

The Needs and Experiences of Caregivers to Persons with Dementia (PWD) who have Lost their
Driving Privileges

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Abstract

The ability to drive a motor vehicle for most older adults is associated with a sense of independence, well-being, quality of life and identity. For many older adults, driving cessation is an inevitability. This is especially the case for older adults with a diagnosis of dementia. Driving cessation has been shown to negatively impact individuals' mobility and, consequently, quality of life. Informal caregivers (i.e., family caregivers) can mitigate the negative consequences associated with driving cessation in persons with dementia (PWD) by meeting their mobility needs and by offering emotional support. The purpose of this study was to examine the experience and needs of informal caregivers of PWD who had recently lost their driving privileges. Ten informal caregivers of PWD were recruited from a tertiary memory disorders clinic. Semi-structured interviews were conducted and transcribed. Transcripts of interviews were analyzed using an inductive thematic analysis approach. Thematic analysis revealed that caregivers expressed the need to receive transportation training and more information on transportation alternatives. Caregivers also expressed the need for psychological services, such as individual therapy, grief therapy or group therapy with other caregivers of PWD. The experiences and needs of caregivers indicate that driving cessation of the care recipient is a difficult experience for caregivers and that a therapeutic intervention based on the reported needs may be beneficial.

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The Needs and Experiences of Caregivers to Persons with Dementia (PWD) who have Lost their Driving Privileges

Characteristics of current older adult population in Canada

The Canadian older adult population has been steadily increasing in the last four decades. In 2011, the first members of the baby boomer generation turned 65, creating the highest increase in the older adult population in Canada in the last 70 years (Statistics Canada, 2017a). In 2011, Canada's older adult population increased by 20%. To contrast this, in 2011 the overall Canadian population increased by 5%, and the population of children below the age of 14 increased by 4.1% (Statistics Canada, 2017a). Furthermore, according to the 2016 census, centenarians are the fastest-growing segment of the population, with a 41.3% increase. According to the 2016 census, Canada's older adult population was larger than the population of children below the age of 14 years (Statistics Canada, 2017a).

This rising trend in the older adult population is related to a few factors. Firstly, the baby boomer generation is growing older, adding significant growth to the older adult share of the population. Secondly, the average Canadian life expectancy has been steadily increasing. For instance, in 1871 the average life expectancy was 40 years, with less than one in three individuals reaching the age of 65. Presently, the average Canadian life expectancy has reached over 82 years, with nine out of ten Canadians expected to reach 65 years of age (Statistics Canada, 2017a). Thirdly, Canadian fertility rates have been steadily decreasing since 1970, which restricts the number of youths, and lowers their share in the Canadian population. As such, Canada has been experiencing a significant increase in its older adult population in the last 30 years. Nevertheless, Canada still has a lower older adult population compared to most G7

countries. That is to say, this population trend is not limited to Canada, it is also present in the United States, United Kingdoms, France, Italy, Germany and Japan (Statistics Canada, 2017a).

There are also some trends within the Canadian older adult population. For instance, women have a longer life expectancy than men (Statistics Canada, 2017a). Thus, within the Canadian older adult population (65 years and older), there are up to 20% more women than men. Furthermore, it has been found that in Canada, fewer older adults live in large urban centres than in other types of population centres. Large urban centers were more likely to be highly populated by Canadians between the ages of 15 to 64 (Statistics Canada, 2017a).

According to projections by Statistics Canada (2016b), older adults over the age of 85 will make up over 25% of the total Canadian population by 2036, and up to 28% of the total Canadian population by 2061. On July 1st, 2010, Canada's older adult population stood at 4.8 million, and this number is predicted to more than double, reaching 10.9 million by 2036. According to these projections, by 2061, older adults could reach 12 million while Canadian children are estimated to make up fewer than 8 million. Thus, Canada is experiencing a significant rise in its older adult population. This is important, as Canadian resources and services catering to the older adult population will likely need to be adjusted in order to answer to this steadily increasing demand. In order to adjust Canadian resources and services for the older adult population, it would be imperative to consider the changes, transitions and needs associated with older age. For instance, older adults will experience changes in their lifestyle such as retirement, loss of loved ones, development of chronic illnesses and driving cessation.

Adapting to change in older life

Older age is often associated with a period of growth and serenity which promotes wisdom and the opportunity to gain greater emotional balance (Osborne, 2009; Mather, 2010).

However, the later stages of an adult's life are also marked with other important changes such as retirement, the loss of loved ones, changes in general health and changes in cognitive functions. The adjustment to such transitions can be challenging and can have an impact on an older adult's identity (Osborne, 2009). Transitions can be defined as major changes in an individual's life which can impact their social status, roles, routines and social interactions (Ryser, 2016). Transitions in older age represent changes, challenges and opportunities.

Retirement. Presently, older adults in Canada typically work until they reach age 64, while in 1990 older adults worked until they were 61 (Statistics Canada, 2018). This represents a trend in which older adults have been progressively working later into their lives when compared to previous years. Statistics Canada (2018) explains this trend by noting that Canadians have access to less physically demanding jobs and have longer life expectancies, which represents more years of good health. Over 80% of older adults identified work as the primary activity they engage in. Out of these older adult workers, roughly half signaled that they worked out of necessity (Statistics Canada, 2018). Although this trend reveals that older adults are working later into their lives, the majority retire in their mid-sixties (Statistics Canada, 2018). The transition from working to retirement is one of the main changes older adults will experience.

The transition into retirement can have a variety of impacts on an individual's temporal structure, life rhythm and identity (Jonsson, Borell & Sadlo, 2000; Osborne, 2009; Ryser, 2016). Temporal structure refers to how an individual organizes the structure of their daily living routine. Life rhythm refers to the pace at which an individual will participate in daily tasks, such as preparing a meal or running errands. According to a qualitative study by Jonsson and colleagues (2000), retired older adults indicated that one of the most important changes they experienced was no longer having a fixed structure. Thus, once older adults retire, they must

adapt themselves to an entirely different structure of daily living. The adaptation to a new temporal structure following retirement can prove challenging for older adults. Some participants in a study by Jonsson and colleagues (2000) reported that it was difficult for them to maintain social contact with friends and family that were still working. Participants also expressed that it was challenging for them to replace the external temporal structure that work had offered them for so many years. Thus, one of the challenges associated with retirement is the need for retired older adults to develop and implement a new temporal structure and routine for their everyday living (Jonsson et al., 2000).

Furthermore, participants expressed that their life rhythm slowed down as they adjusted themselves to retirement (Jonsson et al., 2000). Nonetheless, participants also reported that it was difficult to find the time to pick up new activities. Participants specified that while they technically had more free time, they did not start new projects and activities which they had anticipated for their retirement. However, despite observing that they were not engaging in the activities they had planned for their retirement, retired older adults generally saw their adaptation to a slower life rhythm in a positive light (Jonsson et al., 2000).

According to Osborne (2009), as older adults reach later stages of life, they experience fluctuations in their identity. Retirement represents the loss of a professional role, which can have impacts on one's living condition and social interactions (Ryser, 2016). Osborne (2009) also contends that following retirement, older adults may face identity issues due to leaving behind a professional role and adapting to new roles. These kinds of changes can also prompt older adults to experience existential issues as they become progressively more aware that they are reaching the later stages of their lives (Osborne, 2009). In summary, retirement is a normal transition for older adults which involves some adaptation on behalf of the individual. Notably,

older adults will need to develop their own routine to structure their daily lives, will likely need to adapt themselves to a slower pace of living, and may also experience changes in their identity and roles (Jonson et al., 2000; Osborne, 2009; Ryser, 2016).

Loss of loved ones. As was previously mentioned, life expectancy in Canada has been steadily increasing. As of 2016, the average life expectancy is 79 years for men, and 84 years for women (Statistics Canada, 2018). According to the 2014-2016 report on mortality rates by Statistics Canada, there is an increase in the number of deaths in the Canadian population. This can be explained, once again, by the older adult population growth. As the Canadian older adult population increases, mortality rates in the coming years will also rise. This phenomenon also represents the loss of loved ones within the older adult community. One of the most difficult events older adults will experience is the death of a spouse or loss of a loved one. The loss of a spouse can have a wide range of effects on older adults, which vary in terms of the degree and length of mourning and adjustment (Ott, Lueger, Kelber & Prigerson, 2007). The death of a spouse represents several adaptive challenges for the bereaved older adult. For instance, the loss of a spouse entails a change in the individual's marital status, which can consequently change the individual's economic status. Marital status and economic changes can entail identity changes for the bereaved individual.

Furthermore, the loss of a spouse represents a substantial disruption in the individual's enduring bonds of attachment (Raveis, 2000). According to a study by Ott and colleagues (2007), older adults in marriages that promoted positive interactions, low levels of conflicts and higher levels of harmony are more likely to experience difficulties following the loss of their spouse. Ott and colleagues (2007) contend that marriages that promote positive interactions, emotional support and a strong sense of security will likely result in a more devastating loss for

bereaved older adults. The passing of a loved one can generate many significant changes in a bereaved older adult's life, such as changes in identity, changes in attachment bonds and economic changes (Ott et al., 2007; Raveis, 2000).

Adapting to physical and cognitive changes. As an individual reaches older age, the risk of being diagnosed with a chronic health condition increases. Statistics Canada (2016b) estimates that over 10% of the population over the age of 65 will experience a chronic health condition, such as high blood pressure, arthritis, back problems, visual problems, heart disease, osteoporosis, diabetes or urinary incontinence. This report also goes on to indicate that 32% of individuals over 71 will have one chronic condition, that 29% will have two chronic conditions, and that 21% will have three or more chronic conditions.

Chronic illnesses amongst the older adult population can be divided into subsets according to their fatality rate (Lynn & Adamson, 2003). These subsets are nonfatal chronic illnesses, fatal chronic illnesses and frailty. Nonfatal chronic illnesses in the older adult population refer to conditions that gradually worsen over time, but that do not lead to death or pose a serious threat to the individual's life. Nonfatal chronic illnesses include conditions such as vision and hearing problems, back problems and arthritis. To contrast this, fatal chronic illnesses refer to conditions that worsen over time, and that can pose a threat to the individual's life. Some examples of fatal chronic illnesses are organ system failures, strokes, cancers and dementia. The frailty subset refers to the condition of over-all fragility of many systems within the body. Frailty worsens with age and with the concomitance of other chronic conditions. Therefore, frailty can also be understood as an eventually fatal chronic condition, as it impacts several of the body's structures, and can exacerbate other health problems (Lynn & Adamson, 2003).

Older adults who develop a chronic illness will typically engage in some form of self-management for their condition (Clark, Becker & Janz, 1991). Self-management refers to daily or at-home tasks performed by the individual to cope with the symptoms generated by their chronic disease. Self-management includes many dimensions, such as acquiring knowledge on the chronic illness and its treatment options, performing activities to manage symptoms, maintaining adequate psychosocial functioning and managing behaviours to reduce the impact of the chronic illness upon daily living. A study by Clark and colleagues (1991) examined the types of self-management tasks performed by older adults diagnosed with chronic illnesses. Participants in this study were diagnosed with either heart disease, asthma, arthritis, chronic obstructive pulmonary disease or diabetes. Some of the most common self-management tasks reported by participants were recognizing and responding to symptoms, managing acute episodes and emergencies, maintaining specific nutrition, seeking medical information and interacting with health care professionals, adapting to work, managing interpersonal relationships, and managing emotions and psychological responses due to illness (Clark et al., 1991). These chronic health conditions will require medical support and daily self-management in order to be controlled, thus altering an older adult's lifestyle significantly (Clark et al., 1991). Older adults are also subject to other changes, such as age-associated cognitive declines.

While older age is associated with some forms of decline in cognitive functions, Busse (1969) made important distinctions between the normal and atypical impacts of aging on cognition. "Normal aging" describes changes and progression in older age which are not preventable and are irreversible. Thus, "normal aging" refers to a standard aging process. Atypical aging refers to changes in old age which are caused by pathologies. For instance, it is common for older adults to experience some declines in the speed of responses and cognitive

processing (Mather, 2010; Murman, 2015). Several studies reveal some common impacts of normal aging on cognitive functions in older adults. Notably, they studied the impact of normal aging on memory, and on crystalized and fluid abilities (Deary et al., 2009; James et al., 2010; Mather, 2010; Murman, 2015).

Commonly, older age is associated with memory loss. However, not all types of memory have been associated with decline in older age. For instance, implicit memory experiences very little age-related declines (Mather, 2010; Murman, 2015). Implicit memory is related to skills such as remembering the words to a song or recalling how to ride a bicycle. Additionally, older age does not seem to negatively impact semantic memory (Mather, 2010; Murman, 2015). Semantic memory refers to the capacity to retain knowledge such as personal experiences and facts. While implicit and semantic memory do not seem to be strongly affected by age, episodic memory and working memory can be impacted by age. Episodic memory refers to the capacity to recall specific details of past events (Mather, 2010). Working memory is the capacity to engage in new learning, and to manipulate new learning material. Thus, not all types of memories are influenced by normal aging. General knowledge accumulated throughout an individual's life as well as their experiential skills are typically well maintained, while memories associated with recalling specific details or manipulating new material tend to decrease with older age (Mather, 2010; Murman, 2015).

Additionally, crystalized abilities and fluid abilities have been differentiated in the literature to indicate which types of cognitive functions are maintained and which types decline in normal aging (Mather, 2010; Murman, 2015; Tuokko & Hunter, 2002). Crystalized abilities can be understood as the collection of skills and memories acquired and integrated in the past. Fluid abilities require the individual's attention to process, manipulate and integrate. According

to a study by Murman (2015), crystallized abilities improve throughout an individual's life until age 60, then maintain themselves until age 80. However, fluid abilities decline continuously and steadily after the age of 20. Thus, it seems that there are cognitive functions such as semantic memory and crystallized abilities that are not affected by the normal aging process. These functions can be well maintained throughout the normal aging process. On the other hand, cognitive functions such as fluid abilities and working memory can decline in the normal aging process (Deary et al., 2009; James et al., 2010; Mather, 2010; Murman, 2015; Tuokko & Hunter, 2002).

To contrast the process of normal aging, atypical aging refers to changes that are not inherent to the normal aging process. As such, conditions such as dementia, Alzheimer's disease and Parkinson's disease fall under the category of atypical aging, as they are not an inherent part of the normal cognitive aging process (Busse, 1969; Tuokko & Hunter, 2002). Declines in cognitive functions related to atypical aging may lead some older adults to live through major lifestyle changes and adaptations, such as retiring from a career or ceasing to drive (Busse, 2002; Burke, 2007; Carp, 1971; Gesser, 1988; Osborne, 2009). In sum, older age can lead an individual to experience cognitive declines and changes, some of which are a normal part of aging, while others are abnormal and associated with pathologies (Busse, 1969; Deary et al., 2009; James et al., 2010; Mather, 2010; Murman, 2015; Tuokko & Hunter, 2002).

Dementia

According to a report on Alzheimer's disease (AD) and dementia by Statistics Canada (2012), 747, 000 Canadians are living with cognitive impairments. To contrast this, the Alzheimer Society of Canada (2018) indicates that presently there are up to 564, 000 Canadians

who are living with dementia, and roughly 65% of these people are women. These numbers are projected to rise to 937, 000 Canadians living with dementia within the next 15 years.

Dementia is an umbrella term which can be used to describe a number of symptoms that are associated with decreased mental functions and pathologies that affect the brain (Alzheimer Society Canada, 2018). Thus, dementia is a combination of symptoms that can have several different causes. Some of the functions that can be impaired due to dementia include memory, language, communication, capacity to focus, judgement, reasoning, visual perception, emotional control, social behaviour and motivation (Alzheimer Society Canada, 2018; Statistics Canada, 2016a). Dementia is progressive as symptoms gradually worsen with time. The degenerative nature of dementia is associated with the steady and progressive damage of brain cells in the brain, which can eventually be fatal. As mentioned, dementia is not a disease in and of itself, but encompasses a broad range of symptoms and diseases (Alzheimer Society of Canada, 2018; Statistics Canada, 2016a).

The most common diseases which can cause dementia are AD, Parkinson's disease, vascular dementia, dementia with Lewy bodies, frontotemporal dementia and head trauma (Alzheimer Society Canada, 2018; Statistics Canada, 2016a). AD refers to an irreversible condition including the accumulation of amyloid plaques and neurofibrillary tangles which damages and destroys neurons and consequently decreases the ability to think and remember. Vascular dementia is a condition in which the brain's blood vessels are blocked or damaged, causing neurons to die. The most common symptoms of vascular dementia are difficulties with movement, poor balance, and difficulty in the ability to make decisions, organize or plan. Frontotemporal dementia also involves an irreversible degeneration of neurons. This form of dementia specifically encompasses disorders which impact the frontal and temporal lobes of the

brain. Common symptoms of Frontotemporal dementia are behavioral changes, difficulties with movement, difficulties with speech and sudden memory loss. Lewy body dementia occurs when abnormal protein deposits form inside neurons. These deposits are called Lewy bodies. The presence of these deposits in the brain disrupt the brain's functioning, typically causing difficulties in movement such as tremors or stiffness. Lewy body dementia may also present with symptoms such as changes in alertness, loss of memory and progressive loss of language. Thus, dementia is a general term which is used to encompass a range of symptoms associated with memory loss, reduced ability to perform day-to-day activities, changes in moods and behaviours, and difficulty with thinking and problem-solving. As such, dementia symptoms can have significant impacts on a PWD's lifestyle and capacity to perform day-to-day tasks.

There are a variety of basic self-care tasks that are considered essential for healthy living (CNA Training Advisor, 2016; Lawton & Brody, 1969). Activities of daily living (ADLs) can be divided into subsets such as feeding, dressing, bathing, toileting and mobility. Feeding refers to the ability to eat by oneself. Dressing designates the capacity to select clothing, to dress and to undress. Bathing is the ability to wash oneself, whether in a tub, shower or with a sponge. Toileting designates the capacity to use the washroom by oneself, with no incontinence. Grooming refers to abilities such as shaving, brushing hair, cleaning and cutting nails by oneself. Mobility refers to the person's physical ambulation, such as the capacity to walk, stand or sit up straight. Similar to ADLs are instrumental activities of daily living (IADLs). IADLs are specific types of tasks which represent a person's ability to cope, interact and adapt to their environment on a daily basis (Barberger-Gateau, Fabrigoule, Helmer, Rouch & Dartigues, 1999). Some common examples of IADLs include using the telephone, managing one's mode of transportation, managing one's medications and handling money. Both ADLs and IADLs are

necessary for an individual to live comfortably. Some of the main reasons an older adult would be unable to perform ADLs or IADLs is due to decreased endurance, paralysis, or loss of physical function, or due to cognitive disorders, such as dementia.

As the disease progresses, PWD's cognitive and functional capabilities also progressively worsen. PWD's capacity to perform some ADLs can decline as their condition progresses (CNA Training Advisor, 2016; Giebel et al., 2014; Lawton & Brody, 1969). Giebel and colleagues (2014) conducted a study to examine how the progression of different types of dementia would affect ADLs. Participants in this study were either diagnosed with AD, mixed dementia, vascular dementia, frontotemporal dementia, dementia with Lewy bodies or other types of dementia. Participants' dementia progression was categorized in one of three groups, either mild, moderate or severe. Following analyses, it was found that some specific ADLs such as feeding and toileting remained fairly intact throughout the progression of dementia. On the other hand, there were some ADLs which varied according to the progression of the dementia. For instance, in the mild dementia group, participants did not require assistance, or only needed assistance for one or two ADLs activities. In the moderate dementia group, a minority of participants did not need assistance, while some members reported being unable to complete any ADLs without assistance. The severe dementia group participants required the most assistance for ADLs, with very few participants indicating not needing assistance (Giebel et al., 2014).

Performing ADLs is one of the main difficulties encountered by a PWD. When a PWD is experiencing declines in ADLs, they also suffer from significant negative impacts on their quality of life (Giebel et al., 2014). For this reason, a PWD will usually rely on a caregiver, or on a formal institution to help them with ADLs (Marhsall et al., 2015;).

In addition to difficulties performing ADLs, a PWD will also usually experience some difficulties performing IADLs. IADLs are activities that require higher levels of cognitive functioning. They are typically activities which have multiple steps, and they are necessary for independent living within a community. Some IADLs include food preparation, shopping, making telephone calls, housekeeping and managing transportation (Scharre, 2010). According to Scharre (2010), difficulties in IADLs may be amongst the first indicators that an older adult is experiencing some difficulties with intellectual abilities, reasoning skills and memory. As dementia progresses, it may have impacts on memory, problem-solving skills, decision making skills and reasoning (Scharre, 2010). Thus, as dementia progresses, and as these skills are impacted, performing complex IADLs becomes increasingly challenging (Scharre, 2010). Due to the eventual decline in IADLs, most PWD will need to receive support from a caregiver in order to complete these tasks. Thus, it will become the caregiver's responsibility to help or perform IADLs for the PWD. According to a study by Levine and colleagues (2003) on family caregiver perspectives on ADLs and IADLs, caregivers expressed that completing IADLs for their care recipient represented an important challenge. In this study, caregivers identified that taking on shopping, phone calls and transportation were the most straining IADLs (Levine et al., 2003). As such, the majority of PWD in Canada will need to receive some form of assistance or care, either formal or informal to answer their needs with ADLs and IADLs. Caregiving can be divided into two categories, formal and informal. Formal assistance can be provided by institutions, hospitals, nursing homes or other trained professionals. Informal care is described as any unpaid assistance, which is also known as "caregiving". Caregiving is typically provided by family members, friends or neighbours (Statistics Canada, 2016a).

Caregivers

According to Statistics Canada's 2012 report on caregiving, up to 3.8 billion Canadians were providing help for older adults. Spouses represent the majority of caregivers of PWD in Canada; they are estimated to make up 46% of caregivers. Adult children are estimated to make up 44% of caregivers of PWD, with the majority being daughters. Up to 99% of spouses who are caregivers are living with their care recipient (Statistics Canada, 2016a).

The proportion of caregivers who reported feeling stressed, or in poor health due to their caregiving duties is astonishing. Among caregivers dispensing 5 to 9 hours of caregiving duties a week, 27% reported feeling stressed and 17% reported that they are in poorer health as a result of these duties (Statistics Canada, 2016c). These numbers increased steadily along with the number of hours spent dispensing care; among caregivers who spent 15 to 19 hours a week dispensing care, 39% reported feeling stressed, and 31% reported being in poorer health due to these duties. Half of caregivers who dispensed over 20 hours of care services reported feeling stressed, and 37% of them reported poor health due to their caregiving duties. Furthermore, Statistics Canada's (2012a) study on caregiving found that 56% of caregivers reported that they encountered difficulties and challenges in their caregiving role. Caregivers reported that their caregiving duties are emotionally demanding, and some of them also felt they no longer had time for themselves. The act of caregiving can also bring positive aspects, such as giving a caregiver personal satisfaction and making them feel closer to their care recipient. Thus, while the older adult population is on rise, so too is the population of caregivers who will provide them with assistance.

Caregiving duties cover a wide range; they include any unpaid assistance that helps someone in their daily activities. Some common forms of caregiving with PWD include help

with various ADLs or IADLs (Scharre, 2010). A report by Statistics Canada (2012a) provided insight into the types of assistance that Canadian caregivers are supplying for their care receivers. According to this report, the most common type of assistance offered was help managing care. Transportation was the second most common type of assistance offered to PWD, followed by emotional support, meal preparation, help with activities, help with medical needs and lastly help with personal tasks (Statistics Canada, 2012a). This coincides with a study by Taylor & Tripodes (2001) which explored the mobility and transportation patterns of family caregivers and PWD following driving cessation. According to this study, the majority of PWD who stopped driving received transportation from a family member who took on the main driving role. However, according to another study on PWD's driving cessation by Liddle and colleagues (2016), conflicts and challenges within the family dynamics occurred when a family member took on the driving role following the PWD's driving cessation. Thus, caregivers of PWD take on various roles and responsibilities (Statistics Canada, 2012a). Informal caregiving may also cause some caregivers to feel strained and stressed. Furthermore, caregiver stress seemed to increase according to the number of hours spent dispensing care per week. Amongst the most common caregiving tasks performed, it appears that transportation is the second most important responsibility reported by caregivers (Statistics Canada, 2012a).

Older adults and driving

The great majority of older adults in Canada use motor vehicles as their primary method of transportation (Statistics Canada, 2012b). Over three quarters of the older adult population in Canada had a driver's license in 2009. According to the literature, driving is associated with older adults' wellbeing (Edwards et al., 2009b), emotional health (Chihuri et al., 2016; Fonda et al., 2001; Marottoli et al., 1997; Ragland, 2005; Windsor et al., 2007), mobility (Chihuri et al.,

2016; Marottoli et al., 2000; Mezuk, 2008) and mortality (Edwards et al., 2009b; Edwards et al., 2009c; O'Connor et al., 2013; Fonda et al., 2001). The importance of driving on older adults' wellbeing, emotional health, mobility and mortality will be elaborated on in the next section, which explores the impacts of driving cessation. In addition, it is imperative to consider the present driving trends of older adults and the use of transit. Since the older adult population is one of the fastest growing demographics in Canada, the number of older drivers will also increase significantly over time.

Rural and urban residences. (Statistics Canada, 2017a). This is especially true for rural areas, residential areas, suburban areas, small population centres and medium population centres. Population centres are divided into subsets: rural, small, medium and large. Rural areas are defined as being populated by less than 1,000 habitants. Small population centres have between 1, 000 to 29,000 habitants, medium population centres have between 30,000 to 99,999 habitants, and lastly large population centres have over 100,000 habitants. (Statistics Canada, 2017a). In terms of residences, Statistics Canada (2017a) found that there are less older adults in large urban centres compared to 15 to 64-year-olds. In 2011, about 15% of the older adult population lived in rural areas. Additionally, this report found that 17% of older adults lived in small to medium density population centres. This is important, because rural areas and small density areas are less likely to have transportation alternatives available (Carr, 2004b; Statistics Canada, 2017a). Thus, the majority of Canadian citizens need to drive, or be driven in order to have access to their workplace, recreational activities, shopping centers or healthcare services (Statistics Canada, 2017a). Following retirement, the majority of older adults will remain in their own homes, within their communities (Carr, 2004b; Statistics Canada, 2017a). While some older adults will have retired from work, they will still need to go to medical appointments, run errands and engage in

social activities such as visiting friends or family (Carr, 2004b; Wagner, Müri, Nef & Mosimann, 2011). As such, older adults will still require some form of transportation in order to complete these tasks.

According to a survey on the use and accessibility of transit, 49% of older adults who live outside of metropolitan areas indicated that no transit services were offered (Statistics Canada, 2012b). In comparison, only 5% of older adults who lived inside a metropolitan area or its agglomerations indicated that they did not have access to transit services. Furthermore, it appears that older adults do not tend to use alternative transit, even when these options are available to them.

Transit alternatives usage and accessibility. Only 7% of older adults between the ages of 75 to 84 indicated that they regularly used public transit for their transportation needs (Taylor & Tripodes, 2001). The most common transportation methods include walking, biking, driving a privately-owned vehicle, taking a taxi, or using public transportation such as a train, subway or bus (Taylor & Tripodes, 2001). The majority of older adult's report using a privately-owned vehicle for their transportation needs, both before and after the loss of their driving privileges (Taylor & Tripodes 2001). Furthermore, there seems to be no significant increase in the use of transportation alternatives even after driving cessation (Taylor & Tripodes, 2001). Older adults who have stopped driving make less than 6% of their total trips by public transit, and less than 1% by taxi, even if they have no other transportation options (Taylor & Tripodes, 2016). In summary, Canadian older adults, like most of the Canadian population, appear to rely on privately owned vehicles as their main form of transportation (Carr, 2004b; Statistics Canada, 2012b).

Collision risks. Older adults are the safest age group of drivers when the number of crashes per 100 drivers in one year are examined (Carr, 2004b; Wagner et al., 2011). However, this statistic does not take into consideration that older adults tend to spend less time on the road compared to other age groups. When the collision rate per mile driven is examined, there is an increase in collision risk after the age of 65. Thus, motor vehicle collision rates per mile driven are greater in the older adult population, and these rates continue to increase for drivers over the age of 75 (Antsey et al., 2005). Drivers over the age of 65 pose more risks to themselves and to the general public in terms of collisions (Tuokko & Hunter, 2002). Another common trend that has been observed within the older adult population is their reduction in mileage driven, avoidance of highways and freeways, and increased use of local roads. However, it is usually local roads that present more driving hazards such as left-hand turns, congestion, complex intersections and various road signs. Thus, despite efforts to reduce mileage on freeways, the collision risk per mile driven increases for the population of older adults over the age of 65 (Carr, 2004b). Typically, older adult collisions are due to inattention or slowed visual processing, and they occur in complex intersections or during a left-hand turn maneuver. The normal aging process of older adults is accompanied by some vision and cognitive declines, which can affect driving abilities. However, while normal age-related declines can impact vision, motor-skills and cognition, it is important to note that age alone is not typically an indicator of reduced driving abilities (Carr, 2004b). Thus, there is a distinction to be made between older drivers, and older drivers who present with conditions that increase their odds of being at-risk drivers (Antsey, 2011; Antsey et al., 2005; Busse, 1969; Burke, 2007; Carp, 1971; Carr, 2004b; Gesser, 1988; Ledger, 2019; Osborne, 2009; Statistics Canada 1999; Statistics Canada, 2012b; Tuokko & Hunter, 2002).

Medically at risk drivers

The term “at risk driver” in the older adult population refers to individuals who present with potentially unsafe driving abilities, typically due to a health condition. Since the act of driving is complex, it engages an individual’s cognitive abilities, vision and motor skills. Thus, health conditions that impact vision, motor skills or cognition could potentially put a driver at risk of unsafe driving (Antsey et al., 2011; Antsey et al., 2005; Busse, 1969; Burke, 2007; Carp, 1971; Carr, 2004b; Gesser, 1988; Ledger, 2019; Osborne, 2009; Statistics Canada 1999; Statistics Canada, 2012b; Tuokko & Hunter, 2002).

Vision. Vision is the most important sensory input needed for the task of driving (Carr, 2004b; Tuokko & Hunter, 2002). Older adults can experience a range of changes related to their vision, and some of these may impact driving. Medical conditions such as developing cataracts, glaucoma or macular degeneration can significantly impact and reduce visual acuity and visual fields (Antsey et al., 2005; Carr, 2004b; Tuokko & Hunter, 2002). Visual acuity is needed, for instance, to read and recognize road signs and to read maps. Reduced visual fields can decrease with normal aging, or as a result of a medical condition such as glaucoma, stroke, or retinitis. Visual fields and peripheral vision are crucial in driving; they are used to notice and gauge road signs, crosswalks, cars and pedestrians. As such, regular eyesight tests are important to measure whether an individual’s vision is accurate enough for them to drive a motor vehicle safely (Carr, 2004b; Ministry of Transportation, 2009; Tuokko & Hunter, 2002). According to a report by Statistics Canada (2012a), over 14 000 older adults who had very limited eyesight (unable to recognize a friend across the street or read a newspaper with glasses on) held a driver’s license and were actively driving. In a study on the decision to quit driving, 20% of residents in a retirement community indicated that they ceased driving due to visual difficulties, such as having

a hard time seeing cars or people (Statistics Canada, 1999). Thus, visual difficulties, whether brought on by normal aging or by a medical condition, can contribute to whether a driver can be considered at risk. Additionally, visual problems can lead some older adults to make the decision to stop driving (Anstey et al., 2005; Carr, 2004b; Keltner, 1983; Tuokko & Hunter, 2005; Statistics Canada, 2012a; Statistics Canada, 1999).

Motor skills. Other key functions that are needed for safe driving are motor abilities (Carr, 2004b). Driving is a physical activity, and as such it requires the driver to have muscle endurance, muscle strength, and a range of motion for the neck and back. Muscle strength and endurance are needed to get in and out of the vehicle, to handle and maneuver the steering wheel and pedals, and to fasten seatbelts. The range of motion of the neck and back are crucial in order to perform shoulder checks to verify blind spots while driving. Once again, normal aging can potentially impact muscle strength and endurance, however it is older adults who suffer from chronic conditions and physical limitations that will experience more direct impacts on their driving abilities. Some common medical conditions which can affect the motor skills needed for driving are muscular disorders, arthritis and frailty (Carr, 2004b).

Cognition. Similar to vision problems and some chronic health conditions, there are also some cognitive medical conditions which can impact older adults' driving. According to the literature, normal aging does not tend to significantly impair driving (Apolinario, Magaldi, Busse, Lopes, Kasai & Satomi, 2009; Wagner et al., 2011). However, there are some medical conditions such as mild cognitive impairment (MCI) and dementia which can have an impact on older adults' driving abilities.

As a medical condition, MCI somewhat bridges the gap between normal aging and dementia. It can be understood as a type of "grey area between intact cognitive functioning and

clinical dementia”, according to Petersen and colleagues (2014). MCI symptoms include some cognitive declines, which can have some impacts on language, thinking, judgement or memory (Alzheimer Society Canada, 2018; American Psychiatric Association, 2013, p. 605). The changes due to MCI will likely not interfere with the individual’s ability to complete ADLs (American Psychiatric Association, 2013, 605; Petersen et al., 2004; Wagner et al., 2011). However, people with MCI may experience difficulties with IADLs (Apolinario et al., 2009). Depending on the severity and progression of MCI, it can also have some impacts on driving. According to a study by Wadley and colleagues (2009), drivers with MCI had some functional losses, and some decreased driving skills. For instance, this study found that drivers with MCI had slight difficulties with maneuvers such as left-hand turns and lane control. Wadley and colleagues (2009) found that MCI does not severely impair driving, but MCI can lower performance control and make driving skills less optimal. Additionally, Fritteli and colleagues (2009) conducted a study to compare the level of impairment that MCI and AD had on driving in a simulated driving test. According to the results of this study, MCI had a limited impact on driving performance, while mild AD caused significant impairment to driving abilities. Thus, MCI does not seem to significantly impair driving, but it is important to consider that MCI can exacerbate the risk of developing other conditions which can impair driving, such as dementia (Peterson et al., 2014). Additionally, MCI and mild forms of dementia sometimes present similarly, and they can therefore be difficult to differentiate (American Psychiatric Association, 2013, 610). Thus, while MCI may not cause impaired driving, it is still an important medical condition to monitor when assessing fitness to drive.

As previously mentioned, dementia impacts several cognitive abilities such as insight, judgement, problem solving, memory, attention, visual processing and time of reaction. These

abilities are all crucial for safe driving and as such, dementia negatively impacts safe driving (Byszewski et al., 2013). Memory is needed for tasks such as navigation, driving through familiar areas and recalling how to operate a car (Lloyd et al., 2001). Impairment in attention can impact a PWD's ability to focus or shift attention to various stimuli while driving. In addition, a study by Yamin, Stinchcombe & Gagnon (2015) examined the simulated driving patterns of patients diagnosed with mild dementia with Lewy bodies (DLB). This study found that cognitive abilities such as visuospatial functioning, attention and global attention were indicative of poorer simulated driving in DLB drivers. Thus, it appears that the cognitive abilities of attention and visuospatial functioning are important predictors of poor driving (Yamin, Stinchcombe & Gagnon, 2015). Furthermore, impaired judgement can impact a PWD's ability to make timely, accurate and safe decisions while driving a car. Some examples of errors of judgement include merging into the path of another car or entering into the wrong lane, or going the wrong direction on a highway. Lastly, impaired insight is a common symptom for PWD which can have important impacts on driving. The main impact of this symptom is that a PWD will not necessarily realize that their driving abilities are deteriorating. In a qualitative study, Chacko and colleagues (2015) interviewed seven PWD one month after driving cessation, and then once more at follow-up, six months following the decision to stop driving. In Chacko and colleagues' interviews, memory loss of PWD was predominant. Five out the seven participants mentioned having no memories regarding the decision to stop driving. Most of Chacko and colleagues' (2015) participants were not aware that they had dementia, and only two participants were aware that they had stopped driving. Two participants even disclosed that they had engaged in driving against the medical advice they had received. The majority of PWD in Chacko and colleagues' research (2015) disagreed with the decision to stop driving. This lack of insight can partially

explain why PWD do not necessarily give up driving, even when it is no longer safe for them to engage in this task (Lloyd et al., 2001).

According to a study by Hopkins and colleagues (2004), roughly 8.7% of older adults over the age of 65 had dementia in 2000. The prevalence of dementia reaches up to 30% of the population of older adults over the age of 85 (American Psychiatric Association, 2013, 608). It is estimated that there could be up to 100 000 drivers with a dementia diagnosis in Ontario by 2028 (Hopkins et al., 2004). According to the literature, it is estimated that drivers with dementia will continue to drive for four years following the onset of their dementia symptoms (Breen et al., 2007; Hopkins et al., 2004). While the early stages of dementia sometimes pose little risk for driving, negative impacts on driving abilities increase and pose more risk for the PWD and for other drivers as the disease progresses (Breen, Breen, Moore, Breen & O' Neill, 2007; Hopkins et al., 2004; Lloyd et al., 2001). In general, PWD have higher collision rates than their cognitively intact counterparts. Drivers with dementia are estimated to be up to 2 to 5 times more likely to have collisions compared to drivers who do not have dementia (Hopkins et al., 2004). Stinchcombe, Paquet, Yamin & Gagnon (2016) conducted a study using a driving simulator to compare driving errors among mild AD drivers and a healthy control group. According to this study, AD drivers had a higher number of errors at intersections, vehicle control errors and preparation period errors compared to healthy driver counterparts (Stinchcombe et al., 2016). The preparation period errors made by AD drivers included driving at higher speeds, and using brakes inappropriately (Stinchcombe et al., 2016). Furthermore, according to Dobbs (1997) in Lloyd (2001), 80% of PWD who are involved in a collision will continue to drive, and subsequently, 80% of them are likely to be involved in a second collision. The most common types of crashes that PWD are engaged in are in intersections, which implies the risk of a

collision which can involve multiple cars. Indeed, a study by Yamin, Stinchcombe & Gagnon (2016) found that AD driver collisions mostly occurred at intersections (Yamin, Stinchcombe & Gagnon 2016). Thus, there are several factors which indicate that dementia can impair driving and make a driver at risk. Dementia impairs and deteriorates some necessary cognitive functions such as memory, attention, judgement and insight which are crucial for these complex IADLs (Breen et al., 2007; Byszewski et al., 2013). While the population of older adults is on the rise, so too are the number of people who will be diagnosed with dementia (Hopkins et al., 2004). Many of these individuals will continue to drive, even after the appearance of their symptoms, possibly due to reduced insight caused by dementia (Lloyd et al., 2001). As a result of this reduced insight, the decision of when to stop driving for a PWD is typically handled by multiple individuals, including family members, caregivers, family physicians and local licensing institutions (Breen et al., 2007; Byszewski et al., 2013; Hopkins et al., 2004; Lloyd et al., 2001).

The decision to stop driving

The decision to stop driving can be a difficult and stressful event that an individual and their family must face. The decision to stop driving is typically made by the driver, by the driver's physician, or by the driver's respective vehicle licensing institution (Adler, 2010). For some older adults, a physician's input on the decision to stop driving can be essential.

Compensatory strategies. Older adults often engage in self-regulatory driving behaviours according to their attitude, comfort and perception towards their driving abilities (Statistics Canada, 1999; Tuokko, 2016). Some of the most common self-regulatory driving strategies include reducing driving speed, changing driving trajectories, avoiding busy roads and highways, avoiding adverse driving conditions (e.g., snow or rain), avoiding driving at night or deciding to stop driving entirely (Statistics Canada, 1999; Tuokko, 2016). Thus, depending on

how an older adult perceives their driving capacity, they may modify their driving habits by restricting them or by putting a stop to driving entirely (Tuokko, 2016). To engage in compensatory strategies, older adults demonstrate awareness of their driving ability, and of their level of comfort with their driving abilities (Byszewski et al., 2013). Using this self-regulation, older adults attempt to reduce the risks involved with driving. While engaging in compensatory behaviours is used to help maintain safe driving and reduce risky driving, older adults may eventually decide to stop driving altogether. Older adults can engage in compensatory strategies, however PWD might not engage in such strategies due to reduced insight (Byszewski et al., 2013). Thus, PWD may not have the capacity to reflect on their driving abilities or to choose to modify their driving patterns to reduce risks. Once again, this can explain why some PWD do not always make the decision to stop driving, even when their symptoms and condition is impairing their driving (Byszewski et al., 2013).

The driver's choice to stop driving. Older adults can choose to stop driving for a range of reasons. Some common factors which have been found to motivate the decision to stop driving are health issues and to promote safety. According to Pellerito (2009) in Mullen and colleagues (2017), older adults who decided for themselves to stop driving due to health declines indicated that they felt relieved and had a greater sense of safety. Dellinger and colleagues (2001) have similar results in their study, which also revealed that medical conditions were the main reason older adults made the decision to stop driving.

Physicians and duty to report. Physicians play a crucial role in the decision to stop driving. The Canadian Council of Motor Transport Administrators (CCMTA) entrusts physicians to assess and determine whether their patients are fit to drive. In fact, there are some jurisdictions in Canada in which physicians are legally required to perform reporting duties for certain

medical conditions which are deemed at risk (CCMTA, 2017; Ontario Ministry of Transportation, 2017). Some other health care professionals may also be involved in the process to determine an individual's fitness to drive. For instance, some jurisdictions will collaborate with physiotherapists, neuropsychologists and occupational therapists. In Ontario physicians are required by law, according to Section 203 of the Ontario Highway Traffic Act, to report any patient that they deem to be unfit to drive due to a medical condition, such as dementia (Ontario Ministry of Transportation, 2017). However, there does not seem to be a fixed protocol in place for physicians to assess fitness to drive (Hopkins et al., 2004). Due to the complex nature of dementia, healthcare professionals such as physicians can face some challenges in their endeavour to assess fitness to drive (Lloyd et al., 2001). According to a study by Adler & Rottunda (2011), only 59% of physicians reviewed and discussed driving and driving cessation with patients who held a dementia diagnosis. These physicians also referred their patients to receive further driving evaluations. According to this study, physicians could be reticent to initiate conversations regarding driving cessation due to fear that patients could be negatively impacted, become angry, or react defensively. Nevertheless, according to a study by Statistics Canada (1999) over 27% of residents in a retirement community made the decision to stop driving based on their physician's advice (Ontario Ministry of Transportation, 2017; Statistics Canada, 1999). Thus, physicians play a crucial role in the decision-making process to stop driving. Drivers and caregivers of PWD rely on the support and input of physicians for this important life transition (Adler & Rottunda, 2011; Andrew et al., 2015; CCMTA, 2017; Hopkins et al., 2004; Lloyd et al., 2001; Mizuno et al., 2008; Molnar et al., 2006; Ontario Ministry of Transportation, 2017; Statistics Canada, 1999).

Licensing body. According to the CCMTA's Medical Standards guide (2017), there are several risk factors and tools that can be used to make a decision regarding an individual's fitness to drive. For instance, a driver's vision, cognition, motor skills and chronic health conditions can be assessed. Additionally, on-road tests and written exams can be administered to measure a driver's skills and knowledge. The CCMTA (2017) offers several guidelines as a base model to assess risk and fitness to drive, however, each jurisdiction may implement their own battery of tests to determine fitness to drive (CCMTA, 2017). Unlike other provinces and territories, the provinces of British Columbia, Alberta, Ontario, and Newfoundland and Labrador implement license renewal protocols based on the driver's age. The Ontario Ministry of Transportation implements a driver's license renewal program for older adults who wish to maintain an active driver's license. This program requires that every two years, all drivers over the age 80 take a vision test, undergo a driving record review, participate in a 45-minute education session and, if required, perform a road test (CCMTA, 2017; Ontario Ministry of Transportation, 2017). Thus, depending on how an applicant driver performs on these tests and examinations, they may lose their license. In this case, older drivers do not have a choice to decide to stop driving, but they will be required stop driving as per their respective vehicle licensing institution (Tuokko & Hunter, 2002).

PWD and the decision to stop driving. The issues surrounding the decision to stop driving may be more complex when the driver is diagnosed with dementia. The dementia diagnosis alone is not enough to establish the decision to stop driving, as the impact and severity of dementia on cognitive functions varies from person to person (Andrew et al., 2015). Neurodegenerative conditions such as dementia may place older adults at higher risks of motor vehicle collisions or traffic violations (Tuokko & Hunter, 2002). It has been found that dementia

patients have roughly 4.7 more motor vehicle collisions than cognitively sound older adults (Tuokko & Hunter, 2002).

Nevertheless, PWD will want to make their own decisions regarding their driving status (Adler, 2010). This can be problematic, as PWD may be suffering from diminished insight and judgement regarding whether they have the necessary abilities to continue driving (Adler, 2010; Statistics Canada, 2016c; Tuokko & Hunter, 2002). As such, PWD will require special consideration in the process of driving cessation. PWD may experience difficulty understanding how and when they should make the decision to stop driving, due to how their dementia impairs their capacity for insight and judgement (Adler, 2010; Chacko et al., 2015; Tuokko & Hunter, 2002; Statistics Canada, 2016c). PWD may believe that they should be allowed to continue to drive, and they may not have insight on how their cognitive impairments affect their driving. As such, it is estimated that up to 45% of older adults with dementia will continue to drive. Therefore, drivers with dementia will likely require assistance and support from their family physicians, families and caregivers for the process of making the decision to stop driving (Andrew, Traynor & Iverson, 2015).

However, the responsibility to determine whether a PWD is fit to drive is a daunting task. Dementia progressively impairs cognitive skills required for safe driving (Andrew et al., 2015). As such, it is difficult to determine precisely when a PWD is no longer fit to drive. Some studies suggest that an on-road driving test with a qualified assessor is one of the most reliable methods to determine whether a PWD is fit to drive (Andrew et al., 2015; Molnar, Patel, Marshall, Man-Son-Hing & Wilson, 2006). The responsibility of who needs to make the decision to stop driving with PWD is not clearly established. In a qualitative study by Mizuno and colleagues (2008), 47% of caregivers of PWD believed it was the individual's choice to decide when to stop

driving, 27% of caregivers made the decision for the PWD, and 23% of caregivers encouraged the PWD to stop driving without imposing the decision. In this study, 42% of caregivers stated that having reinforcement from a physician greatly facilitated the decision to stop driving (Mizuno et al., 2008). Thus, the decision process to stop driving for PWD is more complicated than with their cognitively intact counterparts. PWD can decide for themselves to stop driving, although some of them may not have the insight or the judgement to make this decision (Adler, 2010; Chacko et al., 2015; Tuokko & Hunter, 2002; Statistics Canada, 2016c). When a PWD does not have the necessary insight or judgement to make the decision to stop driving, it may become the responsibility of a caregiver and or physician to initiate the process of driving cessation with them (Andrew et al., 2015; Mizuno et al., 2008; Molnar et al., 2006). Once the decision to stop driving has been recognized, the PWD and their caregivers will still need to address the PWD's transportation needs.

The impact of driving cessation on older adults and PWD

Driving cessation may affect several dimensions including the former driver's health, mental health, social life, mobility and mortality. Several studies have addressed some of the numerous effects that driving cessation may instill upon older adults' lifestyle and wellbeing (Edwards, 2009a; Edwards, 2009b; Chihuri et al., 2016; Fonda et al., 2001; O'Connor, 2013; Marottoli et al., 1997 & Taylor & Tripodes, 2001).

Older adult's general health. Driving cessation is associated with a negative impact on older adults' health. Edwards and colleagues' (2009b) research revealed that former drivers showed steeper physical performance declines compared to their driving counterparts. According to this study, the general health of older adults can be aggravated following driving cessation. While driving cessation itself is not linked causally to health declines within the older adult

population, it is associated with exacerbating general health decline within this population (Edwards et al., 2009b). In sum, driving cessation has not been found to cause health problems within older adults, but it is a reliable indicator of oncoming health declines (Edwards et al., 2009b).

Development of depressive symptoms in older adults. Driving cessation is also strongly associated with the development of depressive symptoms in older adults. Former drivers report significantly more depressive symptoms compared to counterparts who continued to drive (Chihuri et al., 2016; Fonda et al., 2001; Marottoli et al., 1997; Ragland, 2005; Windsor et al., 2007). According to the results of Chihuri and colleagues' (2016) meta-analysis on driving cessation and depressive symptoms, former drivers had up to twice the risk of developing depressive symptoms compared to active drivers. Fonda and colleagues (2001) contended that the development of depressive symptoms may be related to the impact that driving cessation has on the older adult's quality of life. Fonda and colleagues (2001) also investigated whether the development of depressive symptoms would be mitigated if a former driver had a spouse who could drive for them. This study revealed that the development of depressive symptoms, or the increase of depressive symptoms, was not mitigated by the presence of a spouse who was a driver (Fonda et al., 2001). Windsor and colleagues (2007) also conducted a study to examine the relationship between driving cessation and depressive symptoms. According to this community-based cohort study, driving cessation was indeed associated with an increase in depressive symptoms when comparing the Centre for Epidemiologic Studies-Depression scale (CES-D) scores of former driving participants from baseline to follow-up (Windsor et al., 2007). Windsor and colleagues' research also observed that perceived control acted as an important moderator in the relationship between developing depressive symptoms and driving cessation (Windsor et al.,

2007). This study suggests that driving cessation can symbolize a threat to older adult's perceived control, which can in turn exacerbate depressive symptoms. (Windsor et al., 2007) Windsor and colleagues' (2007) research suggests that maintaining well adjusted, realistic control beliefs may serve as a buffer against the development of depressive symptoms in older adults facing driving cessation. Thus, several studies have observed and established clear links between driving cessation and the development of depressive symptoms in older adults (Chihuri et al., 2016; Fonda et al., 2001; Marottoli et al., 1997; Ragland, 2005; Windsor et al., 2007). Furthermore, driving cessation will also have an impact on older adult's mobility.

Reduction of mobility in older adults. Driving cessation leads to a significant reduction in older adult's mobility, and it decreases their out-of-home activities (Marottoli et al., 2000). Driving cessation negatively impacts former drivers' participation in activities, which in turn impacts their general health and wellbeing (Marottoli et al., 2000). Marottoli and colleagues' (2000) research suggests that mobility and activity levels of older adults play a significant role in reducing risks of mortality. Driving cessation in older adults may also have important effects on the former driver's social life. According to Chihuri and colleagues (2016), former drivers experience a 51% reduction in their social network over a 13-year period. The meta-analysis goes on to reveal that these former drivers are also more likely to spend their time in solitary leisure rather than engaging in social activities they previously enjoyed (Chihuri et al., 2016). In addition to Chihuri and colleagues' (2016) study, Mezuk (2008) conducted a research study on the social support among adults who ceased driving. Mezuk's (2008) study used interviews to measure the quality and quantity of social interactions participants had with both their friends and family. One interview was conducted at baseline, and then a follow-up interview was held 13 years later. Participants were split into two groups; one group was made up of adults over the

age of 60 who had stopped driving, while the other group consisted of participants who were still driving. Mezuk's (2008) analyses revealed that over the 13-year period, older adults who had ceased driving also experienced significant reduction in their social integration compared to their driving counterparts. Thus, driving cessation has been significantly associated with older adults' decreases in participation in social and recreational activities with both their friends and family (Mezuk, 2008; Taylor & Tripodes 2001). This diminished mobility and participation in social activities is also linked to negative impacts on general health and mortality in older adults (Marottoli et al., 2000).

Mortality risks in older adults. Driving cessation in older adults has also been associated with greater mortality risks. According to O'Connor and colleagues' study (2013), non-drivers may be up to 1.68 times at higher risk of mortality than drivers; this relation was significantly mediated by the individual's physical performance levels, social life and general health (O'Connor et al., 2013). In another study, Edwards and colleagues (2009c) also examined how driving cessation may impact an individual's risk of mortality. Edwards and colleagues (2009c) also gathered data regarding mortality risks using a sample of non-drivers compared to a sample of drivers, over a period of three years. Edward and colleagues administered a battery of tests in order to measure participant's health, physical performance, sensory function, psychological health and cognition. Using this data, Edwards and colleagues (2009c) were able to observe the impact of these variables, both on the drivers and non-drivers in regard to their mortality risks. Edward and colleagues (2009c) developed a model which indicates that non-drivers are overall 4.86 times more likely to die within a three-year period compared to drivers. This model includes and controls for the variables of comorbidity, visual acuity, depression and performance on the Mini-Mental State Exam (MMSE). Thus, while one could argue that driving

cessation may simply serve as a marker of diminishing ability, and therefore mortality, Edwards and colleagues' (2009c) study has established a relationship between an individual's driving status and mortality risk within a three-year period, while considering the role and impact of the individual's sensory, physical, psychological and cognitive functions. Although driving cessation is not a causal factor linked to mortality, it can serve as a reliable indicator of increased risk of mortality within the older adult population (O'Connor, 2013; Edward et al., 2009b; Edwards et al., 2009c; Fonda et al., 2001).

In summary, the literature indicates that driving cessation can have vast impacts on the former driver's overall health and wellbeing. The impact of driving cessation on older adults may include a reduction in their mobility, an increase in their chances of developing depressive symptoms, a decrease in their social circle, and a negative impact on their general health and even mortality. Thus, although driving cessation is a normative experience for older adults, it still represents a significant transition (Windsor et al., 2007).

The impacts of driving cessation on caregivers

Driving cessation has been found to have a wide range of effects upon former drivers by disturbing their general health, potentially increasing their odds of developing depressive symptoms, decreasing their mobility, and significantly reducing their social network. The effects of driving cessation do not end there. Caregivers of former drivers are also considerably affected by driving cessation. Retirement from driving represents a dilemma in terms of transportation not only for the former driver, but also for the caregiver who adopts the role of the sole driver. This transition represents an important shift in roles and dynamics for the caregiver within the care dyad (Connel et al., 2012; Liddle et al., 2016; Perkinson, 2005; Taylor & Tripodes, 2001).

Family dynamics. The majority of caregivers of a PWD are family members, either grown-up children or a spouse (Connel et al., 2012; Liddle et al., 2016; Ory, 1999; Perkinson, 2005; Taylor & Tripodes 2001). Ory and colleagues (1999) found that caregivers of dementia patients were much more likely than caregivers of non-dementia patients to be the spouse of the care receiver, instead of an adult child. Caregivers of dementia and non-dementia patients are typically adult children, spouses, or other family members of the care recipient (Ory et al., 1999). Most former drivers who hold a dementia diagnosis depend on family members such as a spouse or a child for all of their transportation needs (Taylor & Tripodes, 2001). Unofficial transportation arrangements such as these may prove to be difficult to organize and may be demanding for all members involved (Taylor & Tripodes, 2001). For instance, the preferred method of transportation for former drivers are privately owned vehicles, both before and after driving cessation (Taylor & Tripodes 2001). According to Taylor and Tripode's (2001) study, 95% of dementia patients used their own private vehicles for their transportation needs prior to driving cessation, and 92% of these dementia patients relied on transportation in privately owned vehicles of family members following driving cessation. In comparison, less than 2% of the participant's in Taylor and Tripode's (2001) study indicated using alternative methods of transportation such as walking, cycling, public transit or taxis. Thus, the burden of transportation typically falls upon caregivers. The majority of caregivers of dementia patients tend to be family members, and these family members will also adopt the role of designated driver following driving cessation.

Caregivers of former drivers diagnosed with dementia may take on several roles and responsibilities, including but not limited to driving. While it can be a very difficult adjustment for a driver to adapt to the role of former driver, at times it can also be strenuous for a caregiver

to adopt the role of driver within the care dyad (Connell et al., 2012; Liddle et al., 2016). For instance, Liddle and colleagues' (2016) study on the effects of dementia and driving cessation on caregivers revealed that it can be a challenging process for an adult child or a spouse to take over the driving role that the former driver once held, as it may create tension within the established family roles and dynamics. Similarly, Connell and colleagues (2012) conducted a study on the perspectives of adult children on driving cessation. Several participants in this study (adult children with a former driver parent) reported that they feared the upcoming burden of being responsible for their parent's transportation needs. As found in Perkinsons' (2005) research, some adult children will even minimize the risks and dangers associated with their parent's driving in order to avoid taking on a caregiving role.

The caregiver's employment. Providing care and transportation for a former driver diagnosed with dementia can prove to be very demanding on a caregiver's everyday life and schedule. One of the dimensions in a caregiver's life which can be affected by their taking on caregiving duties, is their employment and employment-related activities. In fact, in Taylor and Tripodes' (2001) study on the effects of driving cessation on caregivers, up to 42% of caregivers signaled missing work very frequently to provide transportation and 13% reported that they left work entirely in order to take care of the former driver (Taylor and Tripodes 2001). Similarly, Ory and colleagues (1999) conducted a study on the impacts of caregiving on dementia and non-dementia caregivers, in which effects on employment were measured using a survey. According to this study, caregivers of dementia patients were significantly more likely to report the need to change to a less stressful job, to reduce their hours at work, to take an early retirement, to turn down promotions or to leave work due to their caregiving duties. Furthermore, this study also found that the caregivers of dementia patients were up to 15% less likely to be employed

compared to the caregivers of non-dementia patients (Ory et al., 1999). Taylor and Tripodes (2001) and Ory and colleagues' (1999) study found that caregivers of dementia patients may experience employment related impacts as a consequence of their caregiving duties. This represents an important shift within the roles and dynamics of the family unit, which can subsequently cause conflict within the care dyad during and following the decision of retiring from driving (Liddle et al., 2016). These significant findings on the effects of driving cessation on caregivers have been used in subsequent studies to develop intervention approaches that take into consideration family dynamics and roles to address the needs of former drivers and caregivers in the family setting (Liddle et al., 2016).

The caregiver's emotional well-being. Caregivers of former drivers with dementia may take on several roles and responsibilities in order to sustain and address the needs of the dementia patient. These responsibilities can also take a toll on caregivers, leading them to emotional and physical exhaustion. According to Ory and colleagues' (1999) research on the impacts of caregiving, caregivers of dementia patients reported a higher level of emotional and physical strain compared to caregivers of non-dementia patients. In this study, 22.3% of caregivers of dementia patients reported suffering from mental or physical problems as a result of caregiving (Ory et al., 1999). In comparison, this same study revealed that 12.6% of caregivers of non-dementia patients reported suffering from mental or physical problems as a result of their caregiving duties (Ory et al., 1999). Furthermore, according to a study conducted by Truzzi and colleagues (2012) on burnout symptoms of caregivers of dementia patients, several caregivers experienced one or several burnout symptoms (emotional exhaustion, depersonalization and reduced sense of accomplishment). This study revealed high levels of emotional exhaustion in up to 42% of family caregivers. Furthermore, 22% of caregivers reported feeling depersonalized,

and 38.6% of caregivers reported that they felt a reduced sense of personal accomplishment (Truzzi et al., 2012). Additionally, Truzzi and colleagues (2012) found that anxiety was the most reported emotional symptom by caregivers of PWD. As such, an ideal intervention protocol to help caregivers of PWD should include a focus on the emotional needs of caregivers.

In summary, caregivers of PWD who stopped driving are also subject to negative emotional effects following driving cessation. The transition into driving cessation has been found to disturb familial roles and dynamics, which can cause friction and conflict within the care dyad (Liddle et al., 2016). It's also important to note that caregivers will likely assume responsibility over the PWD's decision to stop driving (Adler et al., 2010; Stern, 2008). Initiating this decision-making process is a challenging task. Furthermore, it is also stressful for caregivers of former drivers with dementia to adapt to the role of private driver. Caregivers usually become entirely responsible for the mobility and transportation needs of their care receiver (Liddle et al., 2016; Taylor and Tripodes, 2001). These substantial transportation arrangements can encumber a caregiver's personal life, career and emotional health (Connel et al., 2012; Liddle et al., 2016; Perkinson, 2005; Taylor and Tripodes 2001; Truzzi et al., 2012). As such, it is vital to incorporate the caregivers and their wellbeing in the development of an intervention framework, which could address both their needs and those of the former drivers throughout the process of driving cessation.

Interventions regarding driving cessation

Studies have established the range of effects of driving cessation, both on former drivers as well as on their caregivers. As such, recent studies have aimed to continue to investigate how future intervention protocols and community supports could be adapted to help counter or address some of the negative impacts of driving cessation.

Taylor & Tripodes (2001) conducted a large survey-based study to examine the effects of driving cessation of PWD on their household (i.e., family members who were also caregivers). The survey was addressed to the live-in caregivers of the PWD who had stopped driving. All participants had to be above the age of 65. A total of 315 surveys were completed and returned. This study found that following the loss of driving privileges, the PWD relied heavily on family members (i.e., caregivers) for all of their transportation needs. Following the loss of driving privileges, 61% of PWD depended on a spouse and 15% depended on an adult child. Caregivers reported that being in charge of transportation was demanding. As a result of this responsibility, 42% of caregivers indicated missing work frequently, and 15% stopped working altogether to be able to meet the PWD's transportation needs and general care. Furthermore, less than 1% of caregivers indicated using other transportation alternatives following the PWD's driving cessation. This study found that less than 10% of caregivers used specialized services such as home-deliveries or paid drivers to help with transportation duties. To contrast this, 89% of participants did not use any delivery services, and 73% indicated not using paid drivers. Participants did not report transportation duties to be an issue. On the other hand, up to 50% of caregivers also signaled that they experienced problems accessing destinations, 38% indicated that shopping and accessing social activities was difficult, and 38% also expressed that travelling to medical appointments was difficult. Taylor & Tripodes (2001) found that caregivers tended to "downplay problems" related to transportation in their answers. The researchers explain this tendency being due to caregivers being worried that their "complaining" will depict them as inadequate caregivers. Taylor & Tripodes' (2001) study offers valuable data regarding the caregiver's responsibilities following the PWD's driving cessation. Furthermore, the study offered information on how driving responsibility impacts the caregiver's employment. Their

study also indicated that PWD and caregivers did not increase their use of alternative transportation alternatives following driving cessation. Taylor and Tripodes' (2001) study offers a better understanding of caregivers' employment and transportation related concerns following the PWD's driving cessation.

Liddle and colleagues' (2016) study is also centered on the impacts of driving cessation on the PWD's family caregivers. Liddle and colleagues' (2016) qualitative study specifically investigated the importance of family roles and dynamics throughout the driving cessation process. Liddle (2016) used a phenomenological approach and semi-structured interviews to gather and analyze data. The participants of this study were five PWD who had stopped driving, 12 family caregivers and 15 healthcare professionals. The qualitative data was analyzed and grouped into four themes to better understand the types of dynamics used to manage driving cessation. These themes were placed on a continuum according to their level of collaboration or conflict regarding the management of driving cessation. Liddle and colleagues' (2016) continuum consisted of the following themes, in order of most collaborative to most conflictual: 1) *in it together*, 2) *behind the scenes*, 3) *active negotiations*, and lastly 4) *at odds*. Liddle and colleagues (2016) describe the collaborative end of the spectrum, "*in it together*", as a theme with groups approaches and interventions which generated a minimal amount of conflict in managing the PWD's driving cessation. On the other end of this spectrum, "*at odds*" is described as interventions which created significant tension and open conflict between the PWD and caregiver. This study then developed an intricate framework which may be used to structure family interventions to help manage driving cessation. The framework is adapted to help address each family's unique needs, dynamics and contexts in regard to driving cessation. Thus, Liddle and colleagues (2016) have conducted a study which allowed them to develop a potential

intervention framework which specifically focuses on the entire family unit's needs for the decision of driving cessation. Further research could potentially address how to help family members and caregivers following driving cessation.

Similarly, there is a group intervention protocol called "At the Crossroads" which is meant to address the needs of caregivers of PWD that has been developed and evaluated by Stern and colleagues (2008). Stern and colleagues' intervention is meant to help both caregivers and PWD in the decision-making process to stop driving. This study evaluated the implementation of this protocol using a group which received the intervention, a second group which received written materials only and a third group which received written materials only following the post-test (Stern et al., 2008). The "At the Crossroads" intervention used four group sessions to provide caregivers with knowledge pertaining to memory disorders and driving cessation (Stern et al., 2008). The first session offers participants information regarding dementia and how it may impair an individual's insight and driving related skills (Stern et al., 2008). The second session offers participants toolkits for driving transitions, which include a guide to observe and rate risky driving behaviours (Stern et al., 2008). This session also includes a discussion on the participant's support circle, encouraging them to also reach out and get help during this transition (Stern et al., 2008). The second session also informs caregivers about how to identify secondary driving benefits and encourages participants to try and ensure their continuation once the dementia patient stops driving (Stern et al., 2008). The second session will also inform participants about how to plan and conduct a conversation related to driving cessation (Stern et al., 2008). The third session includes watching a case study video of a dementia patient and care dyad throughout the driving cessation process (Stern et al., 2008). This video is meant to normalize and inspire participants, as well as model how to effectively use the content covered

thus far in sessions (Stern et al., 2008). Lastly, the fourth session informs participants about how to use “last resort techniques” with a family member who has dementia and can no longer drive safely (Stern et al., 2008). Then, the session reviews the content and engages participants in planning what the next step might be for them and their care recipient (Stern et al., 2008).

Results determined that the group which received the active interventions reported significantly higher rates of feeling prepared, readiness to communicate with dementia patients and feeling generally self-efficacious compared to the other two groups (Stern et al., 2008). A few examples of benefits reported by caregivers who participated in the “At the Crossroads” interventions included feeling more confident in being able to help and feeling less concerned about making the former driver angry (Stern et al., 2008). Participants were also more likely to speak to patients about driving cessation and elaborate on a plan to navigate the situation (Stern et al., 2008). Stern and colleague’s (2008) study results indicate that the “At the Crossroads” intervention protocol effectively helped address driving cessation related needs of caregivers so that they may help their loved ones through this important life event.

Thus, these studies have made important suggestions for future research and interventions to address caregiver needs in relation to a patient’s driving cessation. Taylor and Tripodes’ (2001) study examined how being the designated driver of a PWD can impact caregivers. Taylor and Tripodes’ (2001) research provided important information on the impacts of driving cessation upon caregivers’ employment. This study also contends that a significant number of caregivers experienced difficulties managing transportation duties (Taylor & Tripodes, 2001). However, this study also indicated that neither caregivers nor PWD used transportation alternatives following driving cessation. Thus, Taylor and Tripodes’ (2001) study supplied valuable information on how caregivers manage transportation responsibilities following driving

cessation. Liddle and colleagues' (2016) study focused on the importance of taking into consideration the family dynamics and specific contexts which play a crucial role within the care dyad, especially during important life events such as retirement from driving. Stern and colleagues' (2008) study developed a group intervention protocol which focused on providing caregivers with tools and information on how to address driving cessation with dementia patients by using interactive teaching methods, and educational group sessions. Considering the studies and interventions that have been presented, it is important to continue to promote the wellbeing of the entire care dyad by also addressing the caregiver's emotional and grief-related needs throughout the driving transition. For instance, an individual counselling intervention protocol could help address caregiver needs and wellbeing; this has not yet been studied or implemented.

Many studies have been conducted to investigate the effects of driving cessation on older adults, exploring how this event may impact their health, mobility, emotional state, social life and mortality. Some studies have even explored how driving cessation may impact the caregivers of former drivers (including PWD), by studying family dynamics, burnout risks for caregivers, roles within the care dyad and communication methods used for the decision to stop driving. However, there seems to be no research which aims to better understand and address the comprehensive needs of caregivers of PWD who have recently ceased driving. Comprehensive needs would likely include the use of alternative transportation methods, emotional coping, and helping a PWD grieve the loss of driving privileges.

Research has demonstrated that driving cessation of PWD may have far reaching impacts on caregivers. This study aims to elucidate the experiences of caregivers of PWD who have lost their driving privileges, so that we may have a better understanding of the emotional and

practical needs of these caregivers. Based on this study's findings a counselling intervention for caregivers of PWD who have recently lost their driving privileges will be developed.

Method

Recruitment

Research Ethics Board approval was obtained at Saint-Paul University and at Bruyere Research Institute (BRI). Recruitment was done through a research collaboration with BRI. BRI offers several research supports to affiliated researchers including access to a research coordinator and their database of patients that have previously consented to being contacted for research purposes. A research coordinator at the BRI identified patients that fit our inclusion and exclusion criteria, collated their data, and provided it to the research assistant working on this study. The research assistant reviewed all of the potential participants and contacted those who met criteria by telephone. During the telephone call, the research assistant reviewed the inclusion and exclusion criteria once again with the caregiver. Our inclusion criteria comprised participants who were the live-in caregiver of the care-receiver, the care-receiver had to have been diagnosed with dementia, and the care-receiver also had to have lost their driving privileges. Our exclusion criteria comprised participants who did not live with their care-receiver, patients who were not diagnosed with dementia, and patients who had not ceased driving. The researcher also verified that each participant understood and spoke English fluently. This verification was done informally, by assessing the fluidity of the telephone conversation between the researcher and the participant. Participants who met criteria were invited to participate in a 45-minute interview at the Bilodeau-Yamin laboratory at Saint-Paul University. The research assistant scheduled the interview based on the participant's availability.

Participants

A total of ten participants were recruited to participate in this study, including four men and six women. All ten participants were Canadians, with nine Caucasian participants and one Middle-Eastern participant. Eight participants' mother tongue was English, one participant indicated that French was their mother tongue, and one participant indicated that Arabic was their mother tongue. Seven participants identified that they were retired, two participants were still engaging in part-time work and one participant maintained a full-time job. Nine participants were living in an urban setting, and one participant indicated living in a rural dwelling. Nine of the ten participants confirmed that they were the spouse of their care recipient, and one participant indicated being the son of their care recipient. As per our inclusion criteria, all participants identified as being a live-in caregiver of a PWD who had lost their driving privileges.

Procedures

The research assistant met each participant at the main entrance of Saint-Paul University and led them to the Bilodeau-Yamin Laboratory. The research laboratory was organized with three chairs, a table, a water pitcher, paper cups, as well as a box of tissues. The research assistant reviewed the consent form with the participant, addressed all questions, and then, if the participant agreed to participate, they signed the consent form (Appendix B). One copy of the signed consent form was given to the participant, while a second signed copy was kept by the research assistant in a locked cabinet in the laboratory along with all other confidential information. The research assistant reiterated with participants that their participation was on a voluntary basis, that they could choose not to answer any question or withdraw from the interview at any time with no consequence. Participants were then invited to partake in a semi-

structured interview (refer to Appendix A for interview protocol). The interview protocol was used as a general structure for the interview and occasionally the research assistant used prompts that were off-script in order to redirect the participant to the subject matter. The interview protocol was developed with the aim of elucidating the personal experiences and needs of caregivers of PWD who had lost their driving privileges, including 1) The participants' experiences as caregivers of a PWD; 2) The PWD's loss of driving privileges; 3) The impacts of driving cessation on both the PWD and on the caregiver; 4) The caregivers' needs following the PWD's driving cessation; and 5) The participants' recommendation for an intervention program. At times, participants expressed moments of sadness or frustration during the interview. The research assistant who is a student in the MA in Counselling, Psychotherapy and Spirituality was able to respond to those participants in a caring and empathic way, and waited until the participant was ready to resume the interview. The interviews ranged in duration between 30 to 75 minutes depending on the participant's verbosity. Interviews were audio-recorded using a digital recorder. The audio-recording device was kept in a locked cabinet in the laboratory, to which only the principal investigator and research assistants had access. Each participant was assigned a number in order to keep their information confidential. A master list contained the names of participants and the number they were assigned was created and kept separately in a locked cabinet. The interviews were transcribed verbatim by two research assistants using the audio-recordings.

Measures

All transcripts were coded by two independent research assistants using inductive thematic analysis (Braun & Clarke, 2006). The inductive thematic analysis method was chosen because it provided a rich and detailed organization of the themes and patterns within the data

(Braun & Clarke, 2006). The thematic analysis method is typically used for the purpose of analyzing qualitative data, with the use of codes and themes which are attached to data. Thematic analysis is not bound to any single theoretical framework, and it can therefore be used in several different theoretical frameworks. Thematic analysis can use two different methods, the essentialist method and the constructivist method. The essentialist method is focused on the experiences and the meaning of the reality of participants, whereas the constructivist method examines the ways in which events and experiences can be the result of a discourse operating in a society. Based on the research goal to have a better understanding of the needs and experiences of caregivers of PWD who lost their driving privileges, this study used an essentialist method focused on examining the caregivers' reality, and the meaning of their experiences. Furthermore, during the data analysis, an inductive "bottom-up" approach was used to identify themes within the data. The inductive approach extracted themes which were closely linked to the data. This research also used a semantic approach during data analysis. The semantic approach extracted themes related to the explicit meaning of the data. Therefore, the themes were obtained directly by observing the surface meaning of the data, rather than by using a latent approach which would have examined underlying ideologies and concepts within the data (Braun & Clarke, 2006).

Based on Braun & Clarke's (2006) article, the following steps were used in our thematic analysis: 1) The data was transcribed by two independent research assistants, following the transcription the researcher familiarized herself with all of the transcripts and began to outline some general ideas for potential themes; 2) The two research assistants used a semantic approach to generate initial codes as they coded each data set line-by-line by adding comments to identify each coded extract; 3) The two research assistants began to classify the codes into potential themes as they independently gathered and sorted the codes into different potential themes; 4)

The research assistants reviewed codes and themes to ensure each coded extract was paired with the appropriate theme. The two independent research assistants met to compare codes and themes and any discrepancies in codes and themes were discussed and resolved when both research assistants reached an agreement as to where a code or theme belonged, some themes were added, modified, collapsed or removed based on the consensus reached by the two independent research assistants; 5) The two research assistants reviewed all the themes and their respective codes to make sure that they were coherent and also discussed and developed clear and concise names for the themes; 6) The researcher then selected compelling extracts which related back to the initial research goal and current literature to produce a report of the research analysis (Braun & Clarke, 2006).

Results

Ten caregivers of PWD who stopped driving were recruited to participate in a forty-five-minute semi-structured interview. The goal of the interviews was to have an in-depth understanding of the caregivers' experiences, challenges and needs throughout the process of driving cessation of their care recipient. The interview was composed of four sections. The first section was focused on the caregivers' challenges and adjustments to their day-to-day caregiving responsibilities with the PWD. The second section of the interview was focused on the PWD's loss of driving privileges. The third section of the interview prompted caregivers to explain how the loss of driving privileges impacted them and the PWD. Lastly, the fourth section of the interview was focused on the needs of caregivers following driving cessation. The last section also prompted caregivers to offer their own suggestions as to what should be included in an intervention program for caregivers of PWD who stopped driving.

Caregiver challenges and adjustment to dementia

The first section explored caregivers' experiences as caregivers of a PWD. When discussing their day-to-day experiences and challenges as caregivers, the caregivers expressed their grief and negative emotional wellbeing. Additionally, caregivers talked about their frustration with the PWD's reduced ADLs, and other behaviours. Furthermore, caregivers discussed their adoption of new roles within their caregiving duties. Lastly, caregivers reported the loss of their own independence, free time and social interactions.

Caregiver grief. Reoccurring emotions expressed by caregivers in this part of the interview consisted of grief, guilt, feeling overwhelmed, feeling hopeless and feeling exasperated. Nine out of ten caregivers expressed emotions of grief when discussing their experiences as caregivers. Caregivers expressed their grief in different ways. Four caregivers made parallels between death, the progression of dementia, and the loss of their spouse as a person.

"She is dying by inches, she's slipping away from me"- Caregiver A

Caregiver A described their grief towards the gradual loss of the care recipient. Two other caregivers made associations between the progression of dementia, loss, degradation and death of their loved one. Another four caregivers expressed their grief by specifically referring to the loss of their relationship.

"It's lonely. I'm alone in a relationship, it's a very bad place to be. When you've got a relationship, you supposedly should be functioning well. People would say, that's one of their worst nightmares: to feel alone in the relationship" – Caregiver C

These caregivers expressed their grief by communicating the loss of their long-standing attachment bonds. Thus, the majority of caregivers expressed grief when they spoke of their experiences as caregivers.

Negative emotional wellbeing. While caregivers explained their tasks and duties as caregivers, they also expressed a range of emotions associated to their experiences as caregivers. When discussing their personal experiences, several caregivers stated the emotional strain involved in their caregiving role. For instance, caregivers expressed feeling guilty, angry, impatient, devalued and/or overwhelmed throughout their caregiving duties.

“If you’re a caregiver, you take your own thoughts, your own personality and everything, you put it in an envelope and you put them in your back pocket. You do not exist as a person anymore. You have no thoughts, no feelings, no will. Your entire existence is for: taking care of the patient” – Caregiver A

Three caregivers expressed hopelessness when discussing their own emotional wellbeing in their caregiving role. Two caregivers expressed feeling guilty related to their experiences as caregivers. They both explained different reasons for feeling this way. One caregiver seemed to feel guilty in regard to the authority they had in deciding what the PWD could and could not do, while another caregiver sometimes felt guilty when they engaged in social or work-related outings which fell outside of caregiving duties. Three caregivers also expressed feeling overwhelmed when discussing their personal experiences as caregivers for a PWD. Three caregivers expressed the strain related to being responsible for everything in the household, as well as anything related to the PWD’s health and wellbeing.

Caregivers explained how the responsibility associated with their caregiving duties had been overwhelming at times. As such, the results yielded by this portion of the interviews

seemed to indicate that the majority of caregivers felt some grief-related emotions in their caregiving duties. Caregivers also expressed a variety of other emotional responses, such as feeling guilty, feeling angry, feeling hopeless, feeling devalued, feeling impatient and feeling overwhelmed. Furthermore, all ten caregivers expressed that they felt frustrated with some of the PWD's behaviours and decreased ADLs.

Frustrations with ADLs. Seven out of the ten caregivers indicated that they regularly lived through some challenges and frustrations in regard to the PWD's diminishing ADLs and IADLs. Three caregivers were responsible for the PWD's dressing, medication intake, showering, cooking and washroom needs. Three caregivers were responsible for the PWD's dressing and cooking needs. One caregiver reported that they were responsible for the PWD's medication intake.

"I don't do [baths]! I do not become, and I am not a nurse and I don't want to be one. I can do it if I need to, but that's not something I would choose to do"
– Caregiver F

Caregiver F expressed their frustration towards the ADL of bathing, other caregivers also expressed frustrations in regard to the ADLs they must perform for the PWD. The majority of caregivers expressed that they have become responsible for some, or all of the PWD's ADLs. Caregivers reported that such activities can be frustrating and time-consuming. Three caregivers felt frustrated with the responsibility to help the PWD with ADLs, other caregivers also expressed that they felt sad when they were faced with the decline of their spouses.

Public space dysfunction. Beyond the ADLs, four caregivers expressed that they had experienced frustration when faced with public space dysfunction during outings with the PWD.

“I cannot trust her in Saint Laurent alone anymore. She’s gotten locked into a dressing room. She got locked into a washroom which is really problematic, because how the hell do I go into a lady’s washroom?” – Caregiver A

Some caregivers explained the challenges they faced in public spaces, such as the PWD getting locked into a washroom, or the PWD getting lost. One caregiver also expressed anger regarding the reactions of the public towards the PWD’s behaviours.

PWD’s new habits. Caregivers discussed their responsibilities with the PWD’s ADLs, IADLs and public space dysfunctions. Additionally, five caregivers experienced some irritation related to the PWD’s development of new habits. Caregivers reported that the PWD engaged in various new behaviours, which they qualified as unusual. One caregiver described how the PWD developed a fixation on going to bed at a specific time. Another reported that the PWD started picking and pulling their nails apart. One caregiver explained how the PWD was taking household objects apart, and another caregiver stated that the PWD was always cutting up newspapers.

“The other thing that’s a challenge is we get the newspaper in the morning and he started cutting the articles out and he sits there and he cuts the newspaper up. And if I don’t read it right away my newspaper is in tatters” – Caregiver B

Five caregivers expressed their frustration concerning the PWD’s development of new habits. Caregivers explained that these behaviours were unfamiliar, because their loved ones did not engage in such behaviours prior to the diagnosis of dementia.

Thus, it appears that caregivers face a variety of frustrating challenges throughout their caregiving role. Seven caregivers communicated challenges and frustrations when helping the PWD with ADLs. Four caregivers faced challenges in public spaces, and five caregivers stated that they experienced some irritation or difficulties responding to the new behaviours of the

PWD. Caregivers also shared how it could be challenging for them to adjust to their caregiving role, and the new responsibilities that it involved.

Challenges adopting new roles. During the first segment of the interview, caregivers shared their personal experiences and challenges as caregivers of a PWD. Additionally, five caregivers discussed the challenges associated with adopting new roles as the caregivers of a PWD. Four of these caregivers expressed how it was challenging to take on different responsibilities to cater to the PWD's needs. For instance, some caregivers expressed they had to take over all of the household's cooking and cleaning duties, which used to be done by the PWD.

“You know, you move from the role of wife to something else. I remember a couple of years ago, one of my friends saying: « Oh, you're now a caregiver » and it stopped me dead in my tracks, like no. I'm a wife. So, it's like the process where Mr. J was diagnosed about five years ago now, so it's been a while. Initially, I was like « No. This is not happening to us », I was in denial. Then, there was anger and frustration. Then, yes, when I heard « you're now a caregiver » I was stunned, and gradually have come to terms with that”- Caregiver J

Caregiver J explained how the transition to becoming a caregiver was initially frustrating and difficult. Five caregivers in this study discussed the endeavours associated with changing roles when describing their experiences as caregivers of a PWD. More specifically, four out of these five caregivers expressed that they took on the responsibility to make the PWD happy on a daily basis.

*“I can start to get tense because I'm trying to keep her happy. I'm keeping her content, and sometimes it's not working... That will impact my [chronic illness'] symptoms, because the more intense you are, the bigger the symptoms become”
– Caregiver H*

Caregivers described how transitions into new roles were involved in their experiences as caregivers of PWD. Caregivers discussed endeavours related to adopting new tasks and

responsibilities in their caregiving role. Four caregivers specifically referred to being responsible for the PWD's happiness. As such, caregivers experienced some difficulties in adapting to their new roles and responsibilities as the caregiver of PWD. In addition to this, several caregivers expressed that they had lost their own independence.

Caregiver loss of independence, free time and social network. Seven out of ten caregivers reported situations where they felt they were losing some of their own independence as a result of their caregiving duties and roles. Three caregivers explained how they would have liked to engage in a hobby or perform certain tasks around the house, but had to remain by the PWD to help them with various tasks instead. One caregiver explained how they took over the PWD's life, and that the caregiving had consequently also taken over their life.

“The challenge to having to organize my days completely, that's a major thing. Because [the PWD] cannot be alone for more than an hour. So, I lost my freedom. I mean I do get out but I have to have everything planned out all the time. So that freedom, to plan my day to just do things. Also, the driving is significant. We each had our own car we did our own things. All of a sudden when he was diagnosed with Alzheimer's he was advised by the family doctor before we went to Bruyère that he should not be driving. He stopped driving just like that even before it was official. [...] He basically handed me the keys the next day and hasn't driven since” – Caregiver F

Caregiver F explained how the caregiving duties had an impact on their freedom; they also specified the significant impact that the PWD's driving cessation had. Thus, seven caregivers described that their own independence was impacted by the responsibilities and tasks they need to perform in their caregiving role. More specifically, four caregivers indicated that they have an unmet need to get some time away from their caregiving duties. Similarly, four caregivers reported that their social interactions and social network had diminished since they took on caregiving duties.

Our result's first main theme was the caregivers' personal experiences as caregivers of a PWD. Reoccurring themes included the caregivers' grief and negative emotional wellbeing, frustration with ADLs, transitions into new roles, and loss of independence. The second main theme consisted of the PWD's loss of driving privileges.

The loss of driving privileges

The second portion of the semi-structured interviews was focused on the PWD's loss of driving privileges. This segment was used to get a better understanding of how the PWD and caregiver initially experienced driving cessation. This theme is divided into sub-themes, which are the loss of driving privileges and the PWD's initial reactions to the loss of driving privileges.

How the driving privileges were lost. Caregivers reported different ways that the PWD lost their driving privileges. Some caregivers lost their driving privileges due to a failed cognitive test, while some stopped driving following the recommendation of their family physicians. One caregiver reported that they were the one who stopped the PWD from driving. Seven caregivers indicated that the PWD lost their driving privileges following failed cognitive tests.

“The police was a big guy and he said « no more driving until you're assessed » and so we got an appointment with the doctor, and our GP gave him a little test back at the office and said « I'm sending you to the memory clinic do not drive » and then the nurse and the doctor said « you're not driving anymore »”

– Caregiver B

Caregiver B explained how the PWD lost their driving privileges following a problematic driving situation. Furthermore, two caregivers explained that the PWD ceased driving following the advice of a family physician. Nine out of the ten caregivers reported that a physician was involved in the loss of driving privileges. One caregiver indicated that they had themselves been

preventing the PWD from driving until they officially lost their privileges through their licensing institution.

“We stopped her from driving. Probably five years before the province took it away, but we stopped her. She still had her license, but we stopped her. It came to a point where the other drugs she was on, her other health issues and her Alzheimer’s, well it came to a point where they took her license away. She kind of fought us a bit on that” – Caregiver I

Caregiver I prevented the PWD from driving. Caregiver I also indicated that they initiated the PWD’s driving cessation by stopping them from driving several years before the official loss of driving privileges. In this portion of the interview, caregivers offered the context in which the PWD stopped driving, by explaining how the PWD lost their driving privileges. The next sub-theme is composed of the initial reactions to the PWD’s driving cessation.

PWD’s reaction to the loss of privileges. In the previous section, caregivers explained the context in which the PWD lost their driving privileges. Caregivers also described the initial reactions of the PWD upon the loss of driving privileges. Caregivers reported whether the PWD accepted or resisted the transition to driving cessation.

PWD accepted the transition to non-driving. Six caregivers indicated that the PWD were compliant to the loss of their driving privileges. Caregivers who stated that the PWD was compliant elaborated on the types of reactions PWD had upon losing their driving privileges. Three caregivers indicated that the PWD did not mind turning in their licenses and stopped driving immediately. Other caregivers explained how the PWD willingly handed in their license because they did not want to cause any harm to other people. One caregiver also indicated that the PWD handed in their license following a medical injury.

“He stopped driving just like that even before it was official. I guess it’s because he’s a man that respects the law he respects the authority. I know a lot of people fight against that. He didn’t! He basically handed me the keys the next day and hasn’t driven since” – Caregiver F

Caregiver F specified how the PWD was compliant with this transition, and that they have not tried to drive since. Thus, six out of the ten caregivers indicated that the PWD was initially compliant with the loss of their driving privileges.

PWD resisting the transition to non-driving. Three caregivers indicated that the PWD did not comply with the loss of their driving privileges. The caregivers described how the PWD would either ask for different testing or for a do-over test. Alternatively, caregivers reported that the PWD was not complying by trying to engage in driving despite the loss of driving privileges.

“He got really angry at the doctor, the man who took it away. For the longest while, every time we were going there he was very angry. I would have to tell him it wasn’t the doctors fault, I’d tell him he’d get it back, because back then I was working in that direction...He was angry at the doctor, « the doctor was stupid, he was more than capable of driving »” – Caregiver J

Caregiver J explained how the PWD did not accept the driving cessation and reacted angrily towards the physician who initiated the driving cessation process. This theme explored both the context and the initial reactions of the PWD upon the loss of their driving privileges. The next theme will be focused on the long-term reactions and adjustments of both caregivers and PWD to driving cessation.

Adapting and coping to the loss of driving privileges

The third main section of the interviews was focused on the caregivers coping with the PWD’s loss of driving privileges. Throughout the interviews, caregivers described how the loss

of driving privileges had a negative impact on the PWD's sense of independence. At this point in the interviews, some caregivers emphasized the importance of their own driver's license.

Following the PWD's driving cessation, caregivers reported feeling overwhelmed by their driving duties and by their responsibility to manage scheduling. Caregivers also expressed some anger and frustration towards their driving duties. In terms of coping, caregivers indicated that they found it helpful to receive help from family, friends and neighbours. None of the caregivers reported using public transportation as a method of coping during this portion of the interview.

PWD's loss of independence. Six caregivers reported how the PWD felt they had lost their independence following the loss of their driving privileges. The caregivers explained how the PWD felt increasingly dependent for their transportation needs. The caregivers also explained how the PWD associated their independence with the freedom of being able to get into a car and drive without needing to rely on somebody.

"It gives us issues but more than anything else the biggest thing about it is an issue of independence, the feeling that you're relying on somebody else that you don't really want to be relying on. In spite of the fact that he's your husband, you don't want to be relying. You want to feel like you can do something and be a part of what's going on, and when you don't have that, it hurts"- Caregiver H

Caregiver H explained how the PWD is now dependent on them for transportation needs. Six caregivers noted that the PWD expressed a loss of independence. These PWD felt dependent on their caregivers for their driving needs. Caregivers also communicated the importance of their own driving privileges.

Caregivers' driving privileges. During this portion of the interview, four caregivers repeatedly mentioned the importance of their own driving privileges. These caregivers

emphasized how important their driver's license was, considering they have become the sole driver.

“If they pull mine because I have Parkinson's, that's going to affect everything...And they will have to get it out of my cold dead hands!” – Caregiver A

Caregiver A expressed the importance of their own driver's license, and how its loss would have significant impacts on their life. Four out of the ten caregivers expressed the importance of their own driver's license when discussing the adjustment to the PWD's loss of driving privileges.

Caregiver difficulties with scheduling. Six caregivers reported how they became responsible for most of the scheduling ever since they became the sole driver. Five of these caregivers reported that they experienced difficulties when planning the driving schedule. These caregivers explained how being responsible for the driving also required planning, and that this could sometimes be difficult to organize. One caregiver specified that keeping up with the PWD's medical appointments was anxiety-provoking. Two caregivers explained how managing to get to their own appointments, as well as the PWD's appointments, was a straining endeavour. Another caregiver explained that as a result of their busy driving schedule following the PWD's driving cessation, they would need to miss or cancel their personal plans.

“Well scheduling is definitely one of [the challenges]. Trying to make sure that we don't conflict, and it also generally means not having appointments on the same days. Then there's the issue that if I have an appointment does she come with me this was an issue” – Caregiver H

Seven caregivers shared how it could be challenging to manage the driving schedule. Some expressed more difficulties with the responsibility to organize the schedule. In the next

section, caregivers also reported difficulties with their driving duties following the PWD's driving cessation.

Caregiver challenges with driving duties. When caregivers were asked to discuss how they were coping with the PWD's driving cessation, some caregivers expressed their frustrations towards their driving duties. Caregivers expressed the feeling of being forced into the driving role, having lost their own freedom and some were frustrated by the criticism they received from the PWD.

Six caregivers indicated that they felt forced into the driving role following the PWD's driving cessation. Caregivers expressed that they did not feel as if they had a choice in becoming the sole driver. Other caregivers reported that they would prefer it if they weren't always the ones who had to be responsible for the PWD's transportation needs. Some caregivers explained how it used to be the PWD who did most of the driving, and that ever since driving cessation they had to take on those responsibilities.

"It's tiring, it's exhausting because even the slightest thing you're always driving you're always the driver. If we go see someone half of the time I just decide not to go somewhere because I have to drive there. It's just more work for me, and then having to drive back at night in the dark because I'm going to be tired. It's pretty rare that someone would pick up my husband" – Caregiver E

Caregiver E expressed the strain of being forced into the driving role for the PWD's driving needs. Caregiver E adds that it's rare for someone else to offer to drive for the PWD. Six out of ten caregivers expressed how they felt forced into the driving role following the PWD's driving cessation. Three caregivers reported that being responsible for the PWD's transportation needs can be tiring and demanding. Additionally, some caregivers also expressed sadness towards the PWD's loss of driving privileges.

Missing the PWD's driving. When caregivers were asked to discuss how they coped with the PWD's loss of driving privileges, three caregivers expressed that they felt sadness or remorse. For instance, caregiver G expressed that they missed how the PWD used to perform part of the household's driving duties.

"[...]we used to share the driving especially when we go out west. If I needed something he could always go to the store for me, and now he cannot so I don't get chocolate bars at 10 o'clock at night anymore" – Caregiver G

Caregiver G described how they misses the way the PWD used to run errands or perform driving-related tasks before the driving cessation. Similarly, caregiver J reported that the PWD's driving used to play a significant role in their business. Caregiver J expressed how they missed receiving help with the driving.

"I didn't have to drive a car! Everyone who know me, knows I don't like driving, I like to be driven. I would do so many things in the car when he was driving me, I could book appointments, make calls, I could multitask. [...] One of my friends said it so nicely, said « when we met [caregiver J], we were so impressed because we thought: wow, she has her own Uber guy! ». And, you know it's like, fancy, I had my own chauffeur. That, got snatched from me all of a sudden, and it was all this stuff I had to do after" – Caregiver J

Caregiver J expressed the significant driving role the PWD used to have in their life. Thus, caregivers expressed how they missed the PWD's driving role following the driving cessation. Some of the caregivers expressed sadness or yearning for the PWD's driving privileges following driving cessation.

Support from neighbours, friends and family. According to our findings, some caregivers indicated that they found it very beneficial when they had family members, friends or neighbours on which they could rely on in terms of transportation needs. Six out of ten

caregivers explained how they occasionally received some help from their friends, family members or neighbours in terms of transportation. Four of these caregivers expressed how neighbours or friends have offered them support in terms of transportation. Caregivers discussed how their neighbours would sometimes offer to drive the PWD to appointments, or to help the caregiver by running some errands for them.

“[...]it did become quite useful for neighbors to use our car to take him out when I could not make appointments. He wanted to go get his haircut so the neighbor across the road would say « I'll drive you » and they would use our car. Everybody was kind of happy”- Mrs. D

Caregiver D expressed how useful it was for them to be able to rely on her neighbours for some driving duties. Similarly, two caregivers specified how they could sometimes rely on family members, such as adult children or siblings to help with driving needs. Caregivers were grateful for the occasional driving alternative. Six out of ten caregivers expressed how they sometimes received help with driving. Thus, caregivers indicated that they appreciated receiving support for transportation from their neighbours, friends and family. While caregivers seemed to find it helpful to receive some help with the driving from friends and family, they did not appear to be increasing their usage of public transportation.

No use of public transportation. None of the caregivers indicated using public transportation as an alternative to driving. Half of the caregivers in our study expressed that they did not use public transportation. The other half of caregivers did not mention public transportation when discussing how they were coping with transportation following the PWD's driving cessation. Some caregivers expressed that they never used public transit. These caregivers also explained that they did not intend to start using it. Other caregivers explained how the PWD could not use public transportation.

“I don’t think he can get on the bus by himself it’s not like you could put him on the bus to go somewhere, you still have to bring him. The bus is not really the solution where I live right now. You have to drive everywhere pretty much. You don’t get a break!” – Caregiver E

Caregiver E explained how public transportation was not a viable transportation option. Caregivers explained how the PWD’s reduced ADLs or IADLs would make it difficult to use public transportation. Alternatively, some caregivers expressed a lack of public transportation options where they lived.

The third portion of the interviews were focused on the caregivers’ and the PWD’s adjustment to driving cessation. Caregivers reported how the PWD expressed a loss of independence when they no longer had the freedom to get into a car and drive where they wanted. Following the PWD’s driving cessation, some caregivers emphasized how important their own driving license was as they were now responsible for all the driving. Caregivers also reported feeling overwhelmed by their driving duties, as well as by their responsibility to manage scheduling. Caregivers also explained how challenging it can be to schedule and respect all of the PWD’s appointments, as well as their own. Additionally, caregivers expressed some frustrations related to driving duties, such as feeling forced into the driving role or losing their own free-time to perform driving duties. In terms of coping, caregivers found it helpful to receive transportation assistance from family members, friends and neighbours. Lastly, none of the caregivers reported using public transportation. While caregivers did not express using public transport, they did express the need for transportation alternatives and support following driving cessation. These needs were explored in more detail during the last portion of the interview.

Caregiver needs and support following PWD's driving cessation

The fourth and final portion of the interview was focused on the caregivers' needs following the PWD's loss of driving privileges. Caregivers were asked to describe what kind of support they would have found helpful during this transition. Caregivers were prompted to discuss what they think would be useful in an intervention program for caregivers of PWD who recently stopped driving. The majority of caregivers expressed the need for more driving alternatives. Caregivers also indicated the need to receive psychological services. Lastly, caregivers reported the need for some information sessions on dementia with trained healthcare professionals.

Information sessions. Six out of the ten caregivers reported the need to receive detailed information for caregivers of PWD. Caregivers specified that they wished to be informed of what to expect throughout the PWD's process of driving cessation. Caregivers expressed the need for information and explanations on how driving cessation can impact the PWD, and how it can impact them as caregivers. Some caregivers also specifically requested to receive information from professionals who have expertise, or experience with PWD. In addition, caregivers expressed how they had a lack of driving alternatives.

Need for transportation alternatives. Seven out of ten caregivers reported the need for more driving alternatives. As previously mentioned, caregivers explained that as they became the sole driver, they became responsible for juggling both their own schedule as well as the PWD's schedule. Caregivers explained that they would find it helpful to have resources or support which could offer driving alternatives to alleviate their driving duties.

“One thing about us as a family, we have a very small family. There's no brothers and sisters there's no cousins there is no other family or relatives apart from myself. We do not have that advantage of « I will call your brother Bill and

he'll take you down to get your haircut tomorrow » or « I'll call your sister »... *All of these things have to be done by me or we have to plan it*” – Caregiver D

Caregiver D expressed a lack of driving alternatives. Three caregivers expressed that they would find it helpful to have access to other driving alternatives to help them with their driving duties, such as running errands or going to appointments. Caregivers explained how the access to driving alternatives would lessen their own driving duties and allow them to engage in other activities.

“Having the support to be able to drive someone, somewhere, it could be casual or it could be for groceries, banking, appointments whatever they might need, being able to offer that I could see how it would be useful” – Caregiver J

Caregiver J explained how they believed it would be useful to receive some driving alternatives to help with errands and outings. Furthermore, some caregivers explained that carpooling, or sharing driving duties with other caregivers of PWD would be an interesting driving alternative. Some caregivers had previously engaged in sharing driving duties with other caregivers and reported that it was helpful. Thus, caregivers reported that they perceived a lack of driving alternatives. Caregivers added that it would be helpful for them to receive some driving alternatives to help lessen their own driving duties. Some caregivers focused on how they would appreciate some driving alternatives to help with medical appointments, while other caregivers said they would be interested in receiving some services to help with errands, groceries and other casual outings.

Psychological services and support. In addition to the need for transportation alternatives, caregivers expressed the need for psychological services and support. Nine out of the ten caregivers expressed the need for some psychological support. Caregivers requested

different types of psychological services. Five caregivers asked for more than one kind of psychological service or support. Some caregivers specified that they would need psychological interventions which can help them manage and cope with their emotions, as well as with the PWD's emotional reactions.

“Emotional support and counselling for the caregivers, would be a good thing. It is a change in life, and I'd have to say that even though we've been through it before with grandmother... Well, when it's yourself, in your hands, learning to cope, learning what to expect, learning not to get upset... You know, the first time that you hear her say that you're not her son, well that can be really hard. So, a bit of emotional counselling, and some laying out of the possibilities of things that we might be looking at, what to expect in the future, that would be helpful”

– Caregiver I

Caregiver I expressed the need for some emotional support and counselling, which could be aimed at developing coping strategies to manage emotional reactions. Other caregivers expressed the need for psychological services such as counselling or talk therapy. For instance, four caregivers reported that they would appreciate having a non-judgmental space in which they can express their emotions and talk.

“I find it was nice to talk to somebody about it because you don't get the chance to.” – Caregiver G

During the interview, caregiver G expressed that they enjoyed the opportunity to talk to someone about their experiences. Furthermore, some caregivers expressed that they would like to get the opportunity to receive psychological services from professionals who have some training, expertise or experience with dementia. One caregiver mentioned that it would be helpful to receive sessions without the PWD being present, so that they may ask questions regarding the PWD's behaviour and how to react or cope with them.

Lastly, in terms of psychological services, some caregivers expressed the need for grief counselling. Caregivers expressed that they could benefit from receiving psychological support on how to process their grief or on how to prepare themselves for upcoming grief.

“But, it’s like grieving I guess, you lose a loved one... You go through the stages of grieving, you go through it in your own way, take your own time. Some people will start with anger, others, anger comes years later. The worse thing I can hear someone say to someone who is grieving is « Oh, you’ll get over it »[...] So, can you teach that?” – Caregiver J

Caregiver J expressed how they experienced the progression of dementia of their loved one as a grieving process. Some caregivers experienced grief related to their caregiving duties, and as such, some of them also indicated that they would find it helpful for an intervention program to include grief-oriented therapy. In the last portion of the interview, most of the caregivers expressed the need for psychological services, which could be oriented towards learning how to cope with some of their own reactive emotions, or with some of the PWD’s emotional reactions. Lastly, some caregivers expressed how they believe it would be helpful to receive grief-oriented psychological services.

Thus, during the last portion of the semi-structured interview, caregivers were asked to discuss their own needs following the driving cessation of the PWD. Caregivers were also asked to give their input on what they believed would be useful in an intervention program focused on the needs of caregivers of PWD who stopped driving. In their answers, caregivers expressed the need for more information for caregivers of PWD. Caregivers requested information which could explain and describe how the process of driving cessation may impact both the PWD and the caregiver. Furthermore, caregivers reported that they had a lack of driving alternatives. Caregivers went on to express their need for more transportation alternatives. Some caregivers

requested transportation help with medical appointments, errands or other casual outings. Additionally, caregivers expressed that it would be helpful for them to receive some psychological support. Caregivers requested psychological services which could help them manage the PWD's emotional reactions, as well as their own emotional reactions. Other caregivers expressed the need for psychological support which could offer them a non-judgmental space where they would have the opportunity to ventilate their emotions and experiences as caregivers. Lastly, some caregivers requested grief-oriented psychological support.

Discussion

The goal of this study was to examine the experiences of caregivers of PWD following driving cessation. This assessment was completed to have a better understanding of the needs of caregivers. Our study's findings indicated that following the PWD's driving cessation, caregivers had some challenges in regards to their own emotional regulation, as well as the PWD's emotional regulation and reactive behaviours. Caregivers also expressed the need for driving alternatives to help alleviate their own driving duties. By exploring the caregivers' needs, this study builds on the existing driving cessation literature. Previous studies have already explored interventions to facilitate the decision to stop driving for the PWD and for the caregivers (Byszewski et al., 2003; Carmody et al., 2014; Rapoport, 2017). Another study by Liddle and colleagues (2016) developed a continuum to examine how family dynamics are impacted during driving cessation. Additionally, a study by Taylor & Tripodes (2001) explored the impacts of driving cessation on the mobility and transportation patterns of the PWD and their caregiver. However, in reviewing the literature, there was a clear gap in regard to the needs of the caregiver

following the driving cessation of their care recipient with dementia. Our study was focused on the needs of caregivers following the PWD's driving cessation. Using semi-structured interviews, ten live-in caregivers of PWD who lost their driving privileges were asked to discuss their own personal experiences and needs throughout the driving cessation process. The interviews yielded interesting findings. The goal of this study was to have a better understanding of the needs of caregivers following the PWD's driving cessation. As such, the results have been sorted in two overarching themes, the first being the caregivers' emotional wellbeing and the second being the caregivers' transportation needs.

Emotional wellbeing

Emotional regulation. One of the first main findings that our study yielded was regarding the caregivers' emotional wellbeing. The majority of the caregivers reported difficulties in regards to emotional regulation as a part of their day-to-day challenges. Many caregivers expressed feeling frustrated, angry or overwhelmed when discussing their experiences caring for the PWD. For instance, caregivers reported that completing ADLs and IADLs (e.g., driving) for their care recipient was a frustrating and straining experience. According to Etters, Goodall & Harrison (2007), up to 80% of informal caregivers of PWD could experience high levels of stress and frustration related to their caregiving duties. This phenomenon is also known as "caregiver burden" (Etters et al., 2007). According to this study, caregiver burden would encompass physical, psychological, social and emotional stressors which are associated with the caregiving role. Thus, Etters and colleagues (2007) make a clear distinction between the actual caregiving role, which refers to providing help and assistance, compared to caregiving burden. Our study did not measure for caregiver burden, although the majority of participants did report feeling stressed, strained and overwhelmed by their duties. A future study could examine the

impact of the PWD's driving cessation on caregiver burden. Our findings support previous research on emotional wellbeing of caregivers of PWD (Ory et al., 2000). Ory and colleagues (2000) found that by consistently responding to the demands of a dependent adult, caregivers of PWD experienced significant emotional and physical strain. Our own findings suggest that caregivers of PWD who lost their driving privileges were subject to feeling frustrated and overwhelmed in their day-to-day caregiving duties.

Challenges managing the PWD's emotions and reactive behaviours. Caregivers expressed facing difficulties when trying to cope with the PWD's emotions and reactive behaviours following driving cessation. Caregivers described challenges in trying to manage the PWD when they became sad, angry, upset or agitated following driving cessation. For instance, some PWD would try to engage in driving despite having lost their driving privileges. Alternatively, some of the PWD expressed anger towards the loss of their driving privileges. Caregivers expressed that they felt guilty, sad or powerless when they had to manage the PWD's reactive emotions and behaviours following driving cessation. Additionally, the PWD also felt upset by the loss of their driving privileges, because it also represented a loss of their independence. Caregivers found it difficult and emotionally straining to cope with their care receivers' sense of diminishing independence. As such, caregivers faced difficulties managing their own emotions, and they also experienced some challenges trying to respond to the PWD's reactive behaviours following the loss of driving privileges. In addition to this, caregivers expressed grief when discussing their day-to-day caregiving duties.

Grief. Some caregivers experienced grief regarding the progressive nature of dementia in their care recipient. Caregivers described feeling sad and remorseful when they were faced with their loved one's diminishing capacities and decreasing health. As the majority of caregivers

were the PWD's spouse, some reported grief for loss of their relationship or marriage. Caregivers also expressed their sorrow when describing the duties and responsibilities they had to take on for their loved ones. Some caregivers reminisced about their loved ones before the dementia diagnosis. Considering our participants' accounts of grief, we considered the possibility that some of them may have been experiencing anticipatory grief. Anticipatory grief refers to a process in which one is coping, adjusting and mourning in anticipation of the death of a loved one (Holley & Mast, 2009). According to a study by Holley & Mast (2009), anticipatory grief for caregivers of PWD would include feeling the loss of roles, grief over the loss of closeness in their relationship with the PWD, loss of freedom, anger and feelings of isolation. Holley & Mast (2009) also found that anticipatory grief added to the caregivers' burdens. We have observed some parallels between our participants' experiences, and Holley & Mast's (2009) study on the impact of anticipatory grief on caregivers of PWD. For instance, the caregivers in our study also expressed grief over the loss of their independence. Caregivers found they had less free time to complete leisurely activities or found their schedules to be constricted with driving duties. Incidentally, the caregivers also felt upset by the PWD's loss of independence following their driving cessation. Caregivers felt sad, guilty or powerless when the PWD expressed their loss of independence following driving cessation. Additionally, some of the caregivers in our study specified that they took on the driving role which used to belong to the PWD before driving cessation. As in Holley & Mast's (2009) study, the caregivers in our study seemed to have expressed feelings of frustration and loss of freedom, and experienced changes in roles. Thus, our findings indicated that caregivers of PWD faced many emotionally challenging situations. Our study found that caregivers felt frustrated, overwhelmed and grieved when they discussed the daily challenges they faced in their caregiving duties following the PWD's driving cessation.

Psychological support for caregivers. The majority of participants reported that it would be helpful for caregivers of PWD to have access to psychological support following driving cessation of their care recipient. Participants requested access to services such as individual therapy or grief-oriented therapy for caregivers. Participants also expressed that it would be beneficial for them to receive support and validation. Some participants expressed a lack of appreciation and validation for their own emotions within the caregiving role. Other participants requested explanations and information to normalize and understand the experiences they lived through as the caregivers of PWD who lost their driving privileges. These caregivers reported that having more information on what to expect as caregivers of a PWD who lost their driving privileges would have been helpful. Some caregivers reported that having a space in which they could speak and express themselves freely would have been beneficial. To the best of our knowledge, there are no studies that have explored the emotional needs of caregivers following the PWD's driving cessation. There also does not seem to be any intervention developed to address the needs of caregivers following the PWD's driving cessation. Previous research was focused on the PWD's and caregiver's needs in the decision to stop driving, (Byszewski et al., 2003; Carmody et al., 2014; Rapoport, 2017), on the impacts of driving cessation on family dynamics (Liddle et al., 2016) as well as the impacts of driving cessation on mobility (Taylor & Tripodes, 2001). Thus, our results indicate that caregivers have a need for psychological support.

Caregivers' transportation needs

Our study revealed that several participants experienced challenges related to their driving role following the PWD's driving cessation. The most reoccurring challenges for

caregivers was receiving criticism from the PWD, being responsible for managing the PWD's schedule, and fulfilling the PWD's driving needs.

Criticism. Some caregivers reported that the PWD would criticize their driving. These caregivers expressed that they were frustrated or angry with this reactive behaviour. Participants explained that the PWD started criticizing their driving following the loss of their driving privileges. Caregivers found it challenging to focus on driving, while also trying to respond to both their own emotional reactions and those of the PWD. This finding suggests that caregivers can sometimes face challenges responding to the PWD's reactive behaviours within the context of driving. Similar findings were reported in Schultz & Martire's (2004) study on the effects of informal caregiving for PWD. According to this study, the PWD's reactive behaviours were one of the primary stressors placed on caregivers. Common reactive behaviors in PWD include agitation, restlessness, aggression and wandering. Schultz & Martire's (2004) study found that managing the PWD's reactive behaviours were frequently linked to a stressful caregiving experience, even more so than providing daily assistance with various ADLs and IADLs tasks. Thus, our findings also seem to suggest that caregivers face some challenges in responding to the PWD's reactive behaviours. It would also appear that these challenges extend to the context of driving.

Caregivers as sole drivers. Our findings also revealed that the caregivers of PWD took on the majority, if not all of the driving responsibility following the PWD's driving cessation. This finding supports previous results by Taylor & Tripodes' (2001) study, which indicated that up to 92% of PWD who stopped driving relied on privately owned transportation provided by family members. Some of the participants mentioned that they occasionally received help with driving from an adult child, friend or neighbour. Participants found it helpful when someone else

helped them with driving duties. However, only a few of our participants reported occasionally receiving help with their driving duties. As such, following the PWD's driving cessation, caregivers took on the majority of driving duties. According to our findings, assuming the transportation needs of a PWD represented a time-consuming engagement which had impacts on caregivers' schedules. According to our results, this represented an important transition in which the caregiver went from sharing the driving responsibilities, to adopting all of the driving and transportation related duties. Participants indicated that becoming the sole driver and adopting all the transportation duties had significantly impacted their schedules.

Overcrowded Schedules. Our study found that following the PWD's driving cessation, caregivers experienced difficulties managing a congested schedule. Caregivers reported that once they became the sole driver, their schedules were filled with tasks such as running various errands and driving to appointments. Some participants expressed feeling sad, frustrated or angry in regard to being responsible for all of the driving duties following the PWD's driving cessation. These results are supported Taylor & Tripode's (2001) findings that as the caregivers' driving increased to fulfil the PWD's driving needs, caregivers experienced difficulties managing work, caregiving duties, shopping, recreational activities and appointments. Future research could examine in more detail how the PWD's driving cessation impacts the caregivers' scheduling. To the best of our knowledge, there are no studies which examine the impacts of the PWD's driving cessation on the caregiver's schedule and time management.

Public transportation. Furthermore, none of the participants reported using public transportation as a method to adjust to the PWD's driving cessation. Some participants expressed that they either did not have access to public transportation or that public transportation was not a useful alternative for them. Participants explained that the PWD would still need a significant

amount of help to navigate public transportation systems such as the bus or train. Our findings once again supported Taylor & Tripode's (2001) results. According to their study, caregivers and their care recipients did not increase their use of public transportation following the PWD's driving cessation. Our findings seem to suggest that the caregivers of PWD who lost their driving privileges did not increase their use of public transportation systems. According to our participants' explanations, depending on the severity and progression of their dementia it could be challenging for a PWD to use the public transportation system by themselves. Caregivers would therefore have to accompany the PWD in order to help them use public transportation. Whether the PWD would use public transportation, or a privately-owned vehicle, the caregiver would still have responsibility over the PWD's transportation needs. In our study caregivers preferred to continue taking on the driving responsibility rather than using public transportation. While the public transportation system did not seem to be a viable transportation alternative for our participants and their care receivers, they expressed the need for other transportation alternatives.

Transportation alternatives. The majority of the caregivers in our study expressed the need to receive help with driving duties by requesting transportation alternatives. Some caregivers reported that having some help to drive the PWD to their activities and non-medical appointments would be useful. Caregivers indicated that they would still prefer to take responsibility for driving the PWD to their medical appointments. One caregiver expressed that it would be helpful to receive help with groceries and errands. According to Liddle and colleagues' (2013) study, limited transportation alternatives within the community was also described as an unmet need by caregivers of PWD who had stopped driving. The participants in our study also

perceived a lack of transportation alternatives which could address their needs and those of the PWD.

Thus, according to our findings, it appears that caregivers adopt the majority of the driving duties following the PWD's driving cessation. Caregivers indicated that it was challenging for them to respond to the PWD's criticism or commentaries while they were driving. Caregivers also reported having difficulties managing an overcrowded schedule. Some of the caregivers expressed feelings of frustration, sadness or anger in regard to these driving challenges. Lastly, caregivers expressed the need for transportation alternatives in order to alleviate some of their driving responsibilities.

Limitations

Our study is not without its limitations. First, it is important to note the possibility that our participants may have presented with response-biases. Due to the intimate nature of the caregiving role to a loved one with dementia, it is possible that some of the participants may have presented with a social desirability bias. It is also possible that participants felt uncomfortable disclosing personal information on caregiving for a loved one with dementia. We recognize the possibility that the intimate nature of our research topic may have had an impact on our participants' answers. We found that throughout the interviews, participants tended to minimize their negative emotions when they discussed their caregiving role. Again, due to the delicate and intimate nature of discussing caregiving for a loved one with dementia, it is possible that some of the participants found it difficult to express their needs, or the challenges they faced in the caregiving role. Nevertheless, participants still reported experiences in which negative emotions, responses and behaviours occurred within their caregiving duties. This phenomenon could be due to a social desirability bias. It is also possible that our participants were concerned

about being judged negatively if they expressed challenges and frustrations within their caregiving role.

A second limitation for this study would be the distribution of the types of caregivers within our sample. This study was focused on the needs of informal caregivers of PWD. Informal caregivers refer to any individual who provides unpaid assistance with day-to-day tasks (Statistics Canada, 2016a). According to the literature on driving cessation, the two most common kinds of caregivers for PWD who stopped driving are spouses or adult children (Statistics Canada, 2016a). Our sample of caregivers was composed of nine spouses, and one adult child. Our study is therefore mostly limited to the experiences and needs of caregivers that are also the spouse of their care receiver. That being said, according to the literature, the majority of caregivers of PWD tend to be spouses (Statistics Canada, 2016a).

A third limitation of this study is with our method of recruitment. Our study completed all of its recruitment through the Bruyère Memory Program. Thus, all of our participants were recruited from one source, which presents a limit in terms of the generalization of our results. For instance, nine out of our ten participants were older adults who lived in urban areas within Ottawa, and only one participant lived in a rural area. Ottawa is a city with a high socioeconomic status compared to other Canadian cities (Statistics Canada, 2008). As such, it is possible that the caregivers in our study have had access to more resources compared to caregivers in other regions in Canada. Thus, our research poses a limitation as it is mostly representative of caregivers who live in urban areas.

Implications

The Canadian older adult population is experiencing significant growth, and this trend is predicted to continue in future years (Statistics Canada, 2017a). Accordingly, dementia

prevalence within the Canadian older adult population is also projected to increase in the next decades (Alzheimer Society Canada, 2018; Statistics Canada, 2016a). While the older adult population increases, it is logical to speculate that Canada will have a growing demand for both formal and informal caregivers to meet the older adult population's needs (Marshall et al., 2015; Statistics Canada 2016a). According to these projections, Canada will also have a growing need for caregivers of PWD. Considering these population trends, our study has focused its attention on the needs of the caregivers of PWD who have lost their driving privileges.

This study adds to the existing research on the impacts of driving cessation by examining the experience of caregivers of PWD who have ceased driving. By exploring the needs of caregivers of PWD, this study has built upon existing literature on the experiences and perspectives of caregivers of PWD. By exploring the needs of caregivers, suggestions and recommendations for future research and clinical interventions for caregivers of PWD following driving cessation can be generated. It was found that caregivers of PWD who stopped driving experienced a range of emotional strain, such as feeling overwhelmed, frustrated or grieved in their day-to-day experiences. This is consistent with previous studies (Holley & Mast, 2009; Ory et al., 1999; Statistics Canada, 2016c). Thus, it would be important to address the caregivers' emotional needs following the PWD's driving cessation. In terms of clinical interventions, we would recommend an approach which could offer caregivers some tools and coping mechanisms to manage their own emotions, and the PWD's emotional reactions following the transition of driving cessation. According to the needs expressed by caregivers in our study, it would be beneficial for them to receive access to psychoeducation. This could include information on dementia and on the possible impacts of driving cessation for both the PWD and the caregiver. Lastly, it would also be helpful for caregivers to have the opportunity to express themselves and

receive validation for their own emotional strain and frustrations following the PWD's driving cessation. Many participants expressed that access to individual psychotherapy services would be helpful.

Furthermore, our study found that caregivers of PWD had some unmet needs and frustrations in regard to transportation alternatives following the PWD's driving cessation. This was consistent with Taylor & Tripodes' (2001) findings. Therefore, it would be important for a potential intervention to include information on alternative transportation. Considering the transportation needs expressed in our study, the development of a mobility training module as part of a larger intervention for caregivers of PWD could be beneficial.

Conclusion

Former studies have explored the impacts of driving cessation on PWD. Previous research has also implemented intervention protocols to assist caregivers and PWD with the decision to stop driving. There exist some studies which have explored the impacts of driving cessation on the PWD's family dynamics and mobility. However, there is no research that has explored the needs of caregivers following the PWD's driving cessation. In the present research study, semi-structured interviews were conducted to obtain in depth information on the needs and experiences of caregivers of PWD following driving cessation. The goal of this study was to have a better understanding of the needs of caregivers following the PWD's driving cessation. The results supported findings of previous research studies on the impacts of driving cessation on caregivers of PWD. Considering Canada's older adult demographic and dementia prevalence, this study provides insight and future directions to help alleviate caregiver burdens following driving cessation. Many of us will eventually become caregivers for a loved one. Some of us may even manage the outcomes of driving cessation of a loved one diagnosed with dementia.

The present study provides valuable information on caregivers' needs in hopes of developing an intervention to improve their quality of life.

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Appendix A

Interview Protocol

Date: _____

Interviewer: _____

Participant Number: _____

Instructions: Sign consent form and remind participant that interviews will be audio-recorded but that everything they say is confidential.

Open-ended Questions:

{Short introduction about who you are, your role in the study, and why we are conducting this interview}

1. Can you describe your experience with living with a loved one who has dementia?
 - What are some of the challenges?
 - Tell me about your loved one's emotional well-being?
 - Tell me about your emotional well-being?
2. Can you describe how and when your loved one lost his/her driving privileges?
 - What happened (did they receive a letter, go for additional testing...)?
 - How did your loved one react to the loss of their driving privileges?
 - Can you tell me about his/her emotions and/or reactive behavior?
 - How did you react to the loss of your loved one's driving privileges?
3. How has your loved one been coping with the loss of driving privileges since?
 - Tell me about their emotions now and/or reactive behavior? Are they coping?

-How have you been coping?

-How is your loved one mobile now (what type of transportation do they take)?

4. Would you have liked support when your loved one lost his/her driving privileges?

-What kinds of support would have been helpful to you (Cues: Emotional support, grief counselling, tools to help with partner, physical help, alternative transportation training)?

5. Let's say we want to build a counselling program for caregivers to patients with dementia who have recently lost their driving privileges, what would you include?

-What topics would have to be covered?

-What skills or tools should be included?

-What kind of resources should be discussed?

6. Is there anything you would like to add on the topic of driving and dementia?

Appendix B

Participant Letter of Information and Consent Form

Principal Investigator: Stephanie Yamin, PhD

Research Assistant: Cassandre Gratton, MA candidate

Introduction

You are being invited to voluntarily participate in a research study. Before agreeing to participate in this research study, it is very important that you read and understand what your participation will involve. This letter of information describes the purpose, procedures, possible benefits and risks. It also describes your right to refuse to participate or to withdraw from the study at any time for any reason. Please ask the research assistant to explain anything you don't understand before signing the consent form.

Purpose of this Study

The goal of this study is to gain a better understanding of the support needs of people who are caring for an older adult diagnosed with dementia who has lost their driver's license. We would like to develop a therapy program for caregivers of people who have dementia and have lost their driver's license but we need to have a better understanding of their specific needs. Approximately 10 people will be recruited to participate in this study.

Description of the Study

We will conduct an interview with you that should last a maximum of 45 minutes. The interview will be held at Saint-Paul University. The date and the time of the interview will be discussed with you and mutually agreed upon. You will be provided with a location map to help you find the room where the interview will be held or someone will meet you at the entrance of Saint-Paul University to take you to the interview room. The interview questions are open-ended and the researcher may ask you to clarify your responses. The interview will be audio-recorded but everything you say will remain confidential. Should you say anything that identifies you we will make sure to delete that portion of the audio-recording at the time of the interview. The interviews will be transcribed but the transcript will never be associated with your name.

Potential Risks to Participating

You may find that some of the questions require you to discuss personal issues, which may make you feel uncomfortable. Please remember that you are not required to answer any question.

Possible Benefits

There may be no direct benefit to you from participating in this study. However, your participation may help others by helping us develop a therapy program for caregivers similar to yourself.

Compensation

You will not be paid to participate in this study. You will receive 10\$ to cover the cost of parking at Saint-Paul University.

Confidentiality

We wish to assure you that your privacy is very important to us. When you join the study, you will be given an ID number. Researchers will use this ID number to organize your data, instead of your name or other information that can identify you directly. Any data collected for study purposes that could potentially identify you will be stored in a highly secure manner and never be released or disclosed in a form that could identify you. Your ID number will be linked to your name and contact information on another “master list” of participants, which will be kept separately from the other research information in a locked office.

By providing consent to this study, you are agreeing that the data collected during this study will be stored on an encrypted memory key. Audio recording of interviews will only be accessible by a select number of researchers who are involved with this study.

Withdrawal from the Study

Participation in this study is voluntary. You may refuse to participate, refuse to answer any of the questions or withdraw from the study completely at any time with no effect on your future care.

You can withdraw from the study at any point. No new data will be collected or linked to other data from that point on. To withdraw from the study, please notify the researcher.

Contacts for Further Information

If you require any further information regarding this project or your participation in the study you may contact Stephanie Yamin, principal investigator for this study at 613-236-1393 ext: 2380.

If you have any questions about your rights as a research participant or the conduct of this study, and if at any time during this study you feel that you have not been informed enough about your privacy rights about your health information, or you feel that the privacy of your health information has not been protected, please contact the Bruyère Continuing Care Research Ethics Board (REB) (a group of people who review the research to protect your rights):

The Bruyère Research Ethics Board
613-562-6262 ext. 4003
reb@bruyere.org

CONSENT FORM

I have read the letter of information, have had the nature of the study explained to me and I agree to participate. All questions have been answered to my satisfaction. I will be given a copy of this letter of information and consent form once it is signed.

_____ I agree to be audio recorded as part of the in-person interview about my experiences. (Please initial if you agree)

Participant's Name (please print): _____

Participant's Signature: _____

Date: _____

Person Obtaining Consent (please print): _____

Signature: _____

Date: _____