), and 3 (8%) over 90 years old. For months since receiving the dementia diagnosis, 7 (18%) were in the 1-20 months category, 12 (30%) had been diagnosed 21-40 months ago, and 13 (33%) were in the 41-60 month category. Furthermore, there were 3 subjects in both the 61-80 month category (8%) and the 81-100 month category (8%). Finally, there were only 2 (5%) subjects who had received their diagnosis 101-120 months ago, or approximately 8-

10 years ago. Although age and months since diagnosis were analyzed as continuous variables, they were categorized for this overview to allow them to be presented in the frequency table.

Slightly over half of study subjects were males (n=23, 58%), and 17 subjects were females (43%). Only one-third of the sample had an educational level beyond secondary school (n=13, 33%), the remaining 26 (65%) has secondary and below. Most subjects were married/common-law (n=32, 80%), the remaining 18% (n=7) were not currently married/single. Options in the latter category were separated, divorced, widowed, and never married. The most common type of dementia that subjects had was AD (n=17, 43%), followed by the ‘other’ category (n=16, 40%), which included dementia with Lewy bodies (DLB), mixed dementia, frontotemporal dementia, Parkinson’s disease dementia (PD), and unspecified. These types of dementia were combined to form the ‘other’ category because there were a very small number of subjects with each of these types of dementia. Finally, 6 subjects had vascular dementia (15%). Home care services, including personal support workers, visiting nursing, or housekeeping, were used by 18 subjects (45%), the remaining 22 (55%) did not use any home care.

Medication use was also examined among study subjects. This included prescription sleep medication use, over-the-counter (OTC) sleep medication use, and prescription drugs for dementia. The majority of subjects did not use any prescription sleep medication (n=31, 78%), the remaining 9 (23%) used one or more types. This observation was similar for OTC sleep medication use, where 37 (93%) subjects did not use any and only 3 (8%) used one or more. Prescription drugs for dementia were used in just over three-quarters of the subjects (n=31, 78%), and the remaining 7 (18%) did not use any. These frequencies are summarized in Table 1.

Table 1: Demographic characteristics of study subjects

		Category	Frequency	Percent
Valid	Age	65-69	3	8
		70-74	8	20
		75-79	11	28
		80-84	11	28
		85-89	4	10
		90-94	3	8
	Sex	Male	23	58
		Female	17	43
	Months since diagnosis	1-20	7	18
		21-40	12	30
		41-60	13	33
		61-80	3	8
		81-100	3	8
		101-120	2	5
	Education	Secondary and below	26	65
		Any post-secondary	13	33
	Marital status	Not currently married/single	7	18
		Married/Common Law	32	80
	Type of Dementia	Alzheimer’s Disease	17	43
		Vascular	6	15
		Other	16	40

	Home care service usage	None	22	55
		One or more	18	45
	Rx sleep medication use	None	31	78
		One or more	9	23
	OTC sleep medication use	None	37	93
		One or more	3	8
	Rx drugs for dementia use	None	7	18
		One or more	31	78

3.2 Demographic characteristics of active versus inactive PWD

A total of 18 (45%) PWD were classified as “inactive”, meaning that they did not obtain an activity score equivalent to that of walking 30 minutes per day. The remaining 22 (55%) of PWD met the criteria to be classified as “active”.

Inactive and active subjects shared very similar mean ages. Inactive subjects had a mean age of 78.22 years (SD=6.9), and the active group had a mean age of 78.86 years (SD=7). There was a very small difference between the length of time since receiving a diagnosis of a dementia between active ($\bar{x}$=49.28 months) and inactive subjects ($\bar{x}$=46.09 months). These differences in age (*P*=.772) and length of time since diagnosis were not statistically significant (*P*=.729).

The active group was composed of more males than females (68% vs. 32%), and conversely the inactive group consisted of more females than males (56% vs. 44%). These differences were not statistically significant (*P*=.131). Regarding the type of dementia that subjects had been diagnosed with, AD was the most common among both the active (41%) and inactive (47%) subjects. This was followed by the ‘other’ category (41% of active subjects and 41% of inactive subjects). Finally, vascular dementia was diagnosed in 18% of active subjects and 12% of inactive subjects. These differences were not statistically significant (*P*=.844).

There were a greater number of married/common-law PWD in both the active and inactive group, as opposed to being single. Specifically, 86% (n=18) of active subjects and over three-quarters (78%, n=14) of inactive PWD in the sample were married/common-law. Overall, only seven subjects (18%) in the entire study sample were not currently married/single. These differences were not statistically significant (*P*=.520).

Education level was also examined. Analysis revealed that the most frequent level of education attained in both active and inactive subjects was secondary school completion or below. For the active subjects, 57% (n=12) had an educational level of secondary school and below, 43% (n=9) had any form of post-secondary including trade school, college, or university. These differences were slightly more pronounced in the inactive group, where 78% (n=14) of subjects had post-secondary and below, and only 22% (n=4) had any post-secondary. These differences were not statistically significant (*P*=.173).

Home care service usage was examined to determine whether having home support affected the activity level of a PWD. For this study home care included personal support, visiting nursing, and housekeeping. In the active group, there were a greater number of subjects who did not use any home care (59%, n=13) compared to those who used one or more (41%, n=9). The inactive group had an equal distribution of PWD who used home care services (50%, n=9) and those who did not (50%, n=9). This was not statistically significant (*P*=.565).

The final category of inactive versus active sample characteristics examined were medication use, including drugs for dementia, prescription sleep medication, and OTC sleep medication. The majority of subjects in both the active and inactive groups used at least one prescription drug for dementia (88% of active and 76% of inactive subjects). Commonly used drugs for dementia were Aricept, Exelon, Reminyl, and Galantamine.

OTC sleep medication use was not found to be commonly used in the sample. This was particularly evident among active subjects, where only 5% used one or more OTC sleep medication compared to 96% who did not use any. The findings were similar, yet slightly less pronounced in the inactive group, where 11% used one or more forms and 89% of subjects refrained from using any OTC sleep medication (*P*=.433). Finally, prescription sleep medication use was examined to determine whether any differences existed between groups. In the active group, the majority of subjects (86%, n=19) did not use any prescription sleep medication. This number was slightly smaller in the inactive group, with two-thirds of subjects using no prescription sleep medication, and only one-third using one or more. Although not statistically significant (*P*=.138), this suggested that individuals who were inactive may have been using more prescription sleep medication than their active counterparts. In summary, statistical analysis revealed no significant differences between the inactive and active group regarding their demographic characteristics. These findings are summarized in Table 2.

Table 2: Characteristics of subjects who are classified as active (≥1.5 kkd) or inactive (<1.5 kkd)

	Inactive subjects (n=18)	**Active subjects (n=22)**	**x^2 or *t***	***P*-values**
	N (%) or mean ± SD	**N (%) or mean ± SD**		
Age in years	78.22 ± 6.9	78.86 ± 7.0	-.292	.772
Months since diagnosis	49.28 ± 22.9	46. 09 ± 32.70	.349	.729
Sex				
Males	8 (44)	15 (68)	2.28	.131
Females	10 (56)	7 (32)		

Type of dementia				
Alzheimer’s	8 (47)	9 (41)	.340	.844
Vascular	2 (12)	4 (18)		
Other	7 (41)	9 (41)		
Marital status				
Married/common-law	14 (78)	18 (86)	.415	.520
Single	4 (22)	3 (14)		
Education level				
Secondary and below	14 (78)	12 (57)	1.857	.173
Any post-secondary	4 (22)	9 (43)		
Home care service usage (nursing, personal support, housekeeping)				
None	9 (50)	13 (59)	.331	.565
One or more	9 (50)	9 (41)		
Use of drugs for dementia				
None	2 (12)	5 (24)	.907	.341
One or more	15 (88)	16 (76)		
OTC sleep medication use				
None	16 (89)	21 (96)	.615	.433
One or more	2 (11)	1 (5)		
Rx sleep medication usage				
None	12 (67)	19 (86)	2.203	.138
One or more	6 (33)	3 (14)		

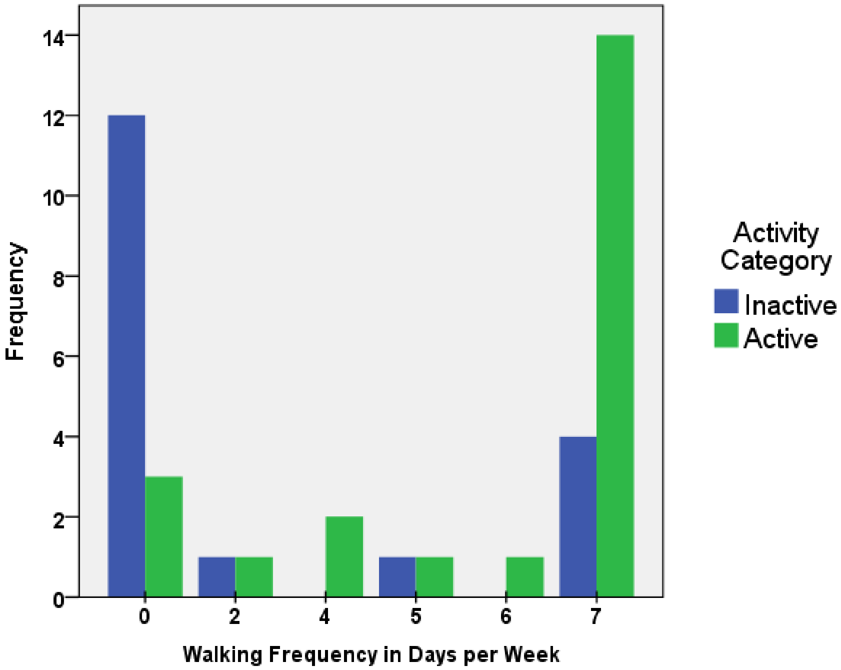
Note: SD= standard deviation. *N*’s for the two groups may not equal the final sample size due to missing data.

3.3 Research Question 1

The first research question asked about the types and levels of engagement in physical activities in the dementia population. Walking was the most frequently cited activity performed by both active and inactive subjects. Overall, almost two-thirds (63%, n=25) of respondents indicated that their loved one did some form of walking for physical activity, the majority of whom walked every day (45%, n=18). Furthermore, results revealed that 86% of active subjects used walking as a form of physical activity compared to the inactive subjects, where only 33% (n=6) of subjects walked for physical activity.

The mean frequency of walking for inactive participants was 1.94 days per week (SD=3.04). This number increased significantly in the active group, where the mean frequency was 5.41 days per week (SD=2.58). Inactive participants walked for less than 5 minutes per day (.07 hour ± .12). Consistent with the frequency pattern, active participants walked for almost one hour per day, although a large standard deviation showed that this number varied quite extensively between subjects (.96 hour ± 1). Figure 1 shows the frequency of walking among active and inactive subjects.

Figure 1: Comparison of walking frequency among inactive and active subjects



In addition to walking, exercise classes and gardening were popular forms of PA in the active group. Both exercise classes and gardening were used as activities for 27% of active subjects one or more times per week. The least popular activities for this group were golfing, skiing, home exercises, tennis, biking, and chair exercises.

Activity preference varied slightly for inactive subjects. Although walking and exercise class were still two of the most commonly used methods, chair exercises were also a popular form of PA. In fact, a greater percentage of inactive subjects participated in chair exercises compared to their active counterparts (17% vs. 3%). Another popular activity was home exercises, although the difference between the two groups was much less notable (6% vs. 0%). Activities that had a 0% participation rate in the inactive group were gardening, weight training, golfing, skiing, tennis, and cycling. Means and standard deviation are summarized below for all of the activities.

Table 3: Frequency and duration of physical activities performed by subjects

	Frequency of activity in days per week mean ± SD		**Duration of activity in hours per day mean ± SD**	
	Inactive subjects	**Active subjects**	**Inactive subjects**	**Active subjects**
Walking	1.94 ± 3.04	5.41 ± 2.58	.07 ± .12	.96 ± 1.0
Exercise class	.17 ± .38	.77 ± 1.54	.13 ± .30	.30 ± .53
Gardening	0 ± 0	.77 ± 1.67	0 ± 0	.41 ± 1.13
Chair exercises*	.94 ± 2.3	.14 ± .64	.03 ± .08	.02 ± .11
Swimming	.28 ± 1.18	.32 ± 1.13	.03 ± .12	.05 ± .21
Weight training	0 ± 0	.41 ± 1.33	0 ± 0	.07 ± .23
Golfing	0 ± 0	.09 ± .43	0 ± 0	.18 ± .85
Skiing	0 (0.0)	.05 ± .21	0 ± 0	.05 ± .21
Home exercise*	.06 ± .24	0 ± 0	.01 ± .04	0 ± 0
Tennis	0 (0.0)	.05 ± .213	0 ± 0	.01 ± .43
Cycling	0 (0.0)	.14 ± .64	0 ± 0	.01 ± .05

*, inactive subjects had a greater participation in activity than active subjects

3.4 Research Question 2

This section provided the findings with respect to sleep quantity and its association with PA. Individuals were classified to one of two sleep quantity categories. If a subject slept an average of 6-9 hours per night they were given an “appropriate” sleep quantity rating. Conversely, a sleep quantity of less than 6 or greater than 9 was considered “inappropriate”. These values were taken from the National Sleep Foundation’s recommended hours of sleep per night for individuals over 65 [72]. Of the 40 respondents, 21 (53%) had an appropriate rating, and the remaining 19 (48%) had inappropriate sleep quantity, A chi-square test was used to determine the relationship between sleep quantity and physical activity. This method was chosen considering good sleep quantity is best evaluated as a categorical variable given that both too little and too much sleep is not recommended. Active PWD experienced significantly more favourable sleep quantity than their inactive counterparts (*P*<0.001). In fact, only 2 inactive subjects experienced appropriate sleep quantity levels compared to 19 in the active group.

Interestingly, prescription sleep medication use was more prevalent among individuals in the poor sleep quantity category. There were only two subjects who regularly took one or more prescription sleep medication and obtained an appropriate sleep quantity rating. In the group of subjects who took no prescription sleep medication, 19 were in the appropriate sleep quantity group compared to 12 who were in the inappropriate group. This difference was statistically significant (*P*=.039). It is interesting to note that although only marginally significant, it was found that of the subjects who took one or more drugs for dementia, 45% had appropriate sleep quantity. This differs substantially from the group who took no drugs for dementia, where 86% had appropriate sleep quantity (*P*=.052). This difference was marginally significant.

Age did not vary significantly between subjects with good and poor sleep quantity. Individuals who experienced poor sleep quantity had a mean age of 78.21, compared to 78.90 in the good sleep quantity group (*P*=.753). It was further found that there was no significant difference between sex (*P*=.554), education (*P*=.365), marital status (*P*=.732), use of home care services (*P*=.356), type of dementia (*P*=.435), use of OTC sleep medication (*P*=.489), and months since diagnosis (*P*=.841). These statistics are further summarized below in Table 4.

Table 4: Characteristics of subjects who obtain appropriate or inappropriate sleep quantity

	Inappropriate Quantity (n=19)	**Appropriate Quantity (n=21)**	**x^2 or *t***	**p-values**
	N (%) or mean ± SD	**N (%) or mean ± SD**		
Activity Category			22.48	.000*
Active	3 (16)	19 (90)		
Inactive	16 (84)	2 (10)		
Age in years	78.21 ± 7.57	78.90 ± 6.26	-.317	.753
Months since diagnosis	50.47 ± 28.99	44.86 ± 28.31	.619	.539
Sex			.351	.554
Males	10 (53)	13 (62)		
Females	9 (47)	8 (38)		
Type of dementia			.033	.984
Alzheimer’s	8 (42)	9 (45)		
Vascular	3 (16)	3 (15)		
Other	8 (42)	8 (40)		
Marital status			.117	.732
Married/common-law	16 (84)	16 (80)		
Single	3 (16)	4 (20)		
Education level			.821	.365
Secondary and below	14 (74)	12 (60)		
Any post-secondary	5 (26)	8 (40)		
Home care service usage (nursing, personal support, housekeeping)			.852	.356
None	9 (47)	13 (62)		
One or more	10 (53)	8 (38)		
Use of drugs for dementia			3.77	.052
None	1 (6)	6 (30)		
One or more	17 (94)	14 (70)		
OTC sleep medication use			.478	.489
None	17 (90)	20 (95)		
One or more	2 (10)	1 (5)		
Rx sleep medication usage			4.269	.039*
None	12 (63)	19 (91)		
One or more	7 (37)	2 (9)		

Note: SD= standard deviation, *Statistical significance at alpha level <0.05.
***N*’s for the two groups may not equal the final sample size due to missing data.**

3.5 Research Question 3

This section presented the findings for the second dependent variable, sleep quality, and its association with PA. The Medical Outcomes Study Sleep Scale (MOS-SS) scoring instrument was used to determine an individual's sleep quality considering the survey tool for this study was modelled after the MOS-SS (see section 2.2). The scoring guide assigned each subject a sleep quality score out of 100 based on their responses to the survey questions that inquired about various aspects of sleep quality. Once this value was obtained, subjects were classified into one of three categories. These categories were modelled after a previous study, which also used the MOS-SS [83]. A score of 0-30 represented a good sleep quality, a score of 30.1-60 indicated moderate sleep quality, and 60.1-100 was considered poor sleep quality. There were 11 subjects who experienced good sleep quality, 18 who had moderate sleep quality, and 11 with poor sleep quality.

A Pearson chi-square test was used to determine the difference in sleep quality among active and inactive PWD for the categorical variables. The non-parametric Kruskal-Wallis *H*-test was used for the continuous independent variables due to unequal sample size between groups. Although the addition of a third group reduced the number of subjects in each category, there was a significantly greater number of active subjects in the good, and moderate sleep quality groups compared to their inactive counterparts. Furthermore, only one inactive PWD experienced good sleep quality, and only two active PWD experienced poor sleep quality. In fact, 91% of subjects who received the highest sleep quality grouping were in the active group. These differences were statistically significant (P=.003).

Statistical analysis revealed no significant differences among subjects in the various sleep quality categories with regards to the secondary independent variables. Nevertheless, prescription sleep medication once again stood out for its relationship with sleep. None of the subjects who took one or more prescription sleep medication experienced the highest level of sleep quality, whereas 36% (n=11) of subjects who took no prescription sleep medication experienced good sleep quality. This finding was interesting to note even though it was not statistically significant (P=.096).

Marital status had a marginally significant effect on sleep quality (P=.057). Within the single category, 86% of subjects experienced moderate sleep quality, and no single subjects experienced poor sleep quality. All of the subjects who experienced poor sleep quality were married/common-law. However, the majority of study subjects were in the married/common law category to begin with so these results should be interpreted with caution.

There were no other significant findings for any of the other secondary independent variables including age (P=.782), months since diagnosis (P=.479), use of medication for dementia (P=.966), OTC sleep medication use (P=.915), sex (P=.888), use of home care services (P=.371), education (P=.470), and type of dementia (P=.360). All of these findings are summarized in Table 5.

Table 5: Characteristics of subjects who had either poor, moderate, or good sleep quality

	Poor Sleep Quality (n=11)	Moderate Sleep Quality (n=18)	Good Sleep Quality (n=11)	x^2 or *t*	p-values
	N (%) or mean ± SD	N (%) or mean ± SD	N (%) or mean ± SD		
Activity Category					
Active	2 (18)	10 (56)	10 (91)	11.758	.003*
Inactive	9 (82)	8 (44)	1 (9)		
Age in years	77.09 ± 5.68	79.61 ± 8.09	78.36 ± 5.84	.491	.782
Months since diagnosis	43 ± 25.22	55.72 ± 34.15	38.64 ± 25.22	1.47	.479

Sex					
Males	7 (64)	10 (56)	6 (55)	.237	.888
Females	4 (36)	8 (44)	5 (45)		
Type of dementia					
Alzheimer’s	4 (36)	10 (59)	3 (27)	4.353	.360
Vascular	1 (15)	3 (18)	2 (18)		
Other	6 (41)	4 (24)	6 (55)		
Marital status					
Married/common-law	11 (100)	12 (67)	9 (90)	5.728	.057
Single	0 (0)	6 (33)	1 (10)		
Education level					
Secondary and below	6 (55)	13 (77)	7 (64)	1.508	.470
Any post-secondary	5 (45)	4 (23)	4 (36)		
Home care service usage					
None	5 (45)	9 (50)	8 (73)	1.983	.371
One or more	6 (55)	9 (50)	3 (27)		
Use of drugs for dementia					
None	2 (20)	3 (17)	2 (20)	.070	.966
One or more	8 (80)	15 (83)	8 (10)		
OTC sleep medication use					
None	10 (91)	17 (95)	10 (91)	.178	.915
One or more	1 (9)	1 (5)	1 (9)		
Rx sleep medication usage					
None	7 (64)	13 (72)	11 (100)	4.694	.096
One or more	4 (36)	5 (28)	0 (0)		
Note: SD= standard deviation, *Statistical significance at alpha level <0.05. *N*’s for the two groups may not equal the final sample size due to missing data.					

The calculation of an ANCOVA further supported the results that physical activity was associated with more favourable sleep quality even when taking into consideration possible confounding variables. Age, months since diagnosis, prescription/OTC sleep medication, and total number of home care services were used as covariates. The raw sleep quality score was used instead of the three categories of sleep quality to make the variable continuous. Analysis revealed that active subjects experienced significantly more favourable sleep quality scores even when adjusting for the possible confounding factors (P=.003, R^2=.382).

Table 6 shows the correlations between the various aspects of sleep quality that were used to compute the overall sleep quality score and their correlations with PA in a Spearman's correlation matrix. This included restlessness, sleep onset latency, frequency and duration of nighttime awakenings, daytime drowsiness, and daytime napping. There was a moderate correlation between the sleep quality aspect of experiencing restless sleep, such as snoring and tossing and turning, with the frequency of nighttime awakenings (r=.53, *P*=.001). Sleep onset latency showed a significant correlation with both the frequency (r=.39, *P*=.017), and duration (r=.58, *P*<0.001) of nighttime awakenings. There was a small and negative correlation between sleep onset latency and activity score (r=-.37, *P*=.021). This relationship makes sense considering higher sleep quality scores indicate poorer quality. Frequency of nighttime awakenings showed a moderate and significant correlation with duration of nighttime awakenings (r=.51, *P*=.001). Daytime drowsiness showed a small correlation with daytime napping (r=.38, *P*=.015), and was also negatively correlated with physical activity score (r=-.55, *P*<0.001). Furthermore, daytime napping and overall sleep quality were negatively correlated with PA score, respectfully (r=-.38, *P*=.015; r=-.49, *P*=.001). All of the components of sleep quality showed a significant correlation with overall sleep quality average at the *P*=<0.01 level including restlessness (r=.68), SOL (r=.55), frequency of nighttime awakenings (r=.76), duration of awakenings (r=.59), daytime drowsiness (r=.63), napping (r=.49), and activity score (r=-.49).

Table 6: Spearman's correlations showing the relationship between the aspects of sleep quality with overall sleep quality and physical activity score

Spearman's rho		**Restless sleep**	**Sleep onset latency**	**Frequency of nighttime awakenings**	**Duration of nighttime awakenings**	**Daytime drowsiness**	**Daytime napping**	**Sleep quality average**	**Physical activity (KKD)**
Restless sleep	Correlation Significance	1.000 .	.136 .408	.531** .001	.257 .119	.252 .121	.245 .133	.678** .000	-.104 .530
Sleep onset latency	Correlation Significance		1.000 .	.385* .017	.577** .000	.201 .219	-.102 .535	.550** .000	-.369** .021

Nighttime awakening frequency	Correlation Significance			1.000 .	.514** .001	.174 .290	.266 .102	.758** .000	-.217 .104
Duration of nighttime awakenings	Correlation Significance				1.000 .	.216 .193	-.086 .608	.589** .000	-.316 .053
Daytime drowsiness	Correlation Significance					1.000 .	.382* .015	.631** .000	-.546** .000
Daytime napping	Correlation Significance						1.000 .	.485** .001	-.383* .015
Sleep quality average	Correlation Significance							1.000 .	-.486** .001
Physical activity (KKD)	Correlation Significance								1.000 .
** Correlation is significant at the 0.01 level * Correlation is significant at the 0.05 level									

3.6 Summary

Taken together, there is preliminary evidence to suggest that PA may have a positive effect on both sleep quality and quantity in older adults with dementia in the Durham Region of Ontario, Canada. The results were based on a sample size of 40 PWD, with ages ranging from 65-92, and length of time since diagnosis ranging from 4 months to 120 months.

Although types of activity varied extensively among PWD, walking was the most popular activity performed among both active and inactive PWD.

Interestingly, chair exercises and home exercise were performed more frequently in the inactive group, suggesting that more attempts should be made to extend the frequency or intensity of these activities for PWD who are not meeting activity recommendations.

There was a significantly greater number of active subjects who experienced favourable sleep quantity than inactive PWD. It was interesting to note that prescription sleep medication was associated with significantly worse sleep quantity outcomes.

PWD who were active experienced significantly greater sleep quality even when adjusting for covariates. Further investigation is needed with larger sample sizes to investigate the relationship between PA and covariates with sleep quality and quantity in the community-dwelling dementia population.

Chapter 4: Discussion

Dementia represents a significant public health concern that will continue to grow as the population ages. As of April 2016, there were 47.5 million people worldwide living with dementia [88]. The World Health Organization predicts that this number will double in the next 15 years [2]. Of the 747,000 Canadians currently living with dementia [89], up to 70% experience some form of sleep disturbance [26]. The purpose of this research was to examine and determine whether being physically active impacted the sleep quality and quantity of community-dwelling PWD. This study also examined the physical activities that community-dwelling PWD participated in, and determined what forms of PA were favourable to these individuals. Although previous studies have explored this topic to some extent, they often focused on institutionalized PWD and explored a variety of non-pharmacological interventions at once in addition to PA. To my best knowledge, this was the first Canadian study which documented the isolated effects of PA on sleep in the community-dwelling PWD population.

The findings from this research added to a growing body of knowledge surrounding alternative options to medication for improving sleep. Regular engagement in physical activity was associated with favourable sleep quantity and quality. The individual sleep quality components that were positively and significantly correlated with PA level were daytime fatigue, napping, and sleep onset latency. These results were consistent with studies conducted by McCurry et al., who found that interventions that encouraged PA in PWD lead to improvements in sleep quantity, decreased daytime fatigue, and reduced nighttime awakenings [38, 53]. The results from my study are more current and more specific than McCurry et al. Specifically, McCurry et al. explored a variety of interventions used in conjunction with one another such as light therapy, sleep education, and physical activity [38]. The present study examined the isolated effects of PA on sleep among community-dwelling persons with dementia, and provided the most up-to-date findings on this relationship.

4.1 Research Question 1

This research question examined how frequently and for how long PWD participated in physical activities. The literature defined being physically active as achieving an activity level that was equivalent to walking for 30 minutes per day [85]. My study found that 55% of PWD met the criteria to be active, which was much higher than the general population. Statistics Canada reported for 2012 and 2013 that just over 10% of Canadians age 60-79 met the activity guidelines to be active [90]. This data was from the Canadian Health Measures Survey. My findings contradicted existing literature, which claimed that dementia was often associated with diminished mobility and a decrease in activity participation compared to the general population [91]. The physical activity component of this study was modelled after the Canadian Community Health Survey, which displayed similar physical activity rates of 43% for persons over 65 [92]. Katzmarzyk and Tremblay argued that this may be due to the inclusion of PAs such as gardening/yard work and walking, which were previously not considered PA [93]. The "other" category also allowed participants to include other types of PA their care recipient participated in, which may not be included in standard PA reporting questionnaires. Furthermore, the reported activity levels in this study may have been subject to recall bias considering participants answered questions over to the phone and the social desirability to seem healthy.

There were no significant differences in any of the demographic characteristics between active and inactive subjects. Some notable differences were that there were more active males than females, and more inactive females than males. These findings were supported by previous research, which found that males were more active than females in their leisure-time with respect to moderate-intensity activities. Gender-bias may have played a role, where activities which were typically male-dominated were asked about while other domains such as household work were not [94, 95]. It was also noted that although not statistically significant, a greater number of married PWD were active than inactive. Considering women live longer than men and frequently out-live their partner, a lack of marital support may have contributed to decreased activity levels.

Prescription sleep medication usage showed a pattern of being associated with inactivity, although this finding was not statistically significant. This finding was supported by a previous study which found that individuals who were physically active used sedative medication less frequently than their inactive counterparts [95]. The small sample in the present study was likely a large contributor to the lack of significant findings with respect to the demographic characteristics of active versus inactive PWD. Future studies with larger sample sizes are warranted to determine what demographic differences contribute to being physically active/inactive in order to develop appropriate interventions to increase physical activity engagement.

Walking was found to be the most popular form of PA in both the active and inactive group. These findings were supported by Katzmarzyk and Tremblay, who found that walking, along with gardening, were the most popular forms of PA in their research [93]. In my study, the majority of active subjects who engaged in walking did so every day (63%), suggesting that it became a habit of daily living for those who used it as a form of PA. Conversely, two-thirds of inactive subjects did not engage in walking. The high discrepancy suggested that walking was an effective and popular way to obtain adequate PA levels, and that interventions to increase walking frequency and duration should be developed to target sedentary PWD.

As mentioned above, Katzmarzyk & Tremblay reported that gardening was one of the most commonly used modes of PA in their research [93]. The findings from this study reflected that, considering gardening was tied with exercise class as the second most commonly used mode of PA among active subjects. This suggested that interventions should be developed to engage inactive PWD in gardening, which has proven to be an enjoyable activity that requires minimal caregiver supervision and has the potential to improve sleep in this population [52].

An interesting finding was that chair exercises were performed more frequently among inactive subjects than active ones. Chair exercises were included under the “other” category, which were automatically classified as “moderate-intensity” and therefore included, as modelled after a previous study [85]. This finding may reflect the fact that active subjects typically engaged in activities that were more strenuous than chair exercises, which have been identified as “low-intensity” by previous studies [96], and therefore may not have been appropriate for this study. Due to this, it is recommended that interventions should be developed to increase the frequency and intensity of chair exercises since they do seem to be a popular form of PA among PWD who do not typically engage in high levels of PA.

4.2 Hypothesis 1

Hypothesis 1 stated that PWD who were active would achieve more favourable sleep quantity than those who were inactive. The active subjects in this study had significantly better sleep quantity than their inactive counterparts, therefore supporting this hypothesis. This finding was consistent with Lee & Kim (2008), who implemented a daily gardening PA intervention to determine its impact on PWD’s sleep. The total nocturnal sleep time of the PA group was significantly improved over the control group. These findings were recorded and reported by use of sleep diaries completed by Registered Nurses at the Long-Term Care facility where the PWD lived [52]. Interestingly, these findings contradicted previous studies [39, 53] on sleep quantity and PA in PWD that used subjective methods of measuring sleep such as polysomnography and wrist actigraphy. McCurry et al. utilized wrist actigraphy to determine the impact of their intervention, which included walking for 30 minutes per day as well as light exposure, on various measurements of sleep. Although sleep quantity did not significantly improve, other measurements of sleep did, such as nighttime awakenings and sleep efficiency [53]. Furthermore, Ouslander et al. did not report any changes in the nighttime sleep of institutionalized persons with a cognitive impairment following a physical activity intervention. Their study used polysomnography [39]. This suggested that the mode of collecting data on sleep quantity may impact its reported duration.

My analysis further suggested that sleep quantity was negatively impacted by prescription sleep medication. PWD who took sedative medication experienced significantly poorer sleep quantity than those who did not. There is a growing body of evidence advising against the use of prescription sleep medication due to its ineffectiveness and potentially dangerous side effects. Although sedative medication may have shortened the sleep onset latency in previous studies, there was a lack of empirical evidence indicating that it helped maintain sleep throughout the night and that it was effective for use long-term [25, 97].

Bain reported that sedative medication may have a rapid development of tolerance, and what minimal improvements it offered for sleep may be diminished within a few weeks of initiating treatment [97]. This was one of the reasons why chronic use of sedative medication was strongly discouraged. Persons who took sedative medication may not have explored other options for treatment which could have been more effective at treating the underlying causes of the sleep disturbance. Bain also discussed studies which suggested that pharmacotherapy offered no benefit over behavioural techniques for improving various aspects of sleep, including total sleep time [97]. Another explanation for the observed less favourable sleep quantity may be that the chemical properties of sedative medication supress delta-wave and REM sleep. In turn, Stage 2 sleep is increased, which is a lighter-wave sleep. The body is more easily awoken in this stage of sleep, resulting in increased nighttime awakenings and a reduction in total sleep quantity [10, 87]. Finally, a common side-effect of prescription sleep medication is daytime drowsiness. This has resulted in napping during the day, which is associated with poorer nocturnal sleep quantity [97]. It was important to acknowledge that research discussing the ineffectiveness of sedative medication may be biased by the fact that people who use prescription sleep medication likely had a worse sleep quantity baseline than the general population. Interestingly, in a pilot study conducted by Landi, findings indicated that subjects who engaged in physical activity consumed less sleep medication than their inactive counterparts [51]. Therefore, physical activity may actually help reduce this negative lifestyle characteristics and improve sleep quantity as a result.

There were no significant differences in any of the other covariates between PWD who experienced poor and good sleep quantity. This included sex, marital status, education, months since diagnosis, use of home care services, type of dementia, medication for dementia, and use of OTC sleep medication.

Some of these covariates have been explored in the literature for their impact on sleep quantity. Specifically, being a female, having an education greater than high school, and being married have been associated with significantly greater quantities of sleep [98, 99]. These observed trends contradicted the present study’s results. It should be noted that these studies consisted of much larger sample sizes than my study, and that poor sleep quantity was only defined as obtaining too little sleep as opposed to this study which saw both too little and too much sleep as unfavourable.

Home care supports were not found to have a significant impact on the sleep quantity of PWD. This finding may be explained by the fact that a main objective of home care for PWD is caregiver respite. Therefore, the potential positive effects that home care has on stress and sleep may be disproportionately displayed in caregivers instead of the PWD receiving service. There is a dearth of empirical evidence to support or dispute this finding.

Beyond demographic characteristics, previous research supported the present study's finding that characteristics associated with dementia including length of time since diagnosis, type of dementia, and medication for dementia had no significant impact on sleep quantity. Specifically, existing research that made efforts to randomize PWD into active and control intervention PA groups based on these factors still observed significant improvements in the sleep quantity of the active group [38, 60]. Lastly, previous research, or lack thereof, supported the finding from this study that OTC sleep medication had no significant impact on sleep quantity. Bain reported that OTC sleep medication effectiveness has not been supported by controlled clinical trials. It was also reported that tolerance to OTC sleep medication can develop within 1-2 weeks, therefore reducing its ability to be used chronically [97].

4.3 Hypothesis 2

The second hypothesis stated that PWD who were active would experience more favourable sleep quality than those who were not. Based on my data, it appeared that active PWD were indeed more likely to experience better sleep quality. Specifically, active PWD achieved significantly higher sleep quality scores, and this was displayed when looking at both the raw and categorized sleep quality score. This study considered six aspects of sleep quality including restlessness, sleep onset latency, frequency and duration of nighttime awakenings, daytime drowsiness, and daytime napping.

Research examining PA on sleep quality was sparse. This was expected given the complexity associated with trying to measure such an intricate entity. Multiple studies found sleep quality aspects, including daytime napping and frequency and duration of nighttime awakenings, were significantly improved by being physically active, and therefore supported the above finding [38, 52-54].

Previous research identified education as a significant determinant of sleep quality. A study by Patel et al. examined the social determinants of sleep quality among 9,714 randomly selected subjects, and found that each increment in level of education had a significant protective effect on sleep quality [100]. Although my research only distinguished between those who obtained any post-secondary education and those who did not, Patel et al. reported that respondents who had any post-secondary had an 82% reduction in odds of experiencing poor sleep quality [100]. Nomura et al. also reported that poor education was associated with significantly poorer sleep quality in their study of 1,792 survey respondents [101]. My research did not show this association, likely due to a small sample size and the fact that there were only 9 subjects who obtained any post-secondary education.

Age was another variable that failed to show any significant variation in sleep quality. This may have been explained once again by small sample size. Furthermore, age is the primary risk factor for developing dementia, so the age range of subjects displayed limited variation to begin with. Although previous research identified older age as a significant determinant of poor sleep quality [12, 18, 100, 101], a small sample size and age range may have prevented these effects from being observed.

There were no observed differences in sleep quality among males and females. However, existing research typically found that women experienced worse sleep quality than men [101]. There were more sample subjects who were males than females in the present study, specifically 23 males and 17 females. This may have been due to more women than men attending support groups, who then answered as proxies on behalf of their male partner. Social norms and pressures may have contributed to the lack of men attending support groups. As a result, there was a small number of female subjects which may have contributed to the insignificant findings observed, although a small sample size was likely the primary cause.

OTC and prescription sedative medication usage has been heavily scrutinized in recent literature. The present study reported no significant differences between the sleep quality of PWD who used OTC and/or prescription sleep medication and those who did not. Existing research supported this finding. Deschenes & McCurry conducted a literature review on medication’s utility to improve sleep quality [41]. They reported that although OTC medication is widely used due to its accessibility, existing placebo-controlled trials have found no significant difference in the sleep quality of the treatment and control group. Even more concerning was the reported side-effects that can result from taking OTC medication, including increased daytime sleep and fatigue [41].

Deschenes & McCurry reported similar findings regarding prescription sleep medication. They concluded that although prescription sedatives may shorten the onset of sleep, they are ineffective at reducing disturbances throughout the night. The potential side effects of sedative medication can be even more severe than OTC sleep medication, such as amnesia, disorientation, daytime fatigue, and excessive napping [41]. As a result, prescription sedatives should be used judiciously, and the findings from the present study supported existing literature, suggesting that non-pharmacological interventions should be considered as a first-line of treatment against poor sleep quality.

Home care was not found to have a significant impact on sleep quality. Although a lack of existing evidence made it difficult to explain this finding, one particular study performed by Lee & Morgan examined the impact of respite care for caregivers on the sleep quality of persons with dementia. The authors found that when PWD were admitted to community hospitals for two weeks and given routine care, their sleep quality was significantly reduced. Observed sleep quality indicators included an increase in SOL and a poorer ability to regulate the circadian rhythm (i.e. more napping during the day and restlessness at night). Conversely, the subjective sleep quality of caregivers significantly improved [102]. This suggested that respite care may only be beneficial for caregivers. The potentially negative impact that it can have on sleep quality for PWD may not have been observed in the present study due to a small sample size.

The various types of dementia warranted exploration into how sleep disturbances were manifested throughout the associated dementia subgroups. The present study’s findings suggested that sleep quality is independent of type of dementia. Existing research provided strong evidence that dementia subtypes were in fact associated with varying sleep quality. The present study may have failed to report this due to a small sample size and poor representation of subjects with less common forms of dementia. Chwiszczuk et al. conducted a cross-sectional study that found that sleep quality was significantly lower in persons with DLB than in those with AD [86]. Deschenes & McCurry also explored the presence of sleep disturbances within dementia subgroups in a literature review. Their findings further suggested that sleep disturbances were more markedly prevalent in DLB compared to AD, including poor SOL, a high frequency of nighttime awakenings, daytime napping, and the presence of violent actions and movements during nocturnal sleep [41]. Deschenes & McCurry noted that the onset of sleep disturbances in persons with AD was much more progressive than the other subtypes, and occurred in only 25-35% of cases. Common characteristics of sleep disturbances in the later stages of AD included nighttime awakenings, increased SOL, increased daytime napping, and a decrease in the slow-wave, restorative sleep [41].

The literature review further associated PD with poorer sleep quality than AD, and partially attributed this to the increase in uncontrollable body movements that occurred in PD which were harmful to sleep maintenance. In addition, the medication taken to alleviate PD symptoms has been associated with increased nighttime awakenings and daytime fatigue, therefore putting these individuals at a greater risk of disrupting their circadian rhythm [41]. Khachiyants et al. provided similar findings with respect to vascular dementia, noting that the deterioration of the circadian rhythm may be more prominent in this subtype compared to AD [29]. The reviews cited above suggested a strong association between type of dementia and severity of sleep disturbances. Future research is needed with a greater representation of subjects with less-common forms of dementia to determine how PA may work to improve sleep within each of these subgroups. This topic is further explored in Appendix 16.

Existing research has suggested that being married or common-law was associated with significantly more favourable sleep quality outcomes [100]. Although not statistically significant, my study found that married/common-law subjects experienced worse sleep quality than their single counterparts. An explanation may be that of the married subjects, it was typically the spouses who acted as proxies for their loved one, where children and grandchildren played this role for the single PWD. Spouses were likely more aware of sleep disturbances like nighttime awakenings or daytime napping because they shared a bed with their care recipient. A small sample size and a particularly small amount of single subjects could have also explained the above finding.

The non-parametric Spearman's correlation matrix was used to examine each individual aspect of sleep quality and its relationship with PA. This included restlessness, sleep onset latency, frequency and duration of nighttime awakenings, daytime drowsiness, and daytime napping. Every aspect of sleep quality showed a significant, positive, and for the most part moderate to high correlation with overall sleep quality. This indicated that aspects of sleep quality were interconnected. For future studies, measuring one or two aspects may be sufficient to give an overall picture of an individual's sleep quality.

The scoring guide for the MOS-SS indicated that lower scores were associated with more favourable sleep quality. Frequency of nighttime awakenings was the most highly correlated component with overall sleep quality showing a strong, positive correlation coefficient of r=.758. This showed that as frequency of awakening scores improved (i.e. an individual experienced fewer awakenings), sleep quality scores also improved. Daytime napping was the least correlated with overall sleep quality, however this relationship was still statistically significantly. It showed a positive, moderate correlation with overall sleep quality (r=.485), suggesting that improvements in daytime napping (i.e. less napping) were slightly associated with more favourable sleep quality scores. Nonetheless, daytime napping may be more associated with boredom, and thus is a poor indicator to use when examining overall sleep quality. These findings were similar to a study by King et al., who looked at the results of a moderate-intensity PA program for older adults over a 12 month period. Their results indicated that the PA group showed significant improvements in subjective sleep quality and polysomnography-measured nighttime awakenings, but not for napping [48]. Although the results from my study showed that napping was significantly associated with overall sleep quality, this correlation was weak and should be used with caution in future studies.

PA level was significantly and negatively correlated with SOL, daytime drowsiness, daytime napping, and overall sleep quality. It was once again important to note that the scoring guide for MOS-SS assigned higher values to less-favourable sleep quality scores. A score of 100 indicated the worst possible score, where 0 indicated perfect subjective sleep quality. The significant, negative correlation between PA level and SOL (r=-.369) suggested that as PA levels increased, SOL scores were lower therefore indicating less of the problem of SOL being observed, which was more favourable. This suggested that engaging in PA shortened the latency between going to bed and falling asleep. Existing research supported this finding, by observing that interventions consisting of PA lead to decreased SOL in the treatment group compared to inactive controls [48, 64, 72].

As mentioned above, a significant and negative correlation was found between PA level and daytime drowsiness and napping (r=.546, r= -.383). As PA levels increased, active PWD took fewer naps and felt less drowsy than those with lower PA scores. Thune-Boyle found that PA could help decrease naps by keeping PWD out of bed during the day. He further reported that PA could directly improve mood, therefore reducing feelings of drowsiness [6]. As a result, PA's impact on these two factors may be two-fold, by directly reducing feelings of drowsiness and indirectly reducing napping by keeping PWD occupied and out of bed during the day.

Overall, PA and sleep quality displayed a significant and negative relationship (r=-.486), indicating that as PA levels increased sleep quality significantly improved. This further supported the findings from my study. Together, my findings suggested that being physically active could lead to significant improvements in overall sleep quality.

4.4 Strengths and Limitations

This study consisted of various strengths and limitations that should be considered for interpretation of findings and implications. The study design was a cross-sectional survey method that examined how being physically active or inactive impacted sleep in the dementia population. The data were collected via telephone surveys administered to caregivers of PWD residing in the Durham Region.

Gordis described a cross-sectional design as that in which the exposure and disease outcome are determined simultaneously for each subject [79]. This design is relatively easy and economical to perform, and data can be collected from a large number of people in a short period of time with no risk of loss to follow-up. Due to this, the cross-sectional design was a convenient and effective method to employ when trying to determine whether an association existed between multiple exposures and determinants [103].

Another advantage of this study was its use of telephone interviews to administer the survey instrument. Previous research has suggested that telephone interviews are more efficient and convenient than in-person interviews and obtain a similar quality of data [81]. Telephone surveys are the fastest survey method, and can address many variables without significantly increasing time or cost [81]. Telephone interviews also allow the interviewer to clarify questions and confirm answers with the respondent. Finally, this method is highly preferred over mailed questionnaires, which are more expensive and have high levels of non-response. Mailed questionnaires also prevent the interviewer from interacting with the respondent, and can result in incomplete responses [104].

This study had four notable limitations including small sample size, cross-sectional design, use of proxy respondents, and the use of a convenient sample. A small sample size was the most notable weakness of this study, which decreased the likelihood that my study could uncover significant differences among the study participants. The small sample size also limited the generalizability of my results, because the sample was likely unrepresentative of the larger population [79, 104].

Regarding the cross-sectional design, a disadvantage of this was the weak ability to establish causal mechanisms or a time-sequence. Schutt defined time-sequence as, “a criterion for establishing a causal relationship between two variables. The variation in the presumed cause (independent variable) must occur before the variation in the presumed effect (dependent variable)” (I-39)[104]. Considering my data were collected at one time, it was impossible to determine whether being active lead to more favourable sleep outcomes, or whether the poorer sleep and resulting fatigue caused a lack of PA. Furthermore, the cross-sectional design was unable to account for all potential confounding variables [104]. The weather was one of these variables. Considering data was obtained in the spring, physical activity levels may have varied if the data was collected during colder times of the year. A systematic review of 37 studies that examined the impact of weather on physical activity reported that 73% of the articles found that the time of year had a significant impact on physical activity engagement. That is, colder months were associated with worse physical activity rates [105]. In addition, the survey design was unable to account for all possible medication that the PWD was taking or all co-morbidities due to time constraints and the attempt to minimize participant burden.

The use of proxy respondents introduced potential biases in the way that exposure and outcome data were obtained. Information bias occurs when some of the information regarding exposures and outcomes is inaccurate due to inadequate reporting procedures [79]. The proxy respondents may not have been fully aware of the PA and sleep habits of their care recipient, or they may have erroneously misreported this information. There is a general understanding that

PA and sleep are associated with health benefits. Considering I administered the survey over the phone to caregivers, it was possible that the PA levels or sleep characteristics of the care recipient were over-estimated to satisfy this desirability. This may have resulted in misclassification of the exposure and/or outcome [79]. PA levels may have also been impacted by misclassification of exposure or outcome bias considering they were self-reported by caregivers, who could not speak to how vigorous these activities were for the PWD. As a result, activities may have been included which were not moderate-level.

Lastly, the use of a convenient sample may have limited the generalizability of the results. A sampling error occurs when a small sample does not accurately represent the larger population's variables [103]. Given that the sample was drawn from caregivers attending support groups in the Durham Region, this limited geographical area made it unrepresentative of all PWD living in Ontario, Canada, and worldwide. Also, free transportation was not available to the support groups, so caregivers who did not have access to a car or public transportation were excluded. Furthermore, caregivers had to decide on behalf of the PWD if they wanted to complete the survey, and some PWD may have been excluded even if they would have opted to participate. Finally, non-response bias may have occurred, further harming the representativeness of the sample. This bias occurs when the demographic, sociocultural, lifestyle, and medical characteristics differ systematically between those who completed the questionnaire and those who did not [103]. Caregivers who declined to participate could have been too busy to complete the questionnaire, or they may not have believed in the utility of PA as a method for improving sleep. Due to this, they may not have time to help their care recipient engage in PA, or fail to promote it in their daily life.

4.5 Implications for Future PA Programs

Identifying ways to overcome or minimize barriers to PA will be crucial in ensuring that physical activity is used to its maximum potential. Findings from the studies discussed throughout this thesis suggested some possible methods to achieve this goal. It is also of pivotal importance to make the potential benefits of physical activity known to the dementia population. Furthermore, participants from previous studies recognized that this information was even more persuasive when it came directly from a health professional. If the individual with dementia is engaging in an exercise program, the characteristics of the program and the physiotherapist or recreational therapist running the program were identified as of crucial importance. The program must have an appropriate duration, convenient time, and encompass favourable exercises. The physiotherapist should act professionally and empathetically to maximize adherence. Establishing a sense of commitment will also aid in program adherence. This can be achieved through methods such as a recording sheet, where PWD can record and reflect on what they have accomplished [75]. Finally, increased dietary intake has been shown to be beneficial to physical activity engagement and adherence [74]. This will ensure that the individual has sufficient energy levels to safely engage in activities.

4.6 Conclusion

The aim of this study was to examine the relationship between sleep and PA in the community-dwelling PWD population. To my best knowledge, this was the first study that used a cross-sectional design to examine this relationship. Previous research often used short-term PA interventions, which provided minimal information on how habitual PA engagement impacted sleep. These studies often focused on institutionalized PWD and were performed outside of Canada. Considering the high level of health behaviour variance between countries, these findings were often inapplicable to Canadians living with dementia. Although this study's data was gathered through the Alzheimer Society of Durham Region, the thoughts expressed in this paper did not reflect the views of the organization.

This study provided preliminary evidence that being physically active can lead to more favourable sleep outcomes for community-dwelling PWD. PA levels fluctuate throughout the lifespan, and longitudinal studies can help determine the frequency and intensity of activities that are necessary to obtain the recorded sleep benefits. In addition, longitudinal studies are needed to establish a causal relationship between physical activity and sleep given their bi-directional relationship. There is also a need for studies that use objective measures to determine PA and sleep levels to reduce bias and provide an accurate picture of the PA levels PWD should aim to achieve. Validity can be increased in future studies by applying more stringent inclusion and exclusion criteria. Lastly, studies which examine the motivation behind being physically active and the impact of the activity levels of the caregiver are needed to help reduce barriers and increase PA levels.

There were also public health implications from this study. Current numbers of dementia are expected to double by 2030, which could drastically increase the economic costs that result from this condition. In 2012, Canada spent $33 billion dollars in direct and indirect costs associated with dementia [3]. Due to the absence of a cure, interventions that increase quality of life for the PWD, caregivers, and families are essential to reduce the burden of this condition. Sleep has a significant impact on quality of life, and PA is an inexpensive and accessible method that this study has shown may improve sleep and serve as a safe alternative to pharmacotherapy. Also, sleep disturbances represent a major reason that caregivers decide to institutionalize a PWD [27]. If sleep disturbances are reduced, it can lead to a decrease in the number of institutionalized PWD, and as a result reduced health care costs for the system to endure. Nonetheless, the results from this study should be interpreted with caution, and future research is needed with more diverse subjects to fully understand the public health implications that this non-pharmacological method can have for our aging population.

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Appendices

Appendix 1: Previous Studies Investigating Various Modes of Physical Activity

Authors	Title/Date	Date	Subjects	Methods	Results	Comments	Country of Origin
Alessi C, Martin J, Webber A, Kim C, Harker J, Josephson K	Randomized, Controlled Trial (RCT) of a Nonpharmacological Intervention (NPI) to Improve Abnormal Sleep/Wake Patterns in Nursing Home Residents	2005	N= 118 -Nursing home residents	- RCT - Intervention: sleep hygiene, low-level PA, daily sunlight exposure	- No significant difference in: sleep percentage, number of night-time awakenings, total sleep time (TST) - Significant improvements: reduced daytime sleep, increase social participation	- Short treatment duration - Lack of objective sleep measures - Lack of blinding - Multitude of statistical tests performed therefore increasing risk of Type I error	United States of America (USA)
Brand S., Gerber M., Beck J, Hatzinger M, Puhse U, Holsboer-Trachsler E	High Exercise Levels Are Related to Favorable Sleep Patterns and Psychological Functioning in Adolescents: A Comparison of Athletes and Controls	2010	N= 434 - High school students: 258 athletes, 176 controls (non-athletes) - Mean age of 17.2	- Cross-sectional design (CSD) - Athletes and controls completed self-report sleep questionnaires and sleep logs	- Athletes experienced higher sleep quality, shortened SOL, fewer night-time awakenings, increased daytime energy, and less depression and anxiety than controls	- Limitations due to CSD - Response bias regarding sleep logs	Switzerland
Chen K, Chen M, Chao H, Hung H, Lin H, Li C	Sleep quality, depression state, and health status of older adults after silver yoga exercises: Cluster randomized trial	2009	N= 128 - Community-dwelling (CD) adults - 60 years and older - No cognitive impairment	- RCT - Intervention: 70-minute yoga class 3 times per week for 6 months - Survey tools utilized to collect information regarding sleep quality,	- Intervention group saw significant improvements in sleep quality, daytime fatigue, depression, and physical and mental health perception. Control group also saw significant	- Sampling and response bias - Lack of clustering analysis	Republic of China

				depression, and self-perception of health	improvements in sleep latency, daytime dysfunction, physical health perception, and depression state.		
Connell BR, March J, Lewis R.	Therapeutic Effects of an Outdoor Activity Program on Nursing Home Residents with Dementia	2007	N=20 Institutionalized PWD	- Outdoor and indoor group - Both engaged in structured PA for 2 weeks - Both groups were measured at baseline and at the end of the intervention	- Outdoor group showed significant improvements in sleep duration and decreased agitation	- Small sample size	USA
Eggermont LH, Blankevoort CG, Scherder EJ	Walking and night-time restlessness in mild-to-moderate dementia: a randomized controlled trial	2010	N=112 - PWD - Institutionalized	- RCT - Intervention 1: Walking for 30 minutes - Intervention 2: Social activities - 5 times per week for 6 weeks - One-week, and six-week follow up	- No significant findings related to night-time restlessness, sleep efficiency, number of wake bouts, and daytime activity	- Lack of sleep disturbances at baseline - Subjects had high cardiovascular morbidity which could have reduced PA intensity - Short treatment duration	Netherlands
Federici A, Bellagamba S, Rocchi MB	Does dance-based training improve balance in adult and young old subjects? A pilot randomized controlled trial.	2005	N=40 - Aged 58-68	- RCT - Intervention: exercise program with three month duration - Control group did not engage in PA	- Intervention group: significant improvements in balance, sexual activity, sleep quality, reductions in smoking and alcohol consumption compared to controls	-Overrepresentation of males - Small sample size - Used intent-to-treat	Italy
Ferris L, Williams J, Li Shen C,	Resistance training improves sleep	2005	N=8 - Aged 60 and over	- Intervention: 3 resistance PA sessions per week for 6 months	- Significant improvements in body strength, and sleep	- Small sample size - Subjects had good baseline sleep	USA

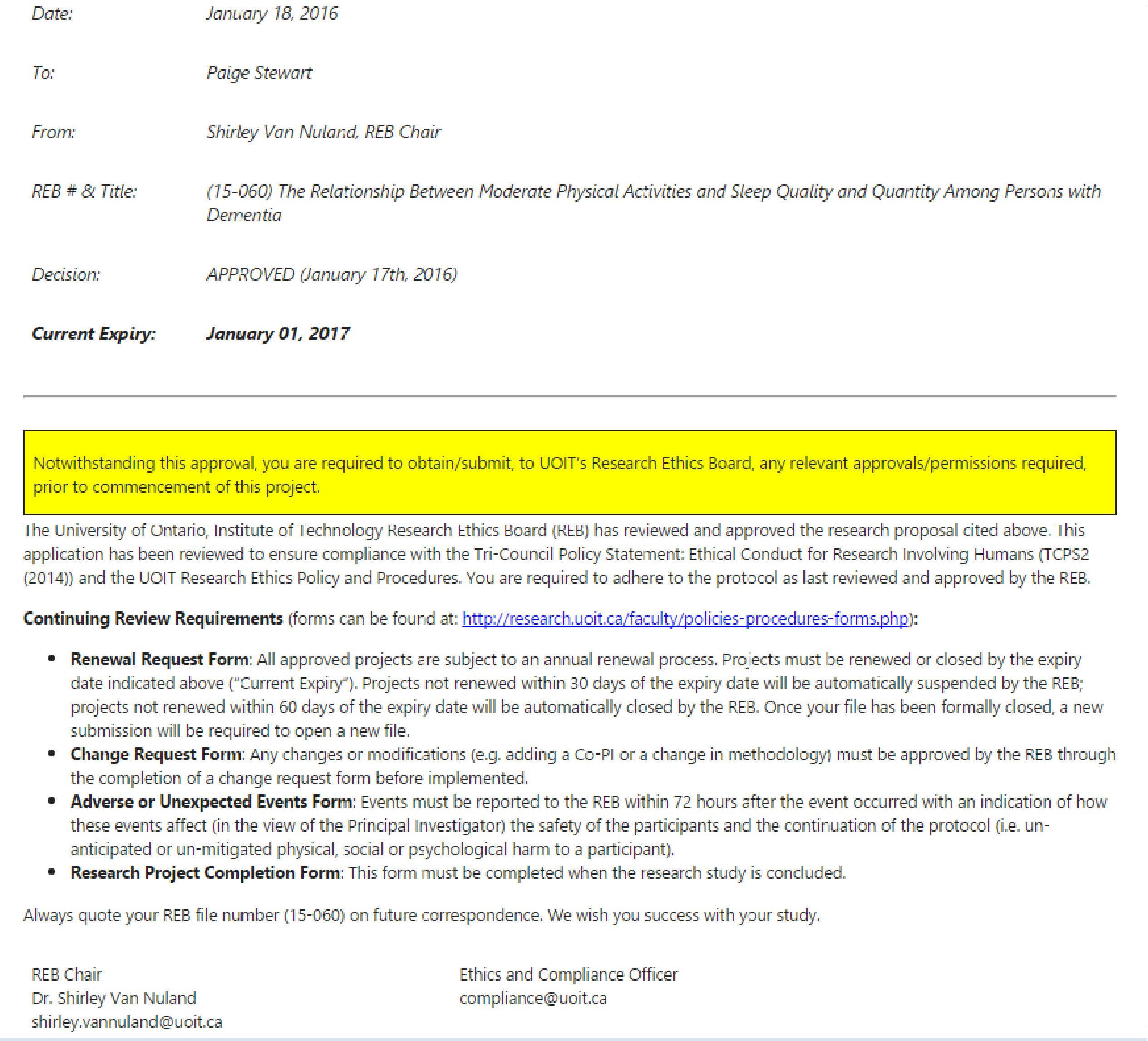
O'Keef K, Hale K	quality in older adults: a pilot study			- Measurements done at baseline, months, and 6 months	quality at 3 month follow-up - Strong adherence		
Fuzhong L, Fisher J, Harmer P, Irbe D, Tearse R, Weimer C	Tai Chi and Self-Rated Quality of Sleep and Daytime Sleepiness in Older Adults: A Randomized Controlled Trial	2004	N= 118 - Ages 60-92 - Inactive - Community-dwelling	- RCT - Intervention 1: Tai chi - Intervention 2: Low-impact exercise - 60 minutes 3 time per week for 24 weeks.	-Tai chi group showed significant improvements in sleep quality, SOL, TST, SE, sleep disturbances, and dysfunction - Low-impact exercise group: no significant improvements	- Voluntary sign up - No diagnosis of a sleep disorder needed - Self-report measures - Lack of true control group	USA
King A, Pruitt L, Woo S, Castro C, Ahn D, Vitiello M, Woodward S, Bliwise D	Effects of Moderate-Intensity Exercise on Polysomnographic and Subjective Sleep Quality in Older Adults With Mild to Moderate Sleep Complaints	2008	N= 66 - Over 55 - Mild to moderate chronic sleep complaints - Community-dwelling	- Two interventions: health education or a moderate-intensity aerobic PA group	- PA group spent significantly less time in Stage 1 sleep, more time in Stage 2 - PA group had fewer night-time awakenings, reduced SOL, increased feelings of restfulness	- Lack of true control group - Intent-to-treat approach - Small sample size	USA
Landi F, Russo A, Bernabei R	Physical activity and behaviour in the elderly: a pilot study	2004	N= 30 - Institutionalized persons with Alzheimer's Disease	- Pilot study - Intervention: exercise training, behaviour management, psychosocial training - Control: just behaviour management and psychosocial training	- Exercise group had significant reductions in wandering, physical and verbal abuse, sleep disorders compared to controls - Decrease in sleep medication use for exercise group	- Small sample size - No definition of 'sleep disturbance'	Italy

Lee Y, Kim	Effects of indoor gardening on sleep, agitation, and cognition in dementia patients—a pilot study	2008	N=23 - Institutionalized PWD - Sleep disturbances at baseline	- Intervention: Indoor gardening 2 hours per day total - 4 week duration	- Significant improvements in WASO, daytime napping, nocturnal sleep, and SE	- Small sample size - Lack of control group - Short treatment duration	Republic of Korea
Nascimento C, Ayan C, Cancela J, Bucken L, Gobbi S, Stella F.	Effect of a multimodal exercise program on sleep disturbances and instrumental activities of daily living performance on Parkinson's and Alzheimer's disease patients	2014	N= 64 - Persons with Parkinson's or Alzheimer's disease	- Intervention: 3, 1-hour training sessions per week for 6 months - Program included warm up, resistance exercises, balance, aerobics, and motor coordination	- Exercise group showed significant improvements in sleep disturbances and increased physical fitness compared to controls	- Voluntary PA sign up resulted in lack of a true control group - Subjective sleep quality measures utilized	Brazil
Meija-Downs A, Fruth SJ, Clifford A, Hine S, Huckstep J, Merkel H, Wilkinson H, Yoder J	A Preliminary Exploration of the Effects of a 6-week Interactive Video Dance Exercise Program in an Adult Population	2011	N= 27 - University of Indianapolis faculty, students, and their friends and family	- 6-week PA intervention utilizing interactive video dance exercises 3 times per week - Pre- and post-testing	- 40% reported improvements in sleep quality or quantity and were motivated to continue this program	- Small sample size - Women overrepresented in sample - Lack of control group	USA
McCurry S, Gibbons S, Logsdon R, Vitiello M, Teri L	Nighttime Insomnia Treatment and Education for Alzheimer's Disease: A Randomized, Controlled Trial	2005	N= 36 - PWD - Community-dwelling	- RCT - 6 week program - Active group: sleep hygiene, behavior management, 30 minutes of daily	- Active group: significant improvements in number and duration of night-time awakenings and depression	- Small sample size - Subjective measures of sleep were used	USA

				walking and daytime light exposure - 2 and 6 month follow-up	- Continued adherence to exercise regime after intervention		
McCurry, SM, Pike JC, Vitiello MV, Logsdon RG, Larson EB, Teri L	Increasing walking and bright light exposure to improve sleep in community-dwelling persons with Alzheimer's disease: results of a randomized, controlled trial.	2011	N= 132 - PWD - Community-dwelling	- 3 interventions: walking, walking plus light exposure, or combined walking and light exposure - Control group	- Active groups showed significant decreases in night-time awakenings and increase in SE	- Less adherence to interventions was associated with less favourable outcomes - High attrition rate - Lack of objective sleep measures at baseline to rule out previous sleep disorders	USA
Ouslander J, Connell B, Bliwise D, Endeshaw Y, Griffiths P, Schnelle J	A Nonpharmacological Intervention to Improve Sleep in Nursing Home Patients: Results of a Controlled Clinical Trial	2006	N= 160 - 76% diagnosed with dementia - Institutionalized	- RCT - Immediate and delayed treatment group - Intervention: PA, bright light exposure, sleep hygiene	- No significant findings related to medication use, daytime napping, night-time sleep and awakenings in delayed versus immediate treatment group	- High attrition rate - Used evening bright light exposure	USA
Reid K, Baron K, Lu B, Naylor E, Wolfe L, Zee P	Aerobic exercise improves self-reported sleep and quality of life in older adults with insomnia	2010	N= 17 - 55+ - Sedentary with insomnia	- RCT - Pre-post design - Intervention 1: aerobic PA and sleep hygiene - Intervention 2: Sleep hygiene - 16 week duration	- PA group: significantly better sleep quality, SOL, sleep duration, daytime napping and fatigue, SE than controls	- Reliance on self-reporting - Small sample size - Sample overrepresented by females - High attrition rate In non-PA group	USA

Richards K, Lambert C, Beck C, Bliwise D, Evans W, Kalra G, Kleban M, Lorenz R, Rose K, Goonerate N, Sullivan D	Strength Training and Walking Exercise and Social Activity Improve Sleep in Nursing Home and Assisted Living Residents: Randomized Control Trial	2012	- N= 165 - Institutionalized - Some with dementia	- RCT - Three arms: exercise group (E), social activity group (SA), combined E and SA - Exercise consisted of strength and walking 4 times per week for 1 hour per session - Social activity consisted of social activities 4 days per week for 1 hour - Control group received usual care	- Combined ESA group: significant improvements in NST, SE, and NREM sleep	- Lack of blinding for participants - Individual treatment groups alone did not yield significant findings with regards to sleep (E and SA)	USA
Viana VA, Esteves AM, Boscolo RA, Grassmann V, Santana MG, Tufik S	The effects of a session of resistance training on sleep patterns in the elderly	2012	- N= 40 - Males only - Aged 65-80 - Community-dwelling - Sedentary	- RCT - Intervention group: resistance training approximately 60 minutes per session - Control group	- Intervention group: Significant decrease in night-time awakenings and more time spent in deeper sleep	- Absence of females enrolled in study - Sleep disturbance was not assessed at baseline	Brazil
Wang Y, Boehmke M, Wu Y, Dickerson S, Fisher N	Effects of a 6-Week Walking Program on Taiwanese Women Newly Diagnosed With Early-Stage Breast Cancer	2011	- N= 160 - Women - Cancer diagnosis required	- Intervention: low-moderate intensity walking - 3-5 times per week - 6 week duration	- Intervention group: improved quality of life, reduced fatigue, fewer sleep disturbances than control - Good adherence to exercise regime	- Limited to early-stage persons with cancer - Response bias present	Republic of China

Appendix 2: Certificate of Approval from the University of Ontario Institute of Technology Research Ethics Board



Date:	*January 18, 2016*
To:	*Paige Stewart*
From:	*Shirley Van Nuland, REB Chair*
REB # & Title:	*(15-060) The Relationship Between Moderate Physical Activities and Sleep Quality and Quantity Among Persons with Dementia*
Decision:	*APPROVED (January 17th, 2016)*
Current Expiry:	***January 01, 2017***

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

The University of Ontario, Institute of Technology Research Ethics Board (REB) has reviewed and approved the research proposal cited above. This application has been reviewed to ensure compliance with the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2 (2014)) and the UOIT Research Ethics Policy and Procedures. You are required to adhere to the protocol as last reviewed and approved by the REB.

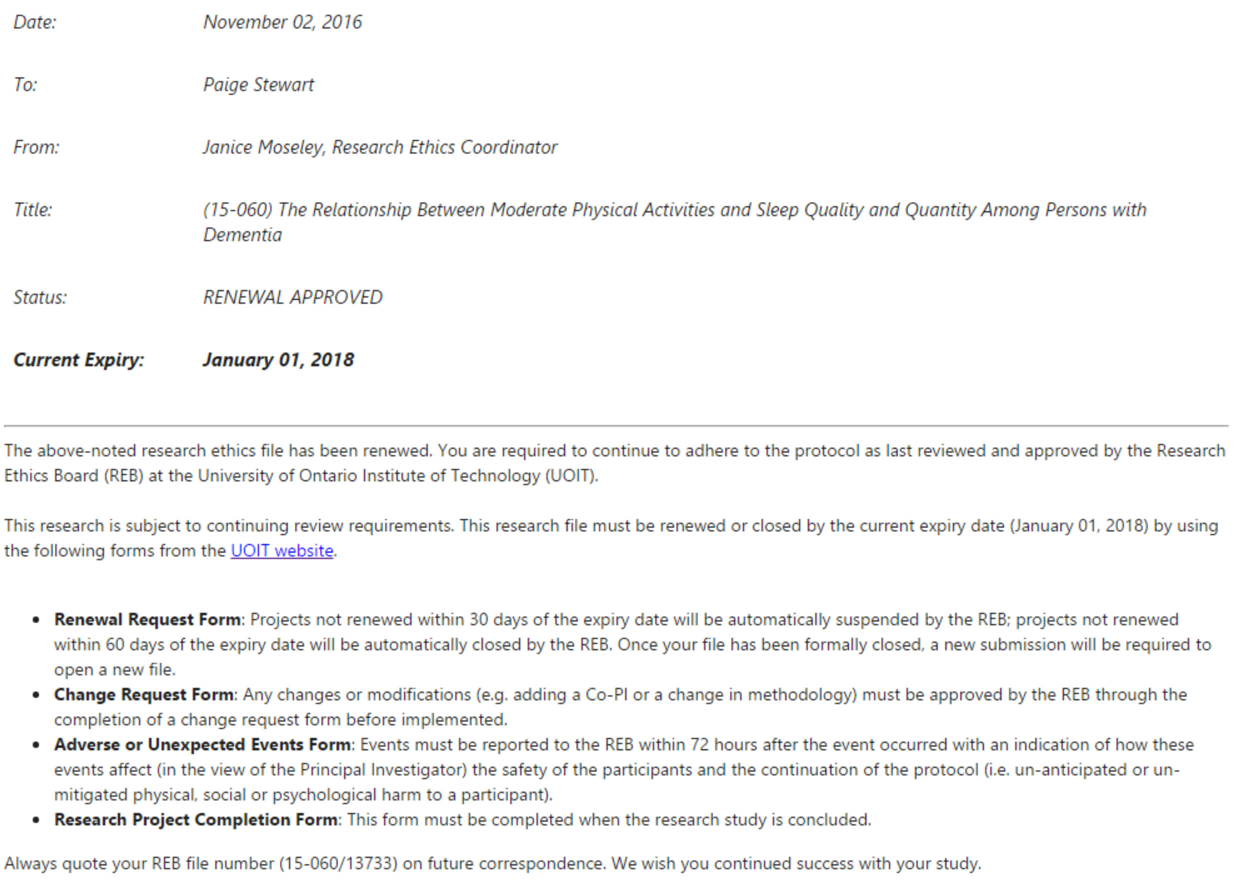
Continuing Review Requirements (forms can be found at: http://research.uoit.ca/faculty/policies-procedures-forms.php):

- **Renewal Request Form**: All approved projects are subject to an annual renewal process. Projects must be renewed or closed by the expiry date indicated above ("Current Expiry"). Projects not renewed within 30 days of the expiry date will be automatically suspended by the REB; projects not renewed within 60 days of the expiry date will be automatically closed by the REB. Once your file has been formally closed, a new submission will be required to open a new file.
- **Change Request Form**: Any changes or modifications (e.g. adding a Co-PI or a change in methodology) must be approved by the REB through the completion of a change request form before implemented.
- **Adverse or Unexpected Events Form**: Events must be reported to the REB within 72 hours after the event occurred with an indication of how these events affect (in the view of the Principal Investigator) the safety of the participants and the continuation of the protocol (i.e. un-anticipated or un-mitigated physical, social or psychological harm to a participant).
- **Research Project Completion Form**: This form must be completed when the research study is concluded.

Always quote your REB file number (15-060) on future correspondence. We wish you success with your study.

REB Chair Dr. Shirley Van Nuland shirley.vannuland@uoit.ca	Ethics and Compliance Officer compliance@uoit.ca

Appendix 3: REB Renewal Approval



Date: *November 02, 2016*

To: *Paige Stewart*

From: *Janice Moseley, Research Ethics Coordinator*

Title: *(15-060) The Relationship Between Moderate Physical Activities and Sleep Quality and Quantity Among Persons with Dementia*

Status: *RENEWAL APPROVED*

Current Expiry: ***January 01, 2018***

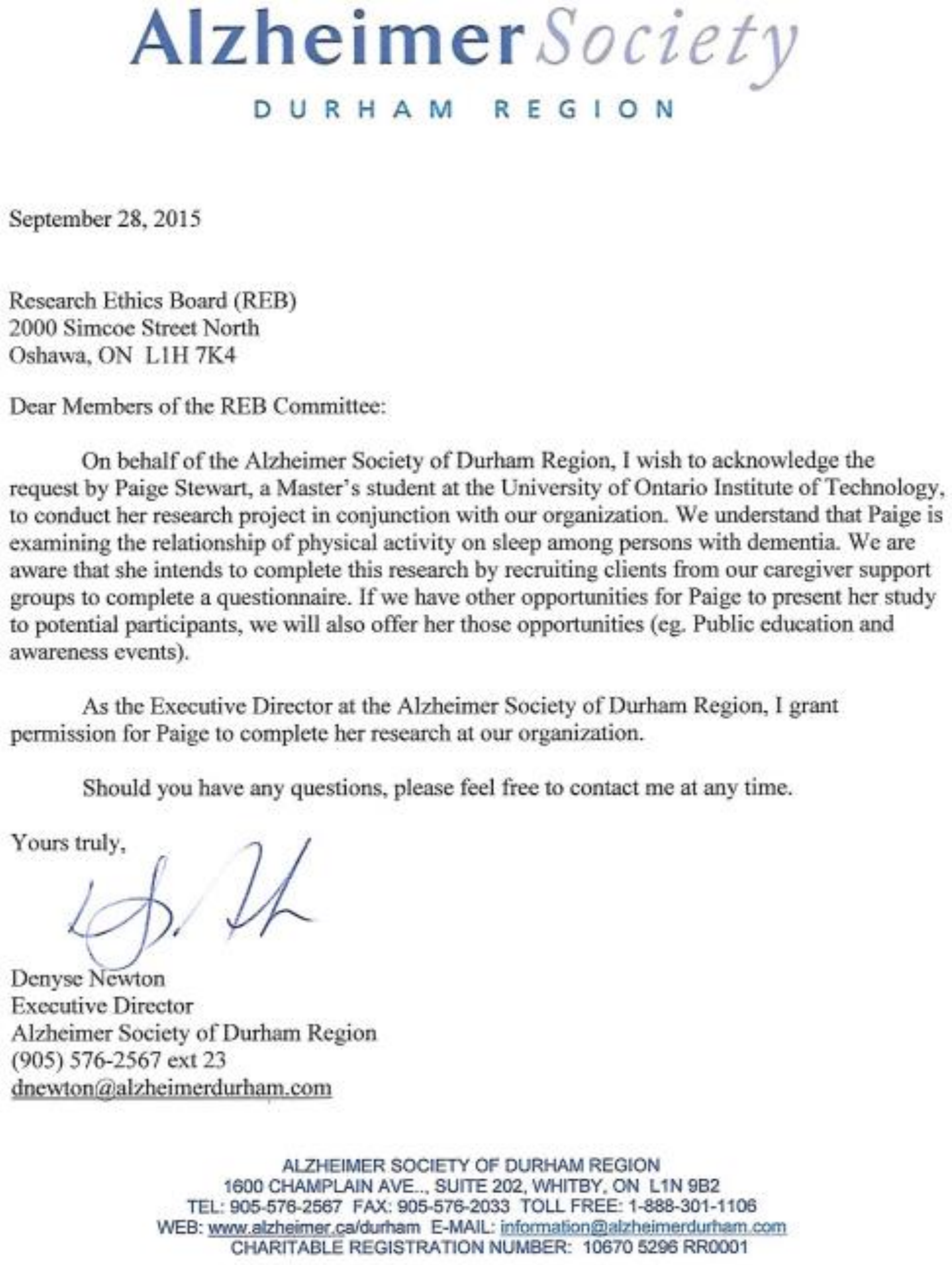
The above-noted research ethics file has been renewed. You are required to continue to adhere to the protocol as last reviewed and approved by the Research Ethics Board (REB) at the University of Ontario Institute of Technology (UOIT).

This research is subject to continuing review requirements. This research file must be renewed or closed by the current expiry date (January 01, 2018) by using the following forms from the UOIT website.

- **Renewal Request Form**: Projects not renewed within 30 days of the expiry date will be automatically suspended by the REB; projects not renewed within 60 days of the expiry date will be automatically closed by the REB. Once your file has been formally closed, a new submission will be required to open a new file.
- **Change Request Form**: Any changes or modifications (e.g. adding a Co-PI or a change in methodology) must be approved by the REB through the completion of a change request form before implemented.
- **Adverse or Unexpected Events Form**: Events must be reported to the REB within 72 hours after the event occurred with an indication of how these events affect (in the view of the Principal Investigator) the safety of the participants and the continuation of the protocol (i.e. un-anticipated or un-mitigated physical, social or psychological harm to a participant).
- **Research Project Completion Form**: This form must be completed when the research study is concluded.

Always quote your REB file number (15-060/13733) on future correspondence. We wish you continued success with your study.

Appendix 4: Letter of Support from Alzheimer Society of Durham Region



Alzheimer Society
DURHAM REGION

September 28, 2015

Research Ethics Board (REB)
2000 Simcoe Street North
Oshawa, ON L1H 7K4

Dear Members of the REB Committee:

On behalf of the Alzheimer Society of Durham Region, I wish to acknowledge the request by Paige Stewart, a Master's student at the University of Ontario Institute of Technology, to conduct her research project in conjunction with our organization. We understand that Paige is examining the relationship of physical activity on sleep among persons with dementia. We are aware that she intends to complete this research by recruiting clients from our caregiver support groups to complete a questionnaire. If we have other opportunities for Paige to present her study to potential participants, we will also offer her those opportunities (eg. Public education and awareness events).

As the Executive Director at the Alzheimer Society of Durham Region, I grant permission for Paige to complete her research at our organization.

Should you have any questions, please feel free to contact me at any time.

Yours truly,

Denyse Newton
Executive Director
Alzheimer Society of Durham Region
(905) 576-2567 ext 23
dnewton@alzheimerdurham.com

ALZHEIMER SOCIETY OF DURHAM REGION
1600 CHAMPLAIN AVE.., SUITE 202, WHITBY, ON L1N 9B2
TEL: 905-576-2567 FAX: 905-576-2033 TOLL FREE: 1-888-301-1106
WEB: www.alzheimer.ca/durham E-MAIL: information@alzheimerdurham.com
CHARITABLE REGISTRATION NUMBER: 10670 5296 RR0001

Appendix 5: Letter of Invitation for Caregivers Participating in the Study

UOIT
CHALLENGE INNOVATE CONNECT

FACULTY OF HEALTH SCIENCES

Letter of Invitation #1: For Caregivers

Study Title: The Relationship Between Moderate Physical Activities and Sleep Quality and Quantity among Persons with Dementia

Investigator:
Paige Stewart Faculty of Health Sciences
University of Ontario Institute of Technology
paige.stewart@uoit.ca

Supervisor:
Dr. Emma Bartfay Faculty of Health Sciences
University of Ontario Institute of Technology
emma.bartfay@uoit.ca

Dear Caregiver:

You are being asked to take part in a research study with the University Of Ontario Institute Of Technology (UOIT), Faculty of Health Sciences. Before agreeing to participate in this study, it is important that you read and understand the following explanation of the study procedures.

Eligibility: To participate, you must be the **primary caregiver** (a family member who takes primary responsibility for the care of a loved one) of someone who has received a formal diagnosis of a dementia by a health professional. The person you care for must be **community-dwelling** (primary residence is a private home).

Purpose: The purpose of this research study is to explore the relationship between physical activity levels and sleep quality and quantity among persons with dementia. This study has been reviewed by the UOIT Research Ethics Board and has received ethics clearance (REB file #15-060).

Procedures: You will participate in a one-time 5-10 minute telephone questionnaire administered by a Master's student from the University Of Ontario Institute Of Technology. You will complete a series of questions related to the physical activity levels and sleep experienced by the individual you care for.

Risks: There is no risk of injury, harm, or discomfort associated with participating in this study. Potential inconveniences include feeling uncomfortable about completing the questionnaire in the presence of a researcher. This will be minimized by allowing you to complete the questionnaire in a familiar, comfortable environment.

Benefits: Although you may not benefit directly, the information that you provide will be used to assist in the process of understanding how physical activity may be a valuable treatment option for the management of sleep disturbances. The community will also benefit from this research by being more aware about the effectiveness of physical activity for addressing sleep concerns.

Confidentiality: You will not be asked to provide your name, or the name of the individual that you care for on the questionnaire. All of your information will be coded, and stored securely. The results of this study may be published in scientific journals and be summarized in a report to the Alzheimer Society of Durham Region. No identifying information will be used in any publications, and/or presentations. Any information released will be in aggregate (group) form and no individual results will be reported. Alzheimer Society of Durham Region will be informed of the results of the research, and this information will be available to all participants.

Participation: Participation in the research is voluntary. You can choose not to participate, or if at any time during the study you wish to withdraw you can do so just by saying you wish to stop. Your relationship with the Alzheimer Society of Durham Region will not be affected in any way and all data related to you will be eliminated.

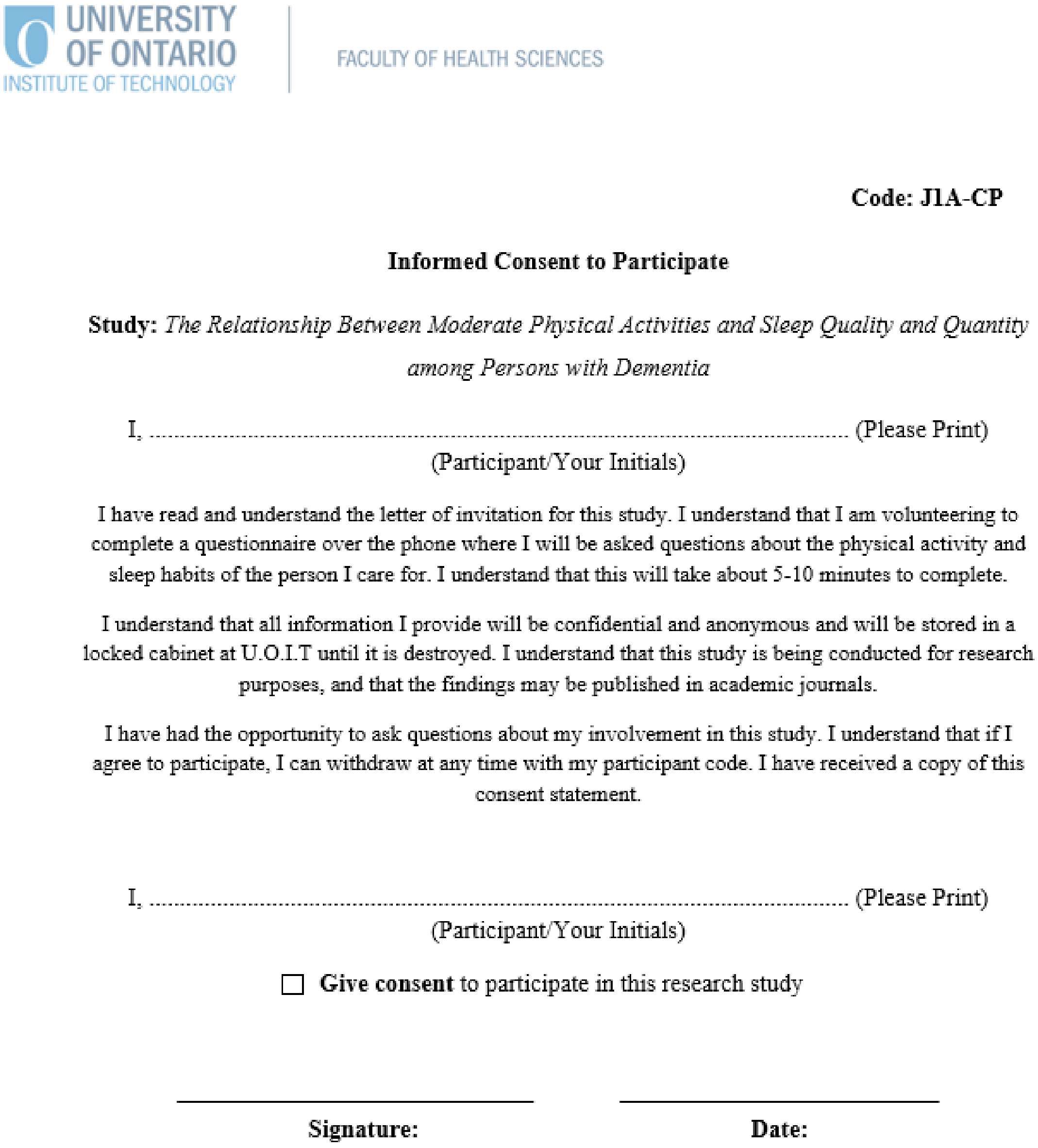
Questions: If you have any questions about this study, please contact Paige Stewart at 905-431-0397, or Dr. Emma Bartfay at 905-721-8668, ext. 2950. If you have any questions about your rights as a research participant, please contact University of Ontario Institute of Technology REB Administration at 905-721-8668, ext. 3693 or compliance@uoit.ca. This office is not involved with the research project in any way and calling this office will not affect your participation in the study.

Copy of the Statement of Consent:
'I have read and understand the letter of invitation for this study. I understand that I am volunteering to complete a questionnaire over the phone where I will be asked questions about the physical activity and sleep habits of the person I care for. I understand that this will take about 10-15 minutes to complete.

I understand that all information I provide will be confidential and anonymous and will be stored in a locked cabinet at U.O.I.T. until it is destroyed. I understand that this study is being conducted for research purposes, and that the findings may be published in academic journals.

I have had the opportunity to ask questions about my involvement in this study. I understand that if I agree to participate, I can withdraw at any time with my participant code. I have received a copy of this consent statement.'

Appendix 6: Letter of Informed Consent for Caregivers



UNIVERSITY OF ONTARIO
INSTITUTE OF TECHNOLOGY

FACULTY OF HEALTH SCIENCES

Code: J1A-CP

Informed Consent to Participate

Study: *The Relationship Between Moderate Physical Activities and Sleep Quality and Quantity among Persons with Dementia*

I, ... (Please Print)
(Participant/Your Initials)

I have read and understand the letter of invitation for this study. I understand that I am volunteering to complete a questionnaire over the phone where I will be asked questions about the physical activity and sleep habits of the person I care for. I understand that this will take about 5-10 minutes to complete.

I understand that all information I provide will be confidential and anonymous and will be stored in a locked cabinet at U.O.I.T until it is destroyed. I understand that this study is being conducted for research purposes, and that the findings may be published in academic journals.

I have had the opportunity to ask questions about my involvement in this study. I understand that if I agree to participate, I can withdraw at any time with my participant code. I have received a copy of this consent statement.

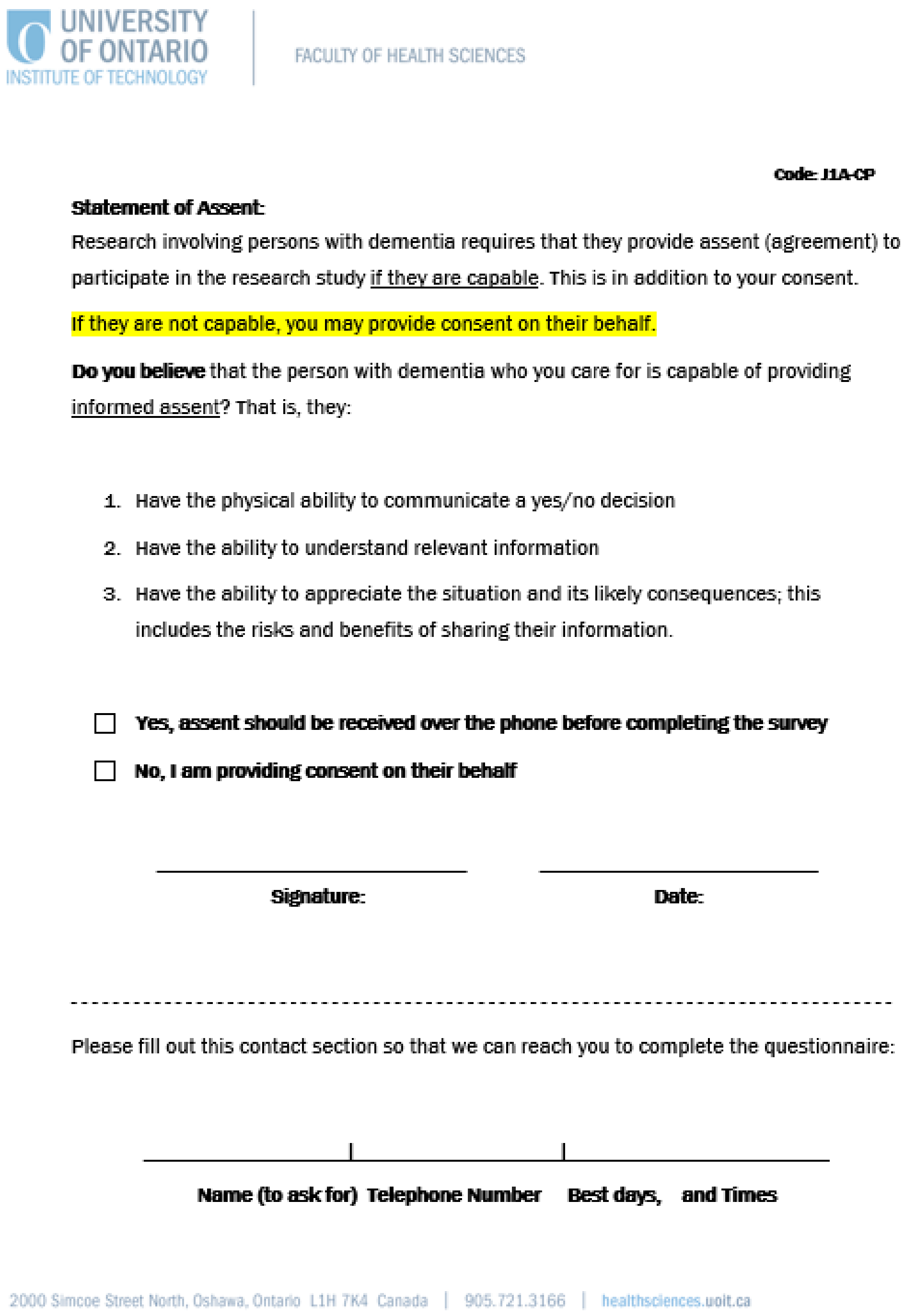
I, ... (Please Print)
(Participant/Your Initials)

☐ **Give consent** to participate in this research study

Signature:

Date:

Appendix 7: Evaluation of Assent Capacity and Caregiver Contact Information Form



UNIVERSITY OF ONTARIO INSTITUTE OF TECHNOLOGY | FACULTY OF HEALTH SCIENCES

Code: J1A-CP

Statement of Assent:

Research involving persons with dementia requires that they provide assent (agreement) to participate in the research study if they are capable. This is in addition to your consent.

If they are not capable, you may provide consent on their behalf.

Do you believe that the person with dementia who you care for is capable of providing informed assent? That is, they:

1. Have the physical ability to communicate a yes/no decision
2. Have the ability to understand relevant information
3. Have the ability to appreciate the situation and its likely consequences; this includes the risks and benefits of sharing their information.

☐ **Yes, assent should be received over the phone before completing the survey**

☐ **No, I am providing consent on their behalf**

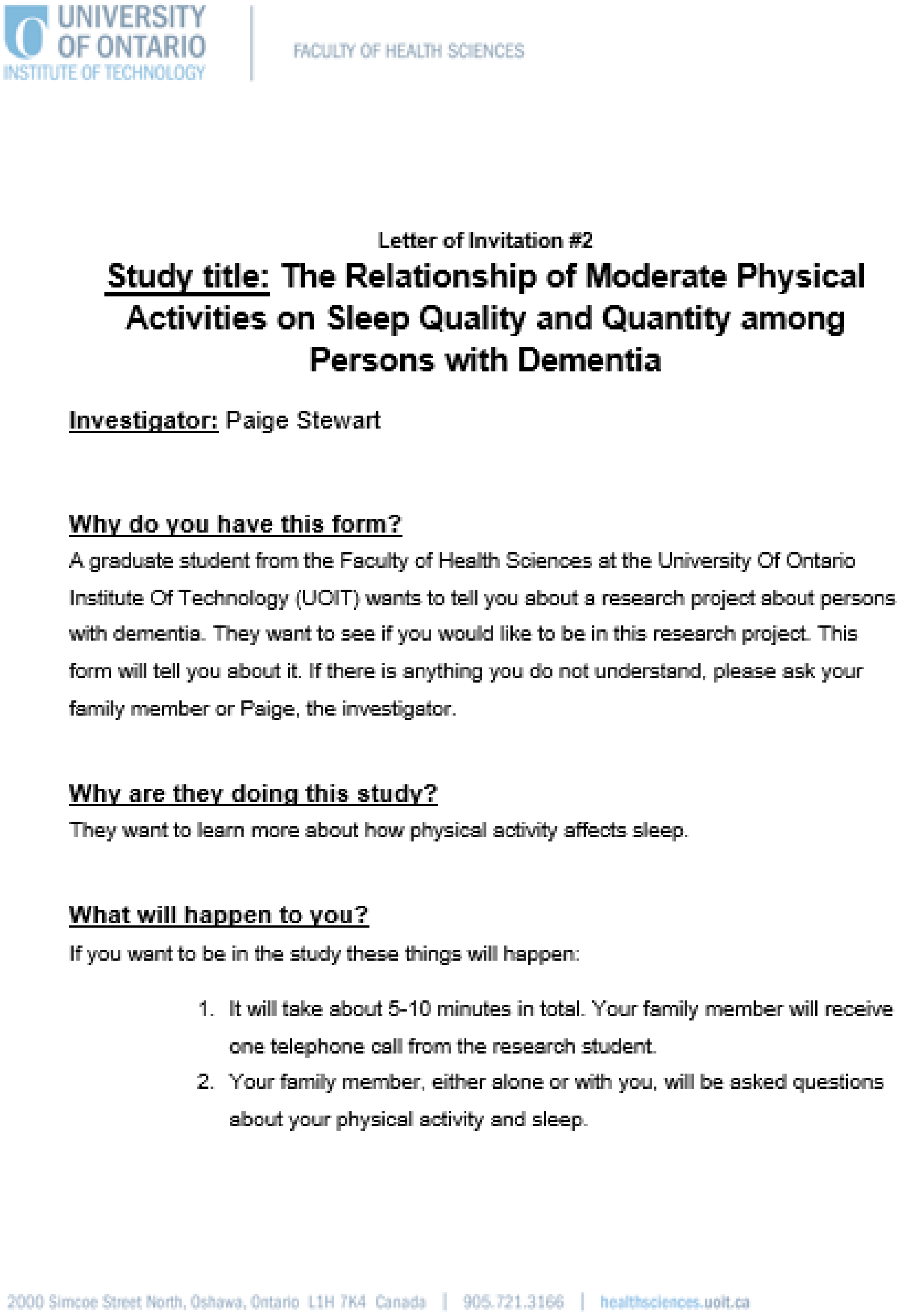
Signature: **Date:**

Please fill out this contact section so that we can reach you to complete the questionnaire:

Name (to ask for) Telephone Number Best days, and Times

2000 Simcoe Street North, Oshawa, Ontario L1H 7K4 Canada | 905.721.3166 | healthsciences.uoit.ca

Appendix 8: Letter of Invitation for Person with Dementia



UNIVERSITY OF ONTARIO
INSTITUTE OF TECHNOLOGY
FACULTY OF HEALTH SCIENCES

Letter of Invitation #2

Study title: The Relationship of Moderate Physical Activities on Sleep Quality and Quantity among Persons with Dementia

Investigator: Paige Stewart

Why do you have this form?

A graduate student from the Faculty of Health Sciences at the University Of Ontario Institute Of Technology (UOIT) wants to tell you about a research project about persons with dementia. They want to see if you would like to be in this research project. This form will tell you about it. If there is anything you do not understand, please ask your family member or Paige, the investigator.

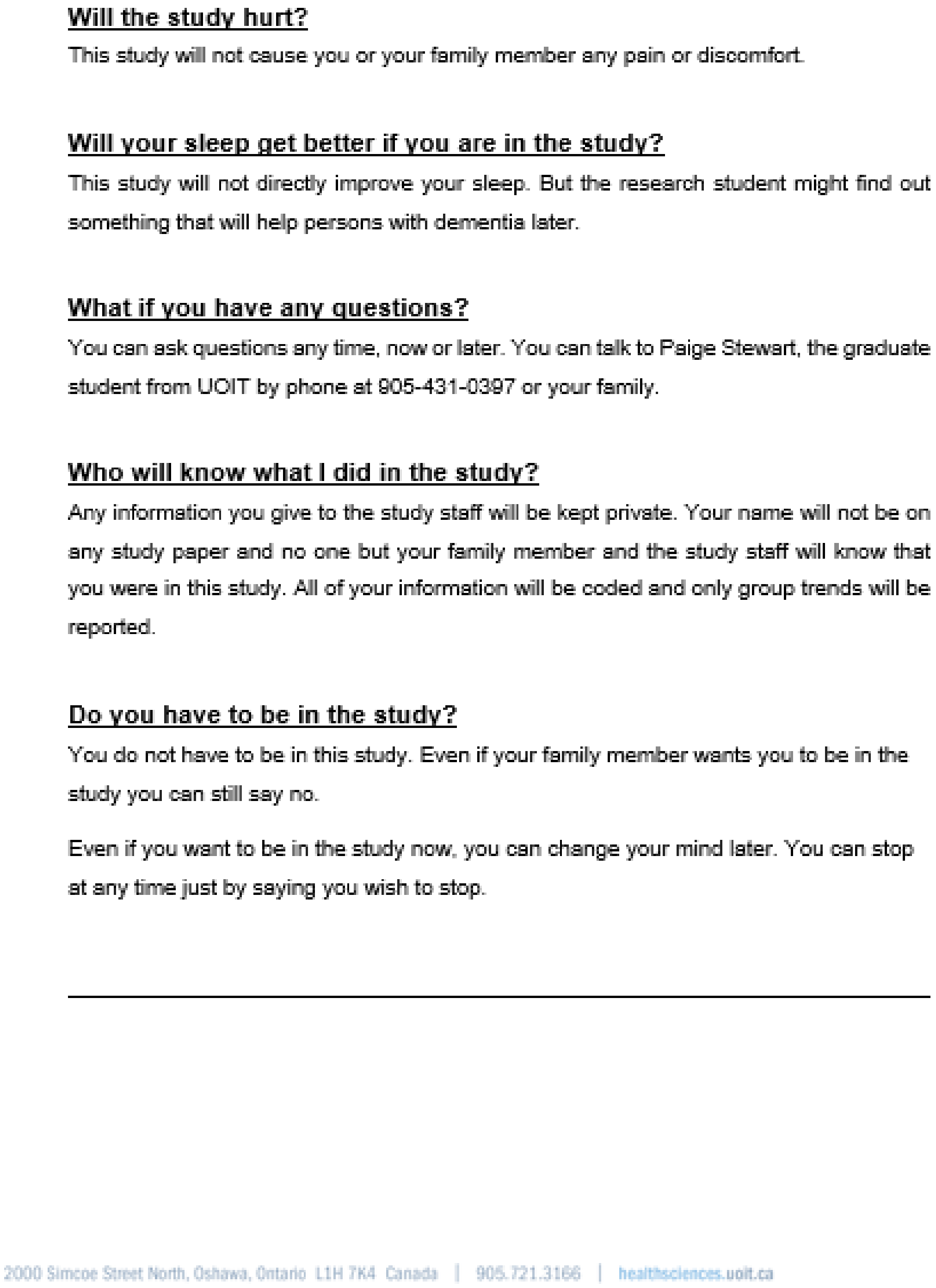
Why are they doing this study?

They want to learn more about how physical activity affects sleep.

What will happen to you?

If you want to be in the study these things will happen:

1. It will take about 5-10 minutes in total. Your family member will receive one telephone call from the research student.
2. Your family member, either alone or with you, will be asked questions about your physical activity and sleep.



Will the study hurt?

This study will not cause you or your family member any pain or discomfort.

Will your sleep get better if you are in the study?

This study will not directly improve your sleep. But the research student might find out something that will help persons with dementia later.

What if you have any questions?

You can ask questions any time, now or later. You can talk to Paige Stewart, the graduate student from UOIT by phone at 905-431-0397 or your family.

Who will know what I did in the study?

Any information you give to the study staff will be kept private. Your name will not be on any study paper and no one but your family member and the study staff will know that you were in this study. All of your information will be coded and only group trends will be reported.

Do you have to be in the study?

You do not have to be in this study. Even if your family member wants you to be in the study you can still say no.

Even if you want to be in the study now, you can change your mind later. You can stop at any time just by saying you wish to stop.

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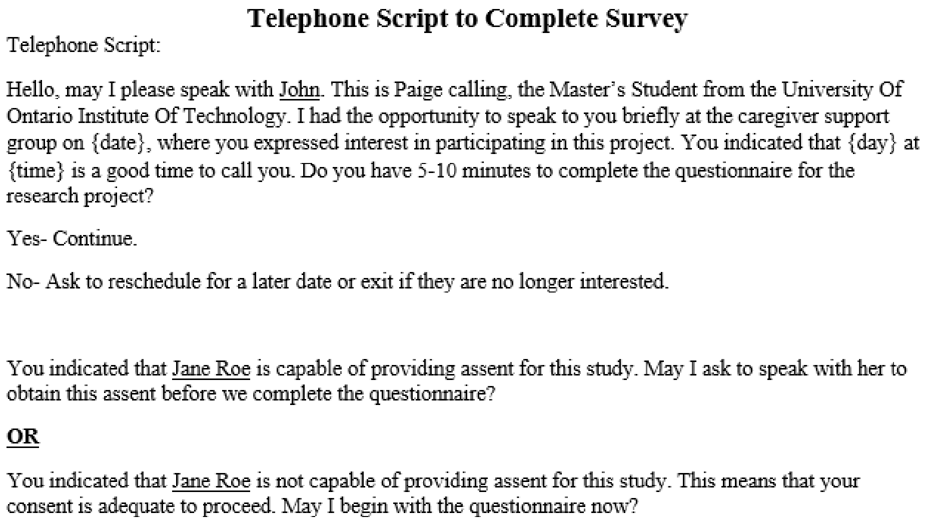
Appendix 9: Telephone Script for Questionnaire



Telephone Script to Complete Survey

Telephone Script:

Hello, may I please speak with John. This is Paige calling, the Master's Student from the University Of Ontario Institute Of Technology. I had the opportunity to speak to you briefly at the caregiver support group on {date}, where you expressed interest in participating in this project. You indicated that {day} at {time} is a good time to call you. Do you have 5-10 minutes to complete the questionnaire for the research project?

Yes- Continue.

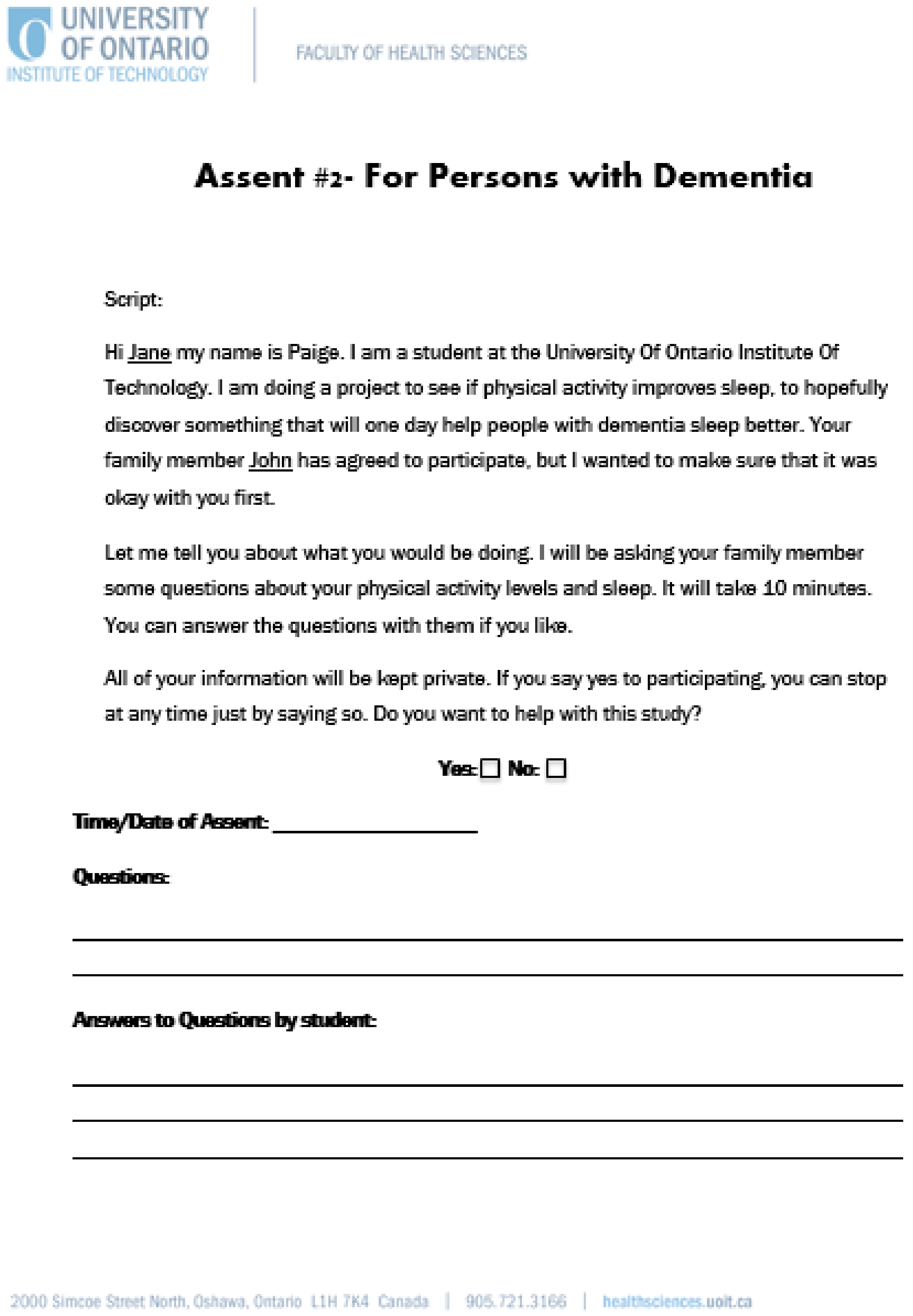
No- Ask to reschedule for a later date or exit if they are no longer interested.

You indicated that Jane Roe is capable of providing assent for this study. May I ask to speak with her to obtain this assent before we complete the questionnaire?

OR

You indicated that Jane Roe is not capable of providing assent for this study. This means that your consent is adequate to proceed. May I begin with the questionnaire now?

Appendix 10: Statement of Assent Script for Person with Dementia



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Assent #2- For Persons with Dementia

Script:

Hi Jane my name is Paige. I am a student at the University Of Ontario Institute Of Technology. I am doing a project to see if physical activity improves sleep, to hopefully discover something that will one day help people with dementia sleep better. Your family member John has agreed to participate, but I wanted to make sure that it was okay with you first.

Let me tell you about what you would be doing. I will be asking your family member some questions about your physical activity levels and sleep. It will take 10 minutes. You can answer the questions with them if you like.

All of your information will be kept private. If you say yes to participating, you can stop at any time just by saying so. Do you want to help with this study?

Yes: ☐ **No:** ☐

Time/Date of Assent: ____________________

Questions:

Answers to Questions by student:

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Comments from PWD:

____

____

____

____

____

Code of Person Giving Assent Date

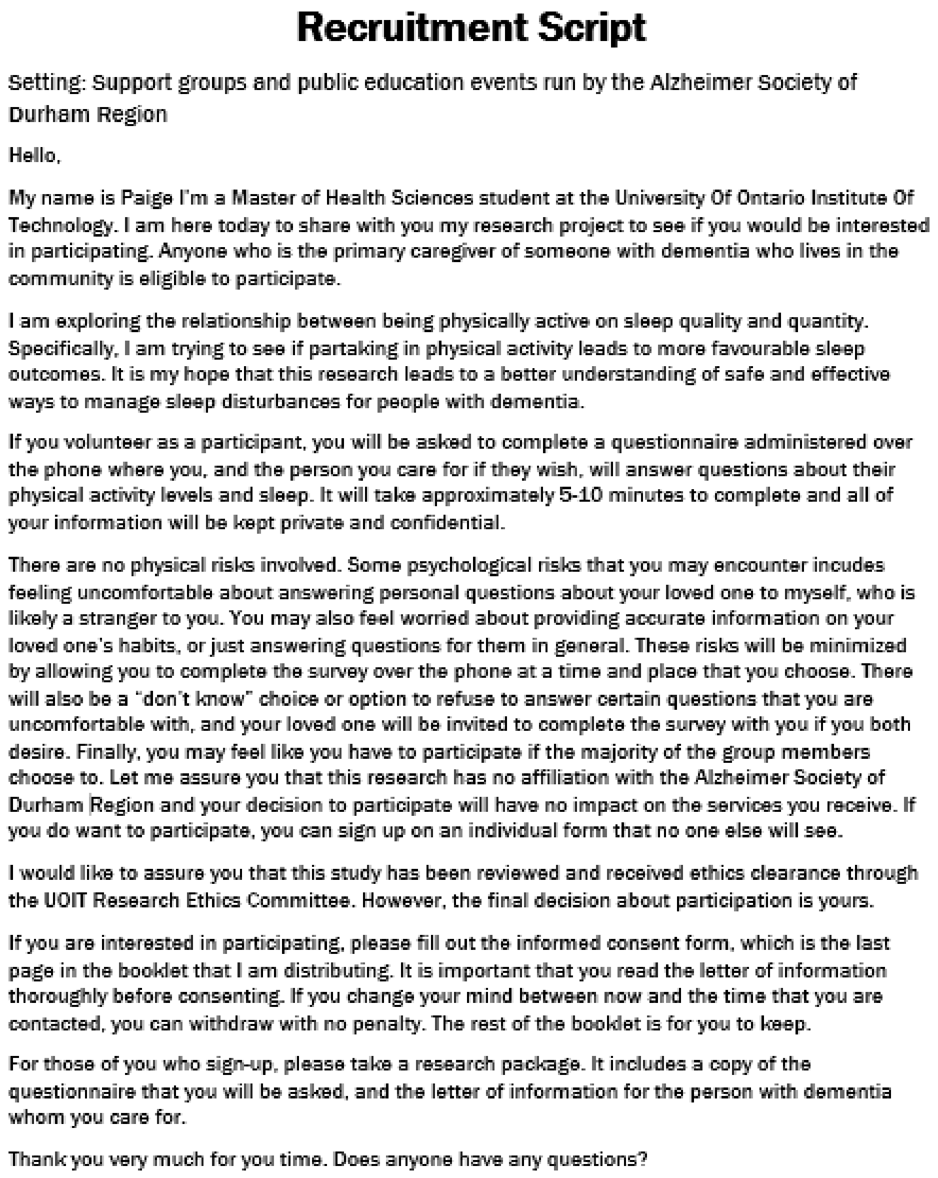
____

Name of Person Obtaining Assent Date

____

Signature of Person Obtaining Assent Date

Appendix 11: Recruitment Script for Initial Contact



Recruitment Script

Setting: Support groups and public education events run by the Alzheimer Society of Durham Region

Hello,

My name is Paige I'm a Master of Health Sciences student at the University Of Ontario Institute Of Technology. I am here today to share with you my research project to see if you would be interested in participating. Anyone who is the primary caregiver of someone with dementia who lives in the community is eligible to participate.

I am exploring the relationship between being physically active on sleep quality and quantity. Specifically, I am trying to see if partaking in physical activity leads to more favourable sleep outcomes. It is my hope that this research leads to a better understanding of safe and effective ways to manage sleep disturbances for people with dementia.

If you volunteer as a participant, you will be asked to complete a questionnaire administered over the phone where you, and the person you care for if they wish, will answer questions about their physical activity levels and sleep. It will take approximately 5-10 minutes to complete and all of your information will be kept private and confidential.

There are no physical risks involved. Some psychological risks that you may encounter incudes feeling uncomfortable about answering personal questions about your loved one to myself, who is likely a stranger to you. You may also feel worried about providing accurate information on your loved one's habits, or just answering questions for them in general. These risks will be minimized by allowing you to complete the survey over the phone at a time and place that you choose. There will also be a "don't know" choice or option to refuse to answer certain questions that you are uncomfortable with, and your loved one will be invited to complete the survey with you if you both desire. Finally, you may feel like you have to participate if the majority of the group members choose to. Let me assure you that this research has no affiliation with the Alzheimer Society of Durham Region and your decision to participate will have no impact on the services you receive. If you do want to participate, you can sign up on an individual form that no one else will see.

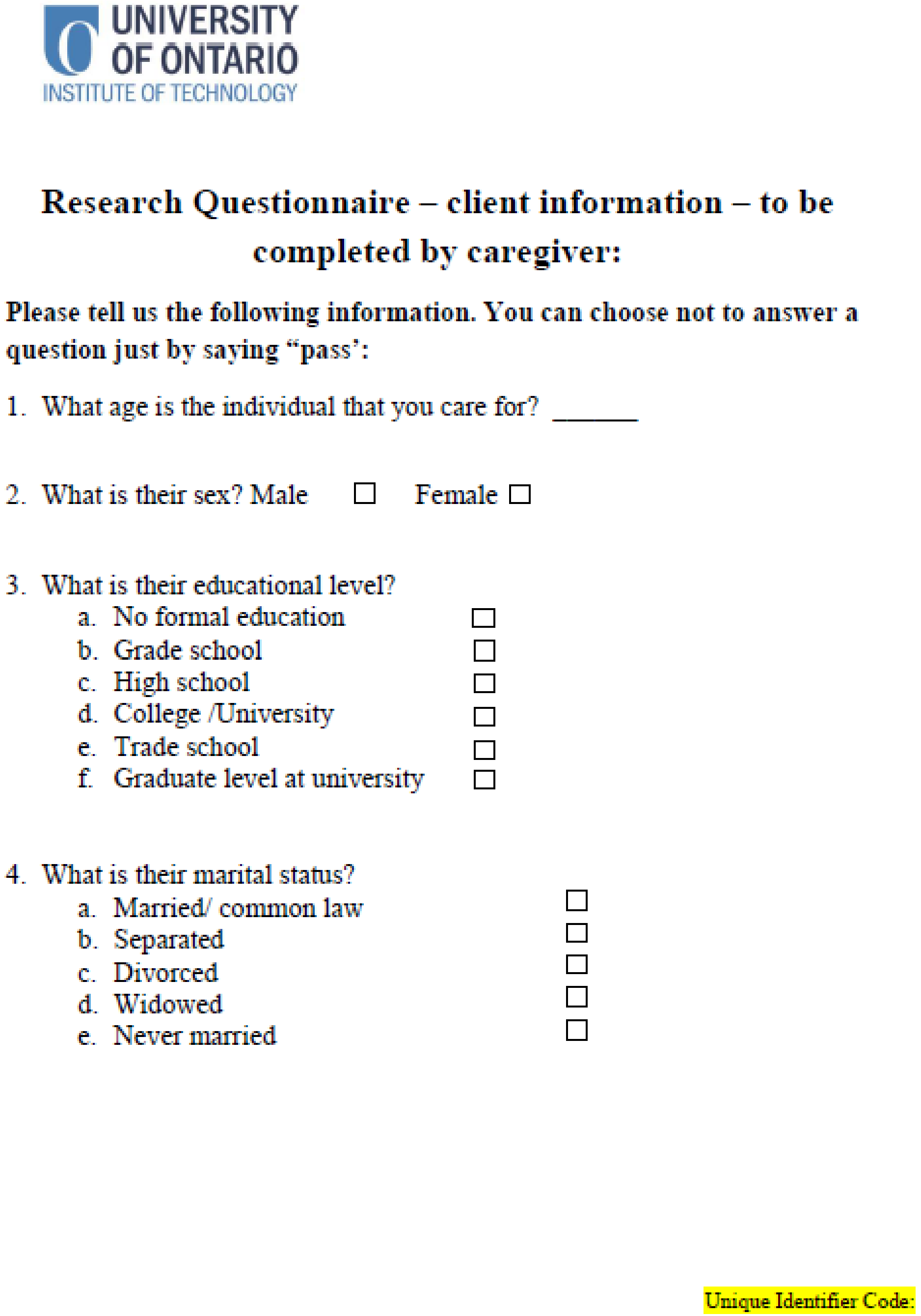
I would like to assure you that this study has been reviewed and received ethics clearance through the UOIT Research Ethics Committee. However, the final decision about participation is yours.

If you are interested in participating, please fill out the informed consent form, which is the last page in the booklet that I am distributing. It is important that you read the letter of information thoroughly before consenting. If you change your mind between now and the time that you are contacted, you can withdraw with no penalty. The rest of the booklet is for you to keep.

For those of you who sign-up, please take a research package. It includes a copy of the questionnaire that you will be asked, and the letter of information for the person with dementia whom you care for.

Thank you very much for you time. Does anyone have any questions?

Appendix 12: Research Questionnaire



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Research Questionnaire – client information – to be completed by caregiver:

Please tell us the following information. You can choose not to answer a question just by saying "pass':

1. What age is the individual that you care for? _______

2. What is their sex? Male ☐ Female ☐

3. What is their educational level?
    a. No formal education ☐
    b. Grade school ☐
    c. High school ☐
    d. College /University ☐
    e. Trade school ☐
    f. Graduate level at university ☐

4. What is their marital status?
    a. Married/ common law ☐
    b. Separated ☐
    c. Divorced ☐
    d. Widowed ☐
    e. Never married ☐

Unique Identifier Code:

5. What type of dementia have they been diagnosed with by a health professional?
    a. Alzheimer's ☐
    b. Vascular dementia ☐
    c. Frontotemporal dementia ☐
    d. Lewy Body dementia ☐
    e. Mixed ☐
    f. Other ☐

6. When did they receive their diagnosis?

    ______ years, _______ **months ago**

7. Are they currently taking any of the following drugs for Dementia:
    a. Aricept ☐
    b. Exelon ☐
    c. Reminyl ☐
    d. Ebixa ☐
    e. Other ☐
    f. No ☐ Please specify: ____________

8. Are they receiving home care services?
    a. Yes
        i. Please specify:
            1. Personal Support Workers ☐
            2. Registered Practical Nurses/Registered Nurses ☐
            3. Housekeeping ☐
            4. Other ☐

9. Are they currently taking any sleep medication?
    a. Prescription
        i. Zopiclone ☐
        ii. Ambien ☐
        iii. Lunesta ☐
        iv. Lorazepam ☐
        v. Triazolam ☐
        vi. Doxepin ☐
        vii. Diazepam ☐
        viii. Other ☐

Please specify: ________

    b. Over-the-counter
        i. Melatonin ☐
        ii. Vitalis ☐
        iii. Nytol ☐
        iv. Unisom ☐
        v. Other ☐

Please specify: ________

Please turn page over to fill out a brief questionnaire.

Leisure-Time Physical Activity Component

10. Now we are going to discuss their physical activity. I am going to read a list of six activities, and I would like you to tell me how many days per week on a typical week they perform these activities.

These are meant to be moderate physical activities. That means, we are interested in activities that increase your heart rate and breathing, but where it is still possible to speak comfortably. If you suspect these tasks are performed at a greater intensity than this, please say pass.

Days per Week

	Don't Know/ Refuse	0	1	2	3	4	5	6	7	Minutes per day
Walking at a comfortable pace										
Gardening										
Swimming (including Aqua fitness)										
Dance Therapy										
Weight Training										
Exercise Class										
Other:										

Sleep Component

The final section of this questionnaire asks about the sleep habits of the person you care for. State the answer that most closely represents the sleep they experience.

11. How long did it usually take for them to fall asleep during the past week?

(Circle One)

0-15 minutes……………..1

16-30 minutes…………..2

31-45 minutes……… …3

46-60 minutes……… ….4

More than 60 minutes. …5

---

12. In the past week, how many hours did they sleep each night on the weekdays?

Write in number
of hours per night: ☐☐

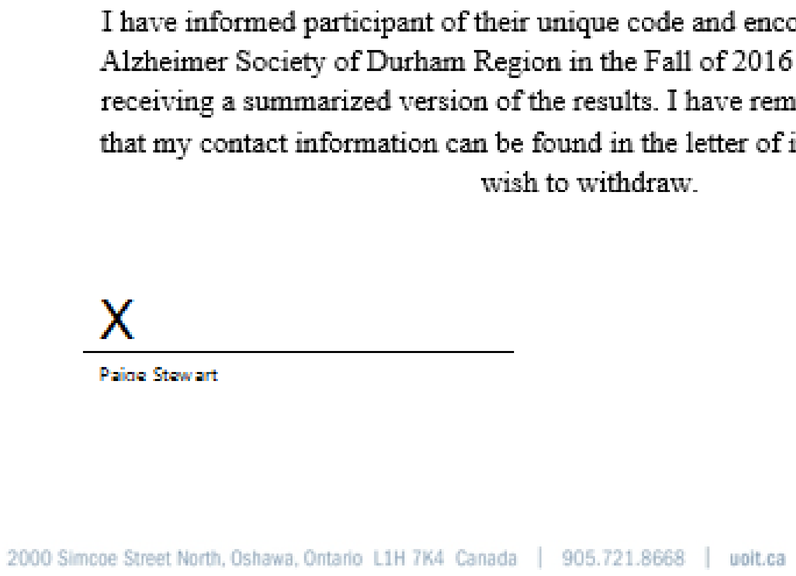
On the weekends?

Write in number
of hours per night: ☐☐

---

13. How many times in the past week did they….. (Circle One)

	Don't Know/ Refuse ▼	All of the Time ▼	Most of the Time ▼	Some of the Time ▼	A little of the Time ▼	None of the Time ▼
a) experience sleep that was not quiet (e.g. moving restlessly, snoring, speaking etc., while sleeping)?	0	1	2	3	4	5
b) have trouble falling asleep?	0	1	2	3	4	5
c) awaken during the night?	0	1	2	3	4	5
d) have difficulty getting back to sleep upon awakening during the night?	0	1	2	3	4	5
e) complain about feelings of fatigue or drowsiness during the day?	0	1	2	3	4	5
f) take naps (5 minutes or longer) during the day?	0	1	2	3	4	5



I have informed participant of their unique code and encouraged them to contact Alzheimer Society of Durham Region in the Fall of 2016 if they are interested in receiving a summarized version of the results. I have reminded the participant(s) that my contact information can be found in the letter of information should they wish to withdraw.

X

Paige Stewart

2000 Simcoe Street North, Oshawa, Ontario L1H 7K4 Canada | 905.721.8668 | uoit.ca

Appendix 13: Research Package Instructions

Start Here

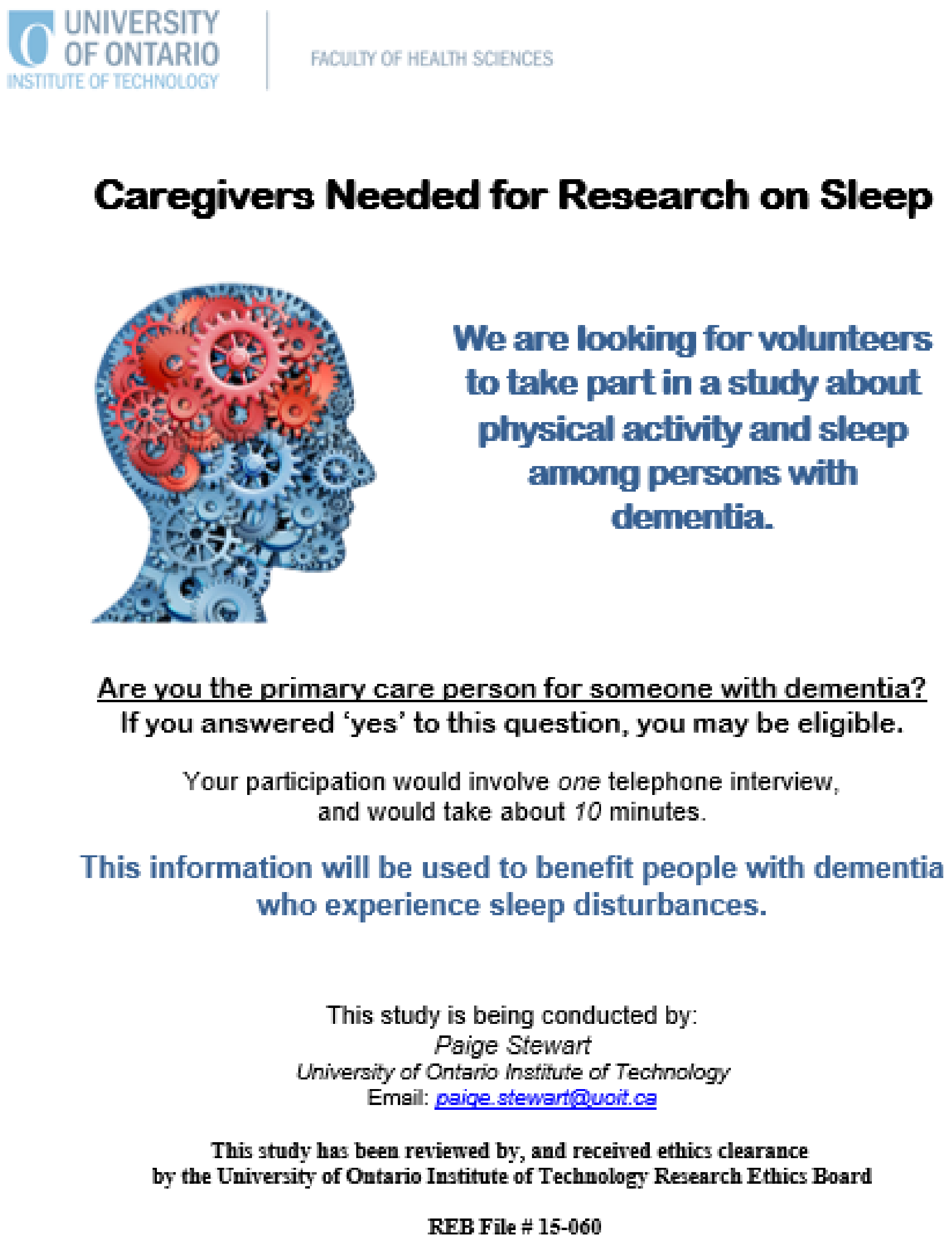
You have received this research package because you expressed interest in participating in this study.

Please read through the resesarch package in the following order:

1) **Letter of Invitation #2- This is for the person you care if you believe they are capable of providing assent.**

2) **The questionnaire that you will be asked to complete over the phone.**

Appendix 14: Recruitment Poster



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Caregivers Needed for Research on Sleep

We are looking for volunteers to take part in a study about physical activity and sleep among persons with dementia.

Are you the primary care person for someone with dementia?
If you answered 'yes' to this question, you may be eligible.

Your participation would involve *one* telephone interview,
and would take about *10* minutes.

This information will be used to benefit people with dementia who experience sleep disturbances.

This study is being conducted by:
Paige Stewart
University of Ontario Institute of Technology
Email: paige.stewart@uoit.ca

This study has been reviewed by, and received ethics clearance by the University of Ontario Institute of Technology Research Ethics Board

REB File # 15-060

Appendix 15: Canadian Community Health Survey Physical Activity List

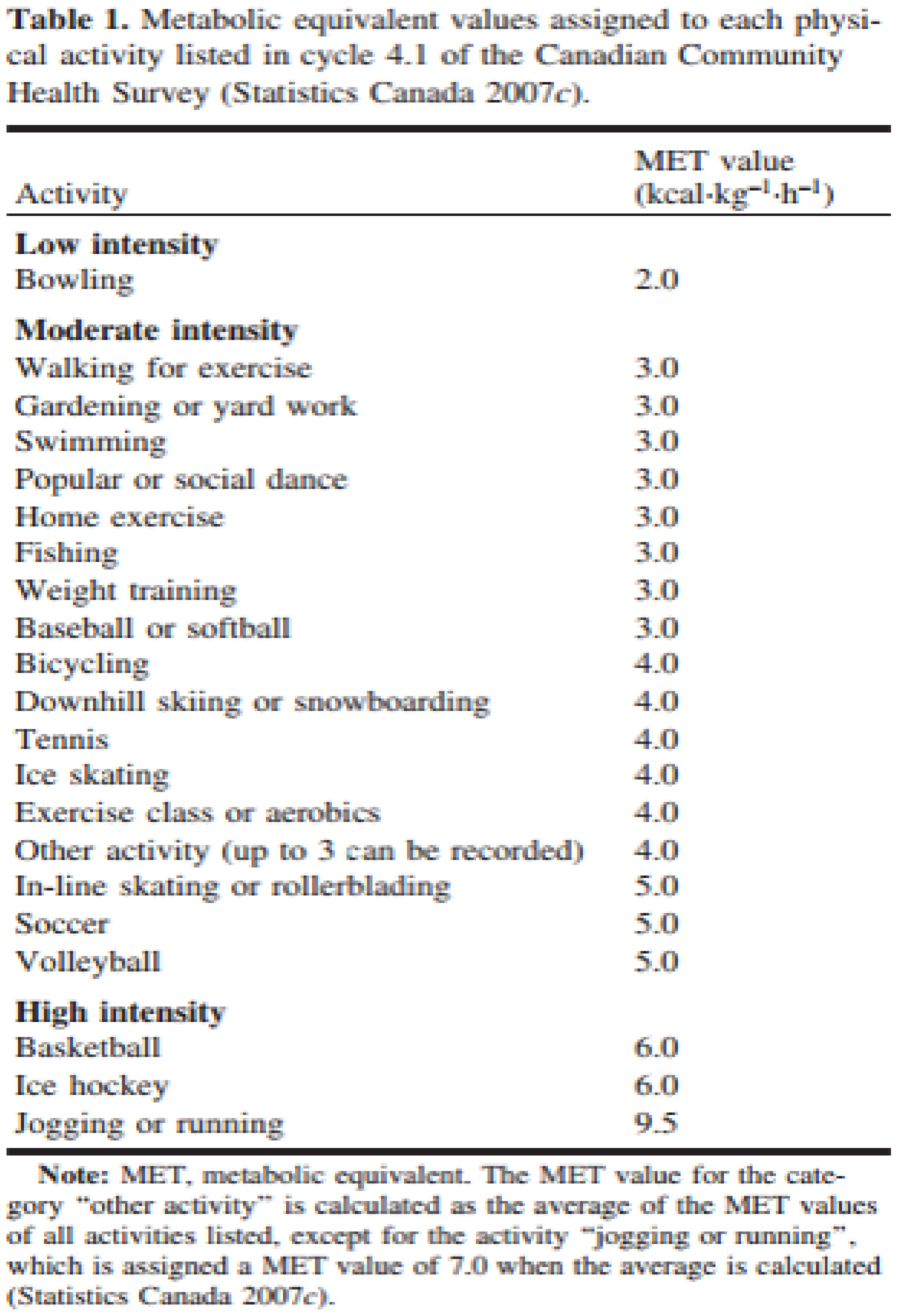

Table 1. Metabolic equivalent values assigned to each physical activity listed in cycle 4.1 of the Canadian Community Health Survey (Statistics Canada 2007*c*).

Activity	MET value (kcal·kg^{-1}·h^{-1})
Low intensity	
Bowling	2.0
Moderate intensity	
Walking for exercise	3.0
Gardening or yard work	3.0
Swimming	3.0
Popular or social dance	3.0
Home exercise	3.0
Fishing	3.0
Weight training	3.0
Baseball or softball	3.0
Bicycling	4.0
Downhill skiing or snowboarding	4.0
Tennis	4.0
Ice skating	4.0
Exercise class or aerobics	4.0
Other activity (up to 3 can be recorded)	4.0
In-line skating or rollerblading	5.0
Soccer	5.0
Volleyball	5.0
High intensity	
Basketball	6.0
Ice hockey	6.0
Jogging or running	9.5

Note: MET, metabolic equivalent. The MET value for the category "other activity" is calculated as the average of the MET values of all activities listed, except for the activity "jogging or running", which is assigned a MET value of 7.0 when the average is calculated (Statistics Canada 2007*c*).

Appendix 16: Sleep disturbances among subtypes of dementia

Type of dementia	Impact on sleep
Alzheimer's disease	• Sleep disturbances affect approximately 44% of persons with Alzheimer's disease • Onset of sleep disturbances are more progressive than other subtypes of dementia • Manifestation of poor sleep includes sleeping more than usual and daytime napping, awakening too early, and nighttime awakenings with accompanying aggressive behaviour [41, 106]
Dementia with Lewy bodies (DLB)	• Associated with significanhtly worse sleep disturbances than persons with Alzheimer's disease • Poor sleep onset latency, high frequency of nighttime awakenings, and daytime naps that exceed 2 hours in length are extremely common • DLB is also associated with development of rapid eye movement sleep behaviour disorder (RBD), which involves repeated episodes of complex motor behaviours during sleep such as kicking, punching, and vocalizations [86, 106]
Parkinson's disease dementia (PD)	• Approximately 77% of persons with PD experience sleep disturbances • The disturbance in sleep quality is much greater in PD compared to Alzheimer's disease • Common sleep disturbances include difficulty initiating and maintaining sleep and excessive daytime drowsiness • Medication taken for PD has also shown to have a negative impact on sleep, including an increase in nighttime awakenings and daytime fatigue [41, 106]
Frontotemporal dementia (FTD)	• Sleep disturbances are characterized as increased nocturnal activity, decreased morning activity, decreased total sleep time, and decreased sleep efficiency • Previous study of 13 subjects with FTD found that the disturbances may be less severe than people with more advanced stages of Alzheimer's disease, however they impact a greater percentage of FTD than any other form of dementia [106]
Vascular dementia	• Onset of sleep disturbances are typically more rapid and are manifested as difficulty maintaining the circadian rhythm (i.e. more awakenings during the night and drowsiness during the day) • The damage to the frontal-subcortical neuronal circuit that occurs in vascular dementia may contribute to the excessive daytime somnolence that occurs in this subtype [106]

Glossary

Dance therapy: a form of moderate intensity physical activity that involves movement of the head and trunk and the shifting of the center of gravity in every direction from the axis of support.

Dementia: a syndrome due to condition of the brain; usually of a chronic or progressive nature; in which there is a disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement.

Exercise: a component of physical activity, differing in the fact that it is planned, structured, and defined by its frequency, intensity, and duration.

Exercise class: a program run by a professional outside of an individual's home that consists of more than one mode of exercise such as strength, flexibility, aerobic, and balance.

Light therapy: a type of non-pharmacological intervention, where individuals place themselves in a position that exposes their eyes to a full-spectrum light box of a certain intensity for a set duration of time.

Long-term memory: Memory with perhaps limitless capacity and infinite storage time for memories many years in the past.

Metabolic expenditure of task (MET) value: the ratio between an activity's energy expenditure and the energy expenditure that occurs when a person is at rest.

Moderate physical activities: Physical activities that have a MET value of 3.0-5.99.

Moderate intensity physical activity: any activity that increases heart rate and breathing but where it is still possible to speak comfortably.

Physical activity: any bodily movement produced by skeletal muscles that requires energy expenditure which increases heart rate and breathing.

Rapid Eye Movement: a sleep state that recurs in intervals throughout the night, in which energy is restored to the brain and body, dreams occur, eyes dart back and forth, and the body becomes immobile and relaxed.

Short-term memory: memory with a limited capacity to store new information for the preceding hours, days, or months.

Sleep: a natural and reversible state of reduced responsiveness to external stimuli and relative inactivity, accompanied by loss of consciousness.

Sleep disturbance: difficulty in initiating sleep, difficulty maintaining sleep, waking up too early, or sleep that is chronically non-restorative in quality. In general, any real or perceived disruption in sleep patterns that results in altered daytime function as defined by the patient.

Sleep efficiency: The total time asleep at night divided by the total time in bed.

Sleep hygiene: a non-pharmacological intervention that attempts to manage an individual's behaviours with regards to sleep habits and routines, as well as creating an environment conducive to sleep.

Sleep onset latency (SOL): the length of time between when an individual goes to bed and the onset of sleep.

Sleep quantity: the number of hours that an individual sleeps per night.

Sleep quality: one's satisfaction of the sleep experience, integrating aspects of sleep initiation, sleep maintenance, quantity, and refreshment upon awakening.

Slow wave sleep (SWS): a stage of the sleep cycle characterized by slow brain waves combined with smaller, faster waves where restorative processes take place.

Sundowning: a common clinical phenomenon manifested by the emergent of increment or neuropsychiatric symptoms in the late afternoon, evening, or at night.

Swimming: a form of aerobic physical activity performed in water that uses the body's large muscles to move in a rhythmic manner for a sustained period of time.

Wake after sleep onset: A form of sleep measurement, defined as the total amount of time awake at night excluding SOL

Weight training: a form of physical activity that involves muscles contracting against a type of resistance greater than normally experienced to increase skeletal muscle strength, power, endurance, and mass.