Driving and Dementia:
Development and Evaluation of an Interactive Toolkit for Use with Caregivers

by

Alexandra Jouk
M.Sc., University of Victoria, 2011
B.A., Scripps College, 2007

A Dissertation Submitted in Partial Fulfillment
of the Requirements for the Degree of

DOCTOR OF PHILOSOPHY

in the Psychology Department

University of Victoria

Supervisory Committee

Driving and Dementia:
Development and Evaluation of an Interactive Toolkit for Use with Caregivers

by

Alexandra Jouk
M.Sc., University of Victoria, 2011
B.A., Scripps College, 2007

Supervisory Committee:

Dr. Holly A. Tuokko, (Department of Psychology)
Supervisor

Dr. Colette M. Smart, (Department of Psychology)
Departmental Member

Dr. Patricia MacKenzie, (Department of Social Work)
Outside Member

Abstract

Supervisory Committee:

Dr. Holly A. Tuokko, (Department of Psychology)
Supervisor

Dr. Colette M. Smart, (Department of Psychology)
Departmental Member

Dr. Patricia MacKenzie, (Department of Social Work)
Outside Member

Concerns about safe driving practices in individuals with dementia often fall to caregivers, who are frequently faced with the difficult task of initiating the conversation about driving and driving cessation with their loved ones, a topic that can be a very emotional and sensitive for older adults. Several print-based resources are currently available to caregivers, however, emerging research suggests that disseminating information through a medium that depicts the complexities involved in decision-making about driving, such as applied theatre, may be more effective than these traditional print-based methods. Currently, there are no resource guides available for caregivers that incorporate applied theatre into their dissemination methods.

In light of this research, this dissertation followed the principles of Knowledge Translation to work closely with caregivers to develop (Study 1) and evaluate (Study 2) a toolkit centered around an applied-theatre production called *No Particular Place to Go*. In Study 1, the comments and suggestions obtained from focus groups and individual interviews with 17 (eight informal and nine formal) dementia caregivers were incorporated into a toolkit called *Down the Road*, which consists of the play, *No Particular Place to Go* (in DVD-format), an accompanying viewer guidebook, and supplemental information cards. In Study 2, using a pre-post design, a total of 70 general caregivers (31 informal and 39 formal), including dementia caregivers, evaluated *Down the Road* by completing the Driving-Related Self-Efficacy Questionnaire (DRSEQ) and a User Satisfaction survey. Both informal and formal caregivers' self-efficacy around various topics related to older driver safety increased after reviewing *Down the Road*. Additionally, caregivers favourably received the toolkit. This work moved beyond information gathering by incorporating the expressed needs of caregivers to translate knowledge into an effective, research-based toolkit that can provide caregivers with an interactive resource for use individually or in facilitated groups.

Table of Contents

List of Tables

List of Figures

Acknowledgments

I cannot begin to express my gratitude and appreciation to Dr. Holly Tuokko, not only for her guidance on this project, but for her mentorship over the course of my graduate training. It has been an honour to work with one of the leading experts in the field of aging and I will continue to learn from this extraordinary researcher and woman even after my time at the University of Victoria has come to an end. Many thanks to my other committee members, Drs. Colette Smart and Patricia MacKenzie, for sharing their expertise and providing guidance and recommendations to strengthen this project.

I would also like to thank Mr. Wayne Enright and Ms. Janyn Mercado for their assistance with transcribing and data collection, as well as to Mike Meru for his assistance in the graphic design and layout of the toolkit and to Lisa Warren for her consultation. Many thanks to Bayside Press for their services in printing the final toolkit.

Finally, I would like to thank the Canadian Dementia Knowledge Translation Network, the Alzheimer Society of Canada, and the Sara Spencer Foundation for generously funding the production of the toolkit as well as a stipend to help me complete my doctoral degree.

Chapter 1

General Introduction

The Dementia Process

The aged population around the world continues to increase due to improved health care and overall living conditions. Recently, the World Health Organization (2011) estimated that in just a few years the number of persons over the age of 65 will exceed the number of individuals under the age of five worldwide. This number is projected to grow from an estimated 524 million in 2010 to approximately 1.5 billion by 2050 (World Health Organization, 2011). Within this rapidly booming aging population, the number of individuals with physical and mental illnesses will invariably increase. Most notably, the number of older adults suffering from disorders of cognition, including dementia, will reach an all-time high. In 2011, 14.9% of Canadians (747,000 people) were living with a diagnosis of cognitive impairment, including dementia. By 2031, that number is projected to increase to 1.4 million (Alzheimer Society of Canada, 2011).

“Dementia” is a broad term used to describe a cluster of neurodegenerative disorders affecting cognitive and functional abilities in individuals. Brain morphology of individuals with dementia show widespread cell death, leading to cortical atrophy over time (National Institute of Neurological Disorders and Stroke, 2010). According to the Diagnostic and Statistical Manual of Mental Disorders - Fifth Edition (DSM-5), dementia is classified as a Major Neurocognitive Disorder and characterized by significant declines in one or more cognitive domains (e.g., memory and learning, complex attention, language, perceptual-motor, executive functioning, social cognition), which interfere in the ability to independently execute everyday activities (American Psychiatric Association, 2013). These abnormalities can manifest behaviourally as word-finding difficulties, comprehension problems, tremors, rigidity, way-finding difficulties, problems with planning/organizing/executing tasks, lack of awareness, decreased judgment, confusion, as well as other similar difficulties. Other common features of dementia include alterations in personality (e.g., disinhibition), mood (e.g., apathy, depression), and behavioural disturbances (e.g., wandering, agitation). In addition to this symptomotology, an individual with Major Neurocognitive Disorder must display significant impairment in social and/or occupational functioning, which represents a significant decline from previous functioning (American Psychiatric Association, 2013).

There are many different types of dementia. Although all the different types of dementias share similar symptom presentations, the DSM-5 differentiates between the types on the basis of varying etiologies (American Psychiatric Association, 2013). Alzheimer's Disease (AD), characterized by an accumulation of neurofibrillary plaques and tangles, is by far the most prevalent type of dementia, affecting approximately 62% of the dementia population (Alzheimer's Association, 2011; Alzheimer Society of Canada, 2011). Vascular dementia (also known as multi-infarct or post-stroke dementia) is considered the second most common type of dementia and affects approximately 17% of the dementia population (Alzheimer Society of Canada, 2011). This form of dementia results from decreased blood flow to regions of the brain, often caused by a series of small strokes (Alzheimer's Association, 2011). Other types of dementia include, but are not limited to: mixed dementia (characterized by a combination of symptoms of AD and another form of dementia, typically vascular dementia; affects approximately 10% of the dementia population), Lewy-Body dementia (affects approximately 4% of the dementia population), and frontotemporal dementia (affects approximately 2% of the dementia population; Alzheimer's Association, 2011; Alzheimer Society of Canada, 2011).

Little is known about the underlying causes of dementia, although they are most likely due to a number of contributing factors including the presence of the apolipoprotein-4 gene (in AD), a family history of dementia reflective of a genetic predisposition, cerebrovascular disease (including hypertension and hyperlipidemia), and accumulated brain injuries (Alzheimer's Association, 2011). Advancing age is the primary risk factor for developing dementia (Alzheimer's Disease International, 2008). According to Alzheimer's Disease International (2008), only approximately 2% of the dementia population are between the ages of 65 and 69. This number slightly increases to approximately 5% for individuals between the ages of 70 and 79. Once older adults reach their 80s, however, this percentage dramatically increases to 24%. Individuals age 90 and older represent the largest age group with dementia (37%; Alzheimer's Disease International, 2008). More women develop dementia than men, a statistic that can, at least partially, be explained by the fact that women typically live longer than men (Alzheimer's Association, 2011).

Most forms of dementia are progressive, neurodegenerative disorders. Extant research has identified three stages of the dementia process (Ronch & Crispi, 1997). In the first stage, or mild stage, an individual may be less socially competent, less logical, somewhat depressed, and more argumentative compared to previous functioning. He/she may show impaired recent memory (forgetting words and getting lost in familiar places) and make errors in judgment. At this stage, instrumental activities of daily living (IADLs; grocery shopping, cooking, cleaning, managing finances, driving) may begin to be affected. In stage 2, or the moderate stage, the individual with dementia becomes more dependent on family members due to an inability to independently execute IADLs and may lack logical thought, show more signs of memory loss and anxiety, have hallucinations, display embarrassing or bizarre behaviour, become overly suspicious, and behave in a disinhibited manner. In the third, most advanced stage, in addition to progressive deterioration in memory, an individual may be apathetic and remote, unable to communicate, unable to walk, and incontinent. Basic activities of daily living (ADLs; toileting, grooming, bathing, dressing, walking) are compromised at this stage. Given that there is currently no cure for dementia, individuals will continue to decline until inevitable death. The rate of progression varies considerably between individuals and the duration of illness can range between 8 and 25 years (Mayo Clinic, 2013).

Driving and Dementia

It is estimated that 30-40% of individuals who have been diagnosed with a form of dementia continue to drive following the diagnosis (Lloyd, Cormack, Blais, Messeri, McCallum, Spicer, & Morgan, 2001). Although some individuals in the early stages of dementia are safe to drive (Fox, Bowden, Bashford, & Smith, 1997), individuals with AD and related dementias who continue to drive are more at risk for unsafe driving practices and crashes compared to cognitively-intact older adults (Adler, Rottunda, & Dysken, 2005; Brown, Ott, Papandonatos, Sui, Ready, & Morris, 2005; Duchek, Carr, Hunt, Roe, Xiong, Shah, & Morris, 2003; Man-Son-Hing, Marshall, Molnar, & Wilson, 2007).

Driving, although typically an over-learned and automatic task, requires the complex integration of physical, sensory, and cognitive domains (Anstey, Wood, Lord, & Walker, 2005). Cognitive domains include attention, processing speed/reaction time, visual-spatial, psychomotor, memory, and executive functioning abilities (Anderson, Rizzo, Shi, Uc, & Dawson, 2005). According to the DSM-5 (American Psychological Association, 2013), individuals with dementia demonstrate progressive decline in one or more of these very abilities. As a result, it is only a matter of time before dementia begins to limit an individual’s safety on the road and driving cessation must occur (Breen, Breen, Moore, Breen, & O’Neill, 2007). In 2005, Adler and her colleagues conducted a literature review of 11 studies evaluating driving competence in individuals with dementia. Accounting for differences in methodologies, they found that visual-spatial, reaction time, and attention abilities provided the most meaningful correlations with driving performance.

Although these cognitive abilities have been shown to predict driving ability, it has been suggested that safe driving practices are moderated by awareness and self-monitoring skills (Anstey et al., 2005). Considerable evidence has demonstrated that many healthy older adults self-regulate their driving behaviour based on their perception of how declines in physical and cognitive functioning may negatively impact their ability to drive safely (Persson, 1993; Rabbitt, Carmichael, Shilling, & Sutcliffe, 2002). Older adults appear to strategically alter their driving exposure (i.e., avoiding driving at night and in bad weather, changing routes to avoid traffic), speed (i.e., lowering speed), and maneuvers (i.e., avoiding parallel parking) to compensate for any losses associated with primary aging (Baldock, 2004; Ruechel & Mann, 2005). These types of self-regulatory practices appear to increase in number as drivers age (D'Ambrosio, Donorfio, Coughlin, Mohyde, & Meyer, 2008; Donorfio, D’Ambrosio, Coughlin, & Mohyde, 2008) and are particularly employed by women (D’Ambrosio et al., 2008; Gwyther & Holland, 2012; Molnar & Eby, 2008; Turano et al., 2009).

In individuals with dementia, however, insight, awareness, and self-monitoring skills are often compromised, especially in the later stages of the disease (Tomaszewski Farias, Mungas, & Jagust, 2005), leading some patients to insist on driving even when their abilities are impaired (Aronson, 1988). Hunt, Morris, Edwards, and Wilson (1997) reported that 38% of individuals with AD who failed a road test assessing driving competency considered themselves to be safe drivers.

However, this is not to imply that all drivers with dementia have no awareness of their impairments and refuse to restrict their driving. In 1999, Cotrell and Wild conducted a study with 35 individuals with AD, 19 of whom were still active drivers, and their caregivers to evaluate the affected individuals' level of awareness with respect to driving performance. Individuals with AD were given a 16-item questionnaire assessing four domains of function (remote memory, recent memory, attention, and everyday activities). They rated their perception of their current level of ability for all 16 items on a five-point scale from very good to very poor. Caregivers also filled out a parallel questionnaire in order to generate discrepancy ratings. In addition, caregivers completed a 15-item questionnaire examining patients' self-imposed driving restrictions. Caregivers rated whether patients never, sometimes, or always engaged in common restricting behaviours identified in the literature (e.g., avoids driving in bad weather, at night, unfamiliar routes, heavy traffic). The results suggested that individuals with AD voluntarily restrict their driving in certain areas for which they have awareness of their limitations. However, deficits in awareness, particularly attention, were significantly associated with continued driving behaviours.

Other research suggests that some individuals with AD are aware of their cognitive deficits, but have poor awareness of how these impairments may impact their driving abilities (Wild & Cotrell, 2003). In fact, it has been found that some individuals' with AD unwillingness to stop driving may be based on their misconception, as well as their caregivers’ misconception, that the cognitive processes afflicted by the disease do not affect driving abilities (Adler, Rottunda, & Kuskowski, 1999). These deficits in awareness and their relation to driving practices suggest that the problem not only stems from a neurogenic basis, but also from a lack of psychoeducation about how the dementia process affects driving abilities. As a result, individuals with dementia and their caregivers may fail to make appropriate plans for driving cessation (Adler, Rottunda, Bauer, & Kuskowski, 2000).

Dementia Caregivers

An individual can provide care to an older adult with dementia in either an informal or formal capacity. Although many definitions for informal and formal caregivers exist, it is generally accepted that informal caregivers are individuals from the dependent person’s intimate social network (e.g., family members, friends, neighbours) who may not possess any training in the provision of care and who do not receive any monetary remuneration for the task (Carretero, Garces, Rodenas, & Sanjose, 2009; Family Caregiver Alliance, 2014a; Ostwald, 2006). These individuals provide a broad range of assistance for the dependent person and may act in primary or secondary roles. Informal caregivers may live with or separately from the dependent person. Conversely, formal caregivers are professionals or paraprofessionals, typically nurses, nursing assistants, home health aides, and personal care workers, tied to a service system who provide care at home, in community agencies, or at institutions/residential facilities in exchange for monetary compensation (Family Caregiver Alliance, 2014a; Ostwald, 2006).

The vast majority of research on caregivers focuses on the informal caregiver. In Canada, as of 2007, approximately 2.7 million informal caregivers provide care for someone with a long-term health condition, like dementia; 75% percent of these individuals are between the ages of 45 and 64, 16% between 65 to 74, and 8% are over age 75 (Statistics Canada, 2008). Based on these statistics, the majority of informal caregivers (i.e., those between the ages of 45 and 64) must balance their caregiving obligations with their own personal/professional obligations as many are of the age when they are still employed and have children living at home (Statistics Canada, 2008).

The majority of informal caregivers (70%) are immediate family members (e.g., adult children, spouses); with six out of ten caregivers providing assistance to an aging parent or parent-in-law (Statistics Canada, 2008). However, data from Statistics Canada (2008) also shows that approximately one-third of caregivers are friends (14%), extended family (11%), and neighbours (5%).

Informal caregivers, on average, spend five to six years providing assistance (Statistics Canada, 2008). More than half (55%) of individuals with dementia receive support in their homes. Given the shift in the healthcare system for preference for home-based care over long-term residential care, the number of Canadians living at home with dementia is projected to increase to 62% by 2038, inevitably increasing the demands placed on informal caregivers (Alzheimer's Society of Canada, 2010).

More women generally act as caregivers than men (Canadian Study on Health and Aging Working Group, 1994). Caregiving duties, according to Statistics Canada (2008), have been found to differ between women and men and typically based on traditional divisions of labour, such that women tend to perform tasks inside the house (e.g., cooking, cleaning, laundry), whereas men tend to perform tasks outside the house (e.g., yard work, house maintenance). However, this research showed that almost all caregivers assist the older adult for whom they care with their driving and transportation needs.

The issue of driving and, more specifically, driving cessation remains a very sensitive and emotionally-charged topic among older adults and their caregivers (D'Ambrosio, Coughlin, Mohyde, Carrut, Hunter, & Stern, 2009). For many older adults, driving is associated with independence, personal identity, and self-esteem (Coughlin, 2001; Gardezi, Wilson, Man-Son-Hing, Marshall, Molnar, Dobbs, & Tuokko, 2006; Horowitz, Boerner & Reinhardt, 2002; Yassuda, Wilson, & von Mering, 1997). Conversely, driving cessation may result in reduced mobility, increased social isolation, and declines in physical and mental health for the older driver (Bonnel, 1999; Burkhardt, 2000; Johnson, 1999; Ragland, Satariano, & MacLeod, 2004).

Often times, making plans for driving cessation falls to the informal caregiver (Perkinson et al., 2005). Although formal caregivers may be well informed about the course of dementia and its impact on driving, they are often not as intimately involved in this process as informal caregivers (Perkinson et al., 2005). This topic has been shown to be an issue of considerable concern for individuals in this informal role (Wackerbath & Johnson, 1999). It has been shown that caregivers often struggle to balance the personal independence of their loved one with public safety (Fox & Bashford, 1997). In some instances, caregivers' emotional ties to their care recipients make it difficult for them to objectively evaluate driving abilities (Adler et al., 1999 & 2000). In addition, it has been found that caregivers' fear of confrontation can outweigh their rational observation that their loved ones are unsafe to drive (Hebert, Martin-Cook, Svetlik, & Weiner, 2002). These factors make it even more difficult for caregivers to approach the topic of driving cessation with individuals with dementia. Unfortunately, there is no widely accepted guideline for caregivers or clinicians to follow to help make these important and challenging decisions. As a result, informal caregivers are left to make these decisions with little or no assistance.

It has been demonstrated that informal dementia caregivers carry a great deal of stress and burden as a result of their duties, which can affect their mental and physical health. Caregivers are prone to feelings of social isolation, depression, anxiety, and guilt around their abilities to manage the declining functions of individuals with dementia and are at a higher risk of medical illnesses than non-caregivers (Galvin, Duda, Kaufer, Lippa, Taylor, & Zarit, 2010; Gruffydd & Randle, 2006; Mahoney, Regan, Katona, & Livingston, 2005; Sanders, Ott, Kelber, & Noonan, 2008). Some caregivers have reported the need to frequently miss work or quit working entirely in order to care for and chauffeur individuals with dementia who are no longer safe to drive on their own (Taylor & Tripodes, 2001).

Research is beginning to explore issues most relevant to individuals with dementia and their caregivers in order to facilitate the transition from active driving to driving cessation (Dobbs, Harper, & Wood, 2009; Perkinson et al., 2005). Perkinson and her colleagues (2005) conducted a study examining stakeholders’ attitudes and perceptions about factors that influence driving cessation among individuals with AD. They conducted focus groups with 68 stakeholders, including health care professionals, transportation and law-enforcement officials, family caregivers, and current and former drivers with AD and found that each group faces challenges and limitations when discussing driving cessation with individuals with AD. The authors highlighted the great need for the education of both formal and informal caregivers in several areas, including the ability to understand the influence of AD on driving capabilities, identify problem driving behaviours, and access available resources. Although this research was specifically conducted with the AD population, the need for caregiver education and accessibility to helpful resources extends to those working with individuals with all forms of dementia as well as other conditions that affect adults in older adulthood.

Available Resources for Caregivers

In order to address some of these very issues identified by Perkinson and her colleagues (2005), many resources have been developed to aid caregivers approach the topic of driving cessation with individuals with dementia, including support groups and print-based information sources (e.g., pamphlets, resource-guides, brochures, informative websites). Print-based resources are, by far, the most common method of presentation available to caregivers. In general, these resources provide information about the course of AD and other dementias, assessment tips, information about the legalities associated with driving, and strategies to help an individual with dementia transition from being an active driver to a non-driver. Typically, the content is geared to either informal caregivers (and sometimes the patients themselves) or to healthcare professionals.

In this day and age when technological advances and internet use have now become mainstream, it is common for organizations with a vested interest in older adults and/or dementia to include information about driving safety on their websites. For example, national non-profit organizations like the United States' Alzheimer's Association and the Alzheimer Society of Canada provide web pages or links to portable document format (PDF) brochures specific to the issue of driving and dementia to inform both informal and formal caregivers about the topic and available resources (Alzheimer's Association, 2014; Alzheimer Society of Canada, 2007). Other organizations like the American Automobile Association (AAA), American Family Physician, the British Columbia Automobile Association (BCAA), the Canadian Driving Research Initiative for Vehicular Safety in the Elderly (CanDRIVE), the

Family Caregiver Alliance, the Mayo Clinic, and the National Institute on Aging, among many others, also provide information about driving issues in relation to dementia (AAA Foundation for Traffic Safety Senior Driver, 2011; American Academy of Family Physicians, 2006; BCAA, 2014; CanDRIVE, 2014; Family Caregiver Alliance, 2014b; Mayo Clinic, 2013; National Institute on Aging, 2014).

More comprehensive, stand-alone brochures, booklets, and toolkits have also been produced for informal and formal caregivers and are available in web-based or hard-copy forms (e.g., *At the Crossroads: Family Conversations about Alzheimer's Disease, Dementia, and Driving* guidebook (Hartford, 2010), *The Driving and Dementia Toolkit: For Patients and Caregivers* (Champlain Dementia Network, 2009), *The Driving and Dementia Toolkit: For Health Professionals* (Champlain Dementia Network, 2009), *Driving and Dementia: A Guide for Patients and Families* (Kingston, Frontenac, Lennox & Addington Dementia Network, 2013), *Reporting Drivers with Dementia: A Guide for Physicians* (Kingston, Frontenac, Lennox & Addington Dementia Network, 2013).

For example, the resource guide, *Driving and Dementia: A Guide for Patients and Families*, was produced by the Kingston, Frontenac, Lennox, & Addington Dementia Network (2013) to give individuals with dementia and their families information about how the dementia process affects driving abilities and what they can expect in the future. The guide uses a "Question and Answer" format to answer common questions patients and their caregivers may have about driving (e.g., "Why is driving such an important issue in dementia?", "Does the diagnosis of dementia mean that I have to stop driving immediately?", "Won't I know when I am no longer safe to drive?", "What signs should a person look for?", Who decides whether I can still hold a valid driver's license?", "If I am no longer able to drive, what options do I have?”). Much of the content in this toolkit is specific to the province of Ontario, Canada with specific contact information given for resources in the city of Toronto. A parallel resource guide for healthcare professionals called, *Reporting Drivers with Dementia: A Guide for Physicians*, was also developed using the same Question and Answer format as the guide for patients and families. This guide specifically outlines the process of reporting potentially unsafe drivers with dementia to the Ontario Ministry of Transportation (MTO), an issue often times encountered by physicians and other healthcare professionals. Topics/questions include: “Do I have to report a patient?”, “How should I assess the driving safety in patients with dementia”, “How do I report the patient to the Ministry?”, “What about confidentiality?”, “How long does the process take?”, “Can my patient appeal the decision?”, and “Do I have to do anything if my patient appeals?”. The answers provide information about procedures within the MTO as well as guidelines outlined in the Canadian Medical Association’s publication, *Determining Fitness to Drive: A Guide for Families and Physicians*.

The Driving and Dementia Toolkit is another resource available to caregivers. It was first developed in 1997 (and is now in its third edition) to provide health professionals with information and resources to guide driving assessments including an assessment decision tree, a 10-minute office based screening tool (not empirically derived or validated), reporting guidelines, follow-up protocols, and strategies for talking to the patient and family about driving cessation, including a sample written statement to the patient. A list of additional resources is also provided (Champlain Dementia Network, 2009). In 2011, the Champlain Dementia Network created a separate edition of their *The Driving and Dementia Toolkit*, specifically designed for patients and caregivers. In this 27-page version, general information is provided (i.e., how the dementia process affects driving, warning signs, frequently asked questions), a description of the assessment process is given, post-evaluation steps are outlined (i.e., planning ahead for driving cessation, scheduling follow-up assessments, organizing alternative transportation, tips for individuals who may forget they are unsafe to drive), sample letters of advanced directives and doctors' statements are provided, and a list of additional resources is included for reference. Although much of the content in these two toolkits is applicable to caregivers in all provinces across Canada, some of the terms and procedures are specific to the province of Ontario.

In addition to the resource guides produced by the Kingston, Frontenac, Lennox, & Addington Dementia Network (2013) and *The Driving and Dementia Toolkit*s (Champlain Dementia Network 2009 & 2011), *At the Crossroads: Family Conversations about Alzheimer's Disease, Dementia, and Driving* is as another commonly used resource booklet available to patients and their informal caregivers, but may also be helpful to formal caregivers (Hartford, 2010). A collaborative team of researchers from the Hartford Financial Services Group and Massachusetts Institute of Technology's AgeLab integrated findings from interviews with individuals with AD, their caregivers, and experts in gerontology, medicine, and transportation to develop, produce, and distribute *At the Crossroads*. This 25-page booklet provides suggestions for monitoring, limiting, and stopping driving and includes worksheets where individuals with dementia and caregivers can outline alternative transportation options, catalogue driving activities in order to identify areas where driving reductions can be made, and identify areas of social support. The booklet also provides readers with a list of national resources available in the United States. Like *The Driving and Dementia Toolkit*, *At the Crossroads* gives a sample of advanced directive letter.

In 2008, Stern and his colleagues developed a psychoeducational group intervention for caregivers based on the *At the Crossroads* resource booklet after research suggested that group-based educational and support interventions can effectively increase caregivers' knowledge, decrease stress and burden levels, and improve behaviour in the dementia patient (Gallagher-Thompson & Coon, 2007). Stern and his colleagues compared this new *At the Crossroads* group-based intervention with the *At the Crossroads* print-based booklet and with routine standard care. Participants/caregivers were randomly assigned to the psychoeducation group (N = 31), the print-based group (N = 23), or the routine standard care control group (N = 12). The psychoeducation group consisted of four 2-hour sessions. Baseline data examining self-efficacy (Driving-Related Self-Efficacy Questionnaire; DRSEQ), coping (Brief COPE Scale), stage of change (preparation), concern about the relationship, communication with the loved one about driving, and awareness and use of information provided in the toolkit was collected as well as post-test data (approximately 8 weeks following baseline). Caregivers in the psychoeducation group scored significantly better than the other two groups on indices of self-efficacy, communication, and preparedness. In light of these findings, the Hartford Financial Services Group now produces and distributes a kit called, *At the Crossroads: The Support Group Leaders Kit on Alzheimer's Disease, Dementia and Driving* (Hartford, 2007).

Applied Theatre as a Method for Information Dissemination

Although resources for caregivers have primarily been print-based, with some emergence of group-based interventions, promising research suggests that applied theatre is an effective, creative, and interactive alternative for disseminating research compared to print-based materials (Tuokko, Rhodes, Love, Cloutier-Fisher, Jouk, & Schoklitsch, 2013; Tuokko, Rhodes, Love, Cloutier-Fisher, Jouk, & Schoklitsch, in press). Applied theatre is a relatively new field where drama/theatre are used in the context of an important social issue, like older driver safety, to transfer research-based knowledge and education to individuals with a vested interest in that topic for the purposes of change. Highlighting social issues through theatre has the power to engage and entertain audiences or knowledge-users by communicating complex information in an evocative and nuanced manner that transcends the limitations of text (Rossiter, Kontos, Colantonio, Gilbert, Gray, & Keightley, 2008).

Applied theatre productions are often conducted with/for marginalized individuals or communities and performed in non-traditional settings (i.e., schools, prisons, hospitals, museums, community halls; Prendergast & Saxton, 2009; Thompson & Jackson, 2006). From creation to evaluation, applied theatre companies adopt a collaborative approach with the intended audience by using one of four methods/model as the basis for developing a production (e.g., community-based model, curriculum model, transfer model, interview model; Prendergast & Saxton, 2009). Using the interview model, playbuilding or devising, also referred to as “collective creation” (a name which emphasizes the collaborative nature inherent to the applied theatre process), relies on gathering information from the audience or from a sampling of individuals representative of the intended audience through interviews, which are transcribed. The content of the transcriptions becomes the material the theatre company uses to create a play, first relying on improvisation of scenes then re-working the material until a polished script is obtained (T. Pauleth-Penner, personal communication, April 11, 2014). Most applied theatre productions contain endings that remain open and unresolved to actively engage audience members with the content (Prendergast & Saxton, 2009). After a performance, typically audience members evaluate the production. The assessment of applied theatre pieces can be challenging as the emphasis of the productions is placed on process rather than outcome. McKenzie (2001) suggests that all applied theatre performances are, in some manner, concerned with social efficacy, or how a performance positively assists our understanding of ourselves in relation to our culture and specifically in relation to the social issue that is addressed by the performance. The concept of social efficacy is most appropriately examined using “contemplative assessment” strategies (Morgan & Saxton, 1987). Contemplative assessment strategies are akin to qualitative methods in that they are concerned with asking questions that capture the broad effect and affect on individuals and communities rather than finding the “right”/quantitative answer or determining whether a production has succeeded or failed (Morgan & Saxton, 2006; Prendergast, 2009). As a result, the assessment and evaluation of applied theatre performances needs to address the specific purpose of the production using questions that promote reflection (e.g., What new questions has this performance generated for me?, How do they shift my being in the world?”; Prendergast, 2008).

Historically, drama and theatre have been used in primitive and ancient societies all over the world as a means of communicating stories and lessons. The Greeks, most notably Aristotle, Sophocles, Menander, Aristophanes, Aeschylus, and Euripedes, are credited with creating the format of performing a “play” in front of an audience (Lewcock, 2014). Over time, plays became a medium by which social ideas like power and justice could be raised, criticized, and debated in the safe, protected, and accepted confines of fiction and the stage as evidenced in the works of William Shakespeare, Moliere, Bertolt Brecht, Henrik Ibsen, George Bernard Shaw, among others (Prendergast & Saxton, 2009).

Applied theatre productions are the first of their kind to centre and focus their content around a plethora of social issues, like politics and human rights, which were raised by many of the modern, post-modern, and contemporary playwrights. During the 1960s, a time all around the world of social unrest and change, a shift in the theatre world occurred from catering performances to the middle to upper classes to making drama more accessible to the masses (Neelands & Dobson, 2000). At this time, in the United Kingdom, the first forms of applied theatre emerged when the Theatre in Education movement brought drama into the school system. Facilitators with both acting and teaching training incorporated children and adolescents into the acting experience to provide education about important topics such as human rights, anti-drug use, binge-drinking, and LGBT biases (Quek, White, Low, Brown, Dalton, Dow, & Connor, 2012; Neelands & Dobson, 2000; Prendergast & Saxton, 2009). As interest in the field grew and more and more social issues were explored through theatre, a variety of other applied theatre genres developed including Theatre of the Oppressed, Theatre for Development, Popular Theatre, Prison Theatre, Museum Theatre, Community-based Theatre, Reminiscence Theatre, and Theatre for Health Education (Prendergast & Saxton, 2009). Over the last decade as applied theatre methods have rapidly emerged, the approach has come to encompass a variety of alternative theatre practices as well including, but not limited to, grassroots theatre, social theatre, political theatre, and radical theatre (Prendergast & Saxton, 2009).

Within the genre of Theatre for Health Education, plays are devised using the collaborative process outlined above to promote health, safety, and well-being (Bury, Popple, & Barker, 1998). Some of the health issues that have been addressed using applied theatre include: disability awareness, drug abuse, child and elder abuse, sex education, head injury awareness, organ donation, water safety, driving safety, and a variety of mental health issues like dementia (Prendergast & Saxton, 2009). In 2004, the ACT II STUDIO theatre company, in conjunction with researchers from Sunnybrook Health Sciences Centre and York University in Toronto, Canada, developed the applied theatre production entitled, *I'm Still Here*, to challenge the negative attitudes often associated with dementia. The play powerfully depicts the perspectives of individuals with dementia and their caregivers at various stages of the disease to raise understanding and awareness about the complexities of the dementia process for individuals with the disease, their caregivers, health professionals, and anyone with an interest in this topic (Act II Studio, 2014).

Applied theatre productions have also been developed to target other issues, like driving safety, which are important to older adults, their caregivers, and stakeholder groups (Tuokko et al., 2013). For example, researchers and applied theatre specialists at the University of Victoria conducted focus groups with older adults and stakeholders (i.e., individuals with a vested interest in older driver safety including family members, health care professionals, law enforcement officials, and policy makers) on Vancouver Island, British Columbia to understand their attitudes related to positive and negative aspects of driving for older adults, challenges and barriers older drivers face, and strategies employed by older drivers to remain safe on the road. Playbuilding methods were used to embed the themes and content that emerged from these focus groups into a play about a fictionalized intergenerational family of three, each of whom face driving challenges and dilemmas of their own. The play, *No Particular Place to Go*, was shown across British Columbia and quantitatively evaluated with older adults and stakeholders using a pre-play/post-play questionnaire concerning beliefs and social cognition about older drivers. In addition, using applied theatre evaluation methods, audience members were led in a facilitated discussion after the performance to qualitatively understand their reactions to the play. Results from mixed method study showed that older adults', mainly females', openness or willingness to consider changing their driving behaviour increased, while stakeholders' attitudes remained unchanged after viewing the play. Audience members indicated that they found the play to be informative and that it promoted discussion around this very sensitive topic. A comparison/control study was also conducted with older adults who read a print-based manual related to older driver safety to determine if disseminating information through applied theatre is more effective than the passive reading of material (Tuokko et al., in press). This follow-up study demonstrated that individuals who read the print-based materials felt more positively about their driving and more empowered to continue driving. These findings suggest that an intervention that considers older adults and stakeholders' views of driver safety in a manner that is engaging and emotionally-charged can lead to attitudinal outcomes that differ, and may be more effective, compared to traditional print-based methods.

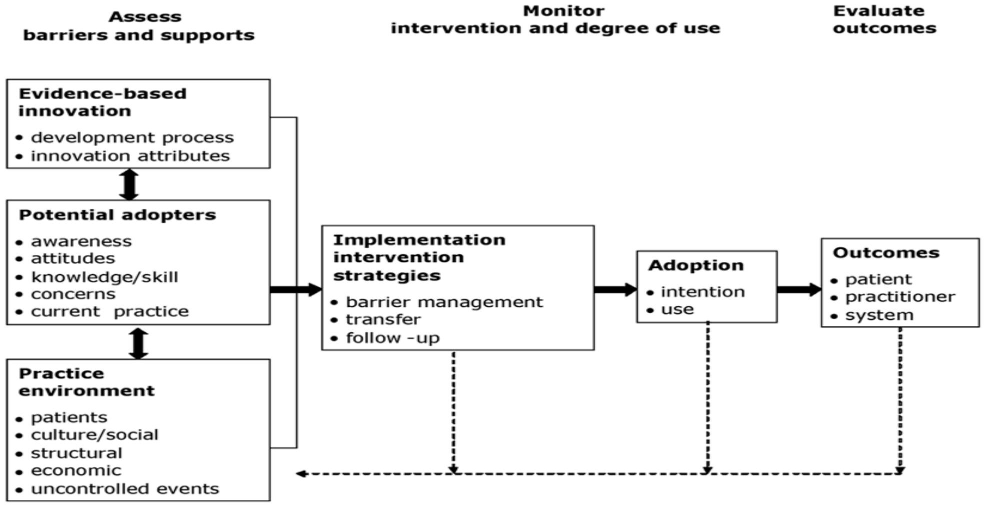
Principles and Models of Knowledge Translation

According to the Canadian Dementia Knowledge Translation Network (CDKTN), Knowledge Translation (KT) is the "adaptation of research findings into effective treatments, services, and products" (Dalhousie University, 2010). The Canadian Institutes of Health Research (CIHR) expands on this definition to underscore the importance of using evidence-based knowledge to create a product that will improve health or healthcare services (CIHR, 2012). Often, there is a gap between research and those who may benefit from the research findings, or knowledge users. Integrated KT actively engages knowledge users into the research process to ensure that research findings can be successfully disseminated, thus closing this gap (CIHR, 2012). Given this definition, the processes involved in the generation, dissemination, and evaluation of applied theatre inherently reflect KT strategies.

Several models have been developed to address the specific process of KT activities, including, but not limited to, the Ottawa Model of Research Use (Graham & Logan, 2004; Logan & Graham, 1998), the Promoting Action on Research Implementation in Health Services model (Kitson, Harvey, & McCormack, 1998; Kitson, Rycroft-Malone, Harvey, McCormack, Seers, & Titchen, 2008; Rycroft-Malone, 2004; Rycroft-Malone, Kiston, Harvey, McCormack, Seers, Titchen, & Estabrooks, 2002), the CIHR Model of Knowledge Translation (CIHR, 2007), and the Knowledge to Action Framework (Graham, Logan, Harrison, Straus, Tetroe, Caswell, & Robinson, 2006; Graham & Tetroe, 2009).

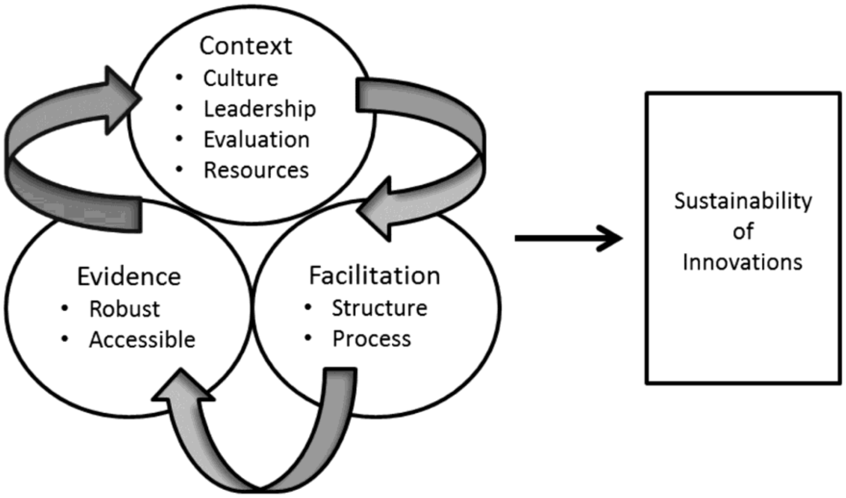
The Ottawa Model of Research Use (OMRU) was one of the first KT models developed to address the implementation and dissemination of existing research knowledge (Graham & Logan, 2004; Logan & Graham, 1998; Figure 1). The OMRU views the implementation of research or innovation as a dynamic process where decisions and actions are made at three distinct phases: (1) before dissemination through the assessment of barriers and supports, (2) during dissemination by monitoring research/innovation use, (3) and after dissemination by evaluating the outcomes (Graham & Logan, 2004; Logan & Graham, 1998). Considerations are made at the research/innovation, potential adopter, and environmental/systems levels.

Figure 1. Ottawa Model of Research Use. Reprinted from “Toward a comprehensive interdisciplinary model of healthcare research use,” by J Logan and I.D. Graham, 1998, *Science Communication, 20(2)*, p. 227-246. Copyright 1998 by Sage Publication, Inc.



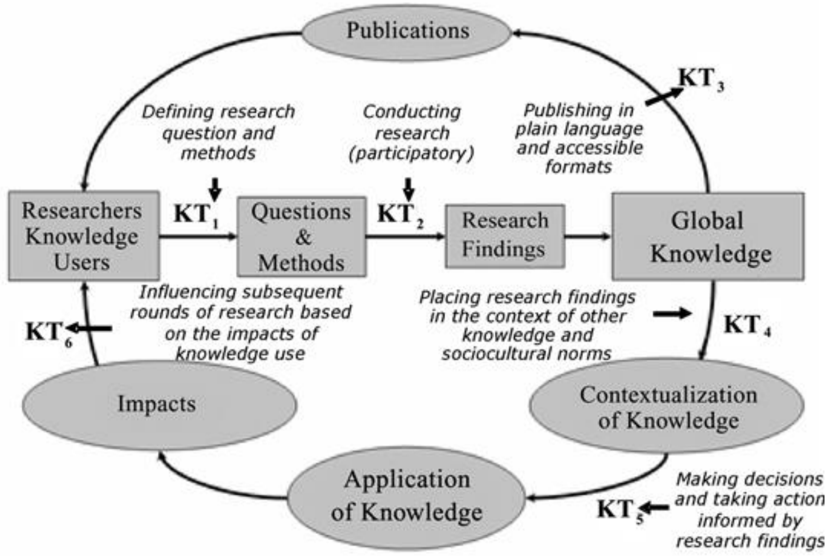
The Promoting Action on Research Implementation in Health Services (PARIHS) model (Kitson et al., 1998, 2008) takes a more conceptual approach to KT compared to the OMRU; see Figure 2 (Slaughter, Estabrooks, Jones, Wagg, & Eliasziw, 2013). According to the PARIHS model, successful implementation of research into practice requires the interaction between three core elements: (1) the level and nature of the evidence to be used, (2) the method by which the research implementation process is to be facilitated, and (3) the context/environment in which the research is to be placed. These three elements share equal importance and are positioned on a low-to-high continuum. The “evidence” element refers to research, clinical experience, patient experience, and local data or information that is the basis of implementation. On the continuum, evidence can be classified on a range from “low” to “high”, where “high evidence” reflects research that is well-conceived and conducted. The “facilitation” element is defined as a technique where KT facilitators (e.g., researchers, authors) help and enable knowledge users to apply evidence to practice. On the low-high continuum, “high facilitation” reflects the presence of an appropriate level of help catered specifically to the knowledge users and their situation. The “context” element refers to the environment or setting where implementation will occur, which can include the physical environment, as well as characteristics of the environment (e.g., patterns of power and authority, decision-making processes, resources, organizational culture, evaluation procedures). This element is rated threefold on the low-high continuum with respect to leadership, culture, and evaluation. “High” context may include effective leadership skills, an organizational culture that respects each member of the team, and the use of multiple methods of evaluation. The most successful implementation strategy under the PARHIS model occurs when all three core elements (evidence, context, and facilitation) are on the high end of the continuum.

Figure 2. Promoting Action on Research Implementation in Health Services (PARIHS) Model. Reprinted from “Sustaining Transfers through Affordable Research Translation (START): Study protocol to assess knowledge translation interventions in continuing care settings,” by S.E. Slaughter, C.A. Estabrooks, C. A. Jones, A. S. Wagg, and M. Eliasziw, 2013, *Trials, 14,* p. 355. Copyright 2013 by Slaughter et al; Licensee BioMed Central Ltd.



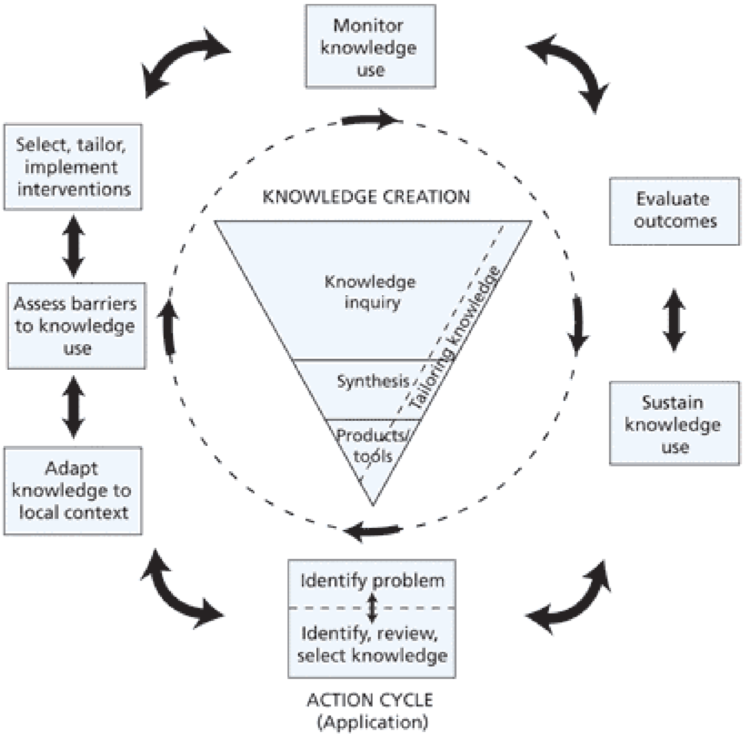
The model proposed by CIHR (2007) focuses more on the research cycle to help scientists integrate KT strategies from conception to termination of their studies (Figure 3). This CIHR Model of Knowledge Translation identifies six opportunities in the typical research cycle where KT activities can be implemented: (1) defining research questions and methodologies, (2) conducting research, (3) publishing research finding in plain language and accessible formats, (4) placing research findings in the context of other knowledge and sociocultural norms research, (5) making decisions and taking action informed by research findings, and (6) influencing subsequent rounds of research based on the impacts of knowledge use. For integrated KT to be achieved, CIHR stresses that research questions, approaches, feasibility, and outcomes are all guided and shaped by participating knowledge users (CIHR, 2012).

Figure 3. CIHR Model of Knowledge Translation. Reprinted from “Knowledge Translation: Introduction to Models, Strategies, and Measures,” by P. Sudsawad, 2007, Austin, TX: Southwest Educational Development Laboratory, National Center for the Dissemination of Disability Research. Copyright 2007 by the Minister of Public Works and Government Services Canada.



Similarly, the Knowledge to Action Framework, created by Graham and his colleagues in 2006, provides guidelines for KT application during various phases involved in the research process (Figure 4). It was derived through conceptual analysis of 31 planned action models and theories (Graham & Tetroe, 2009b; Graham & Tetroe, 2007). Of all the models described, the Knowledge to Action Framework provides the most comprehensive explanation of how KT can be implemented beginning from the knowledge creation or discovery stage all the way through the final stage when knowledge use is sustained. Two components, knowledge creation and translation of knowledge into action, provide the basic framework of this model. Knowledge creation requires three phases: (1) knowledge inquiry, (2) knowledge synthesis, and (3) identification of tools/products. All three of these phases incorporate the expressed needs of knowledge users in a collaborative process so the research itself is tailored and customized to address specific problems of interest to a targeted audience, thus making dissemination of the obtained knowledge through the action cycle applicable to the group of individuals for which it is intended. The action cycle then translates knowledge into action by (1) identifying a problem, (2) reviewing the research relevant to the problem, (3) adapting the identified research to a specific context, (4) assessing the barriers to using the knowledge, (5) selecting, tailoring, and implementing interventions to promote the use of knowledge, (6) monitoring knowledge use, (7) evaluating the outcomes of using the knowledge, and (8) sustaining ongoing knowledge use. A revised version of the Knowledge to Action Framework clarified that action cycle of the model uses a dynamic and iterative approach (as indicated by the double-sided arrows in the figure) to illustrate how each stage in the KT process continually affects the other stages (Graham & Tetroe, 2009a).

Figure 4. Knowledge to Action Framework. Reprinted from “Lost in Translation: Time for a Map?,” by I. D. Graham, J. Logan, M. B. Harrison, S. E. Straus, J. Tetroe, W. Caswell, and N. Robinson, 2006, *The Journal of Continuing Education in the Health Professions*, *26*, pp. 13-24. Copyright 2006 by The Alliance for Continuing Medical Education, the Society for Medical Education, the Society for Academic Continuing Medical Education, and the Council on CME, Association of Hospital Medical Education.



General Aims

Given the information presented above, the need for an applied theatre resource catered to dementia caregivers about driving is evident. As a result, this dissertation research used of the principles of integrated Knowledge Translation to guide the development and evaluation of a toolkit for caregivers about driving using the applied theatre production, *No Particular Place to Go,* as a new and interactive method of engaging caregivers with the topic. The project was conducted in two separate but related studies utilizing mixed methods. In Study 1, qualitative data from focus groups and interviews with informal and formal dementia caregivers provided the research/content base to develop a toolkit centred around *No Particular Place to Go*. In Study 2, quantitative methods were used to evaluate the toolkit with a newly recruited group of informal and formal general caregivers (including dementia caregivers).

Chapter 2

Study 1: Toolkit Development

Introduction

In today’s society, there is a growing number of individuals with dementia who remain on the road as active drivers (Lloyd et al., 2001). Due to progressive neurocognitive decline in many of the areas required to safely operate a vehicle (e.g., memory, visual-motor skills, attention, executive functioning), even individuals in the very mild stages of dementia can have comprised driving abilities (Duchek et al., 2003). In fact, it has been demonstrated that a large subset of drivers with AD and related dementias are more at risk for unsafe driving practices and crashes compared to cognitively-intact older adults (Adler et al., 2005; Brown et al., 2005; Man-Son-Hing et al., 2007).

Issues surrounding driving safety and specifically driving cessation often face caregivers (Perkinson et al., 2005), which pose considerable concerns and challenges to individuals both informally and formally in this role (Wackerbath & Johnson, 1999). Although it has been found that caregivers understand the importance of this topic and the need for it to be addressed, many caregivers report not being well-informed about the subject (Meuser, Carr, Berg-Weger, Niewoehner, & Morris, 2006; Perkinson et al., 2005). For example, in their study with 147 physicians and other healthcare professionals, Meuser and his colleagues (2006) found that the majority of these caregivers reported low knowledge of assessment strategies, resources, and reporting procedures related to driving and older adults with dementia. This study, among others (e.g., Dobbs et al., 2009; Perkinson et al., 2005), highlights the need for resources for caregivers.

The majority of resources currently available to caregivers are predominantly print-based (e.g. pamphlets, resource-guides, brochures, informative websites). Emerging research, however, suggests that applied theatre as an intervention may be a more effective means of delivering information and engaging information users than passively reading print-based materials (Tuokko et al., in press). Through the dramatic expression of applied theatre, information about a current social issue, like driving safety among older adults, can be raised and pondered. The applied theatre medium offers an innovative approach for addressing the complexities of driving cessation by turning passive individuals into active, engaged participants (Ackroyd, 2000). Drama has the unique ability to immerse audience members into a performance by having them witness issues as they unfold. This potentially allows for an emotional experience that can deepen the connection with the material in a play. As a result, applied theatre, when used in the context of older-driver safety, can help raise awareness of important driving-related issues, trigger emotions associated with driving and driving cessation, and help individuals understand the topic from new perspectives, all of which can shift perceptions and attitudes about driving.

Between 2008 and 2010, an applied theatre-based intervention was developed and evaluated to explore issues concerning older driver safety with older adults themselves and with stakeholders (e.g., family members/friends of older adults, health care practitioners, policy makers, transportation providers; Tuokko et al., 2013). The research was conducted in three distinct phases: (1) knowledge building and issue identification using focus groups comprised of individuals recruited from various organizations on Vancouver Island, British Columbia, (2) play development incorporating the issues and themes that emerged from Phase

1, and (3) play-viewing by older adults and stakeholders with pre- and post-performance questionnaires to evaluate shifts in attitudes about older driver safety.

The final production entitled, *No Particular Place to Go*, told the story of three fictitious family members (grandson – "MJ", mother – "Joanne", and grandfather – "Grandpa") who all faced diverse challenges relevant to driving safety. The major themes that emerged from the focus groups (e.g., barriers to safe driving, challenges encountered by older adults, the significance of driving for older adults, intergenerational driving issues, transitioning from active driving to no longer driving, responsibilities for driving-related decision-making, strategies for driver safety, issues related to policy and practice) were interwoven within the dialogue and behaviours of the characters. As prescribed by applied theatre methods (Prendergast & Saxton, 2009), a specific solution for Grandpa (as the older driver) and his family was not presented to let the audience consider their own possible solutions. The play was converted into DVD-format and an accompanying viewer guideboo`k was also created to help facilitate the conversation of driving cessation for home viewers.

Data from 110 older adults was collected pre- and post-play using questionnaires developed specifically for the study to examine changes in attitudes about older driver safety. In a separate study, another group of 100 older adults who read print-based information related to driver safety also completed the same questionnaires pre- and post-reading. The older adults who viewed *No Particular Place to Go* were more willing and open to consider changing their driving behaviour compared to the older adults who read the informational booklet on driver safety. Conversely, the older drivers who read the informational booklet were more empowered to continue driving (Tuokko et al., in press). These results hold implications for driving safety in our society as individuals with dementia or even those with any other health conditions associated with unsafe driving (i.e., problems with ocular, cardiovascular, pulmonary, and musculoskeletal systems; Anstey et al., 2005) may continue to drive if only exposed to print-based driving information. Alternatively, viewing an applied theatre production like, *No Particular Place to Go*, may promote safer driving practices by having drivers be more willing and open to changing their behaviour.

In light of this research and the great need for dementia caregivers to have access to an evidence-based resource about older driver safety using applied theatre, this study used the processes and guidelines associated with integrated Knowledge Translation (KT) to develop a toolkit for dementia caregivers based around the *No Particular Place to Go* DVD. Effective KT incorporates the needs of knowledge users (e.g., dementia caregivers) into the research process to disseminate research findings in an appropriate and accessible way for the intended knowledge users (Dalhousie University, 2010). Although many KT methods are available (CIHR, 2007; Graham, Logan, Harrison, Straus, Tetroe, Caswell, & Robinson, 2006; Graham & Logan, 2004; Graham & Tetroe, 2009; Kitson, Harvey, & McCormack, 1998; Logan & Graham, 1998; Rycroft-Malone, 2004; Rycroft-Malone, Kiston, Harvey, McCormack, Seers, Titchen, & Estabrooks, 2002), this study followed the action cycle of the Knowledge to Action Framework (Graham & Tetroe, 2009) as this model most clearly aligns with the research process and provides an eight-step protocol for how to apply the principles of KT during each phase of the research process: (1) Step One: Identify the problem, (2) Step Two: Identify, review, and select knowledge, (3) Step Three: Adapt knowledge to a local context, (4) Step Four: Assess barriers to knowledge use, (5) Step Five: Select, tailor, and implement an intervention, (6) Step Six: Monitor knowledge use, (7) Step Seven: Evaluate outcomes, and (8) Step Eight: Sustain knowledge use.

In previous work by Tuokko and her colleagues (2013), the problem of driving safety among older adults, in general, was identified and used as a focus of intervention work (e.g., applied theatre development and evaluation). This current study identified dementia caregivers as subset of this general group with their own unique needs (Step One), thus requiring the development of their own resource by adapting the applied theatre production, *No Particular Place to Go,* into an interactive toolkit specifically catered to the needs of dementia caregivers (Step Two and Three). Concerns from both formal and informal caregivers about approaching the topic of driving safety and cessation with individuals with dementia were addressed (Step Four) by holding focus groups and individual interviews with formal and informal caregivers. Themes emerging from these focus groups were then used to create a new viewer guidebook specifically tailored to the expressed needs of dementia caregivers (Step Five). It was hypothesized that both formal and informal caregivers would identify themes specific to the needs of drivers with dementia. These views, however, may differ according to caregiver group (formal vs. informal). It was also expected that the themes generated by formal and informal caregivers would be used incorporated in the final toolkit.

Methods

Participants

A total of 17 caregivers participated in the study; eight self-identified as informal caregivers and nine self-identified as formal caregivers.

Informal Caregivers

Informal caregivers ranged in age from 59 – 84 (M_{age} = 67.75, SD = 9.11) and were primarily female/wives (87.5% and 62.5%, respectively), all of Caucasian race. More than half of participating caregivers were highly educated; 62.5% of the sample holding university or post-graduate degrees. The majority of the participants (75%) acted as informal caregivers for three to six years, spending less than two hours a day on caregiving duties. AD represented their care recipients' most common diagnosis, followed by vascular dementia. One participant cared for a loved one with normal pressure hydrocephalus. All informal caregivers' loved ones had already given up their licenses and were no longer driving. Demographic characteristics of informal caregivers are presented in Table 1.

Formal Caregivers

Formal caregivers ranged in age from 28 - 69 (M_{age} = 54.70, SD = 14.43) and were also primarily female (88.9%) of Caucasian race (77.8%) holding university degrees (55.6%). By profession, participants worked as nurses (44%), occupational therapists (OTs; 33%), or registered care aides (22%); 66.7% of whom were currently employed at the time of the study. The largest proportion of formal caregivers performed their jobs for more than 11 years and reported working approximately seven to ten hours per day. Most (78%) have worked with individuals with all types of dementia, including AD, vascular dementia, frontotemporal dementia, dementia with lewy bodies, mixed dementia, dementia due to Parkinson's, and Korsakoff's Syndrome. Four of the formal caregivers also reported working with individuals with other causes of dementia including Pick's and Creutzfeldt-Jakob Disease. Demographic characteristics for formal caregivers are presented in Table 1.

Table 1. Demographic characteristics of informal and formal caregivers in Study 1.

Characteristic	**Informal Caregivers**	**Formal Caregivers**
Sample size	$N = 8$	$N = 9$
Age		
Mean	67.75	54.70
SD	9.11	14.43
Range	59-84 years	28-69 years
Gender	87.5% Female	88.9% Female
Ethnicity	100% Caucasian	77.8% Caucasian
Born in Canada	87.5%	66.7%
Education		
Post Graduate Degree	37.5%	11.1%
University Degree	25%	55.6%
College Diploma	0%	22.2%
Trade/Technical Certificate	12.5%	11.1%
High School	25%	0%
Grade School	0%	0%
Relationship to Care Recipient	62.5% Wives 25% Daughters 12.5% Sons	44% Nurses 33% OTs 22% Care Aides
Years Caregiving		
< 2 Years	12.5%	11.1%
3-6 Years	75%	22.2%
7-10 Years	12.5%	22.2%
11+ Years	0%	44.4%
Hours per Day Caregiving		
< 2 Hours	52.5%	0%
3-6 Hours	0%	11.1%
7-10 Hours	0%	88.9%
11+ Hours	37.5%	0%
Dementia Type in Care Recipient		78% All Types
AD	50%	
Vascular	37.5%	
Other	12.5%	
Driving Stage of Care Recipient	100% Stopped Driving Completely	77.8% All Stages
Employed	12.5%	66.7%
Volunteer Work	87.5%	55.6%

All caregivers were recruited through various agencies on Vancouver Island and the mainland of British Columbia, including the Alzheimer Society of British Columbia, the Family Caregivers’ Network Society, the Silver Threads Service, the Shoal Centre, the University of Victoria Centre on Aging, community recreational centres, the British Columbia Psychogeriatric Association (BCPGA), and divisions within the Vancouver Island Health Authority (i.e., Home and Community Care, Assisted Living, Residential Services, and

Seniors Health and Seniors Care). Advertisements were circulated at these locations via newsletters, website postings, list-serve emails, and bulletin boards (see Appendix A for advertisement). Convenience and snowball sampling methods were employed.

Procedure

Data Collection

In-person focus groups, telephone focus groups via conference calling, and individual telephone interviews were conducted with informal and formal caregivers to identify their needs and concerns when approaching the topic of driving safety and cessation with their loved ones or patients. Focus groups for informal caregivers were held separately from formal caregivers to create a safe environment where participants could freely express their opinions without potential power-dynamics interfering during group discussions. In-person and telephone focus group size ranged from 2-3 people per group. Participants were initially placed by random in one of two conditions: (1) DVD, or (2) no DVD. Caregivers participating in focus groups as part of the "DVD" condition viewed the DVD with the facilitating researcher and other participants prior to engaging in a facilitated discussion to generate issues specifically relevant to the DVD as well as broader issues related to their needs and concerns. Caregivers in the "DVD" condition who participated in a phone interview were directed to a website where the DVD could be viewed online before engaging in the same discussion. Due to the time demands required of the DVD condition (an extra 50 minutes to watch the DVD), many of the formal caregivers could only participate in the study if placed in the "no DVD" condition. Caregivers who were placed in the "no DVD" condition did not view the DVD to generate topics that were not influenced the content of in *No Particular Place to Go*.

Prior to participating in the study, participants were given either a written consent form to read themselves or verbally read the content of the consent form over the phone (by the moderator) detailing their rights as participants (see Appendices B and C for in-person and over the phone consent forms). All caregivers gave written or verbal consent to participate in the study.

Participants were then asked to complete a demographic questionnaire (see Appendix D) before specific focus group/interview questions were asked. To ensure consistency in approach and data collection, the same moderator (the primary investigator) facilitated each focus group/telephone interview. Questions specific to the "DVD" condition included: (1) "What initial reactions did you have to the DVD?", (2) "Would this DVD be useful for you to use? Why or why not?", (3) "How would you use this DVD?", (4) Can you identify certain places in the DVD that were meaningful to you?", and (5) What additional information would you want to know?". Broader questions included: (1) "Have you had or are you considering having the conversation about driving safety and/or cessation with a loved one/patient? If yes, in general, how did it go? What helped you have this conversation? If not, do you see approaching this topic as part of your role in the future?" What thoughts/feelings did/do you have about having this conversation?", (2) "What challenges do you confront as a caregiver discussing the topic of driving safety with your loved one/patient?", (3) "Have you consulted resources to help you have this conversation? If so, what types? What did you like about these resources? What didn't you like about these resources?", (4) What would be most helpful for you in a resource? Anything specific that I should be including in this toolkit?". The facilitator of the focus groups/telephone interviews used probes when necessary to elicit greater detail from participants without halting the flow of the conversation. Interviews lasted an average of

31 minutes and 22 seconds (range: 14 minutes 45 seconds to 48 minutes 55 seconds, *SD* = 11 minutes 44 seconds), with approximately 20 more minutes to review the consent and demographic forms. Caregivers in the “DVD” condition devoted an additional 50 minutes to watch the DVD.

Each focus group/telephone interview was audio-taped and then transcribed. Participants continued to be enrolled in the study until content saturation (i.e., interviews consistently yielded no new information) had been achieved as outlined by Boychuk, Duchscher, and Mogan (2004).

In lieu of monetary compensation, participants were given a hard copy of the toolkit after it had been completed. The Human Ethics Research Boards at the University of Victoria (#12-081) and the Vancouver Island Health Authority (#H2013-067) approved all methods and procedures described.

Data Analysis

Descriptive statistical analysis of the demographic information was performed using SPSS Version 22 (IBM Corp, 2013). Qualitative data analysis of the focus groups and telephone interviews first required each audio recording to be transcribed. A second research assistant, who was blind to the participants’ identities, then reviewed the audio-recordings and corresponding transcriptions for accuracy.

The focus group and telephone interview transcriptions were analyzed by the primary investigator for relevance, salience, and re-occurrence using an inductive process of “open-coding” (Gerber & Williams, 1996) where broad patterns across the focus groups and telephone interviews were identified and categorized into major themes/content areas. Specific information for each theme/content area was subsequently compiled. A second reviewer, blind to the primary investigator's results, also independently analyzed the transcriptions for themes and specific information pertaining to each theme. The themes/content areas and associated information obtained by the primary investigator and the reviewer were then compared to ensure accuracy of results.

Toolkit Development

In accordance with Step Five of the action cycle of the Knowledge to Action Framework (Graham & Tetroe, 2009), the information generated from the focus groups and phone interviews with informal and formal caregivers, including major theme/content areas and specific details/information within each content area, was assembled into a toolkit. Additional research by the primary investigator was conducted and incorporated into the toolkit to support the information discussed by caregivers, explain findings in further detail, supply additional resources requested by participants, and to verify procedures and policies with individuals from agencies central to the licensing and regulation process in Victoria, British Columbia (e.g., senior policy advisor and manager from the Driver Licensing Policy and Driver Training branch of the Insurance Corporation of British Columbia (ICBC), director of the Medical Fitness and Remedial Programs at the Office of the Superintendent of Motor Vehicles).

Results

Collectively from the focus groups and telephone interviews with informal and formal caregivers, eight major themes emerged: (1) the importance of driving, (2) the assessment process, (3) information about refresher courses and driving schools, (4) risk factors and warning signs, (5) starting the conversation, (6) dealing with resistance, (7) the need for support, and (8) alternative transportation options. In addition, caregivers in the "DVD" condition were able to comment on the applicability of the DVD to their situation and gave suggestions on how the DVD can be incorporated into the toolkit. Several general ideas emerged across caregivers that were not necessarily specific to one of the eight major theme/content areas but were nonetheless important to incorporate into the toolkit (e.g., the complexity of the topic of driving safety and cessation in older adulthood, the fact that each person is unique and what works for one person may not work for another, the idea that driving is a right and not a privilege, inclusion of scenarios to illustrate situations). No major differences between the content discussed by informal dementia caregivers versus formal dementia caregivers were noted, although formal caregivers were able to speak in more detail about the assessment process compared to informal caregivers. Each content area is described below in detail in order of presentation in the toolkit.

Themes/Content Areas

The Importance of Driving

Every caregiver in the study described how important driving is to their loved one or patients. They explained how driving carries with it such personal significance (i.e., power, freedom, independence, respect, status, control, dignity, connection to memories) that talking about driving safety or cessation can be an emotionally charged topic for both drivers and caregivers themselves. Often, the issue of driving and the idea of losing a license is the most important topic facing drivers and caregivers.

> [The conversations about driving] are often linked with strong emotions. And sometimes we come in when their (person with dementia) driver's license has been cancelled or they have got a letter sent off and they know it's coming and it's always the first thing they have on the table to discuss. – Formal caregiver
>
> I would say it's one of the most highly contentious and emotional conversations that we have with people. – Formal caregiver

Many caregivers also discussed gender differences associated with the importance of driving. Specifically, caregivers explained how they felt driving was much more important to men than to women:

> [My husband] never had that kind of car thing that North American men [have]. Their car was a symbol of their masculinity and virility and so on. – Informal caregiver

> For many of the people we worked with the male tended to do the driving as opposed to the spouse. So it was very much tied up with their identity and their attitude and philosophy toward driving and their role. It was much harder for some men [to give up driving]. – Formal caregiver

The Assessment Process

All informal caregivers expressed interest in knowing more about how the formal assessment process works (e.g., who can report unsafe drivers, the steps involved in a formal assessment, who determines whether a license is maintained or revoked and under what circumstances, what happens after a person loses his/her license, legal ramifications of continuing to drive after a license has been revoked). Many informal caregivers were very knowledgeable about this process, but requested that further clarification be included in the toolkit.

> [If you] can pull together information about the legal process…[that would be] useful. – Informal caregiver

All formal caregivers, except one, also mentioned the assessment process during the focus groups and interviews. Many said that assessing a patient’s physical and cognitive status in the context of his/her driving competency was an essential part of their roles as healthcare professionals. They understood the responsibilities of their professions and emphasized that if they felt someone was an unsafe driver then they legally and ethically have to report that person to the Superintendent of Motor Vehicles who then assumes responsibility of the assessment process and decision-making around the granting or revoking of licenses. One formal caregiver specifically requested that a comprehensive list of all the screening measures used to assess these abilities be included in the toolkit.

> There was also the issue of the judiciary and professional responsibility to report concerns observed or assessed during a functional assessment. So you had to have that together first [before reporting]. Was the reason for the concern directly related to their competency as a driver or were there other issues; the cognitive, the physical, the medical? Was there alcohol involved or [were] drugs a factor? – Formal caregiver

Refreshing Skills

Several caregivers commented on how it would be useful to include in the toolkit information on driving schools (e.g., names of businesses, contact information) that offer assessments and refresher courses for older drivers. One informal caregiver specifically suggested how it might be helpful for both a caregiver and person with dementia undergo an assessment and/or driving lessons together so the person with dementia does not feel singled out. This caregiver also highlighted that by completing the assessments/refresher courses together (alternating between “driver” and “passenger” with an instructor present), then a caregiver him or herself can witness how their loved one performed, giving that caregiver more information about their loved one’s driving abilities.

> [Going for a private assessment and lessons] was really valuable. We both went. Well, I’m at an age where so long ago I got my license so it’s good to be caught up. So you do an assessment with the driver, and he makes notes, or the trainer. That indicated a few things about my husband that we both needed to know. If you both did it then no one person would feel like they’re being picked on. – Informal caregiver

Risk Factors and Warning Signs

Many informal and formal caregivers said it would be useful to include in the toolkit information about risk factors for unsafe driving behaviours. Almost all caregivers who desired this information in the toolkit explicitly said this information needs to be presented generally, not in a manner that conveys that having dementia itself results in poor driving abilities so as to stigmatize individuals with dementia. Rather, caregivers explained how it is important to discuss how many factors common in older adulthood can contribute to decreased driving performance including medical conditions, physical limitations, and cognitive problems. They did acknowledge, however, that some background about dementia is needed.

> Just selecting out a specific population [like dementia] can have a real negative effect. We look at all aspects of the driving…what medications the person is on and how they might contribute to difficulties with driving and concentration and alertness. What about [a person's] physical condition, are [they] able to shoulder check. We don't make it totally about the dementia. – Formal caregiver
>
> I think focusing on the medical issues that the person has as opposed to, say, attacking the person themselves was helpful. – Formal caregiver

In addition to risk factors, caregivers also discussed specific examples, or warning signs, that helped them come closer to the decision that their loved ones or patients were no longer safe to drive. Although linked to risk factors, these warning signs were specific incidents that happened on the road that can possibly signal cause for concern (e.g., forgetting routes, not being able to locate the car in a parking lot, unable to provide contact information after an accident, fender-benders when parking).

> My husband, having early onset Alzheimer's, had difficulty with peripheral vision so he couldn't be sure that he would fit into parking spaces and he crunched the fenders of my car several times. – Informal caregiver

Starting the Conversation

Throughout the interviews caregivers discussed issues related to having the conversation with a loved one or patient about their driving. They gave suggestions on what had worked for them in the past, what they wish they would have known in retrospect, and (if applicable) what they learned from the DVD.

Caregivers again commented on how it is helpful for family and healthcare professionals to work together by providing consistent information and, when possible, sitting down with the person with dementia to share their concerns together. Across interviews, caregivers consistently stressed that discussing driving safety and cessation is part of a process and thus it is important to begin having this conversation early and the issue should be revisited often. Caregivers also gave very specific tips for how to start the conversation: choose a specific time to have the conversation and when several family members, friends, or a doctor can be present; remain calm; be respectful, open, and straightforward; collaborate with and involve the person with dementia to provide him/her with a sense of autonomy and decision-making in the process; highlight the things in the person’s life that are working; elicit emotions so feelings around driving cessation can be explored, validated, and processed; present and examine the consequences of continued driving when unsafe by expressing concern for the safety of the person him/herself and others on the road; link concerns to specific examples and assessment results. In addition to these suggestions, many caregivers also wanted specific examples of sentences that can be used as conversation starters to be included in the toolkit. From the DVD group, several caregivers commented how it is unhelpful to approach the conversation using a forceful tone, getting angry, and letting stress show, like the mother, Joanne, displayed in the play.

> It probably took more than one conversation. Most cases it probably took a number of conversations. And getting support from the family, from the doctor, from the geriatric psychiatrist if they’re involved, or home support, or whoever’s involved to try to be alert to the problem, to give them an opportunity to talk about it if that is appropriate. It’s a process. It’s not

> something you can just say, “Ok, now you have to give it up and mail in your license”. – Formal caregiver

Dealing with Resistance

For some informal caregivers, their loved ones voluntarily gave up driving and easily made the transition from being an active driver to a passenger. However, for many of the caregivers who were interviewed, particularly formal caregivers, they discussed encountering difficulties and challenges when concerns arose about their loved ones or patients’ driving. They described how some loved ones or patients denied having any problems that could impact their driving ability. Others described how some individuals with dementia would refuse to follow doctors’ instructions or even orders from the Superintendent to stop driving. Some loved ones or patients, according to caregivers, would become very angry, hostile, and even aggressive when faced with the possibility that their licenses would be taken away.

Caregivers, particularly formal caregivers, described some steps they had taken to deal with resistance. First and foremost, caregivers explained how in these difficult situations, it is especially important for healthcare professionals and family to work together. Then it is important to examine the underlying reasons why a person is resistant to giving up driving. It may be that a person does not have access to alternatives transportation or is worried about not being able to attend social events. In other cases, resistance may be closely tied to a memory deficit where the person with dementia simply forgets that he or she is not supposed to drive. In this situation, one formal caregiver described how placing a large note on the wheel saying, “Do not drive”, prevented the person with dementia from driving. Several informal caregivers explained how they had to sell their loved ones’ cars to remove the physical reminder of driving. In extreme situations, caregivers explained how they sometimes had to (or suggested to family members) disable the car by removing the distributor cap or another vital piece of machinery, immobilize the car by putting The Club on the steering wheel, have new keys made, say the keys are “lost”, or even call the police to report the person if he/she was driving without a license.

> I never did have the situation that I’m certain many people do of having huge resistance and the issue of having to take away the keys. So I can see needing another section on that situation. – Informal caregiver

> Certainly if there was a driver you had grave concerns about or if the family was feeling very concerned about wasn’t compliant you might be able to do things like just [say], “the car keys were just lost” or maybe a family member took them away. Or maybe you might have to do something to disable the car. In some instances we’d have to ask family members to actually remove the car or maybe a car would have to be sold so it wasn’t constantly sitting in the driveway. It is just so dependent on the stage. – Formal caregiver

Support System

All but two caregivers (one informal and one formal) discussed the need for support when confronting the topic of driving safety and cessation with the loved one or patient. Informal caregivers expressed how concerning this topic is for them personally. Many acknowledged feeling of depression, anxiety, stress, and anger as a result of a family member going through the driving cessation process. As much as families want their loved ones to be safe on the road, several caregivers expressed reluctance to act as an intermediary because it may hurt their relationship with their loved one or alter their lifestyle (e.g., taking over driving duties, finding alternatives for themselves if they do not drive). To manage these feelings, informal caregivers reported relying on other family members and friends for emotional support. Several have sought counselling to provide another avenue for emotional support. Informal and formal caregivers also underscored the importance of reaching out to family, friends, and neighbours for practical support (e.g., sharing in providing rides, checking in). If family members or friends do not live nearby and therefore cannot share these responsibilities, caregivers discussed how important it is for these members of the family to still be updated and kept informed about the situation.

> I think we need support so it's not just ourselves that have to do all that.
> – Informal caregiver

> It helped when the family was also worried about the ability to drive and the consequences of driving. That helped a lot. – Informal caregivers

Most importantly, informal caregivers highlighted how essential it is to raise concerns with a family doctor. Many caregivers did not want to be the "bad guys" and felt it was the doctor and Superintendent's duty to help make decisions about when it is time for their loved one to stop driving. Formal caregivers also felt that they, as healthcare professionals, had a responsibility to intervene. To help facilitate the process, they stressed the importance of having family members and other healthcare professionals involved in the patient's care work together as a "team".

> If the family is adamant that things are dangerous then I think the doctors ought to have an obligation to work together, but at least make the report.
>
> – Informal caregiver

> I'd have to say that when we work as a team with the families and physicians it's easier. – Formal caregiver

Alternative Transportation Options

Every caregiver, except one, discussed how important it is to provide information about alternative transportation options so that when a license is taken away another form of transportation can be implemented to ensure mobility is maintained. They suggested including a list of all the alternative transportation options and services (plus contact information) in the community (specifically in Victoria, British Columbia) including taking the bus, using handyDART (a public door-to-door van service for individuals with disabilities), applying for government funded coupons to take taxis, arranging volunteer drivers through community organizations, hiring a private driver, signing up for grocery delivery services, as well as organizing carpools and asking family/friends for rides. Although it may not be feasible for all individuals, several caregivers suggested that a person move closer to services and amenities within walking distance.

It was also raised that many older adults are reluctant to use alternative methods because they believe it will cost more than using their own personal vehicle. To challenge this myth, many formal caregivers suggested including a cost-comparison table in the toolkit that specifically shows the yearly expenses of owning a car (e.g., gas, insurance, depreciation, maintenance) versus taking taxis or using the public transit system.

> A lot of people say, “Oh, but a taxi! I can’t afford that”. Well, you’re running a car, paying for insurance. Those are all the realities too when you really look at expenses. Maybe that’s another [piece to include in the toolkit], how much it costs to run a car as opposed to [alternative methods].
> – Formal caregiver

DVD – Specific Content

Caregivers who watched the DVD all reacted positively to the play. Many expressed how realistic the characters and plotline felt and how they could relate to the story. A few caregivers also said that the DVD provided many teaching and learning moments.

> I thought it was clever and balanced…it portrayed how each of the individuals in the play had their own driving issues, which I think is very true and it’s important for younger generations to pay attention to their own driving. I thought it was respectful. I thought that the old man was portrayed really well; he didn’t come across as a fool. I thought it was realistic and respectful to seniors. – Informal caregiver
>
> The dynamics of the interactions between the family was really realistic. That’s a good way to do it. A lot of people could probably relate to it.
> – Informal caregiver
>
> It was very emotional…all [my] work experience was brought back in my mind. – Formal caregiver

Caregivers commented on how this DVD would be useful for other caregivers and family members to watch. One informal caregiver specifically suggested that the caregiver should watch the DVD first before sharing it with a loved one with dementia to gain a sense of the content. Others added that sharing the DVD with someone with dementia could be useful, but it would be dependent on what stage of the disease process that person was in and in comprehension was still intact. Another caregiver suggested that the DVD be used in a group format at various organizations that provide services to older adults and their caregivers.

With respect to specific suggestions on how the DVD can be included into the toolkit, caregivers proposed that stopping points throughout the DVD can be incorporated so in-depth discussion can occur around important issues (e.g., how to start the conversation, dealing with resistance). They also suggested that follow-up scenarios be added to cater the content more toward individuals with dementia.

Final Toolkit

The final toolkit, called *Down the Road*, incorporated the content and suggestions provided by informal and formal dementia caregivers from the focus groups and interviews, as well as additional information/research gathered by the primary investigator (see Appendix E). *Down the Road*, although developed with dementia caregivers and initially targeted specifically for their use, has a broad focus aimed for all types of caregivers, as requested by the dementia caregivers themselves. It is comprised of the DVD, *No Particular Place to Go,* an accompanying viewer guidebook, and seven rack cards, most of which provide information/resources specific to the city of Victoria, British Columbia.

The viewer guidebook, as caregivers suggested, is formatted around specific scenes related to the eight major theme/content areas that emerged from the focus groups and interviews. For each scene/content area, a description of the scene is given with the place in the DVD where the issue is discussed and caregivers could pause (the applicable scene/stopping point is given in minutes and seconds). Initial questions are then posed to promote more in-depth and critical thinking about that specific scene and issue. Additional questions are also posed under the *Changing the Emphasis* section to give follow-up scenarios catered more toward issues related to dementia, as requested by caregivers. Lastly, each of the eight content areas/scenes contains a section titled, *Background Information*, where detailed, yet generalized, information is provided about each topic. The content in these sections contained information obtained from the focus groups and interviews with dementia caregivers, as well as additional finding from the current research in the field of older driver safety.

Seven rack cards titled, *The Assessment Process, Refresher Skills, Grocery & Meal Delivery, Public & Volunteer Transportation, Private Transportation, Transportation Comparison*, and *Conversation Starters*, were developed to supplement the content in the DVD and viewer guidebook by providing information about procedures and resources specific to Victoria, British Columbia, as requested by caregivers.

Down the Road can be accessed online at http://www.coag.uvic.ca/resources_research_Down-the-Road.html.

Discussion

Following Step One (identify problem), Step Two (identify, review, select knowledge), Step Three (adapting knowledge to the local context), Step Four (assessing barriers to knowledge use), and Step Five (selecting, tailoring, and implementing interventions) of the action cycle of the Knowledge to Action Framework (Graham & Tetroe, 2009), a toolkit for caregivers of older adults about driving safety and cessation was developed using applied theatre as the primary method of disseminating information to this identified group of knowledge users. The final toolkit, *Down the Road,* consists of the applied theatre production (in DVD-format), *No Particular Place to Go*, an accompanying viewer guidebook, and seven informational cards containing resources specific to the city of Victoria, British Columbia. As predicted, informal and formal dementia caregivers identified themes that provided the structure and basis for the content of the toolkit. These eight themes included: (1) The Importance of Driving, (2) The Assessment Process, (3) Refreshing Skills, (4) Risk Factors and Warning Signs, (5) Starting the Conversation, (6) Dealing with Resistance, (7) Support System, and (8) Alternative Transportation Options. These themes, however, did not differ between informal and formal caregivers.

Irrespective of their relationship with their care recipients (informal dementia caregiver vs. formal dementia caregiver), all the caregivers' responses centred on the same eight general themes. Formal caregivers, however, gave more detailed information about the assessment process, likely because in-depth knowledge of this area is required in their professional roles. Informal caregivers' loved ones had all given up driving so these participants could speak retrospectively about their experiences at every stage of the driving cessation process. As a result, the informal caregivers participating in this study were very knowledgeable about how dementia has affected their loved ones' driving abilities and the resources in the community that were available to them. This may have contributed to the similarity in content between both groups.

The knowledge held by the caregivers in this study also explains why theme/content area saturation was obtained with relatively few participants. This, combined with the fact that the topic of driving safety and cessation is one that is very specific and that dementia caregivers represent a specific proportion of the population, decrease the number of individuals needed to achieve the saturation point compared to a study exploring general/ambiguous themes relevant to a broad and varied population.

With respect to the specific content of the toolkit, caregivers requested detailed information about resources in their community. Step Three of the action cycle of the Knowledge to Action Framework (Graham & Tetroe, 2009) also notes that effective KT should be adapted to a local context. As a result, a decision was made on the primary investigator's behalf to focus the information in the rack cards specifically to Victoria, British Columbia, the capital city of the province, to make the toolkit more applicable to residents in that area. Victoria, a city with one of the highest percentages of older adult residents in Canada (Statistics Canada, 2014), is known for the exceptional supports available for seniors, including a multitude of transportation options (Allan & McGee, 2003). The comprehensive list of resources in Victoria that are presented in the toolkit's informational cards, particularly around alternative transportation options, can be used a model for other cities' policy makers and planners who are looking to develop their supports for their older residents.

Keeping in mind that to obtain the greatest impact the toolkit should be easily generalizable to other cities in the future, the content in the viewer guidebook was consciously created with a broad focus (including applicability to caregivers of all types, as well as dementia caregivers) so it can be mass-produced. As a result, future adaptations of *Down the Road* only require that the informational cards be researched, written, and re-printed to fit the needs of the specific city where the toolkit will be used.

It is important to note that although *Down the Road* was developed with dementia caregivers, they suggested to shift the focus of the toolkit on general health conditions that can affect driving in older adulthood rather than specifically targeting dementia to avoid stigmatization of this population. This raised an important dilemma to consider when following KT principles – how to balance focused dissemination of information with knowledge user requests for broader information? The Knowledge to Action Framework (Graham & Tetroe, 2009), among other KT approaches (e.g., CIHR Model of Knowledge Translation, CIHR, 2007; OMRU, Graham & Logan, 2004; PARIHS; Kitson et al., 2008) directs information disseminators to be as targeted and specific as possible in tailoring the KT message, hence the rationale for creating a toolkit specifically for dementia caregivers. Yet, once included in the research process, the participants of this study raised concerns about having the toolkit be too narrowly focused on dementia for fear of possibly increasing stigma associated with this group. To determine how best to approach this dilemma, the core component of integrated KT models was revisited and prioritized – including and incorporating the needs of knowledge users into the research process (CIHR, 2012). As a result, the content of the *Down the Road* was developed to be applicable to all types of caregivers of seniors, rather than focusing solely on dementia caregivers, as requested by the knowledge users participating in this study.

Several resources are currently available to the general caregiver of an older adult about driving safety (e.g., *Aging and Driving Webinar: Making Informed Decisions that Support Independence and Safety* (Griswold Home Care, 2013); *We Need to Talk: Family Conversations with Older Drivers* (Hartford, 2013)), but like the resources for dementia caregivers outlined previously, these guides all disseminate their information in a print-based format. For example, the Hartford group, who also produced *At the Crossroads: Family Conversations about Alzheimer's Disease, Dementia, and Driving* (Hartford, 2010), created a 24-page booklet for general caregivers/family members called *We Need to Talk: Family Conversations with Older Drivers* that outlines many areas relevant to older driver safety and that were also incorporated into *Down the Road*, including information about risk factors and warning signs, tips of how to have the conversation, suggestions on dealing with resistance, a worksheet to help consider alternative transportation options, and a transportation cost worksheet where readers fill in their annual expenses associated with owning a car. Although the information presented in *We Need to Talk* has an "interactive" component in the form of worksheets, this booklet, as well as the other resources available to caregivers of seniors, uses the traditional print-based format causing caregivers to engage in the material more passively than if they lived out the experience through applied theatre. As a result, *Down the Road* still remains the only toolkit available to caregivers that incorporates an applied theatre production that has been shown to promote openness to change driving behaviour compared to reading (Tuokko et al., in press).

It must be acknowledged that although the caregivers in this study were representative of a variety of education levels, number of years spent caregiving, and number of hours per day spent caregiving, there was limited diversity of other sample characteristics (e.g., gender, ethnicity). As a result, generalizability to other demographic groups should be done with caution. Due to time constraints, particularly from formal caregivers, the number of caregivers who watched the DVD compared to those who did not view the DVD was unbalanced. Time constraints, as well as participant burden, also impeded the ability to return to caregivers to present them with a first draft of the toolkit to ensure their needs were incorporated appropriately. However, Study 2 (toolkit evaluation) will assess this area, albeit with a different group of caregivers, comprised of dementia caregivers as well as general caregivers.

In the future, to address generalizability and sustainability, re-conducting focus groups and interviews with individuals who care for older adults with any type of ailment (e.g., ocular problems, cardiovascular problems, pulmonary problems, musculoskeletal problems, general frailty) is required to verify that the material in the toolkit is applicable to all types of caregivers or to modify it to be more applicable to all types of caregivers. Through the KT process of continually receiving and incorporating feedback from knowledge users into the toolkit, it may be necessary to create different versions of the *Down the Road* to fully address each of these specific conditions, in addition to addressing the concerns and needs of other focused audiences, including the type of informal caregiver (e.g., spouse vs. adult child), the specific dementias (e.g., Alzheimer’s Disease vs. Vascular dementia), and differing cultural groups (e.g., Caucasian vs. Hispanic). Although creating different versions of the toolkit for each of these focused audiences would ensure specialization of content, creating multiple versions of the toolkit may limit feasibility and sustainability by drastically increasing production costs, complicating updating procedures, and confusing knowledge users with various copies of the toolkit. Consolidating information into one toolkit while simultaneously addressing the specific needs of various populations within chapters or sub-headings of the toolkit may address this dilemma. The only caveat to this is the creation of different translated versions of the toolkit (with subtitles added to the DVD) to cater to the needs non-English speaking caregivers. Additionally, the DVD itself may limit generalizability if cultural references made in the production (e.g., Canadian Tire, ICBC) prevent other provinces and regions from relating to the material. To determine if this is the case, separate focus groups and interviews should be held with caregivers from different provinces and cities across Canada. These focus groups and interviews will also help adapt and cater the content of the information cards with procedures and resources specific to these cities in order for *Down the Road* to reach a wider audience geographically.

As an increasing number of caregivers are interviewed, it may be expected that some additional topics will need to be incorporated into *Down the Road* to sustain its use. For example, it can be argued that the toolkit in its current form does not address specific contextual factors like how to handle family dynamics, which can lead to resistance. Future versions of the toolkit may require incorporating techniques from certain psychotherapeutic orientations like Motivational Interviewing (e.g., reflective listening, eliciting change talk, decisional balancing/weighing pros and cons, normalizing; Sobell & Sobell, 2008) and Interpersonal Therapy (e.g., communication analysis, role-playing in group settings only; Stuart, 2006) to help caregivers address their unique patterns of interacting with their loved ones. In addition, different versions of the toolkit or additional sections within the current toolkit may be needed to address the specific stage along the driving cessation process within which the care recipient currently is situated (e.g., pre-contemplation, contemplation, preparation; Prochaska & DiClemente, 1982) to offer specific suggestions that are appropriate to each stage of change (i.e., using motivational interviewing techniques with individuals in the pre-contemplation stage). A section specifically addressing the issues relevant to care recipients with dementia may also need to be added, while being mindful of dementia caregivers requests to not stigmatize this population. Currently, the “Risk Factors and Warning Signs” section introduces the topic of dementia, but more detailed information may be needed to address issues specific to this population (e.g., how to approach someone with anosagnosia, detailed psychoeducation about the symptoms of the various types of dementia and how they compromise driving behaviours). To determine how best to incorporate these topics into the toolkit, it is necessary to re-visit Steps One though Five of the Knowledge to Action Framework (Graham and Tetroe, 2009) by following the guidance of the knowledge users in making revisions and adding sections to the toolkit.

When using KT approaches to guide the research process, it is important to address each step outlined by the governing models, in this case, the eight steps of the Knowledge to Action Framework (Graham and Tetroe, 2009). Study 1 followed Step One through Step Five of the Knowledge to Action Framework to develop a toolkit for caregivers of older adults, including dementia caregivers, to help them navigate their concerns about their loved ones’ driving. Within these first five steps, challenges and dilemmas characteristic of KT work emerged and were addressed by weighing knowledge user benefit with model adherence. Study 2 will address Steps Six and Seven of this framework (Step Eight is beyond the scope of this dissertation). As alluded to previously, in order for *Down the Road* to be generalized to the needs of intended knowledge users and sustained in the long-term, it will be important in future research to revisit and administer Steps One through Five, in addition to Steps Six and Seven, each time a new context is introduced for Step Eight (sustain knowledge use) to be achieved.

Chapter 3

Study 2: Toolkit Evaluation

Introduction

In Study 1, a toolkit was created based around the applied theatre production, *No Particular Place to Go,* as a new and interactive method for caregivers to learn about issues surrounding older driver safety. Following Steps One through Five outlined by the action cycle in the Knowledge Translation model, the Knowledge to Action Framework (Graham & Tetroe, 2009), dementia caregivers' needs were assessed and their suggestions incorporated into this toolkit. The final product, *Down the Road: An Interactive Toolkit for Caregivers about Driving*, consists of the *No Particular Place to Go* DVD, an accompanying guidebook to prompt discussion and provide background information, and informational cards with resources specific to Victoria, British Columbia. Although *Down the Road* was developed with dementia caregivers and therefore contains some elements specific to dementia caregivers' needs, its content is also broad in nature to appeal to the "general" caregiver.

Specific aims of Study 2 are to follow Steps Six and Seven of the Knowledge to Action Framework action cycle (monitor knowledge use and evaluate outcomes; Graham & Tetroe, 2009) to evaluate the effectiveness (via self-efficacy) and user satisfaction of the *Down the Road* toolkit using a pre-post design. Many of the toolkits currently available to caregivers about driving (e.g., *The Driving and Dementia Toolkit*, *At the Crossroads*) focus on knowledge gained, self-efficacy or confidence, and user satisfaction as measures of the toolkit's effectiveness with this population (Byszewski et al., 2003; Stern et al., 2008).

For example, Byszewksi et al. (2003) examined the knowledge and confidence gained, as well as usefulness/satisfaction with *The Driving and Dementia Toolkit* in physicians practicing in the Ottawa region by mailing them each a packet, allowing them complete a pre-test questionnaire, review the toolkit, and then complete a post-test questionnaire on their own time. Items on the questionnaires were created specifically for this study based on content of the toolkit and included items assessing knowledge gained (multiple choice and true/false answers to knowledge-based questions, e.g., “Driving too quickly is not a typical error in drivers with dementia”, “Patients deemed unsafe to drive can often pass standard driving tests”), confidence gained (responses on a 5-point Likert scale from “1” = Not Very Confident to “5” = Very Confident; e.g., “Ability to assess driving risk of patients with cognitive loss”, “Ability to discuss compensatory driving strategies with patients and caregivers”), and usefulness/satisfaction with the toolkit (responses on a 10-point Likert scale with “1” representing the lowest score and “10” representing the highest score; e.g., “The toolkit provided new information to me”, “I would recommend the toolkit to other physicians”). The results showed significant increases in physician knowledge and confidence, as well as high satisfaction with the toolkit.

Stern et al.’s (2008) evaluation of their caregiver toolkit about driving, *At the Crossroads*, also examined self-efficacy, as well as five other dimensions related to caregivers’ experiences in the driving decision with loved ones (e.g., coping, stages of change - preparation, concern about the relationship when discussing driving issues with a loved one, communication about driving with a loved one, awareness and use of a key component of the toolkit, the “Agreement with my Family about Driving”). Self-efficacy was measured pre- and post-toolkit exposure (reviewed over the course of four 2-hour group-format sessions) using the 7-item Driving-Related Self-Efficacy Questionnaire (DRSEQ), which asked about caregivers’ ability to handle driving-related issues with their loved ones. Items like “How certain are you right now that you can recognize early warning signs of driving problem in your loved one?" and "How certain right now are you that you can take care of the transportation needs of your loved one?" were rated on a 10-point Likert scale from "1" = Not Certain at All to "10" = Very Certain. This questionnaire, developed for this specific study, was modeled on Fortinsky, Kercher, and Burant's (2002) Self-Efficacy Questionnaire. It was observed that caregivers' self-efficacy in handling driving-related issues with their care recipients increased significantly after they attended the *At the Crossroads* workshop. Compared to participants who only reviewed a written copy of *At the Crossroads* and participants in a control group, caregivers who attended the group workshop had higher self-efficacy scores, suggesting that *At the Crossroads* is most effective when used in a group-format.

Based on the evaluation methods used in previous studies, Study 2 of this dissertation evaluated *Down the Road* for its effectiveness via self-efficacy and user satisfaction in caregivers (formal vs. informal caregivers, as well as informal dementia vs. informal non-dementia caregivers) attending an interactive group presentation of the toolkit. Participant selection was not limited only to dementia caregivers, as in Study 1, but open to all types of caregivers of older adults to examine the toolkit's broad appeal and effectiveness. Ultimately, it was expected that all types of caregivers' (formal vs. informal and informal dementia vs. informal non-dementia caregivers') self-efficacy in handling issues related to driving safety and cessation with their loved one/patients would increase. In addition, it was expected that caregivers would receive the toolkit favourably and recognize it as one source of information available to them. No major differences between caregiver groups were expected as the content of the toolkit, although geared for informal dementia caregivers, provides information that may equally benefit non-dementia caregivers, as well as formal caregivers.

Methods

Participants

In total, 70 caregivers participated in Study 2; 31 self-identified as informal caregivers (13 self-identified as dementia caregivers), 39 self-identified as formal caregivers (all endorsed having cared for patient/s with dementia). Eight of the participants self-identified as both informal and formal caregivers and were later categorized as either an “informal” or “formal” caregiver depending on which session they attended (e.g., an informal/formal caregiver attending a session geared for formal caregivers was placed in the “formal caregiver” category).

Contacts from the recruitment efforts in Study 1 were used to set up three different toolkit evaluation sessions, one at the British Columbia Psychogeriatric Association’s (BCPGA) 18th annual conference in Vancouver, British Columbia, another as part of a continuing education workshop for home support staff at Beacon Community Services in Victoria, British Columbia, and the third at the Support Our Seniors Advocacy Group’s monthly meeting in Courtenay, British Columbia. Attendees of the BCPGA conference and Beacon Community Services workshop were largely comprised of multi-disciplinary healthcare professionals (e.g., nurses, occupational/physio therapists, nurses, physicians, case managers) working in the field of mental health and older adults. “Other” health care professionals self-identified as Alzheimer Society of British Columbia staff, registered care aides, geriatric mental health workers, and support and education workers. Individuals who attended the Support Our Seniors meeting were primarily family members or friends of seniors who reside in facilities or who have a vested interest in the welfare of their older adult loved ones. Participants from the sessions at the BCPGA conference and Beacon Community Services workshop were anticipated to be formal caregivers, while participants in the Support Our Seniors meeting were anticipated to be informal caregivers.

Informal Caregivers

Informal caregivers ranged in age from 54 – 85 years (M_{age} = 69, SD = 8.17) and were primarily female (80.6%) (daughters and wives; 39.3%, and 25%, respectively), all of Caucasian race. Thirteen of these participants (43.3%) identified as dementia caregivers. Table 2 provides a summary of other demographic characteristics.

Formal Caregivers

Formal caregivers ranged in age from 25 – 70 years (M_{age} = 49.10, SD = 11.12) and were predominately female (94.9%) of Caucasian race (79.5%). All formal caregivers had experience caring for individuals with dementia. Table 2 provides a summary of other demographic characteristics.

Table 2. Demographic characteristics of informal and formal caregivers in Study 2.

Characteristic	**Informal Caregivers**	**Formal Caregivers**
Sample size	*N* = 31	*N* = 39
Age		
Mean	69.00 years	49.10 years
SD	8.17 years	11.12 years
Range	54-85 years	25-70 years
Gender	80.6% Female	94.9% Female
Ethnicity	100% Caucasian	79.5% Caucasian
Born in Canada	80.6%	74.4%
Education		
Post Graduate Degree	26.7%	35.9%
University Degree	16.7%	43.6%
College Diploma	13.3%	17.9%
Trade/Technical Certificate	13.3%	2.6%
High School	26.7%	0%
Grade School	3.3%	0%
Relationship to Care Recipient	25% Wives 10.7% Husbands 39.3% Daughters 7.1% Sons 10.7% Friends 3.6% Neighbours	28.4% Nurses 12.9% OTs/PTs 5.1% Physicians 5.2% Managers 18.1% Other
Years Caregiving		
< 2 Years	45.2%	10.5%
3-6 Years	35.5%	13.2%
7-10 Years	64%	23.7%
11+ Years	12.9%	52.6%
Hours per Day Caregiving		
< 2 Hours	67.7%	15.8%
3-6 Hours	12.9%	15.8%
7-10 Hours	6.4%	68.5%
10+ Hours	12.9%	0%
Care for a person/s with dementia?	43.3% Yes	100% Yes
AD	38.5%	97.4%
Vascular	46.2%	92.1%
Frontotemporal	0%	81.6%
Lewy Bodies	0%	86.8%
Mixed	0%	94.7%
Due to Parkinson's	15.4%	86.8%
Due to Korsakoff's	0%	68.4%
Other	0%	13.2%
Driving Stage of Care Recipient	10.7% Not Considering 7.1% Consider Stopping 35.7% Begin/Actively Limiting 46.4% Stopped	80.6% All Stages
Employment Status	22.6% Yes	97.4% Yes
Volunteer Work	70% Yes	28.2% Yes

Comparison of Informal (All Types) and Formal Caregivers

The informal and formal caregiver groups did not differ with respect to gender and country of birth (Canada). The groups did differ from each other on several other variables: age (t(67) = .8.24, $p < .01$), ethnicity ($\chi^2(1, N = 70) = 7.18, p < .03$), education ($\chi^2(1, N = 69) = 18.95, p = .00$), relation to care recipient ($\chi^2(1, N = 60) = 56.99, p < .01$), time spent caregiving in number of years ($\chi^2(1, N = 69) = 25.01, p < .01$) and in hours per day ($\chi^2(1, N = 69) = 44.31, p < .01$), whether or not participants cared for someone with dementia ($\chi^2(1, N = 69) = 29.33, p < .01$), stage of the driving cessation process encountered ($\chi^2(1, N = 59) = 39.70, p < .01$), employment status ($\chi^2(1, N = 70) = 42.15, p < .01$), and volunteer work status ($\chi^2(1, N = 69) = 11.91, p < .01$).

Comparison of Informal Dementia and Informal Non-Dementia Caregivers

Informal dementia and informal non-dementia caregiver groups did not differ with respect to any of the demographic variables examined: age, gender, ethnicity, education, country of birth (Canada), employment status, volunteer work status, relationship to care recipient, time spent caregiving in number of years and hours per day, and stage of the driving cessation process encountered.

Comparison of Informal Dementia and Formal Dementia Caregivers

Given that no demographic differences were found between the informal dementia and informal non-dementia caregivers (who collectively comprised the informal caregiver (all types) group), it can then be deduced that the demographic differences between informal dementia caregivers and formal dementia caregivers replicate the same differences found in the informal caregiver (all types) group compared to formal caregivers (described above).

Procedure

Protocol

The three toolkit evaluation sessions were conducted in an interactive presentation format using a pre-post design to collect questionnaire responses concerning caregivers' self-efficacy in handling driving-related issues with their loved one/patients, as well as a final user satisfaction survey. After welcoming participants/audience members to the sessions, they were each given an envelope containing a copy of the *Down the Road* toolkit as well as color-coded (pre-test, post-test) questionnaires (see section below for detailed information about the questionnaires), two copies of the consent form (one to sign and one to keep for their records), and a demographic questionnaire. Audience members were given approximately 10 to 15 minutes to complete the first set of forms (consent form, demographic form, and pre-test questionnaire). All participating caregivers reviewed and signed the consent form, agreeing to voluntarily partake in this study (see Appendix F for a copy of the consent form). Upon completing these forms, caregivers could peruse the contents of the toolkit.

Background information about the development of *Down the Road* was then presented, in addition to a brief introduction to the *No Particular Place to Go* DVD, as summarized in the "About *Down the Road*" section of the toolkit. It was emphasized that the viewer guidebook contains general information, whereas the supplemental cards contain information specific to resources in Victoria, British Columbia, although the content of the cards can be altered to contain resources specific to other cities like Vancouver, Courtenay, or anywhere else in North America.

Due to time constraints, only portions of the DVD and toolkit were reviewed. The first 21 minutes of the 50-minute DVD and three of the eight sections in *Down the Road* (the "Importance of Driving", "The Assessment Process", and the "Risk Factors & Warning

Signs" sections) were chosen as these sections fall within the first half of the toolkit, addressed content contained in the pre-post questionnaires, and were identified as particularly important to discuss by caregivers from Study 1. Additionally, the first half of the DVD/toolkit was shown and reviewed with audience members to provide them with an uninterrupted introduction to the toolkit which is reminiscent of how it is to be used in the full-length facilitator-led sessions, as well as to leave audience members with a desire to finish reviewing the toolkit on their own time after the research session. The *No Particular Place to Go* DVD was shown and paused at each of the three sections. At each pausing point, the questions from each presented section of the viewer guidebook were read to the audience with one specifically posed for discussion (i.e., "How do emotional ties to driving impact the driving cessation process?", "Who do you feel is responsible to intervene when there is a question of driver safety?", "What are the risk factors associated with unsafe driving"). Audience members were invited to share their thoughts about these topics. The principal investigator facilitated the sessions and validated audience members' comments during the discussions, linked comments to the DVD and to the content in the "Background Information" sections, added any other information presented in the "Background Information" sections of the toolkit that was not specifically addressed by caregivers, and reviewed the content of the informational cards as appropriate. Audience members' attention was also drawn to the "Changing the Emphasis" section as another means of promoting discussion around the topics.

After reviewing the three selected segments in *Down the Road*, participants were given a summary of the other five sections of the toolkit. Caregivers were then asked to complete the post-test self-efficacy questionnaire, as well as the user satisfaction survey.

Caregivers were compensated for their participation with a hard-copy of the toolkit. The Human Ethics Research Boards at the University of Victoria (#12-081) and the Vancouver Island Health Authority (#H2013-067) approved all methods and procedures described.

Questionnaires

Participating caregivers completed the same demographic questionnaire that was administered in Study 1, with only slight wording changes to accommodate all types of caregivers (see Appendix G). The seven-item DRSEQ, developed by Stern and his colleagues (2008), was used pre- and post-toolkit review to determine if caregivers' self-efficacy in handling issues associated with driving safety and cessation with their loved ones/patients increased after exposure to *Down the Road*. This scale asks about caregivers' self-efficacy regarding the ability to handle problems about issues related to the care recipient's driving cessation. Caregivers rate their responses on a 10-point Likert scale from 1 ("Not Certain at All") to 10 ("Completely Certain"). Sample items include: "How certain are you right now that you can recognize the early warning signs of driving problems in your loved one/patient?" and "How certain are you right now that you can take care of the transportation needs of your loved one/patient?" (see Appendix H & I). The DRSEQ was slightly modified to include the term, "patient", in addition to the original term, "loved one", to ensure the questionnaire was appropriate for formal caregivers in addition to informal caregivers.

After reviewing the toolkit, participants also completed a 14-item user satisfaction survey examining participants' views of the overall toolkit (e.g., "This toolkit is a good source of information", "Overall, this toolkit is useful"), components of the toolkit (e.g., "I found the DVD useful", "I found the viewer guidebook easy to use", "I found the discussions useful"), specific sections presented (e.g., The “Importance of Driving” section/discussion helped me understand the emotional aspects tied to driving and how they might affect older adults”), and future use (e.g., “I will use this toolkit again”, “I would recommend this toolkit to others” (see Appendix I, backside).

Data Analysis

DRSEQ

Paired-sample t-tests were used to separately compare informal (all types) and formal caregivers’ mean responses on each item of the DRSEQ to examine if exposure to the toolkit increased caregivers’ self-efficacy in handling driving issues with either their loved ones or patients. A 2 x 2 Repeated Measures Analysis of Variance (RM-ANOVA) was used to examine mean comparisons between informal and formal caregivers’ responses on each item of the DRESQ to determine if self-efficacy after exposure to the toolkit differed by caregiver type. No demographic variables were controlled as the differences between the two groups, aside from ethnicity, are inherently characteristic of the samples. Specifically, by definition, informal and formal caregivers differ in relationship to their care recipients. It is expected that, overall, formal caregivers, given the training involved in becoming a healthcare professional, have more education than informal caregivers. It is also expected that informal and formal caregivers differ in the number of years and hours spent per day caregiving given the nature of the job (e.g., healthcare professionals act as formal caregivers for a career and typically work full-time). These differences, which are based on the relationship to the care recipient, also account for the discrepancies between employment and volunteer work status between informal and formal caregivers. That is, formal caregivers are expected to be employed full-time, allowing little extra time to be used for volunteering, whereas informal caregivers (who were predominately over the typical retirement age) were expected to be unemployed, allowing more time for volunteer activities. This also explains why informal caregivers were older than formal caregivers. Additionally, caregiver type explains the differences between the two groups in relation to dementia status of the care recipient as formal caregivers see a number of clients and presentations in their work, whereas informal caregivers each reported caring for only one family member, friend, or neighbour. Similarly, the stage encountered along the driving cessation continuum differed between informal and formal caregivers because informal caregivers, who only reported caring for one older adult, reported the single specific driving stage of that individual, whereas healthcare professionals were more likely to have encountered patients at all different stages in the driving cessation process. With respect to ethnicity, although there were more Asian participants in the formal caregiver condition, the groups did not differ on their birthplace (Canada), which represents a more meaningful marker of culture (e.g., grew up with Canadian values, are part of the Canadian healthcare system) than racial make-up alone.

A second 2 x 2 RM-ANOVA was conducted to examine mean comparisons between informal non-dementia caregivers and informal dementia caregivers responses on each item of the DRESQ to determine if self-efficacy after reviewing the toolkit differed by the specific type of informal caregiver (general caregivers vs. dementia caregivers). No demographic variables were controlled as the two groups did not differ on any of the variables. Analysis between non-dementia and dementia caregiver status in relation to responses on the DRSEQ in formal caregivers was not needed as all healthcare professionals were both non-dementia and dementia caregivers.

A last RM-ANOVA was conducted for exploratory purposes to examine, within dementia caregivers, if there were any differences between informal and formal caregivers' responses on the DRSEQ. Again, no demographic variables were controlled as the differences between the two groups, aside from ethnicity, are inherently characteristic of the samples (explained in detail above).

User Satisfaction Survey

Informal and formal caregivers' separate mean responses on the individual items on the User Satisfaction survey were examined using percentages, as not enough responses per cell along the Likert scale were obtained to employ Chi-square tests. Mean comparisons on each item of the User Satisfaction survey were conducted between (1) informal (all types) and formal caregivers, (2) informal non-dementia and informal dementia caregivers, and (3) informal dementia and formal dementia caregivers using Independent samples t-tests.

All analyses were conducted using SPSS Version 22 (IBM Corp, 2013).

Results

Changes in Self-Efficacy in Handing Driving-Related Issues after Toolkit Exposure: Responses on the DRESQ

Informal Caregivers (All Types)

Paired sample t-tests were used to determine if informal caregivers' responses on the DRSEQ changed after reviewing the toolkit. Informal caregivers' scores on every item of the DRSEQ significantly increased from pre-test to post-test, except for item #1. That is, after reviewing the toolkit, informal caregivers reported feeling more confident in knowing their loved ones are safe driving ($t(28) = -3.97$, $p < .01$), recognizing early warning signs of driving problems in their loved ones ($t(30) = -3.91$, $p < .01$), monitoring their loved ones for changes in frequency of warning signs of their driving (t(30) = -5.02, $p < .01$), initiating conversations about driving and transporting needs with their loved ones (t(30) = -3.96, $p < .01$), asking outside professionals questions about driving safety (t(30) = -2.72, $p < .01$), and getting information about driving evaluation services in their city or region (t(30) = -3.35, $p < .01$). See Table 3 for a summary of these the results.

Table 3. Pre-post comparison scores on the Driving-Related Self-Efficacy Questionnaire for informal caregivers (all types) only.

	Pre-test		**Post-Test**				
DRSES Items	*Mean*[†]	*SD*	*Mean*[†]	*SD*	*t*	*df*	*d*
1.) Take care of the transportation needs of your loved one?	6.83	3.40	7.70	2.45	-1.59^{ns}	29	.30
2.) Be confident that your loved one is safe driving?	5.17	3.08	7.00	2.27	-3.97**	28	.68
3.) Recognize early warning signs of driving problems in your loved one?	5.68	2.40	7.58	1.96	-3.91**	30	.87
4.) Monitor your loved one for changes in frequency of warning signs in his/her driving?	5.23	2.59	7.35	2.18	-5.02**	30	.89
5.) Initiate conversations about driving and transportation needs with your loved one?	5.29	3.33	7.58	1.80	-3.96**	30	.86
6.) Ask outside professionals questions about driving safety?	7.06	2.86	8.32	1.72	-2.72**	30	.53
7.) Get information about driving evaluation services in your city or region?	7.03	3.05	8.77	1.50	-3.35**	30	.72

[†] 1 = “Not Certain at All” 5 = “Completely Certain”; ns = not significant, ** $p \leq .01$

Formal Caregivers

Paired sample t-tests were also used to determine if formal caregivers’ responses on the DRSEQ changed after reviewing the toolkit. Like informal caregivers’ scores, formal caregivers’ scores on every item of the DRSEQ significantly increased from pre-test to post-test, such that formal caregivers reported feeling more confident in taking care of the transportation needs of their patients (t(37) = -5.70, $p < .01$), knowing their patients are safe driving (t(36) = -5.43, $p < .01$), recognizing early warning signs of driving problems in their patients (t(38) = -4.05, $p < .01$), monitoring their patients for changes in frequency of warning signs of their driving (t(38) = -5.12, $p < .01$), initiating conversations about driving and transporting needs with their patients (t(38) = -3.50, $p < .01$), asking outside professionals questions about driving safety (t(38) = -2.06, $p < .05$), and getting information about driving evaluation services in their city or region (t(38) = -2.56, $p < .05$). See Table 3 for a summary of these the results.

Table 4. Pre-post comparison scores on the Driving-Related Self-Efficacy Questionnaire for formal caregivers only.

	Pre-test		**Post-Test**				
DRSES Items	*Mean*†	*SD*	*Mean*†	*SD*	*t*	*df*	*d*
1.) Take care of the transportation needs of your patient?	5.70	2.45	7.16	2.02	-5.70**	36	.65
2.) Be confident that your patient is safe driving?	5.45	2.51	7.08	1.85	-5.43**	37	.74
3.) Recognize early warning signs of driving problems in your patient?	6.97	2.28	8.28	1.43	-4.05**	38	.69
4.) Monitor your patient for changes in frequency of warning signs in his/her driving?	5.97	2.70	7.77	2.07	-5.12**	38	.75
5.) Initiate conversations about driving and transportation needs with your patient?	7.38	2.34	8.28	1.59	-3.50**	38	.45
6.) Ask outside professionals questions about driving safety?	7.64	2.48	8.36	1.61	-2.06*	38	.34
7.) Get information about driving evaluation services in your city or region?	7.62	2.32	8.26	2.02	-2.56*	38	.30

† 1 = “Not Certain at All” 10 = “Completely Certain”; * = $p \leq .05$, ** $p \leq .01$

Informal (All Types) vs. Formal Caregivers

2 x 2 RM-ANOVAs were used to examine mean comparisons between informal (all types) and formal caregivers’ responses for each of the seven items on the DRSEQ (see Table 5). For each item, there was a significant main effect for Time (DRSEQ Q. 1: F(1, 65) = 16.81, $p < .01$; DRSEQ Q. 2: F(1, 65) = 42.79, $p < .01$; DRSEQ Q. 3: F(1, 68) = 32.29, $p < .01$; DRSEQ Q. 4: F(1, 68) = 51.69, $p < .01$; DRSEQ Q. 5: F(1, 68) = 29.25, $p < .01$; DRSEQ Q. 6: F(1, 68) = 12.14, $p < .01$; DRSEQ Q. 7: F(1, 68) = 19.34, $p < .01$, see Figures 5 - 11), such that informal and formal caregivers’ responses on the DRESQ increased from pre-test to post-test. Significant main effects for Group (informal vs. formal caregivers) were

only noted for two items (DRSEQ Q. 3 and DRSEQ Q. 5), such that formal caregivers' responses on Q. 3 and Q. 5 of the DRSEQ were significantly higher than those of informal caregivers (F(1, 68) = 6.24, $p < .05$ and F(1, 68) = 8.68, $p < .01$, respectively; see Figures 7 and 9, respectively). Significant interaction effects were seen on Q. 5 and Q. 7 of the DRSEQ (F(1, 68) = 5.59, $p < .05$ and F(1, 68) = 4.13, $p < .05$, respectively), such that informal caregivers' confidence in being able to initiate conversations about driving and transportation needs with their loved ones (Q. 5) and get information about driving evaluation services in their city or region (Q. 7) increased more from pre-test to post-test compared to formal caregivers, whose confidence in handling these topics also increased, just not as dramatically (see Figures 9 and 11).

Table 5. Pre-post comparison scores on the DRSEQ for informal (all types) vs. formal caregivers.

Source	*df*	*SS*	*MS*	*F*	*Eta*^{2}
DRSES Q. 1: Take care of the transportation needs of your loved one/patient?					
Between Subjects					
Caregiver Group	1	23.06	23.06	2.15^{ns}	
Error	65	697.90	10.74		
Within-Subjects					
Time	1	44.82	44.82	16.81**	.20
Time x Group	1	2.91	2.91	1.09^{ns}	
Error	65	173.33	2.67		
DRSES Q. 2: Be confident that your loved one/patient is safe driving?					
Between Subjects					
Caregiver Group	1	1.03	1.03	.12^{ns}	
Error	65	620.81	9.55		
Within-Subjects					
Time	1	98.41	98.41	42.79**	.40
Time x Group	1	.32	.32	.14^{ns}	
Error	65	149.49	2.30		
DRSES Q. 3: Recognize early warning signs of driving problems in your loved one/patient?					
Between Subjects					
Caregiver Group	1	34.49	34.49	6.24*	.08
Error	68	375.69	5.53		
Within-Subjects					
Time	1	89.03	89.03	32.29**	.32
Time x Group	1	3.06	3.06	1.11^{ns}	
Error	68	187.51	2.76		
DRSES Q. 4: Monitor your patient for changes in frequency of warning signs in his/her driving?					
Between Subjects					
Caregiver Group	1	11.68	11.68	1.30^{ns}	
Error	68	609.49	8.96		
Within-Subjects					
Time	1	132.96	132.96	51.69**	.43
Time x Group	1	.96	.96	.36^{ns}	
Error	68	174.92	2.57		

DRSES Q. 5: Initiate conversations about driving and transportation needs with your loved one/patient?					
Between Subjects					
Caregiver Group	1	67.50	67.50	8.68**	.11
Error	68	529.08	7.78		
Within-Subjects					
Time	1	87.75	87.75	29.25**	.28
Time x Group	1	16.75	16.75	5.59*	.05
Error	68	204.00	3.00		
DRSES Q. 6: Ask outside professionals questions about driving safety?					
Between Subjects					
Caregiver Group	1	3.24	3.24	.46^{ns}	
Error	68	477.68	7.03		
Within-Subjects					
Time	1	33.72	33.72	12.14**	.15
Time x Group	1	2.52	2.52	.91^{ns}	
Error	68	188.92	2.78		
DRSES Q. 7: Get information about driving evaluation services in your city or region?					
Between Subjects					
Caregiver Group	1	.04	.04	.01^{ns}	
Error	68	534.60	7.86		
Within-Subjects					
Time	1	49.04	49.04	19.34**	.21
Time x Group	1	10.47	10.47	4.13*	.05
Error	68	172.46	2.54		

ns = not significant, * = $p \le .05$, ** $p \le .01$

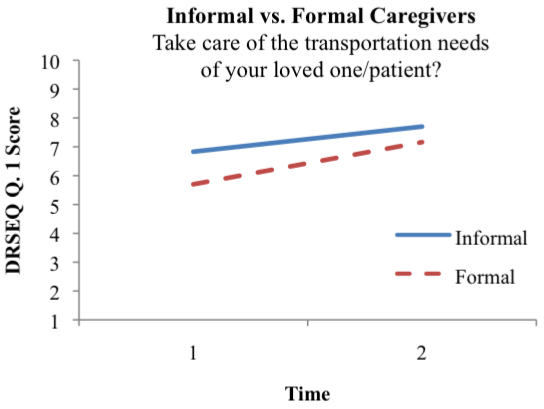


Figure 5. Informal and formal caregivers' responses on the DRSEQ Q. 1

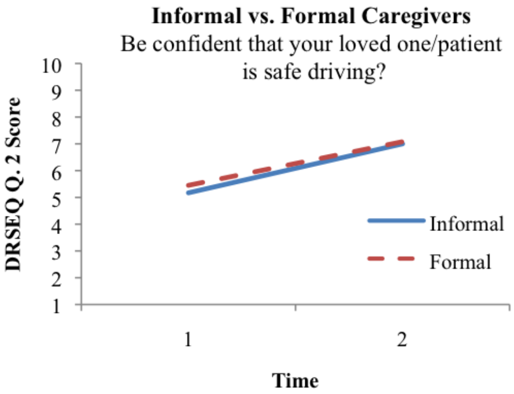


Figure 6. Informal and formal caregivers' responses on the DRSEQ Q. 2.

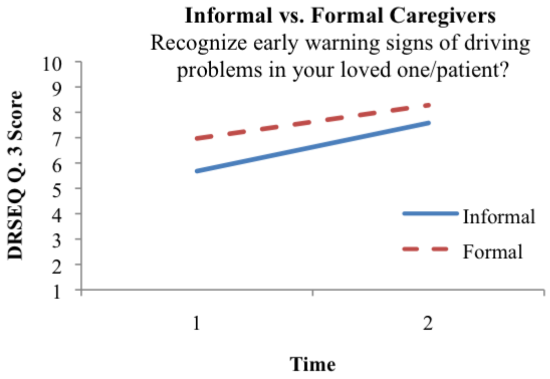


Figure 7. Informal and formal caregivers' responses on the DRSEQ Q. 3.

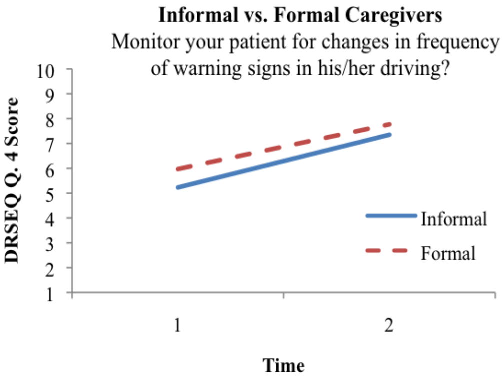


Figure 8. Informal and formal caregivers' Responses on the DRSEQ Q. 4.

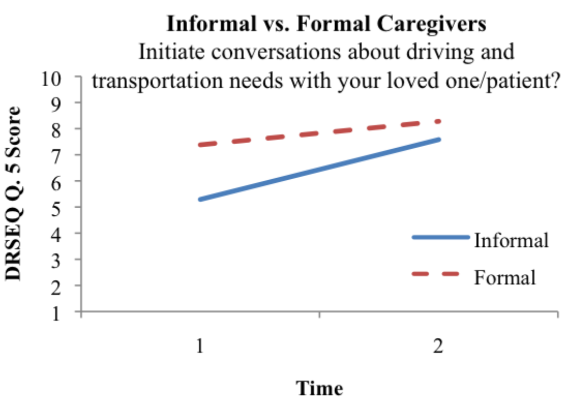


Figure 9. Informal and formal caregivers' responses on the DRSEQ Q. 5.

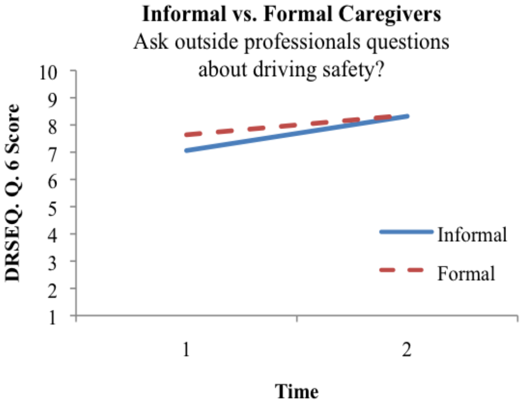


Figure 10. Informal and formal caregivers' responses on the DRSEQ Q. 6.

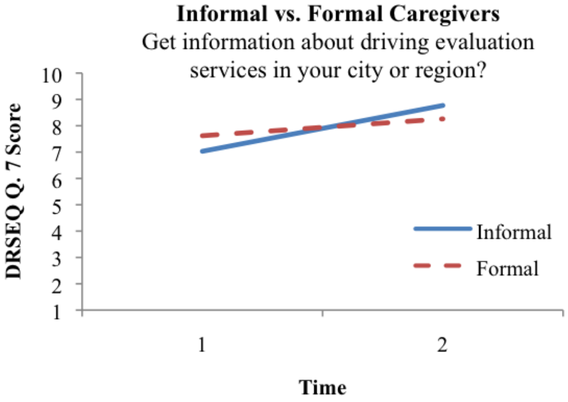


Figure 11. Informal and formal caregivers' responses on the DRSEQ Q. 7.

Informal Non-Dementia Caregivers vs. Informal Dementia Caregivers

To examine whether the toolkit's effectiveness (i.e., increased self-efficacy) differed between general (non-dementia) caregivers and dementia caregivers, 2 x 2 RM-ANOVAs were used to examine mean comparisons between informal non-dementia and dementia caregivers' responses for each of the seven items on the DRSEQ (see Table 6). For each item except Q.1, there was a significant main effect for Time (DRSEQ Q. 2: F(1, 26) = 16.81, $p < .01$; DRSEQ Q. 3: F(1, 28) = 16.55, $p < .01$; DRSEQ Q. 4: F(1, 28) = 24.38, $p < .01$; DRSEQ Q. 5: F(1, 28) = 17.94, $p < .01$; DRSEQ Q. 6: F(1, 28) = 8.76, $p < .01$; DRSEQ Q. 7: F(1, 28) = 12.70, *p* < .01, see Figures 13 - 18), such that informal non-dementia and dementia caregivers' responses on the DRESQ increased from pre-test to post-test. A significant main effect for Dementia Status of the care recipient only emerged on the DRSEQ Q. 2 (F(1, 26) = 4.18, *p* < .05), where informal non-dementia caregivers reported that they were more confident that their loved one was safe driving at pre- and post-test than informal dementia caregivers (see Figure 13). No interaction effects were noted.

Table 6. Pre-post comparison scores on the DRSEQ for informal non-dementia vs. dementia caregivers

Source	*df*	*SS*	*MS*	*F*	*Eta*^{2}
DRSES Q. 1: Take care of the transportation needs of your loved one/patient?					
Between Subjects					
Dementia Status	1	.56	.56	$.04^{ns}$	
Error	27	375.03	13.89		
Within-Subjects					
Time	1	14.35	14.35	3.18^{ns}	
Time x Group	1	.00	.00	$.00^{ns}$	
Error	27	122.00	4.52		
DRSES Q. 2: Be confident that your loved one/patient is safe driving?					
Between Subjects					
Dementia Status	1	43.01	43.01	4.18*	.14
Error	26	267.21	10.28		
Within-Subjects					
Time		52.60	52.60	16.81**	.40
Time x Group	1	.60	.60	$.19^{ns}$	
Error	26	81.33	3.13		
DRSES Q. 3: Recognize early warning signs of driving problems in your loved one/patient?					
Between Subjects					
Dementia Status	1	12.80	12.80	2.27^{ns}	
Error	28	157.93	5.64		
Within-Subjects					
Time	1	61.63	61.63	16.55**	.37
Time x Group	1	1.70	1.70	$.46^{ns}$	
Error	28	104.30	3.73		
DRSES Q. 4: Monitor your patient for changes in frequency of warning signs in his/her driving?					
Between Subjects					
Dementia Status	1	3.55	3.55	$.39^{ns}$	
Error	28	255.93	9.14		
Within-Subjects					
Time	1	69.36	69.36	24.38**	.45
Time x Group	1	4.02	4.02	1.42^{ns}	
Error	28	79.33	2.82		
DRSES Q. 5: Initiate conversations about driving and transportation needs with your loved one/patient?					
Between Subjects					
Dementia Status	1	27.06	27.06	3.12^{ns}	
Error	28	242.62	8.67		
Within-Subjects					
Time	1	88.13	88.13	17.94**	.36
Time x Group	1	17.59	17.59	3.58^{ns}	
Error	28	137.56	4.91		
DRSES Q. 6: Ask outside professionals questions about driving safety?					
Between Subjects					

Dementia Status	1	1.72	1.72	$.22^{ns}$	
Error	28	222.96	7.96		
Within-Subjects					
Time	1	28.52	28.52	8.76**	.24
Time x Group	1	6.92	6.92	2.13^{ns}	
Error	28	91.23	3.26		
DRSES Q. 7: Get information about driving evaluation services in your city or region?					
Between Subjects					
Dementia Status	1	21.18	21.18	3.12^{ns}	
Error	28	190.15	6.79		
Within-Subjects					
Time	1	52.96	52.96	12.70**	.30
Time x Group	1	7.63	7.63	1.83^{ns}	
Error	28	116.77	4.17		

ns = not significant, * = $p \leq .05$, ** $p \leq .01$

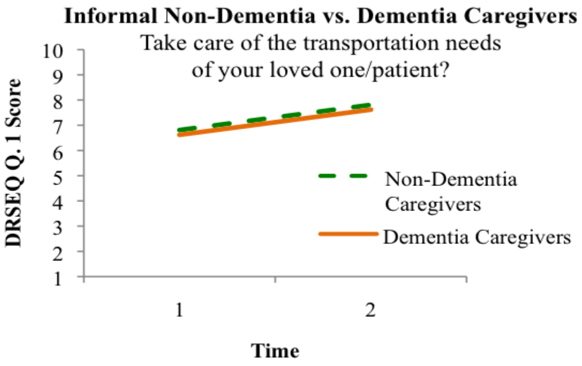


Figure 12. Informal non-dementia and dementia caregivers' responses on the DRSEQ Q. 1.

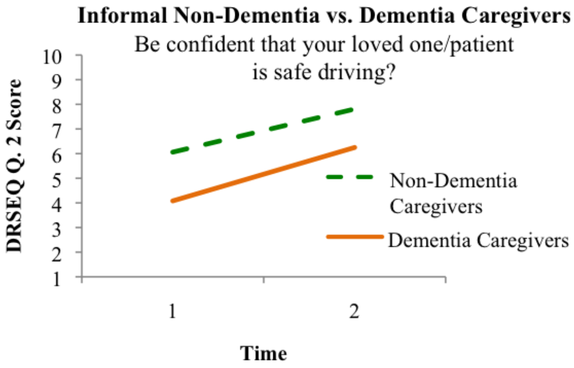


Figure 13. Informal non-dementia and dementia caregivers' responses on the DRSEQ Q. 2.

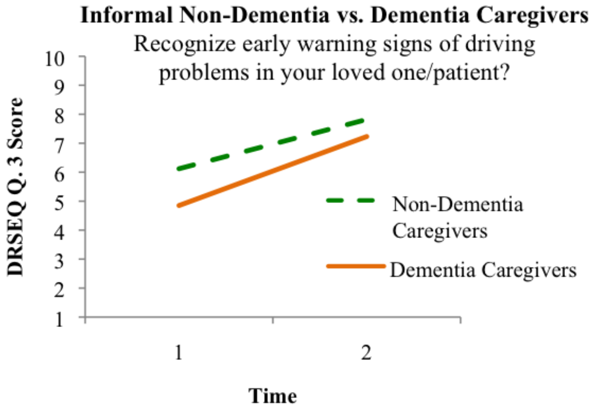


Figure 14. Informal non-dementia and dementia caregiver's responses on the DRSEQ Q. 3.

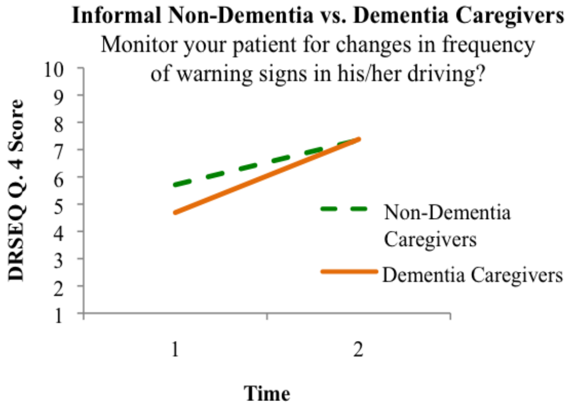


Figure 15. Informal non-dementia and dementia caregiver's responses on the DRSEQ Q. 4.

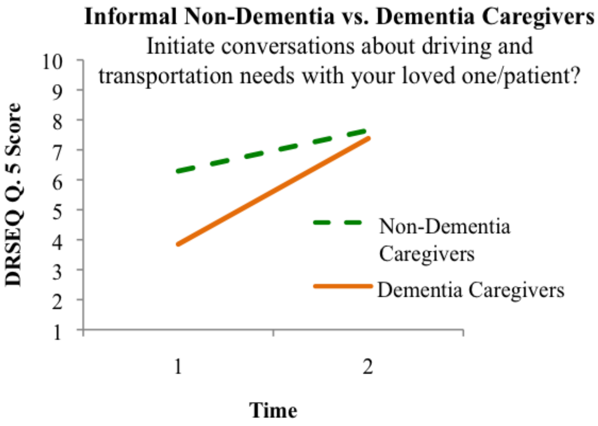


Figure 16. Informal non-dementia and dementia caregivers' responses on the DRSEQ Q. 5.

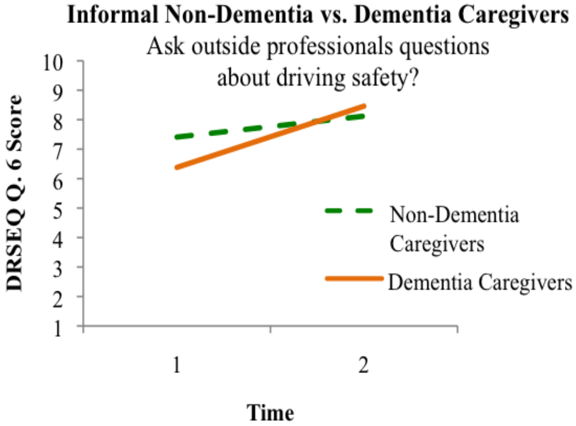


Figure 17. Informal non-dementia and dementia caregivers' responses on the DRSEQ Q. 6.

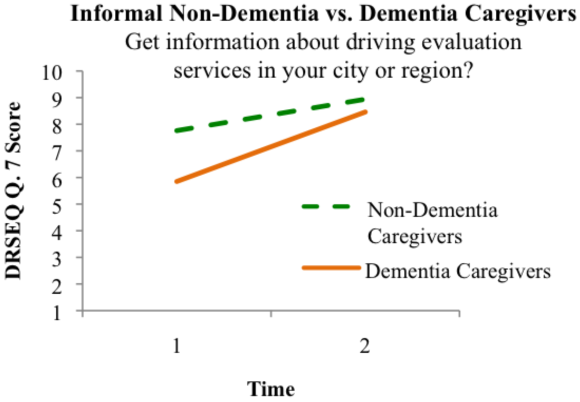


Figure 18. Informal non-dementia and dementia caregivers' responses on the DRSEQ Q. 7.

Informal vs. Formal Dementia Caregivers

Lastly, dementia caregivers' (informal (*N* = 13) compared to formal (*N* = 39)) responses on the DRSEQ were examined using 2 x 2 RM-ANOVAs. Like the results examining all caregivers, there were significant effects for Time on every item of the DRSEQ (DRSEQ Q. 1: F(1, 48) = 14.76, *p* < .01; DRSEQ Q. 2: F(1, 48) = 32.14, *p* < .01; DRSEQ Q. 3: F(1, 50) = 26.02, *p* < .01; DRSEQ Q. 4: F(1, 28) = 40.04, *p* < .01; DRSEQ Q. 5: F(1, 28) = 48.74, *p* < .01; DRSEQ Q. 6: F(1, 28) = 15.68, *p* < .01; DRSEQ Q. 7: F(1, 28) = 23.71, *p* < .01, see Figures 19 – 25), such that both informal and formal dementia caregivers' self-efficacy in handling driving-related issues with their loved ones or patients (as indicated by their responses on each item of the DRSEQ) increased from pre-test to post-test. Significant main effects for Dementia Caregiver type (informal vs. formal) were found on two items: the DRSEQ Q. 3 (F(1, 50) = 9.44, *p* < .01) and the DRSEQ Q. 5 (F(1, 28) = 13.05, *p* < .01), such that formal dementia caregivers reported higher levels of confidence in recognizing early warning signs of driving problems in their patients (Q. 3) and initiating conversations about driving and transportation needs with their patient (Q. 5) than informal caregivers' confidence in carrying out these same tasks with their loved ones (see Figures 21 and 23, respectively). Significant interactions between Dementia Caregiver type and Time were noted for the DRSEQ Q. 5 (F(1, 28) = 17.28, *p* < .01) and the DRSEQ Q. 7 (F(1, 28) = 8.72, *p* < .01), such that informal caregivers' confidence in being able to initiate conversations about driving and transportation needs with their loved ones (Q. 5) and get information about driving evaluation services in their city or region (Q. 7) increased more from pre-test to post-test compared to formal caregivers, whose confidence in handling these topics also increased, just not as drastically (see Figures 23 and 25, respectively).

Table 7. Pre-post comparison DRSEQ scores for informal dementia vs. formal dementia caregivers.

Source	*df*	*SS*	*MS*	*F*	*Eta*^{2}
DRSES Q. 1: Take care of the transportation needs of your loved one/patient?					
Between Subjects					
Dementia Caregiver	1	8.97	8.97	.83^{ns}	
Error	48	520.32	10.84		
Within-Subjects					
Time	1	29.10	29.10	14.76**	.23
Time x Group	1	1.02	1.02	.52^{ns}	
Error	48	94.60	1.97		
DRSES Q. 2: Be confident that your loved one/patient is safe driving?					
Between Subjects					
Dementia Caregiver	1	21.93	21.93	2.41^{ns}	
Error	48	437.07	9.12		
Within-Subjects					
Time	1	65.79	65.79	32.14**	.40
Time x Group	1	1.31	1.31	.64^{ns}	
Error	48	98.25	2.05		
DRSES Q. 3: Recognize early warning signs of driving problems in your loved one/patient?					
Between Subjects					
Dementia Caregiver	1	49.28	49.28	9.44**	.16
Error	50	261.18	5.22		
Within-Subjects					

Time	1	66.46	66.46	26.02**	.33
Time x Group	1	5.65	5.65	2.21^{ns}	
Error	50	127.69	2.55		
DRSES Q. 4: Monitor your patient for changes in frequency of warning signs in his/her driving?					
Between Subjects					
Dementia Caregiver	1	13.54	13.54	1.42^{ns}	
Error	28	477.18	9.54		
Within-Subjects					
Time	1	98.16	98.16	40.04**	.44
Time x Group	1	3.93	3.93	1.60^{ns}	
Error	28	122.56	2.45		
DRSES Q. 5: Initiate conversations about driving and transportation needs with your loved one/patient?					
Between Subjects					
Dementia Caregiver	1	95.93	95.93	13.05**	.21
Error	28	367.49			
Within-Subjects					
Time	1	95.93	95.93	48.74**	.42
Time x Group	1	34.00	34.00	17.28**	.15
Error	28	98.41	1.97		
DRSES Q. 6: Ask outside professionals questions about driving safety?					
Between Subjects					
Dementia Caregiver	1	6.49	6.49	$.87^{ns}$	
Error	28	372.85	7.46		
Within-Subjects					
Time	1	38.08	38.08	15.68**	.23
Time x Group	1	9.00	9.00	3.71^{ns}	
Error	28	121.41	2.43		
DRSES Q. 7: Get information about driving evaluation services in your city or region?					
Between Subjects					
Dementia Caregiver	1	11.93	11.93	1.45^{ns}	
Error	28	412.56	8.45		
Within-Subjects					
Time	1	51.70	51.70	23.71**	.29
Time x Group	1	19.00	19.00	8.72**	.11
Error	28	109.03	2.18		

ns = not significant, ** $p \leq .01$

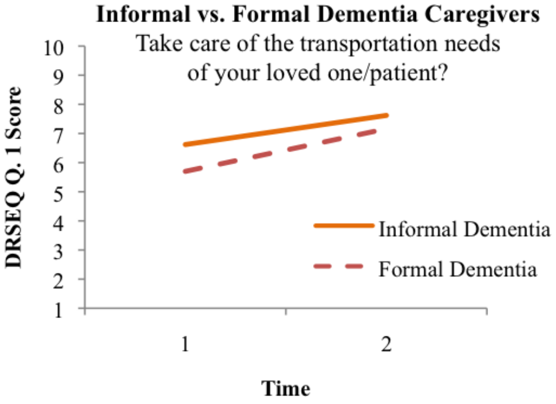


Figure 19. Informal and formal dementia caregivers' responses on the DRSEQ Q. 1.

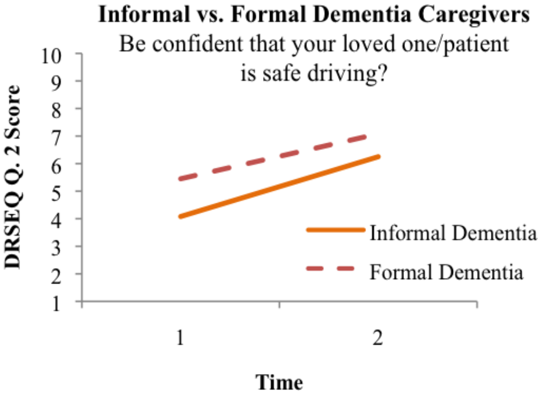


Figure 20. Informal and formal dementia caregivers' responses on the DRSEQ Q. 2.

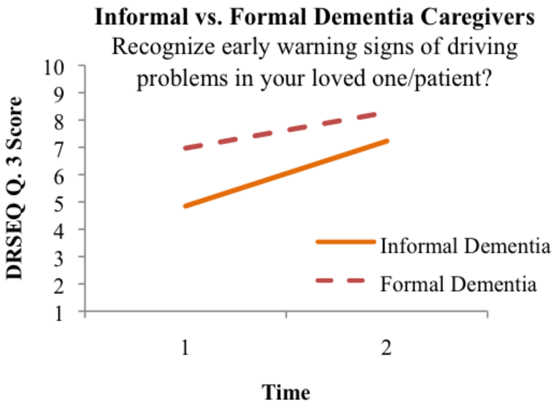


Figure 21. Informal and formal dementia caregivers' responses on the DRSEQ Q. 3.

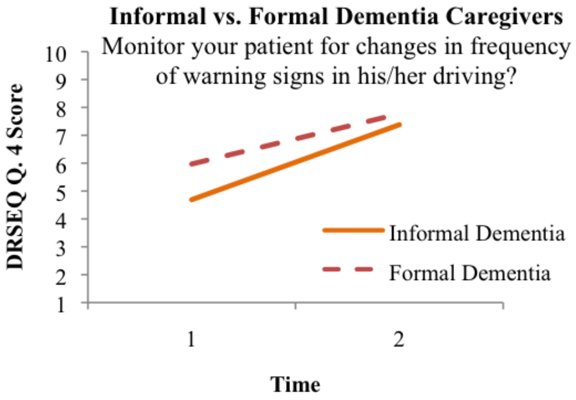


Figure 22. Informal and formal dementia caregiver's responses on the DRSEQ Q. 4.

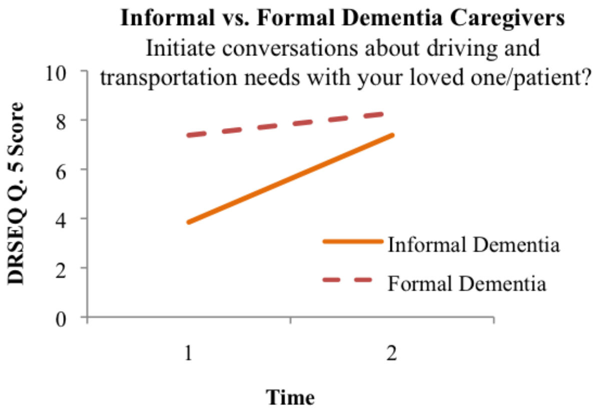


Figure 23. Informal and formal dementia caregivers' responses on the DRSEQ Q. 5.

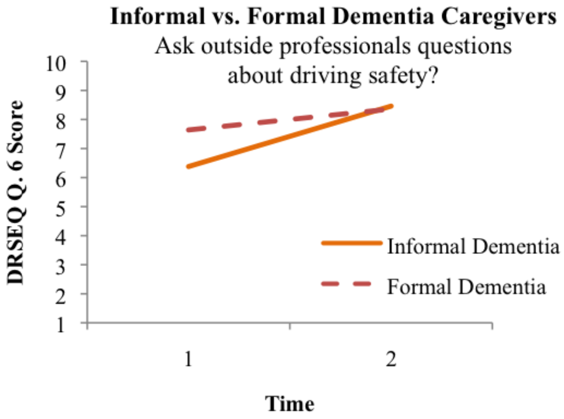


Figure 24. Informal and formal dementia caregivers' responses on the DRSEQ Q. 6.

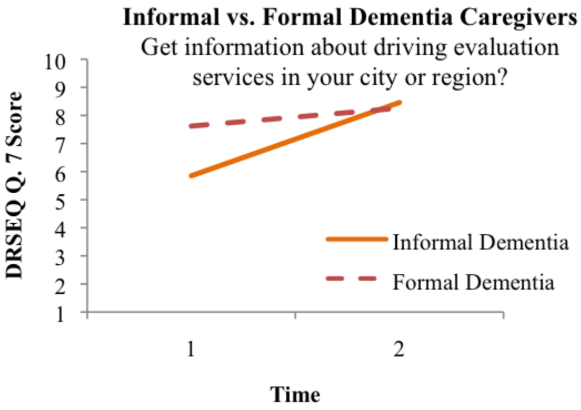


Figure 25. Informal and formal dementia caregivers' responses on the DRSEQ Q. 7.

User Satisfaction with the Toolkit

Informal (All Types) and Formal Caregivers, Examined Separately

Results on the User Satisfaction survey showed that, across all items asked, both informal and formal caregivers positively viewed the toolkit. Overall, 93.6% of informal caregivers and 94.9% of formal caregivers agreed or strongly agreed that the toolkit was useful. 90.3% of informal caregivers and 92.3% of formal caregivers agreed or strongly agreed that the toolkit was a unique way of approaching the topic of older driver safety compared to other methods they may have used. A large percentage of both informal and formal caregivers would use the toolkit again (83.8% and 89.7%) and would recommend the toolkit to others (93.6% and 97.4%, respectively). Generally, caregivers gave the lowest ratings, although still favourable, to items concerning two of the specific sections of the toolkit reviewed, "The Importance of Driving" and the "Assessment Process" section/discussion. See Table 8 for the results for each specific item on the User Satisfaction survey.

Table 8. Informal (all types) and formal caregivers' responses on the User Satisfaction survey.

User Satisfaction Survey Items	**Informal Caregivers Only** *% "Agree" and "Strongly Agree"*	**Formal Caregivers Only**
1.) I found the DVD useful	83.8%	84.6%
2.) I found the viewer guidebook useful	93.5%	94.8%
3.) The viewer guidebook is easy to use	90.4%	89.7%
4.) I found the discussions useful	87.1%	66.6%
5.) The supplemental cards are useful (or could be useful if catered to my region)	83.9%	84.6%
6.) Overall, the toolkit is useful	93.6%	94.9%
7.) The toolkit is a good source of information	93.5%	94.9%
8.) The toolkit helped me consider important factors when approaching the topic of driving safety and/or cessation with older adults	83.9%	76.9%
9.) This toolkit is a unique way of approaching the topic of older driver	90.3%	92.3%

safety compared to other methods I may have used		
10.) The “Importance of Driving” section/discussion helped me understand the emotional aspects tied to driving and how they might affect older adults	74.2%	79.5%
11.) The “Assessment Process” section/discussion helped me learn about the regulations in BC	77.5%	79.5%
12.) The “Risk Factors & Warning Signs” section/discussion helped me learn about changes commonly associated with aging that may impact driving	87.1%	82.1%
13.) I will use this toolkit again	83.8%	89.7%
14.) I would recommend this toolkit to others	93.6%	97.4%

Informal (All Types) vs. Formal Caregivers

Independent samples t-tests were used to examine whether there were differences between informal and formal caregivers’ ratings on the individual items of the User Satisfaction survey. The results indicated no significant differences in user satisfaction between caregiver groups on 13 of the 14 items. Only responses to item #13, “I will use this toolkit again”, significantly differed between informal and formal caregivers such that formal caregivers agreed more with the statement than informal caregivers (see Table 9).

Table 9. User Satisfaction survey response comparison for informal vs. formal caregivers.

	Informal Caregivers		**Formal Caregivers**				
User Satisfaction Survey Items	*Mean*†	*SD*	*Mean*†	*SD*	*t*	*df*	*d*
1.) I found the DVD useful	4.21	.62	4.26	.76	-.33 ^{ns}	65	
2.) I found the viewer guidebook useful	4.28	.46	4.46	.68	-1.27 ^{ns}	66	
3.) The viewer guidebook is easy to use	4.31	.54	4.44	.68	-.82 ^{ns}	66	
4.) I found the discussions useful	4.36	.56	4.45	.69	-.55 ^{ns}	55	
5.) The supplemental cards are useful (or could be useful if catered to my region)	4.27	.69	4.36	.81	-.50 ^{ns}	67	
6.) Overall, the toolkit is useful	4.43	.57	4.51	.68	-.52 ^{ns}	67	
7.) The toolkit is a good source of information	4.50	.57	4.56	.68	-.42 ^{ns}	67	
8.) The toolkit helped me consider important factors when approaching the topic of driving safety and/or cessation with older adults	4.27	.69	4.31	.89	-.21 ^{ns}	67	
9.) This toolkit is a unique way of approaching the topic of older driver safety compared to other methods I may	4.47	.63	4.59	.72	-.75 ^{ns}	67	

have used							
10.) The “Importance of Driving” section/discussion helped me understand the emotional aspects tied to driving and how they might affect older adults	3.97	.77	4.15	.96	$-.88^{ns}$	67	
11.) The “Assessment Process” section/discussion helped me learn about the regulations in BC	4.00	.64	4.24	.80	-1.35^{ns}	65	
12.) The “Risk Factors & Warning Signs” section/discussion helped me learn about changes commonly associated with aging that may impact driving	4.20	.61	4.26	.80	$-.36^{ns}$	66	
13.) I will use this toolkit again	4.03	.56	4.36	.74	-2.01*	67	.50
14.) I would recommend this toolkit to others	4.48	.51	4.67	.62	-1.30^{ns}	66	

† 1 = “Strongly Disagree” 5 = “Strongly Agree”; ns = not significant, * = $p \leq .05$

Informal Non-Dementia Caregivers vs. Informal Dementia Caregivers

Independent samples t-tests were used to examine if there were differences between informal non-dementia caregivers and informal dementia caregivers’ ratings on the User Satisfaction survey. No significant differences between these types of caregivers emerged for any of the items on the User Satisfaction survey. Table 10 provides a summary of the results.

Table 10. User Satisfaction survey response comparison for informal non-dementia vs. informal dementia caregivers.

	Non-Dementia Caregivers		**Dementia Caregivers**			
User Satisfaction Survey Items	*Mean*†	*SD*	*Mean*†	*SD*	*t*	*df*
1.) I found the DVD useful	4.27	.59	4.08	.64	$.81^{ns}$	26
2.) I found the viewer guidebook useful	4.33	.49	4.15	.38	1.08^{ns}	26
3.) The viewer guidebook is easy to use	4.27	.59	4.31	.48	$-.20^{ns}$	26
4.) I found the discussions useful	4.27	.59	4.42	.52	$-.69^{ns}$	25
5.) The supplemental cards are useful (or could be useful if catered to my region)	4.38	.72	4.08	.64	1.17^{ns}	27
6.) Overall, the toolkit is useful	4.50	.52	4.31	.63	$.67^{ns}$	27
7.) The toolkit is a good source of information	4.50	.52	4.46	.66	$.24^{ns}$	27
8.) The toolkit helped me consider important factors when approaching the topic of driving safety and/or cessation with older adults	4.31	.60	4.15	.80	$.31^{ns}$	27
9.) This toolkit is a unique way of approaching the topic of older driver safety compared to other methods I may have used	4.44	.63	4.46	.66	$.86^{ns}$	27
10.) The “Importance of Driving” section/discussion helped me understand the emotional aspects tied to driving and	3.94	.85	3.92	.64	$.05^{ns}$	27

how they might affect older adults							
11.) The "Assessment Process" section/discussion helped me learn about the regulations in BC	4.06	.68	3.85	.56	.92^{ns}	27	
12.) The "Risk Factors & Warning Signs" section/discussion helped me learn about changes commonly associated with aging that may impact driving	4.25	.58	4.08	.64	.77^{ns}	27	
13.) I will use this toolkit again	4.06	.68	3.92	.28	.69^{ns}	27	
14.) I would recommend this toolkit to others	4.53	.52	4.38	.51	.77^{ns}	26	

† 1 = "Strongly Disagree" 5 = "Strongly Agree"; ns = not significant, * = $p \leq .05$

Informal Dementia vs. Formal Dementia Caregivers

Independent samples t-tests were used to examine if there were differences between informal dementia caregivers' and formal dementia caregivers' ratings on the User Satisfaction survey. A significant difference between informal and formal dementia caregivers' responses was noted for only item 13, "I will use this toolkit again", such that formal dementia caregivers reported that they were more likely to use *Down the Road* again compared to informal dementia caregivers. Table 11 provides a summary of the results.

Table 11. User Satisfaction survey response comparison for informal vs. formal dementia caregivers.

	Informal Dementia Caregivers		**Formal Dementia Caregivers**				
User Satisfaction Survey Items	*Mean*†	*SD*	*Mean*†	*SD*	*t*	*df*	*d*
1.) I found the DVD useful	4.08	.64	4.26	.76	-.79^{ns}	49	
2.) I found the viewer guidebook useful	4.15	.38	4.46	.68	-1.54^{ns}	50	
3.) The viewer guidebook is easy to use	4.31	.48	4.44	.68	-.63^{ns}	50	
4.) I found the discussions useful	4.42	.52	4.45	.69	-.14^{ns}	39	
5.) The supplemental cards are useful (or could be useful if catered to my region)	4.08	.64	4.36	.81	-1.14^{ns}	50	
6.) Overall, the toolkit is useful	4.31	.63	4.51	.81	-1.00^{ns}	50	
7.) The toolkit is a good source of information	4.46	.66	4.56	.68	-.47^{ns}	50	
8.) The toolkit helped me consider important factors when approaching the topic of driving safety and/or cessation with older adults	4.15	.80	4.31	.89	-.55^{ns}	50	
9.) This toolkit is a unique way of approaching the topic of older driver safety compared to other methods I may have used	4.46	.66	4.59	.72	-.57^{ns}	50	
10.) The "Importance of Driving" section/discussion helped me understand	3.92	.64	4.15	.96	-.81^{ns}	50	

the emotional aspects tied to driving and how they might affect older adults							
11.) The “Assessment Process” section/discussion helped me learn about the regulations in BC	3.85	.56	4.24	.80	-1.66^{ns}	48	
12.) The “Risk Factors & Warning Signs” section/discussion helped me learn about changes commonly associated with aging that may impact driving	4.08	.64	4.26	.80	-.76^{ns}	49	
13.) I will use this toolkit again	3.92	.28	4.36	.74	-2.06*	50	.79
14.) I would recommend this toolkit to others	4.38	.51	4.67	.62	-1.48^{ns}	50	

[†] 1 = “Strongly Disagree” 5 = “Strongly Agree”; ns = not significant, * = $p \leq .05$

Written Suggestions

On the User Satisfaction survey, space at the bottom of the questionnaire was provided for participants to write in specific comments or suggestions. Of the small percentage of caregivers who completed this section, the majority used the space to express gratitude and appreciation for the development of the toolkit. Some caregivers did provide specific suggestions including using a larger font size for the text of the toolkit and not providing references in the text. Several caregivers noted that *Down the Road* would be best used in a small group format.

Discussion

Study 2 of this dissertation followed Step Six and Step Seven of the Knowledge to Action Framework (Graham & Tetroe, 2009) to monitor and evaluate the effectiveness (via self-efficacy/confidence) and satisfaction of *Down the Road*, the newly developed toolkit for caregivers of older adults about driving issues, among this population. As expected, both informal and formal caregivers’ self-efficacy in their ability to handle various issues related to driving safety and cessation with their loved ones or patients increased after reviewing the toolkit. Both informal (all types) and formal caregivers’ gave similar responses on most of the items examining self-efficacy, however, formal caregivers’ displayed significantly higher levels of confidence before and after reviewing the toolkit with respect to their ability to recognize early warning signs that their patients may be unsafe on the road and to initiate conversations about driving with their patients compared to informal caregivers. As healthcare professionals in the geriatric field, it is expected that formal caregivers possess more confidence in recognizing warning signs of unsafe driving in their patients and initiating conversations about driving with their clients than informal caregivers as these are fundamental responsibilities inherent to their jobs, in which they likely have had much experience. It is encouraging to see, however, that even with relatively high baseline levels of self-efficacy in handling driving-related issues with their patients, formal caregivers' self-efficacy increased after exposure to the toolkit.

The toolkit appeared to educate all types of informal caregivers, including dementia caregivers, mostly in the areas of initiating conversations about driving with their loved ones and obtaining information about driving evaluation services in their region. The implications of this result are threefold: (1) the toolkit achieves its stated goal of helping caregivers initiate conversations about driving safety and cessation with their loved ones, (2) caregivers found the section and informational card, “Refreshing Skills”, helpful even though not directly reviewed, and (3) although the toolkit was developed with dementia caregivers, it is applicable and useful for all types of caregivers (including dementia caregivers). Not surprisingly, informal non-dementia caregivers were more confident that their loved ones were safe driving (compared to informal dementia caregivers) as these individuals may have been caring for healthier (i.e., non-demented) older adults.

Also, as expected, both informal (including dementia caregivers) and formal caregivers favourably viewed *Down the Road*. The toolkit received very high ratings by both caregiver groups as an overall resource, but they also found each of the major components of the toolkit (e.g., DVD, viewer guidebook, supplemental informational cards) useful and easy to use. Additionally, approximately 90% of caregivers considered the toolkit a unique way of approaching the topic of older driver safety compared to other methods they may have used, indicating that caregivers themselves find the applied theatre format is a new and different means of delivering information to this population. Lowest ratings, although still relatively high (74% to 87% positive agreement), were noted for the three individual sections of the toolkit that were reviewed during the evaluation sessions (the "Importance of Driving", the "Assessment Process", and the "Risk Factors & Warning Signs" sections). Given the limited amount of time provided to review these sections, the material was likely presented too quickly and discussions cut short, potentially contributing to the lower ratings. However, the vast majority of both informal and formal caregivers (93.6% and 97.4%, respectively) would recommend the toolkit to others, suggesting favourable views of *Down the Road* as a whole even though lower ratings were given for the individual sections. Caregivers also self-reported that they were likely to use the toolkit again in the future, although formal caregivers' responded that they were more likely to use to the toolkit again compared to informal caregivers. This may be reflective of how the toolkit will be used differently by informal and formal caregivers. That is, informal caregivers may only use the toolkit on occasion, whereas formal caregivers are likely to use *Down the Road* repeatedly in their professional role as they facilitate different groups. As a result, formal caregivers are more likely to use the toolkit more often than informal caregivers.

Given these findings from the self-efficacy questionnaire and user satisfaction survey, it appears that *Down the Road* is an effective and well-received resource for caregivers of seniors (including dementia caregivers) about driving safety and cessation, like some of the other toolkits available to caregivers today about this topic (e.g., *The Driving and Dementia Toolkit, At the Crossroads*; Champlain Dementia Network, 2009 & 2011; Hartford, 2010 & 2013). Unlike these other toolkits, however, *Down the Road* is the only resource to use applied theatre as the primary mechanism to generate thought and discussion around this important topic. In addition to incorporating this unconventional method into the intervention, *Down the Road* also utilizes traditional print-based methods, thus producing a toolkit that combines “the best of both worlds”, offering caregivers a resource unlike any others available today. It is also different from the other available toolkits in that it can be effectively used with any type of caregiver of older adults, including dementia caregivers.

Although *Down the Road* can be used individually, there are several cautions that must be raised regarding this format of use. First, given that driving is a very emotional topic to think about and discuss for both older adults and caregivers (D’Ambrosio et al., 2009), the DVD is likely to trigger an emotional reaction in viewers. There may be issues that caregivers had not considered prior to viewing “No Particular Place to Go”, which may increase the intensity of the emotional reactions and possibly inducing some distress, particularly if this new insight instils a sense of helplessness in the caregiver. One of the aims of the accompanying guidebook and supplemental cards is to ease this sense of helplessness by promoting empowerment and self-efficacy through discussion, education, and resources about the various topics associated with driving. However, a cautionary statement warning of this potential adverse effect should be included in the toolkit to warn caregivers of possible emotional reactions. It should also be suggested in the toolkit that, if caregivers feel unmanageable emotional distress, they follow-up with their primary care provider. Second, as there is no mental health professional present to discuss the content of the toolkit if used individually, it is possible that a caregiver may misinterpret a suggestion and approach a care recipient in a manner that may cause harm. Again, to reduce the possibility of this potential negative event, caregivers are encouraged to consult with their primary care physicians after reviewing the toolkit individually and prior to discussing the subject of driving with their loved one. Lastly, when used individually, other caregivers are not available to provide emotional support, suggestions, and different perspectives. As a result of these three concerns when using *Down the Road* individually, it may, in fact, be safer and more effective to deliver the material in small group/workshop format under the facilitation of a group leader as Stern et al. (2008) has found with the *At the Crossroads* toolkit. The content of the *Down the Road* is particularly conducive to group discussions and exchanges. In addition, the presence of a facilitator may mitigate some of the potential adverse consequences described above.

Another strength of *Down the Road* is its direct applicability to clinical settings. For example, in geriatric hospital-based clinics or non-profit dementia and caregiver organizations (e.g., local chapters of the Alzheimer Society of Canada), healthcare professionals (e.g., family physicians, psychologists, neuropsychologists, occupational therapists, social workers, nurses) can hold *Down the Road* workshops for caregivers about the driving issues they may be facing with the loved ones in a collaborative and interactive manner. The toolkit is purposefully open-ended in its format of use so these workshop leaders can fit the toolkit to the needs of their setting and clients. To promote toolkit use and sustainability, new users should be approached and incorporated into the KT process by presenting the toolkit in a manner that illustrates a desire to hear their input in order to make the toolkit more useful to them. It should be emphasized that their feedback will inform future versions of the toolkit so the content can be more suited to their needs. For example, a social worker may find that, when facilitating workshops, he or she wants more information on the alternatives to driving that are available in the community to better address the needs of his/her caregivers attending the group. This type of feedback will directly impact the content of the "Alternatives to Driving" supplemental card. Conversely, a primary care physician may not require any specific additions or changes to the toolkit itself, but rather desire a supplemental informative sheet on how to present to the toolkit to their patients, estimated time burden of delivering this information, and a list of local facilitators. As a result, a set of instructions may need to be drafted for primary care providers and included with copies of the toolkit when it is introduced to them. Ultimately, for *Down the Road* to be adopted and used by healthcare professionals, its content and format must suit their needs. Continually revisiting the KT process, while being mindful of contextual issues that may differ between various providers, will help ensure its sustainability among healthcare professionals.

Some features of this evaluation study limit its generalizability and must be taken into consideration when interpreting the results. First, in an exploratory analysis comparing informal dementia caregivers with formal dementia caregivers, the sample sizes between these two groups were unequal (N = 13 for informal dementia caregivers vs. N = 31 for formal dementia caregivers). The small sample size in the informal dementia caregiver group decreases power, thereby increasing the likelihood that the differences seen between caregiver groups are illusory, or false positives (Type I errors). Therefore, the results from these particular analyses should be interpreted with caution. Second, the participants were primarily Caucasian females. Although women represent a higher percentage of the caregiver population than men (Canadian Study on Health and Aging Working Group, 1994), this sample is even more skewed for females than the typical gender breakdowns among caregivers. Future validation studies of *Down the Road* should seek participation from men, as well as from caregivers of various ethnic backgrounds, to ensure its generalizability to caregivers of both sexes and various ethnicities. The evaluation results are also limited since it was not possible to review the entire toolkit with the participants due to time constraints. Additionally, due to social desirability bias (Fleming, 2012), participants' scores on the DRSEQ and the User Satisfaction survey may have been inflated, although participant anonymity on both questionnaires was used to curtail this effect. The results should be interpreted with this in mind. Lastly, the scope of this study did not permit a comparison of *Down the Road* with solely print-based interventions, allowing only the speculation that this new form of intervention incorporating applied theatre is more effective than traditional print-based methods.

Future studies would benefit by continuing to follow the Knowledge to Action KT protocol (Graham & Tetroe, 2009) by returning to Step Six (monitoring knowledge use), Step Seven (evaluating outcomes), and Step Eight (sustaining knowledge use) by incorporating participants' suggestions into a revised version of the toolkit (e.g., using larger font, not providing references in the text of the toolkit). Additionally, according to Kitson et al's (2008) Promoting Action on Research Implementation in Health Services (PARIHS) KT framework, it will be important to examine the context/s where the toolkit will be used to determine if adaptations of the toolkit are required. It will then be important to evaluate the revised toolkit/s in a larger, more demographically diverse sample of caregivers using the entire toolkit (all eight sections) in small group format over the course of several sessions. Like the evaluation of the group-based *At the Crossroads* toolkit (Stern et al., 2008), comparison of delivery methods (i.e., small group format vs. individual review vs. control group) is needed to determine which format is best suited for caregivers. It will also be important to compare *Down the Road* with purely print-based interventions (e.g., *The Driving and Dementia Toolkit, At the Crossroads;* Champlain Dementia Network, 2009 & 2011; Hartford, 2010 & 2013) to determine if a toolkit incorporating applied theatre is more effective means of increasing caregiver's self-efficacy in handling driving-related issues with their care recipients compared to print-based methods. Additionally, examining other outcome variables like those used in the studies by Byszewski et al. (2003) and Stern et al. (2008) (e.g., knowledge gained, stress levels around discussing the driving topic, stage of change of care recipient) can provide a more detailed understanding of how the toolkit may benefit caregivers. Lastly, it will be important, in future studies, to monitor the toolkit's actual use (Step Six of the KT protocol) using longitudinal methods as a high percentage of caregivers in this current study said they would use the toolkit again. Periodic follow-ups can be conducted to examine ongoing toolkit use and determine the accuracy of these endorsements. During these follow-up studies, repeated administration of the DRSEQ can be performed to examine if the initial increases seen in caregivers' self-efficacy in handling driving-related issues with their loved ones or patients after reviewing *Down the Road* from this current study are maintained over time.

Chapter 4

General Discussion

According to the mandate set forth by the Canadian Institutes of Health Research (CIHR), their main objective is to "excel, according to internationally accepted standards of scientific excellence, in the creation of new knowledge and *its translation* into improved health for Canadians, more effective health services and products, and by strengthening Canadian health care system" (Minister of Justice, 2000). This mandate speaks to a changing set of values within Canada healthcare system where emphasis is now placed not only developing new research to improve healthcare, but on disseminating/integrating this research to/with knowledge users. In today's society, where the government, granting agencies, and the public require a high level of accountability from scientists and their institutions where their money is invested, it is not enough simply create innovative research. Rather, these bodies are now requiring scientists to integrate their research into "policy, programs, and practice" to directly benefit knowledge-users (Canadian Institutes of Health Research, 2014), the essence of Knowledge Translation.

This dissertation project used integrated KT methods, specifically the Knowledge to Action Framework developed by Graham and Tetroe (2009), to address an important topic for caregivers of older adults with dementia – the issue of driving safety and cessation – through the development and evaluation of a toolkit called *Down the Road*. It was particularly important to follow integrated KT principles when conducting this research to ensure the expressed needs, concerns, and suggestions of the intended knowledge users (dementia caregivers) were incorporated into a final product they would find useful.

The Knowledge to Action Framework consists of eight steps (Graham & Tetroe, 2009). First, the need for dementia caregivers to have a tool to help them approach the topic of driving safety and cessation with their care recipients using an applied theatre format was identified (Step One). Then an existing applied theatre production, *No Particular Place to Go*, was identified as a tool that was originally developed for older adults and stakeholders, in general, to begin thinking about this issue (Tuokko et al., 2013). This production, in DVD-format, was selected as the basis for developing a more comprehensive toolkit that would be catered to dementia caregivers (Step Two). To incorporate the DVD into the newly developed toolkit, focus groups and individual interviews with informal and formal dementia caregivers were held to assess their experiences, needs, and concerns when approaching the topic of driving safety and cessation with individuals with dementia (Step Three and Four). The content from these interviews, including eight major themes, were then integrated into a toolkit called *Down the Road*, which consists of the *No Particular Place to Go* DVD, 23-page a viewer guidebook, and seven informational cards specifically tailored to the meet the needs of dementia caregivers (Step Five). Steps Six and Seven (monitoring and evaluating the toolkit) showed *Down the Road* to be a well-received and effective tool for increasing both informal and formal dementia caregivers', as well as general caregivers', self-efficacy and confidence in handling driving-related issues with older adults. Step Eight, which is beyond the scope of this dissertation study, will sustain *Down the Road's* use among caregivers by continuing to revise and adapt the toolkit to suit the needs of caregivers in other cities and provinces across Canada. It will also be important return to Steps Six (monitoring use) and Seven (evaluating outcomes) as revisions and adaptations are made. This continued monitoring/examination and evaluation speaks to the dynamic and iterative process of the

Knowledge to Action Framework (Graham & Tetroe, 2009), which represents a fundamental component of integrated KT.

By using the principles of integrated KT and specifically following the Knowledge to Action Framework (Graham & Tetroe, 2009), a research-based toolkit incorporating applied theatre now exists for the use of caregivers of older adults in the city of Victoria, British Columbia struggling with the issue of driving safety and cessation. Its future use among both informal and formal caregivers on a larger, nation-wide scale relies on successfully implementing and sustaining its knowledge use (Step Eight of the Knowledge to Action Framework).

According to the Promoting Action on Research Implementation in Health Services (PARIHS) Framework developed by Kitson and her colleagues, successful implementation of research into practice requires the interaction between evidence, facilitation, and context (Kitson et al., 1998; 2008). A strength of this dissertation lies in its use of evidence and facilitation. The development of *Down the Road* was based in evidence and research combining findings from the literature, researcher knowledge, and data collected from knowledge users. Facilitation, or the ability of the researcher to cater the product to the needs of knowledge users, was achieved by conducting focus groups and interviews to inform the tailoring of the toolkit to the needs of caregivers of older adults in Victoria, British Columbia. Although this first edition of *Down the Road* addressed the contextual issues of the participants used to develop the toolkit, the issue of context will need to be continually examined among the representative groups of future toolkit users to determine how and what knowledge will be transferred.

It is clear, as underscored in the CIHR mandate, that KT is becoming an increasingly important part of the research process. As such, following the principles of integrated KT to plan and execute this dissertation demonstrates a significant strength of the project. In dissemination and implementation research, it is more and more common for scientists to employ mixed methods approaches (Shortell, 1999). Mixed methods are inherently suited to KT as the qualitative methodology provides researchers an opportunity to collaborate with, respond to, and gain a deeper understanding of the needs and concerns of the targeted knowledge users (the very core of KT), while the quantitative methodology offers greater opportunity for generalizability (Green, Duan, Gibbons, Hoagwood, Palinkas, & Wisdom, 2014). This dissertation used mixed methods by developing *Down the Road* (Study 1) through qualitative methodology, while its evaluation (Study 2) was conducted through quantitative means. Within this methodology, it was important, and a strength of the study, that the development and evaluation of the toolkit was performed with different sets of informal and formal caregivers so the evaluations were not biased from previous enrolment in the study.

As with any research protocol, conducting KT research includes several inherent challenges. The length of time needed to conduct integrated KT research can be considerable as a researcher must not only communicate directly with the intended knowledge users – a step often overlooked in non-KT research procedures - but also return to the knowledge users repeatedly to evaluate and monitor the end product’s use. The length of time needed to properly conduct integrated KT, however, will vary depending on the depth of the project, accessibility to and population size of the knowledge users, and other factors specific to the project at hand. The time needed to conduct quality KT research may repel some scientists. However, the KT process can be framed to researchers as merely akin traditional scientific inquiry methods where pilot studies are created and executed, then subsequent studies are adapted and/or replicated until enough evidence has been collected to be deemed sufficient by the scientists, research community, or private and public bodies utilizing the research results. Integrated KT research can also be challenging since a researcher must balance the needs he/she has identified in the extant literature with the needs of the intended knowledge users. For example, in Study 1 of this dissertation, the intended knowledge users (informal and formal caregivers) specifically requested that the toolkit not be dementia-specific. However, a need was identified in the literature for targeted information specifically addressing the effects of cognitive impairment, including dementia, on driving behaviour and abilities. To overcome these seemingly contradictory needs, it was decided to include information about dementia and the effects of its process on driving behaviours and abilities in relation to many of the themes identified in the toolkit by highlighting dementia as one of many other conditions that can occur in an aging driver. To remain true to the core principles of integrated KT, as delineated in this example, the researcher must strive to take all perspectives into account through compromise and not simply choose one perspective over another.

This dissertation work provides the building blocks for many future studies. The goal is for this toolkit to be made available to caregivers nationwide. To achieve this goal, first it will be necessary to cater the informational cards to various cities/towns across Canada by contacting experts in those regions to help develop content specific to their region. Then, to validate toolkit for use across Canada, focus groups in these cities/towns need to be held to either ensure the content of the viewer guidebook is applicable to a nationwide audience or modify the guidebook based on the focus group results. During this phase of the toolkit's revision process, emphasis should be placed on addressing the needs of older adults in rural communities, as their mobility issues and ability to access alternative transportation greatly differs from older adults living in urban areas (Allan & McGee, 2003). Continually following the Knowledge to Action Framework (Graham & Tetroe, 2009), any modifications to *Down the Road* need to be evaluated, monitored, and revised accordingly in order to sustain its use. More specifically, each step of the Knowledge to Action Framework will need to be revisited and re-administered when the new contexts outlined above are introduced, as prescribed by the PARIHS model of KT.

In its current form or as future editions become available, *Down the Road* serves as a potentially important tool for healthcare professionals who work closely with older adults and their caregivers. Its format and content do not require specialized training to use. As a result, *Down the Road* is suitable for use by healthcare professionals of all types (e.g., family physicians, nurses, occupational therapists, social workers, psychologists, neuropsychologists). For example, a family physician who is beginning to worry about his/her patient's driving may give a copy of *Down the Road* to the patient's caregiver at the end of an appointment, bearing in mind cautions of using the toolkit individually (e.g. possible emotional distress without immediate processing, potential harm to care recipient). To mitigate these risks, after the caregiver reviews the toolkit on his/her own at home, a follow-up appointment with the physician should be made to allow the caregiver to check-in and discuss with the physician any concerns that were raised while reviewing *Down the Road*. Alternatively, a physician may be able to refer the caregiver to a facilitated group where the toolkit is used.

The toolkit may be particularly helpful to healthcare professionals who specialize in the assessment of cognitive abilities, like neuropsychologists. Neuropsychologists examine brain-behaviour relationships and, as a result, are tasked with the job of determining how a person's cognitive functioning (e.g., intelligence, processing speed, motor skills, visuo-spatial skills, language, verbal and non-verbal memory, executive functioning, mood/psychological profile) impacts their everyday functioning (i.e., ability to execute ADLs/IADLs). Geriatric neuropsychologists, in particular, frequently encounter individuals with dementia and other age-related conditions that directly impact IADLs, like driving. As a result, the issue of driving is often raised during a neuropsychological evaluation. *Down the Road* can help geriatric neuropsychologists learn to navigate this topic themselves, particularly in the early stages of a career, and also provides them a resource they can recommend to their patients' caregivers during feedback sessions, following the same protocol outlined above for physicians. When appropriate, geriatric neuropsychologists can also hold psychoeducational workshops or even support groups based around *Down the Road* to provide caregivers an opportunity to explore and discuss these issues in a therapeutic context.

Since the first automobile was introduced in North America in the early 1900s, personal vehicles have become as essential part of our society. Now, as our population ages and continues to drive, concerns from caregivers about older driver safety have risen. Although solely print-based toolkits for caregivers around this topic are currently available, *Down the Road: An Interactive Toolkit for Use with Caregivers* represents a new, useful, and effective approach for promoting thought, discussion, and education among caregivers about important issues relevant to older driver safety and cessation by combining both applied theatre and print-based intervention delivery methods. Through the development of the *Down the Road* toolkit, both informal and formal caregivers of older adults in Victoria, British Columbia, and eventually across Canada, will be more confident in approaching the topic of driving and driving cessation with their loved ones. It is anticipated that if driving interventions such a this can be made available to caregivers when they enter this role or introduced into the mainstream education agenda for public safety, then individuals who may eventually become caregivers, or even older drivers themselves, will be equipped with the information necessary to handle this important topic when the need arises, thereby promoting driving safety for all road users.

References

AAA Foundation for Traffic Safety Senior Driver. (2011). *Driving and dementia*. Retrieved on April 1, 2014 from http://seniordriving.aaa.com/understanding-mind-body-changes/mind-cognition/driving-dementia.

Ackroyd, J. (2000). Applied theatre: Problems and possibilities. *Applied Theatre Researcher, 1*, 1 – 12.

Act II Studio. (2014). Research-based theatre: Awareness and understanding of current health and social issues. Retrieved on April 14, 2014 from http://www.act2studio.ca/?q=content/research-based-theatre-awareness-and-understanding-current-health-and-social-issues.

Adler, G., Rottunda, S. Bauer, M., & Kuskowski, M. (2000). Driving cessation and AD: Issues confronting patients and family. *American Journal of Alzheimer's Disease, 15,* 212 – 216.

Adler, G., Rottunda, S., & Kuskowski, M. (1999). Dementia and driving: Perceptions and changing habits. *Clinical Gerontologist*, *20,* 23 – 34.

Adler, G., Rottunda, S., & Dysken, M. (2005). The older driver with dementia: an updated literature review. *Journal of Safety Research*, *36*(4), 399 – 407.

Ajzen, I. (1991). The theory of planned behaviour. *Organizational Behavior and Human Decision Processes*, *50*(2), 179 – 211.

Allan, D.E. & McGee, P.D. (2003). *Accessible transportation for all in the capital region district: Where are we now? Where should we be going?* Prepared for BC Transit, Capital Region District, and the Vancouver Island Health Authority.

Alzheimer's Association. (2011). 2011 Alzheimer's Disease facts and figures. *Alzheimer's Disease and Dementia*, *7(2),* 1 – 68.

Alzheimer Association. (2014). *Dementia and driving resource center*. Retrieved Aril 1, 2014 from http://www.alz.org/care/alzheimers-dementia-and-driving.asp#resources.

Alzheimer's Disease International. The prevalence of dementia worldwide. 2008. Available at: http://www.alz.co.uk/adi/pdf/prevalence.pdf. Retrieved March 20, 2013.

Alzheimer Society of Canada. (2007). *Tough issues: Driving*. Retrieved April 1, 2014 from http://www.alzheimer.ca/~/media/Files/national/brochures-tough-issues/Tough_Issues_Driving_e.pdf.

Alzheimer Society of Canada. (2010). Rising tide: The Impact of dementia on Canadian society. Retrieved on April 11, 2014 from http://www.alzheimer.ca/~/media/Files/national/Advocacy/ASC_Rising_Tide_Full_Report_e.pdf.

Alzheimer Society of Canada. (2011). *About dementia*. Retrieved March 31, 2014 from http://www.alzheimer.ca/en/About-dementia.

American Academy of Family Physicians. (2006). Driving and dementia: What you should know. *American Family Physician, 73*(6), 1035 – 1036.

American Psychiatric Association. (2013). *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.). Arlington, VA: American Psychiatric Publishing.

Anderson, S. W., Rizzo, M., Shi, Q., Uc, E. Y., & Dawson, J. D. (2005). Cognitive abilities related to driving performance in a simulator and crashing on the road. *Proceedings of the Third International Driving Symposium on Human Factors in Driving Assessment, Training, and Vehicle Design*, 286 – 292.

Anstey, K. J., Wood, J., Lord, S., & Walker, J. G. (2005). Cognitive, sensory, and physical factors enabling driving safety in older adults. *Clinical Psychology Review, 25,* 45 – 65.

Aronson, M. (1988). Caring for the dementia patient. In Aronson, M. (Ed.), *Understanding Alzheimer's Disease.* New York: Charles Scribner.

Baldock, M. R. J. (2004). *Self-regulation of the driving behavior of older drivers* (Doctoral dissertation). Retrieved from PsychInfo.

British Columbia Automobile Association. (2014). *Older drivers: Plan to stop driving*. Retrieved on April 1, 2014 from http://www.bcaa.com/road-safety/older-drivers/plan-to-stop-driving.

Belle, S. H., Burgio, L., Burns, R., Coon, D., Czaja, S. J., Gallagher-Thompson, D., Gitlin, L. N., Klinger, J., Koepke, K. M., Le, C. C., Martindale-Adams, J., Nichols, L., Schulz, R., Stahl, S., Stevens, A., Winter, L., Zhang, S. & Resources for Enhancing Alzheimer's Caregiver Health (REACH) II Investigtors. (2006). Enhancing the quality of life of dementia caregivers from different ethnic or racial groups: A randomized, controlled trial. *Annals of Internal Medicine*, *145*(10), 727 – 738.

Bonnel, W. B. (1999). Giving up the car: Older women's losses and experiences. *Journal of Psychosocial Nursing, 37*(5), 10 – 15.

Boychuk-Duchscher, J.E. & Mogan, D. (2004). Grounded theory: Reflections on the emergence vs. forcing debate. *Journal of Advanced Nursing, 48*(6), 605 – 12.

Breen, D. A., Breen, D. P., Moore, J. W., Breen, P. A. and O'Neill, D. (2007). Driving and dementia. *BMJ*, *334*, 1365 – 1369.

Brodaty, H., Green, A., & Koschera, A. (2003). Meta-analysis of psychosocial interventions for caregivers of people with dementia. *Journal of the American Geriatrics Society*, *51*(5), 657 – 664.

Brown, L. B., Ott, B. R., Papandonatos, G. D., Sui, Y., Ready, R. E., & Morris, J. C. (2005). Prediction of on-road driving performance in patients with early Alzheimer's disease. *Journal of the American Geriatrics Society*, *53*(1), 94 – 98.

Burkhardt, J. E. (2000). Limitations of mass transportation and individual vehicle systems for older persons. In K. W. Schaie and M. Pietrucha (Eds.), *Mobility and Transportation in the Elderly* (pp. 97-123), New York: Springer Publishing.

Bury, A., Popple, K., & Barker, J. (1998). "You've got to think really hard: Children making sense of the aims and content of theatre in health education. *RIDE: Research is Drama Education*, *3*(1), 12 – 27.

Byszewski, A. M., Graham, I. D., Amos, S., Man-Son-Hing, M., Dalziel, W. B., Marshall, S., & ... Guzman, D. (2003). A Continuing Medical Education Initiative for Canadian Primary Care Physicians: The Driving and Dementia Toolkit: A Pre- and Postevaluation of Knowledge, Confidence Gained, and Satisfaction. *Journal of the American Geriatrics Society*, *51*(10), 1484 – 1489.

Canadian Study of Health and Aging Working Group. (1994). Patterns of caring for people with dementia in Canada. *Canadian Journal on Aging*, *13*(4), 470 – 487.

CanDRIVE. (2014). *Resources.* Retrieved on April 1, 2014 from https://www.candrive.ca/en/resources.html.

Carretero, S., Garcés, J., Ródenas, F., & Sanjosé, V. (2009). The informal caregiver's burden of dependent people: Theory and empirical review. *Archives of Gerontology and Geriatrics*, *49*(1), 74 – 79.

Champlain Dementia Network. (2011). *The driving and dementia toolkit (for patients and caregivers), 1st edition.* Champlain Dementia Network: Ottawa, ON.

Champlain Dementia Network. (2009). *The driving and dementia toolkit (for health professionals), 3rd edition*. Champlain Dementia Network: Ottawa, ON.

Canadian Institutes of Health Research. (2014). More about Knowledge Translation at CIHR. Retrieved on May 27, 2014 from http://www.cihr-irsc.gc.ca/e/39033.html.

Canadian Institutes of Health Research. (2012). Guide to knowledge translation planning at CIHR: Integrated and end-of-grant approaches. Retrieved on March 30, 2014 from http://www.cihr-irsc.gc.ca/e/45321.html#a2.

Canadian Institutes of Health Research (2007). *Canadian Institutes of Health Research knowledge translation [KT] within the research cycle chart*. Ottawa, ON. Retrieved on March 1, 2013 from http://198.214.141.98/kt/products/ktintro/ktmodels.html.

Cotrell, V., & Wild, K. (1999). Longitudinal study of self-imposed driving restrictions and deficit awareness in patients with Alzheimer disease. *Alzheimer Disease And Associated Disorders*, *13*(3), 151 – 156.

Coughlin, J. (2001). *Transportation and Older Persons: Perceptions and Preferences: A Report on Focus Groups*. AARP, Washington, D.C. (Available at http://research .aarp.org/il/2001_05_transport.pdf).

Dalhousie University. (2010). *Canadian Dementia Knowledge Translation Network (CDKTN).* Retrieved on October 21, 2010 from http://geriatricresearch.medicine.dal.ca/cdktn.html.

D'Ambrosio, L. A., Coughlin, J. F., Mohyde, M., Carrut, A., Hunter, J. C., & Stern, R. A. (2009). Caregiver communications and the transition from driver to passenger among people with dementia. *Topics in Geriatric Rehabilitation*, *25*(1), 33 – 42.

D'Ambrosio, L. A., Donorfio, L. M., Coughlin, J. F., Mohyde, M., & Meyer, J. (2008). Gender differences in self-regulation patterns and attitudes toward driving among older adults. *Journal Of Women & Aging*, *20(3-4)*, 265 – 282.

Dobbs, B. M., Harper, L. A., & Wood, A. (2009). Transitioning from driving to driving cessation: The role of specialized driving cessation support groups for individuals with dementia. *Topics in Geriatric Rehabilitation*, *25(1)*, 73 – 86.

Donorfio, L. K. M., D’Ambrosio, L. A., Coughlin, J. F., & Mohyde, M. (2008). Health, safety, self-regulation and the older driver: It’s not just a matter of age. *Journal of Safety Research*, *39*, 555 – 561.

Duchek, J., Carr, D., Hunt, L., Roe, C., Xiong, C., Shah, K., & Morris, J.C. (2003). Longitudinal driving performance in early-stage dementia of the Alzheimer type. *Journal of the American Geriatrics Society*, *51*(10). 1342 – 1347.

Family Caregiver Alliance. (2014a). *Definitions*. Retrieved on April 10, 2014 from http://caregiver.org/definitions-0.

Family Caregiver Alliance. (2014b). *Dementia & driving*. Retrieved on April 1, 2014 from http://caregiver.org/dementia-driving.

Fleming, P. (2012). Social desirability, not what it seems: A review of the implications for self-reports. *The International Journal of Educational and Psychological Assessment, 11*(1), 3 – 22.

Fortinsky, R. H., Kercher, K., & Burant, C. J. (2002). Measurements and correlates of family caregiver self-efficacy for managing dementia. *Aging and Mental Health, 6,* 153 – 160.

Fox, G. K. & Bashford, G. M. (1997). Driving and dementia: Balancing personal independence and public safety. *Medical Journal of Australia, 167,* 406 – 407.

Fox, G. K., Bowden, S. C., Bashford, G. M., & Smith, D. S. (1997). Alzheimer disease and driving: Prediction and assessment of driving performance. *Journal of the American Geriatric Society, 45,* 949 – 953.

Gallagher-Thompson, D. & Coon, D. W. (2007). Evidence-based psychological treatments for distress in family caregivers of older adults. *Psychology and Aging, 22,* 37 – 51.

Galvin, J. E., Duda, J. E., Kaufer, D. I., Lippa, C. F., Taylor, A., & Zarit, S. H. (2010). Lewy body dementia: Caregiver burden and unmet demands. *Alzheimer Disease and Associated Disorders, 24(2),* 177 – 181.

Gardezi, F. G., Wilson, K. G., Man-Son-Hing, M., Marshall, S. C., Molnar, F. J., Dobbs, B. M., & Tuokko, H. A. (2006). Qualitative research on older drivers. *Clinical Gerontologist, 30(1),* 5 – 22.

Gerber, R. & Williams, M. (1996). Qualitative Research in Geographical Education, Univerity of New England Press, Australia.

Graham, I. D. & Logan, J. (2004). Innovations in knowledge transfer and continuity of care, *Canadian Journal of Nursing Research, (36),* 89 – 103.

Graham, I. D., Logan, J., Harrison, M. B., Straus, S. E., Tetroe, J., Caswell, W., & Robinson, N. (2006). Lost in knowledge translation: Time for a map? *Journal of Continuing Education in the Health Professions, 26,* 13 – 24.

Graham, I. D., & Tetroe, J. (2007). Some theoretical underpinnings of knowledge translation. *Academic Emergency Medicine, 14,* 936 – 941.

Graham, I. D., & Tetroe, J. M. (2009a). Getting evidence into policy and practice: Perspective of a health research funder. *Journal of The Canadian Academy of Child and Adolescent, 18*(1), 46 – 50.

Graham, I. D., & Tetroe, J. M. (2009b). Theories of Knowledge to Action: Planned Action Theories. In S. Straus, J. M. Tetroe, and Graham, I. D. (Eds.). *Knowledge Translation in Health Care Moving from Evidence to Practice*. London: Wiley-Blackwell.

Green, C. A., Duan, N., Gibbons, R. D., Hoagwood, K. E., Palinkas, L. A., & Wisdom, J. P. (2014). Approaches to mixed methods dissemination and implementation research: Methods, strengths, caveats, and opportunities. *Administration and Policy in Mental Health and Mental Health Services Research*, doi:10.1007/s10488-014-0552-6.

Gruffydd, E. & Randle, J. (2006). Alzheimer's disease and the psychosocial burden for caregivers. *Community Practice*, *79,* 15 – 18.

Gwyther, H., & Holland, C. (2012). The effect of age, gender and attitudes on self-regulation in driving. *Accident Analysis And Prevention*, *45,* 19 – 28.

Hartford. (2013). *We need to talk: Family conversations with older adults*. Hartford, DT: The Hartford Financial Services Group, Inc.

Hartford. (2010). *At the crossroads: Family conversations about Alzheimer's disease, dementia, and driving.* Hartford, CT: The Hartford Financial Services Group, Inc.

Hartford. (2007). *At the crossroads: The support group leaders kit on Alzheimer's disease, dementia & driving*. Hartford, CT: Author. Available at http://www.thehartford.com/alzheimers/support_group_leader_brochure.html

Hebert, K., Martin-Cook, K., Svetlik, D. A., Weiner, M. F. (2002). Caregiver decision-making and driving: What we say versus what we do. *Clinical Gerontologist, 26(1/2),* 17 – 29.

Horowitz, A., Boerner, K., & Reinhardt, J. P. (2002). Psychosocial aspects of driving transitions in elders with low vision. *Gerontech Journal, 1*(4), 262 – 273.

Hunt, L., Morris, J., Edwards, D., & Wilson, B. (1997). Reliability of the Washington Road Test. *Archives of Neurology, 54,* 707 – 712.

IBM Corp. (2013). IBM SPSS Statistics for Windows, Version 22.0. Armonk, NY: IBM Corp.

Johnson, J. E. (1999). Urban older adults and the forfeiture of a driver's license. *Journal of Gerontological Nursing, 25*, 12 – 18.

Kingston, Frontenac, Lennox, & Addington Dementia Network. (2013). Driving and dementia: A guide for patients and their families. Retrieved on March 1, 2014 from http://www.providencecare.ca/clinical-tools/Documents/Driving-and-Dementia-Patient-Info.pdf.

Kitson, A., Harvey, G., & McCormack, B. (1998). Enabling the implementation of evidence based practice: A conceptual framework. *Quality in Health Care*, *7,* 149 – 158.

Kitson, A.L, Rycroft-Malone, J. Harvey, G., McCormack, B., Seers, K., & Titchen, A. (2008). Evaluating the successful implementation of evidence into practice using the PARIHS framework: theoretical and practical challenges. *Implementation Science, 3(1),* 1 – 12.

Krueger, R. (1988). *Focus groups: A practical guide for applied research.* Thousand Oaks: SAGE Publications, Inc.

Lewcock, D. (2014). The origins of drama: An introduction. Retrieved on April 13, 2014 http://www.academia.edu/202853/The_Origins_of_Drama_an_Introduction.

Lloyd, S., Cormack, C., Blais, K., Messeri, G., McCallum, M. A., Spicer, K., & Morgan, S. (2001). Driving and dementia: A review of the literature. *Canadian Journal of Occupational Therapy, 68,* 149 – 155.

Logan, J. & Graham, I. D. (1998). Toward a comprehensive interdisciplinary model of healthcare research use. *Science Communication, 20(2),* 227 – 246.

Mahoney, R. Regan, C., Katona, C., & Livingston, G. (2005). Anxiety and depression in family caregivers of people with Alzheimer disease: The LASER-AD study. *American Journal of Geriatric Psychiatry, 13(9),* 795 – 801.

Man-Son-Hing, M., Marshall, S. C., Molnar, F. J., & Wilson, K. G. (2007). Systematic review of driving risk and the efficacy of compensatory strategies in persons with dementia. *Journal of the American Geriatrics Society, 55(6),* 878 – 884.

Mayo Clinic. (2013). Alzheimer's stages: How the disease progresses. Retrieved March 15, 2013 from http://www.mayoclinic.com/health/alzheimers-stages/AZ00041/NSECTIONGROUP=2.

Mayo Clinic. (2013). Alzheimer's: When to stop driving. Retrieved on April 1, 2014 from http://www.mayoclinic.org/healthy-living/caregivers/in-depth/alzheimers/art-20044924.

Meuser, T. M., Carr, D. B., Berg-Weger, M., Niewoehner, P. and Morris, J. C. (2006). Driving and dementia in older adults: Implementation and evaluation of a continuing education project. *Gerontologist*, *46*, 680 – 687.

Minister of Justice. (2000). *Canadian Institutes of Health Research Act*. Retrieved on May 27, 2014 from http://laws-lois.justice.gc.ca/eng/acts/C-18.1/.

Molnar, L. J., & Eby, D. W. (2008). The relationship between self-regulation and driving related abilities in older drivers: An exploratory study. *Traffic Injury Prevention*, *9*, 314 – 319.

Morgan, D. L. (Eds.). (1993) Successful focus groups: Advancing the state of the art. Newbury Park: SAGE Publications, Inc.

Morgan, N. & Saxton, J. (1987). *Teaching drama: A mind of many wonders.* London, UK: Hutchinson Education.

Morgan, N. & Saxton, J. (2006). *Asking better questions* (2nd Ed.). Markham, ON: Pembroke.

Munro, B. H. (2005). *Statistical methods for health care research* (5th ed.). Philadelphia, PA: Lippincott Williams & Wilkins.

National Institute of Neurological Disorders and Stroke. (2010). *Dementia: Hope through rese arch.* Retrieved March 20, 2013, from http://www.ninds.nih.gov/disorders/dementias/detail_dementia.htm.

National Institute on Aging. (2014). *Caregiver guide: Tips for caregivers of peoplewith Alzheimer's Disease: Driving.* Retrieved April 1, 2014 from http://www.nia.nih.gov/alzheimers/publication/caregiver-guide#driving.

Neelands, J. & Dobson, W. (2000). Advanced drama and theatre studies (2nd Ed.) London, UK: Hodder Education.

Ontario Ministry of Transportation. (2004). *Ontario road safety annual report, 2002.* Toronto, ON: The Ministry of Transportation.

Ostwald, S. K. (2006). The caregiver in dementia. In *Supporting the caregiver in dementia: A guide for health care professionals* (pp. 25-45). Baltimore, MD: Johns Hopkins University Press.

Perkinson, M. A., Berg-Weger, M. L., Carr, D. B., Meuser, T. M., Palmer, J. L., Buckles, V. D., Powlishta, K.K., Foley, D. J., & Morris, J. C. (2005). Driving and dementia of the Alzheimer type: Beliefs and cessation strategies among stakeholders. *Gerontologist, 45(5),* 676 – 685.

Persson, D. (1993). The elderly driver: Deciding when to stop. *Gerontologist, 33,* 411 – 416.

Prendergast, M. (2008). *Teaching spectatorship: Essays and poems on audience in performance.* Amherst, NY: Cambria Press.

Prendergast, M. & Saxton, J. (2009). Applied theatre: International case studies and challenges for practice. Malta: Gutenberg Press.

Prochaska, J. O., & DiClemente, C. C. (1982). Transtheoretical therapy: Toward a more integrative model of change. *Psychotherapy: Theory, Research & Practice, 19*, 276 – 288.

Quek, L., White, A., Low, C., Brown, J., Dalton, N., Dow, D., & Connor, J. P. (2012). Good choices, great future: An applied theatre prevention program to reduce alcohol-related risky behaviours during schoolies. *Drug and Alcohol Review, 31*(7), 897 – 902.

Rabbitt, P. M. A., Carmichael, A., Shilling, V., & Sutcliffe, P. (2002). *Age, health, and driving: Longitudinally observed changes in reported general health, in mileage, self-rated competence and in attitudes of older drivers.* Manchester: Foundation for Road Safety Research.

Ragland, D. R., Satariano, W. A., & MacLeod, K. E. (2004). Reasons given by older people for limitation or avoidance of driving. *The Gerontologist*, *44*, 237 – 244.

Ronch, J. L., & Crispi, E. (1997). Separation and loss in Alzheimer's disease: Impact on the family. In I. Deitch, C. Howell (Eds.), *Counseling the aging and their families* (pp. 105-119). Alexandria, VA US: American Counseling Association.

Rossiter, K., Kontos, P., Colantonio, A., Gilbert, J., Gray, J., & Keightley, M. (2008). Staging data: Theatre as a tool for analysis and knowledge transfer in health research. *Social Science & Medicine*, *66*(1), 130 – 146.

Ruechel, S., & Mann, W. C. (2005). Self-regulation of driving by older persons. *Physical & Occupational Therapy In Geriatrics*, *23*(2-3), 91 – 101.

Rycroft-Malone, J., (2004). The PARIHS framework – A framework for guiding the implementation of evidence-based practice. *Journal of Nursing Care Quality, 19*(4), 297 – 304.

Rycroft-Malone, J., Kiston, A., Harvey, G., McCormack, B., Seers, K., Titchen, A., & Estabrooks, C. (2002). Ingredients for change: Revisiting a conceptual framework. *Quality and Safety in Health Care, 11*, 174 – 180.

Sanders, S., Ott, C. H., Kelber, S. T., & Noonan, P. (2008). The experience of high levels of grief in caregivers of persons with Alzheimer’s disease and related dementia. *Death Studies, 32*, 495 – 523.

Shortell, S. M. (1999). The emergence of qualitative methods in health services research. *Health Services Research*, *34*(5Pt2), 1083 – 1090.

Slaughter, S. E., Estabrooks, C.A., Jones, C.A., Wagg, A. S., & Eliasziw, M. (2013). Sustaining Transfers through Affordable Research Translation (START): Study protocol to assess knowledge translation interventions in continuing care settings. *Trials, 14*, 355.

Sobell, L. C. & Sobell, M. B. (2008). Motivational interviewing strategies and techniques: Rationales and examples. Retrieved on April 24, 2015 from http://www.nova.edu/gsc/forms/mi_rationale_techniques.pdf

Sörensen, S., Pinquart, M., & Duberstein, P. (2002). How effective are interventions with caregivers? An updated meta-analysis. *The Gerontologist*, *42*(3), 356 – 372.

Statistics Canada. (2014). The Canadian population in 2011: Age and sex. Retrieved on April 25, 2014 from http://www12.statcan.ca/census-recensement/2011/as-sa/98-311-x/98-311-x2011001-eng.cfm.

Statistics Canada. (2008). *Eldercare: What we know today*. Retrieved on April 11, 2014 from http://www.statcan.gc.ca/pub/11-008-x/2008002/article/10689-eng.htm#a2.

Stern, R. A., D'Ambrosio, L. A., Mohyde, M., Carruth, A., Tracton-Bishop, B., Hunter, J. D., Daneshvar, D. H., & Coughlin, J. F. (2008). At the crossroads: Development and evaluation of a dementia caregiver group intervention to assist in driving cessation. *Gerontology and Geriatrics Education, 29(4),* 363 – 382.

Stuart, S. (2006). Interpersonal psychotherapy: A guide to the basics. *Psychiatric Annals, 36*(8), 542 – 549.

Sudsawad, P. (2007). *Knowledge translation: Introduction to models, strategies, and measures.* Austin, TX: Southwest Educational Development Laboratory, National Center for the Dissemination of Disability Research.

Taylor, B. D., & Tripodes, S. (2001). The effects of driving cessation on the elderly with dementia and their caregivers. *Accident Analysis And Prevention*, *33*(4), 519 – 528.

Thompson, J. & Jackson, A. (2006). Applied theatre/drama: An e-debate in 2004: Viewpoints. *RIDE: Research in Drama and Education*, *11*(1), 90 – 95.

Tomaszewski Farias, S., Mungas, D., & Jagust, W. (2005). Degree of discrepancy between self and other-reported everyday functioning by cognitive status: dementia, mild cognitive impairment, and healthy elders. *International Journal of Geriatric Psychiatry, 20(9),* 827 – 834.

Tuokko, H., Rhodes, R., Love, J., Cloutier-Fisher, D., Jouk, A., & Scholitsch, A. (2013). Change in beliefs about older drivers through applied theatre. *Educational Gerontology, 39(1),* 45 – 56.

Tuokko, H., Rhodes, R., Love, J., Cloutier-Fisher, D., Jouk, A., & Scholitsch, A. (In press). Just the facts: Changes in older driver attitudes after exposure to educational interventions. *Traffic Injury Prevention.*

Turano, K. A., Munoz, B., Hassan, S. E., Duncan, D. D., Gower, E. W., Roche, K. B., Keay, L., Munro, C. A., & West, S. K. (2009). Poor sense of direction is associated with constricted driving space in older drivers. *The Journals of Gerontology: Series B: Psychological Sciences and Social Sciences*, *64B*(3), 348 – 355.

Wackerbath, S. & Johnson, M. (1999). What decisions are made by family caregivers? *American Journal of Alzheimer's Disease, 14,* 111 – 119.

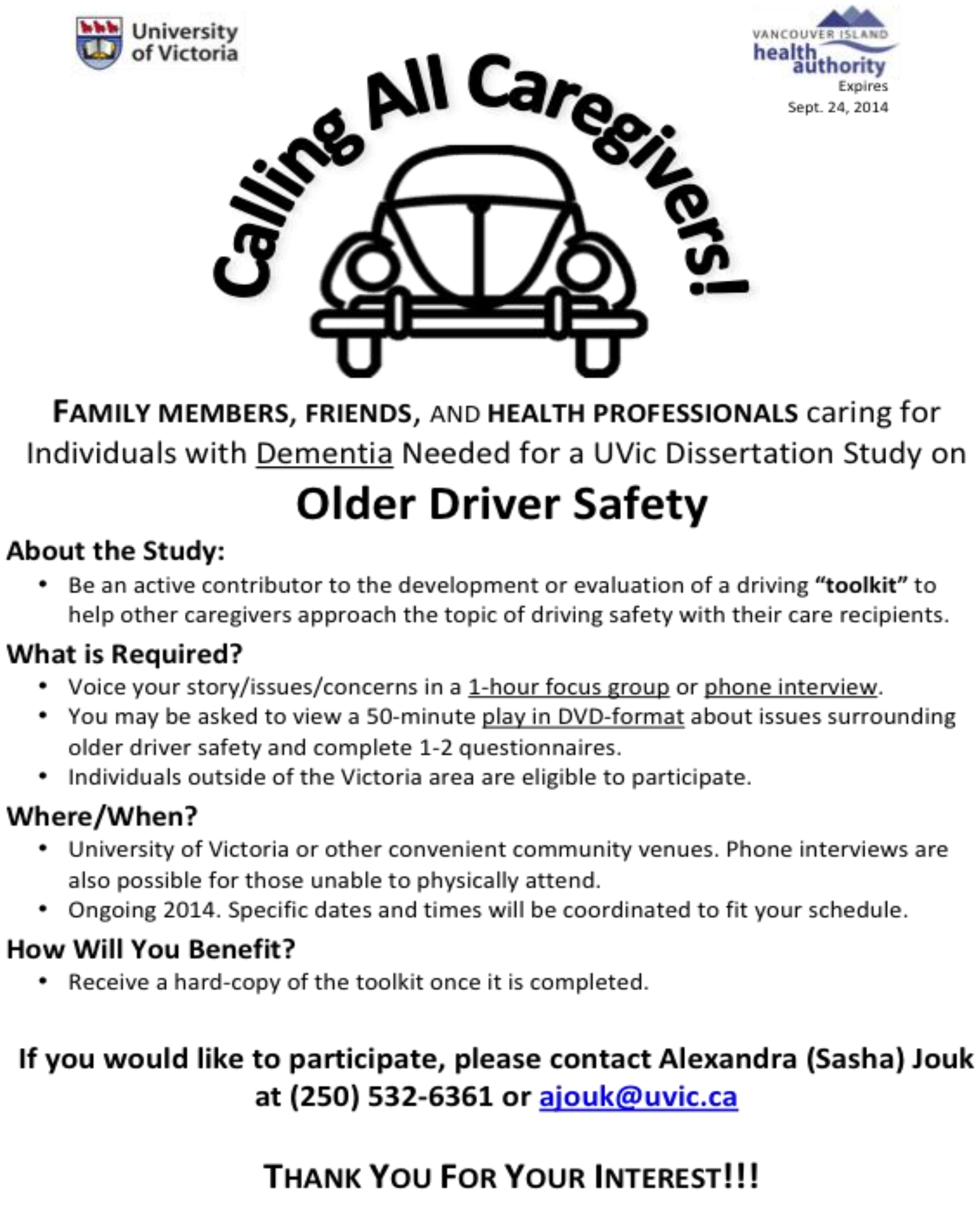
Wild, K., & Cotrell, V. (2003). Identifying driving impairment in Alzheimer disease: A comparison of self and observer reports versus driving evaluation. *Alzheimer Disease And Associated Disorders*, *17*(1), 27 – 34.

World Health Organization. (2011). *Global health and aging*. Retrieved on March 31, 2014 from http://www.nia.nih.gov/sites/default/files/global_health_and_aging.pdf.

Yassuda, M. S., Wilson, J. J., & von Mering, O. (1997). Driving cessation: The perspective of senior drivers. *Educational Gerontology*, *28*, 525 – 538.

Appendices

Appendix A: Poster Advertisement



University of Victoria

VANCOUVER ISLAND health authority

Expires
Sept. 24, 2014

Calling All Caregivers!

FAMILY MEMBERS, FRIENDS, AND **HEALTH PROFESSIONALS** caring for Individuals with Dementia Needed for a UVic Dissertation Study on

Older Driver Safety

About the Study:

- Be an active contributor to the development or evaluation of a driving **"toolkit"** to help other caregivers approach the topic of driving safety with their care recipients.

What is Required?

- Voice your story/issues/concerns in a 1-hour focus group or phone interview.
- You may be asked to view a 50-minute play in DVD-format about issues surrounding older driver safety and complete 1-2 questionnaires.
- Individuals outside of the Victoria area are eligible to participate.

Where/When?

- University of Victoria or other convenient community venues. Phone interviews are also possible for those unable to physically attend.
- Ongoing 2014. Specific dates and times will be coordinated to fit your schedule.

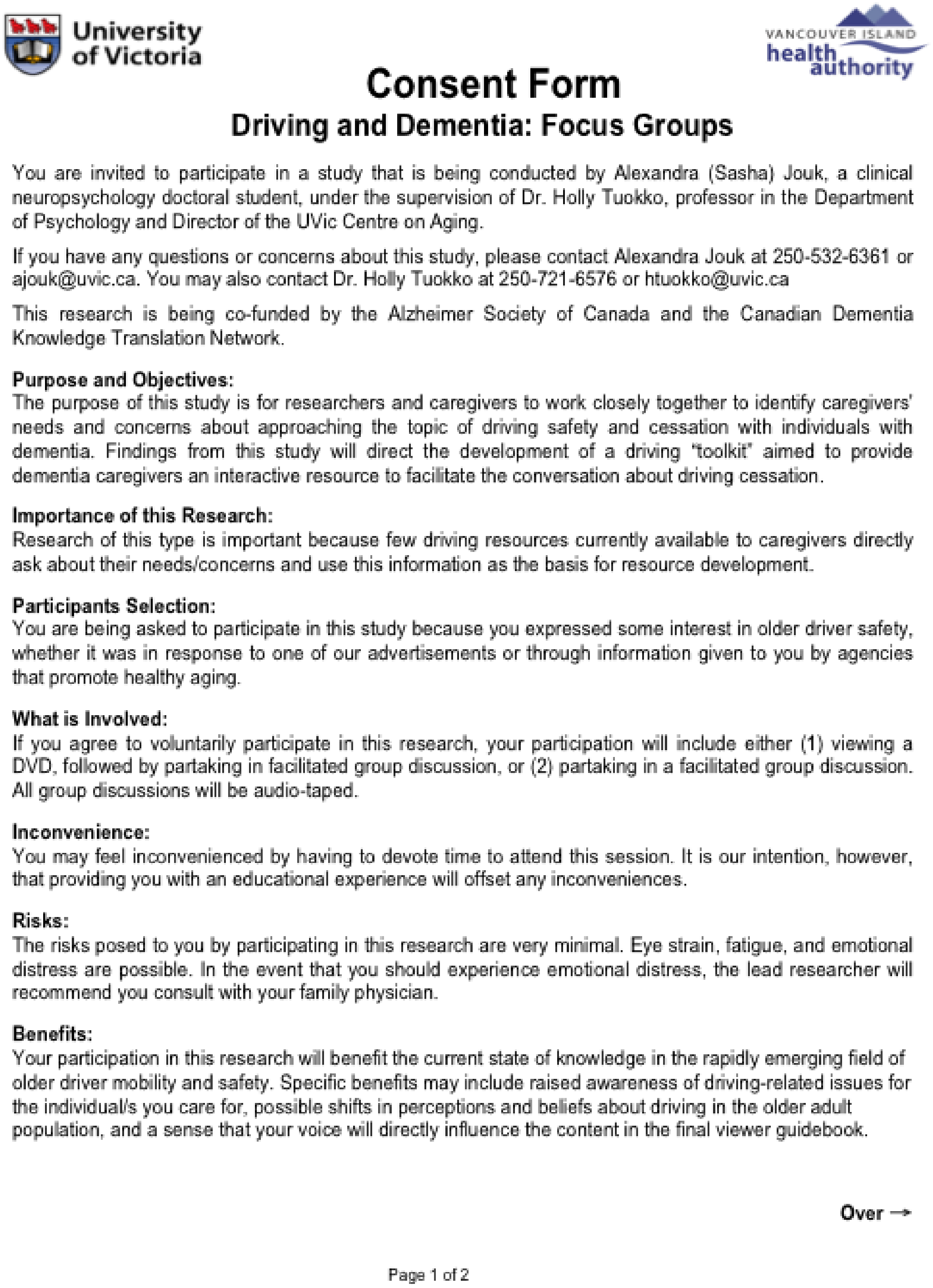
How Will You Benefit?

- Receive a hard-copy of the toolkit once it is completed.

If you would like to participate, please contact Alexandra (Sasha) Jouk at (250) 532-6361 or ajouk@uvic.ca

THANK YOU FOR YOUR INTEREST!!!

Appendix B: Study 1 In-Person Consent Form
Front Side



University of Victoria

VANCOUVER ISLAND
health authority

Consent Form
Driving and Dementia: Focus Groups

You are invited to participate in a study that is being conducted by Alexandra (Sasha) Jouk, a clinical neuropsychology doctoral student, under the supervision of Dr. Holly Tuokko, professor in the Department of Psychology and Director of the UVic Centre on Aging.

If you have any questions or concerns about this study, please contact Alexandra Jouk at 250-532-6361 or ajouk@uvic.ca. You may also contact Dr. Holly Tuokko at 250-721-6576 or htuokko@uvic.ca

This research is being co-funded by the Alzheimer Society of Canada and the Canadian Dementia Knowledge Translation Network.

Purpose and Objectives:
The purpose of this study is for researchers and caregivers to work closely together to identify caregivers' needs and concerns about approaching the topic of driving safety and cessation with individuals with dementia. Findings from this study will direct the development of a driving "toolkit" aimed to provide dementia caregivers an interactive resource to facilitate the conversation about driving cessation.

Importance of this Research:
Research of this type is important because few driving resources currently available to caregivers directly ask about their needs/concerns and use this information as the basis for resource development.

Participants Selection:
You are being asked to participate in this study because you expressed some interest in older driver safety, whether it was in response to one of our advertisements or through information given to you by agencies that promote healthy aging.

What is Involved:
If you agree to voluntarily participate in this research, your participation will include either (1) viewing a DVD, followed by partaking in facilitated group discussion, or (2) partaking in a facilitated group discussion. All group discussions will be audio-taped.

Inconvenience:
You may feel inconvenienced by having to devote time to attend this session. It is our intention, however, that providing you with an educational experience will offset any inconveniences.

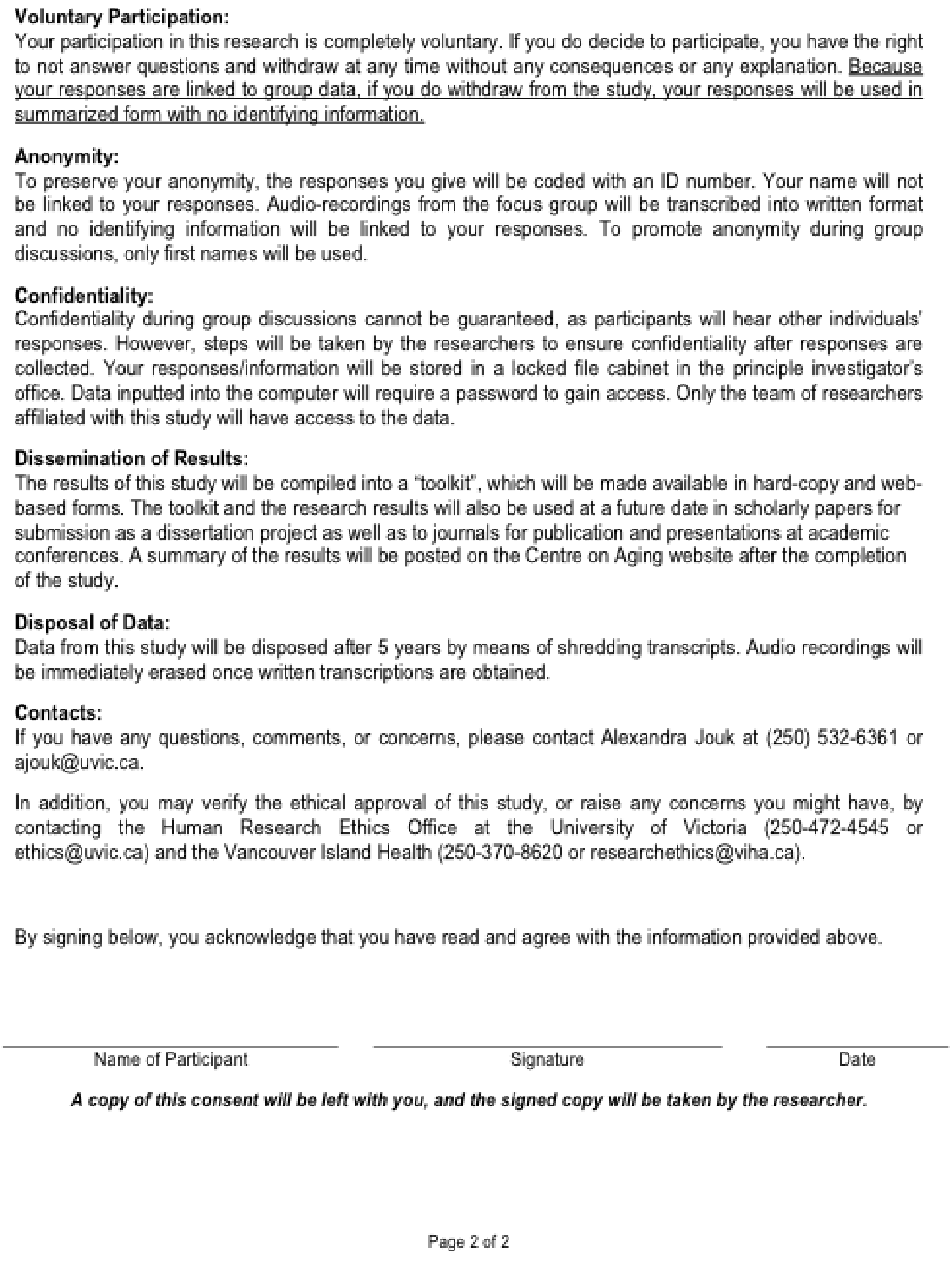
Risks:
The risks posed to you by participating in this research are very minimal. Eye strain, fatigue, and emotional distress are possible. In the event that you should experience emotional distress, the lead researcher will recommend you consult with your family physician.

Benefits:
Your participation in this research will benefit the current state of knowledge in the rapidly emerging field of older driver mobility and safety. Specific benefits may include raised awareness of driving-related issues for the individual/s you care for, possible shifts in perceptions and beliefs about driving in the older adult population, and a sense that your voice will directly influence the content in the final viewer guidebook.

Over →

Page 1 of 2

Appendix B: Study 1 In-Person Consent Form
Back Side



Voluntary Participation:
Your participation in this research is completely voluntary. If you do decide to participate, you have the right to not answer questions and withdraw at any time without any consequences or any explanation. Because your responses are linked to group data, if you do withdraw from the study, your responses will be used in summarized form with no identifying information.

Anonymity:
To preserve your anonymity, the responses you give will be coded with an ID number. Your name will not be linked to your responses. Audio-recordings from the focus group will be transcribed into written format and no identifying information will be linked to your responses. To promote anonymity during group discussions, only first names will be used.

Confidentiality:
Confidentiality during group discussions cannot be guaranteed, as participants will hear other individuals' responses. However, steps will be taken by the researchers to ensure confidentiality after responses are collected. Your responses/information will be stored in a locked file cabinet in the principle investigator's office. Data inputted into the computer will require a password to gain access. Only the team of researchers affiliated with this study will have access to the data.

Dissemination of Results:
The results of this study will be compiled into a "toolkit", which will be made available in hard-copy and web-based forms. The toolkit and the research results will also be used at a future date in scholarly papers for submission as a dissertation project as well as to journals for publication and presentations at academic conferences. A summary of the results will be posted on the Centre on Aging website after the completion of the study.

Disposal of Data:
Data from this study will be disposed after 5 years by means of shredding transcripts. Audio recordings will be immediately erased once written transcriptions are obtained.

Contacts:
If you have any questions, comments, or concerns, please contact Alexandra Jouk at (250) 532-6361 or ajouk@uvic.ca.

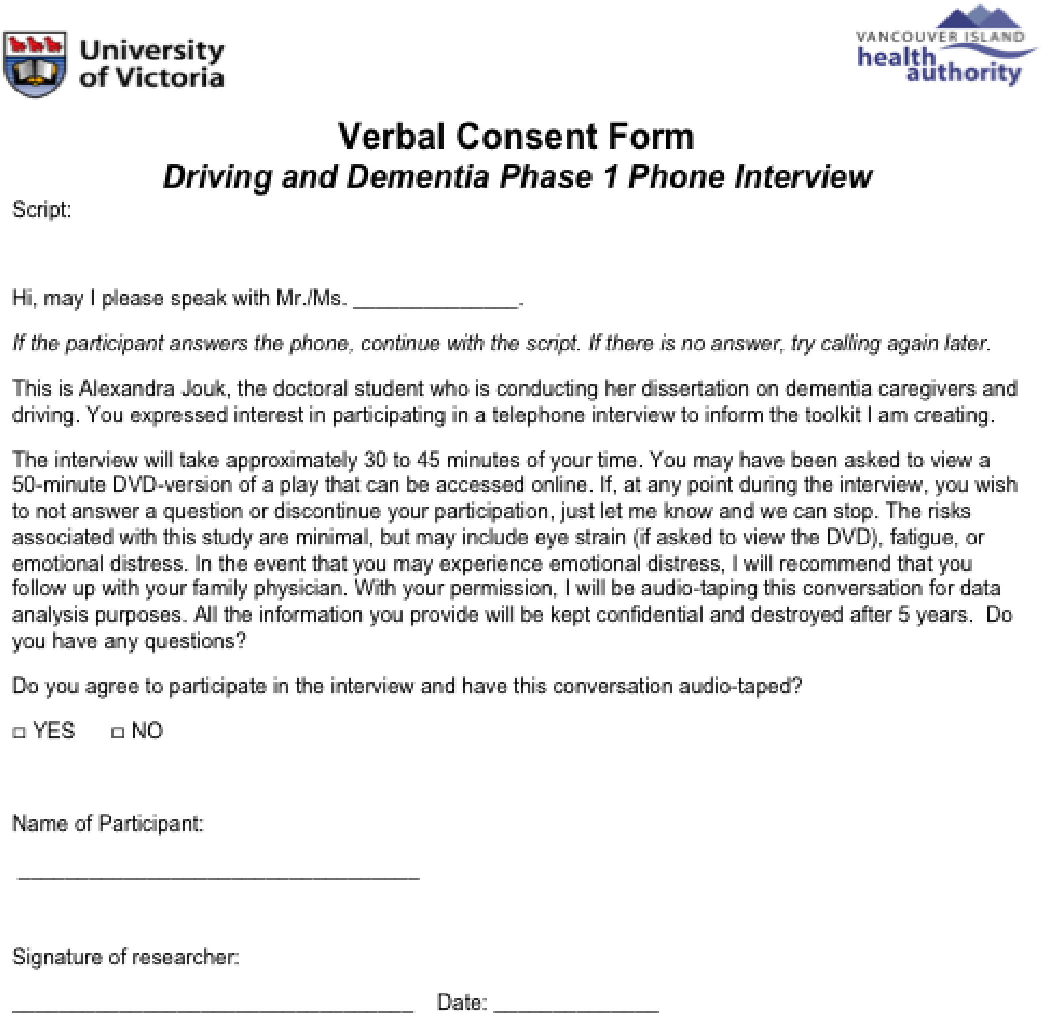
In addition, you may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Human Research Ethics Office at the University of Victoria (250-472-4545 or ethics@uvic.ca) and the Vancouver Island Health (250-370-8620 or researchethics@viha.ca).

By signing below, you acknowledge that you have read and agree with the information provided above.

Name of Participant	Signature	Date

A copy of this consent will be left with you, and the signed copy will be taken by the researcher.

Appendix C: Study 1 Verbal Consent Form



University of Victoria

VANCOUVER ISLAND health authority

Verbal Consent Form

Driving and Dementia Phase 1 Phone Interview

Script:

Hi, may I please speak with Mr./Ms. ______________.

If the participant answers the phone, continue with the script. If there is no answer, try calling again later.

This is Alexandra Jouk, the doctoral student who is conducting her dissertation on dementia caregivers and driving. You expressed interest in participating in a telephone interview to inform the toolkit I am creating.

The interview will take approximately 30 to 45 minutes of your time. You may have been asked to view a 50-minute DVD-version of a play that can be accessed online. If, at any point during the interview, you wish to not answer a question or discontinue your participation, just let me know and we can stop. The risks associated with this study are minimal, but may include eye strain (if asked to view the DVD), fatigue, or emotional distress. In the event that you may experience emotional distress, I will recommend that you follow up with your family physician. With your permission, I will be audio-taping this conversation for data analysis purposes. All the information you provide will be kept confidential and destroyed after 5 years. Do you have any questions?

Do you agree to participate in the interview and have this conversation audio-taped?

☐ YES ☐ NO

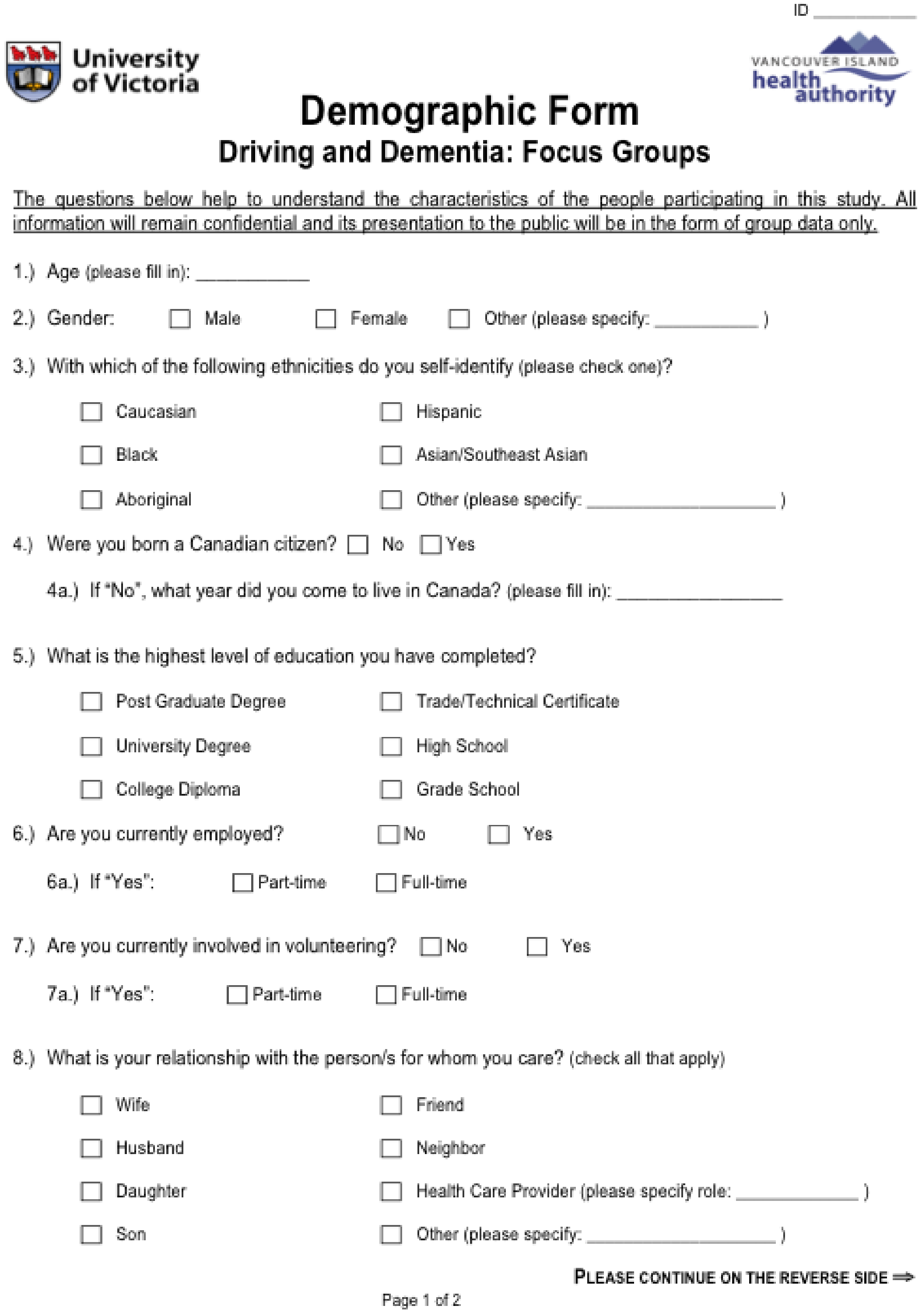
Name of Participant:

____

Signature of researcher:

___________________________________ Date: ______________

Appendix D: Study 1 Demographic Form
Front Side



ID ____________

University of Victoria

VANCOUVER ISLAND health authority

Demographic Form
Driving and Dementia: Focus Groups

The questions below help to understand the characteristics of the people participating in this study. All information will remain confidential and its presentation to the public will be in the form of group data only.

1.) Age (please fill in): ____________

2.) Gender: ☐ Male ☐ Female ☐ Other (please specify: ___________)

3.) With which of the following ethnicities do you self-identify (please check one)?

☐ Caucasian
☐ Black
☐ Aboriginal
☐ Hispanic
☐ Asian/Southeast Asian
☐ Other (please specify: ____________________)

4.) Were you born a Canadian citizen? ☐ No ☐ Yes

4a.) If "No", what year did you come to live in Canada? (please fill in): _________________

5.) What is the highest level of education you have completed?

☐ Post Graduate Degree
☐ University Degree
☐ College Diploma
☐ Trade/Technical Certificate
☐ High School
☐ Grade School

6.) Are you currently employed? ☐ No ☐ Yes

6a.) If "Yes": ☐ Part-time ☐ Full-time

7.) Are you currently involved in volunteering? ☐ No ☐ Yes

7a.) If "Yes": ☐ Part-time ☐ Full-time

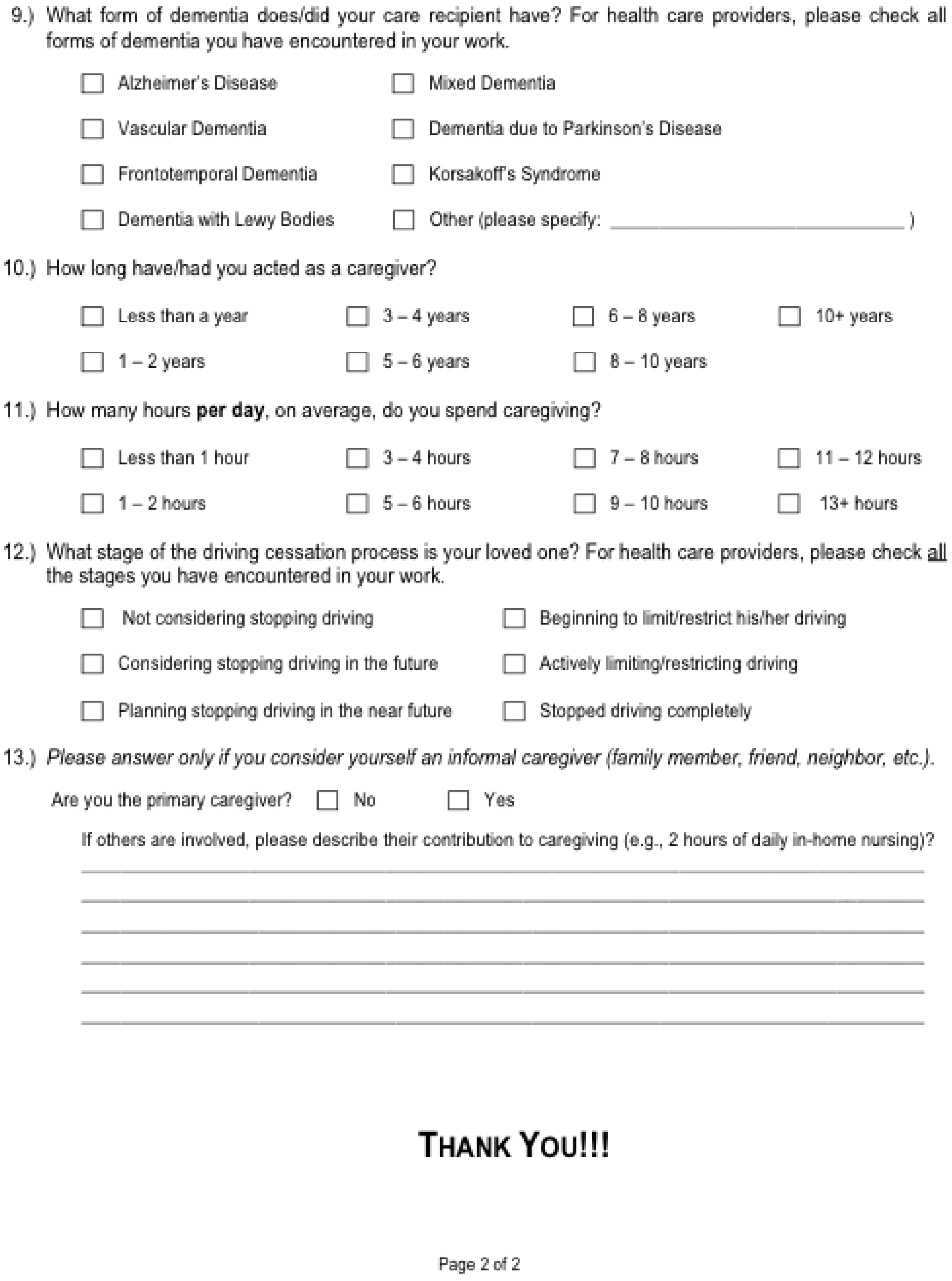
8.) What is your relationship with the person/s for whom you care? (check all that apply)

☐ Wife
☐ Husband
☐ Daughter
☐ Son
☐ Friend
☐ Neighbor
☐ Health Care Provider (please specify role: _____________)
☐ Other (please specify: ____________________)

PLEASE CONTINUE ON THE REVERSE SIDE ⇒

Page 1 of 2

Appendix D: Study 1 Demographic Form
Back Side



9.) What form of dementia does/did your care recipient have? For health care providers, please check all forms of dementia you have encountered in your work.

☐ Alzheimer's Disease
☐ Vascular Dementia
☐ Frontotemporal Dementia
☐ Dementia with Lewy Bodies
☐ Mixed Dementia
☐ Dementia due to Parkinson's Disease
☐ Korsakoff's Syndrome
☐ Other (please specify: ______________________________)

10.) How long have/had you acted as a caregiver?

☐ Less than a year
☐ 1 – 2 years
☐ 3 – 4 years
☐ 5 – 6 years
☐ 6 – 8 years
☐ 8 – 10 years
☐ 10+ years

11.) How many hours **per day**, on average, do you spend caregiving?

☐ Less than 1 hour
☐ 1 – 2 hours
☐ 3 – 4 hours
☐ 5 – 6 hours
☐ 7 – 8 hours
☐ 9 – 10 hours
☐ 11 – 12 hours
☐ 13+ hours

12.) What stage of the driving cessation process is your loved one? For health care providers, please check all the stages you have encountered in your work.

☐ Not considering stopping driving
☐ Considering stopping driving in the future
☐ Planning stopping driving in the near future
☐ Beginning to limit/restrict his/her driving
☐ Actively limiting/restricting driving
☐ Stopped driving completely

13.) *Please answer only if you consider yourself an informal caregiver (family member, friend, neighbor, etc.).*

Are you the primary caregiver? ☐ No ☐ Yes

If others are involved, please describe their contribution to caregiving (e.g., 2 hours of daily in-home nursing)?

____
____
____
____
____
____

THANK YOU!!!

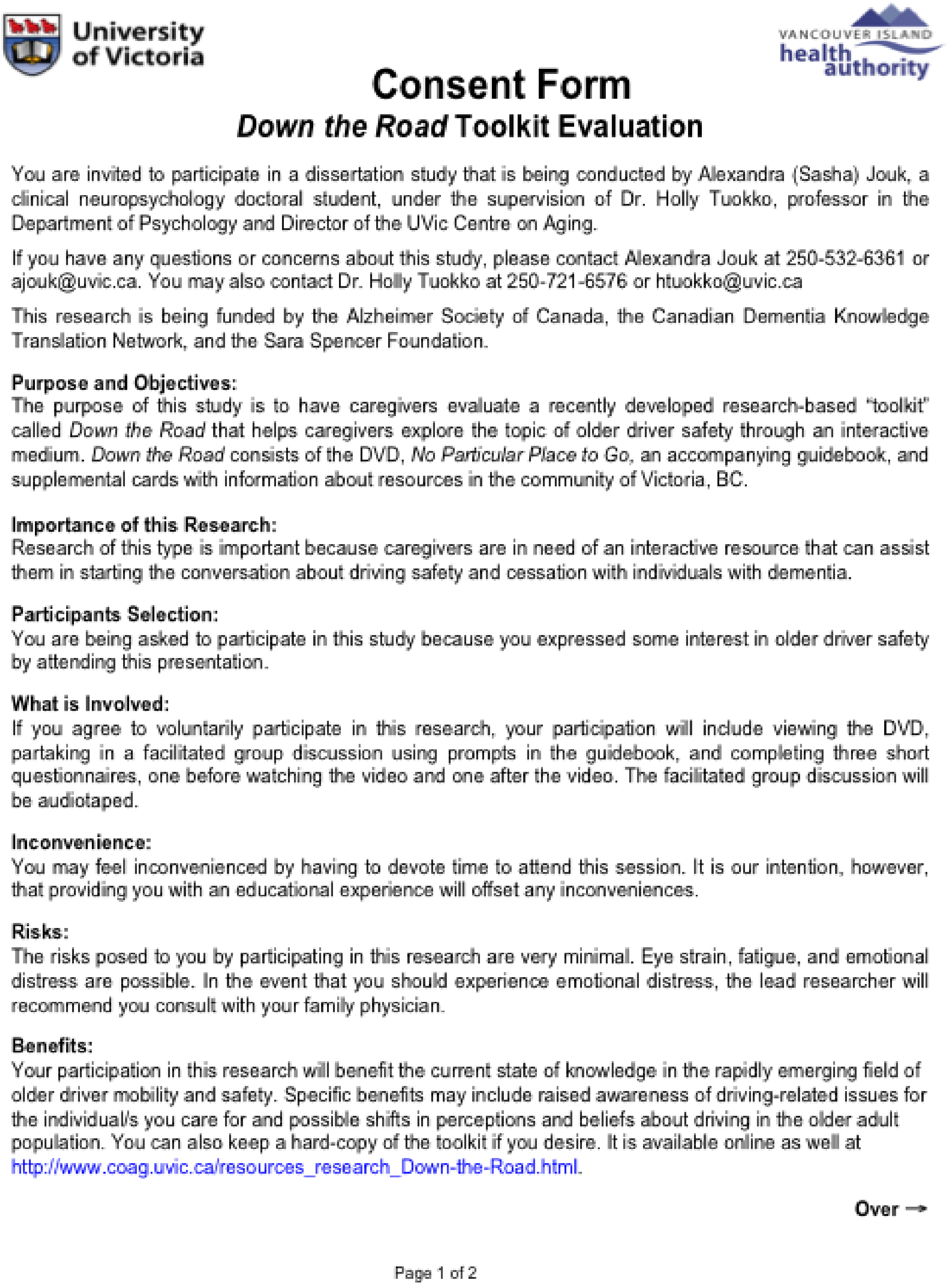
Page 2 of 2

Appendix E: *Down the Road* Toolkit

Available online at:

http://www.coag.uvic.ca/resources_research_Down-the-Road.html

Appendix F: Study 2 Consent Form
Front Side



University of Victoria

VANCOUVER ISLAND health authority

Consent Form
Down the Road Toolkit Evaluation

You are invited to participate in a dissertation study that is being conducted by Alexandra (Sasha) Jouk, a clinical neuropsychology doctoral student, under the supervision of Dr. Holly Tuokko, professor in the Department of Psychology and Director of the UVic Centre on Aging.

If you have any questions or concerns about this study, please contact Alexandra Jouk at 250-532-6361 or ajouk@uvic.ca. You may also contact Dr. Holly Tuokko at 250-721-6576 or htuokko@uvic.ca

This research is being funded by the Alzheimer Society of Canada, the Canadian Dementia Knowledge Translation Network, and the Sara Spencer Foundation.

Purpose and Objectives:
The purpose of this study is to have caregivers evaluate a recently developed research-based "toolkit" called *Down the Road* that helps caregivers explore the topic of older driver safety through an interactive medium. *Down the Road* consists of the DVD, *No Particular Place to Go*, an accompanying guidebook, and supplemental cards with information about resources in the community of Victoria, BC.

Importance of this Research:
Research of this type is important because caregivers are in need of an interactive resource that can assist them in starting the conversation about driving safety and cessation with individuals with dementia.

Participants Selection:
You are being asked to participate in this study because you expressed some interest in older driver safety by attending this presentation.

What is Involved:
If you agree to voluntarily participate in this research, your participation will include viewing the DVD, partaking in a facilitated group discussion using prompts in the guidebook, and completing three short questionnaires, one before watching the video and one after the video. The facilitated group discussion will be audiotaped.

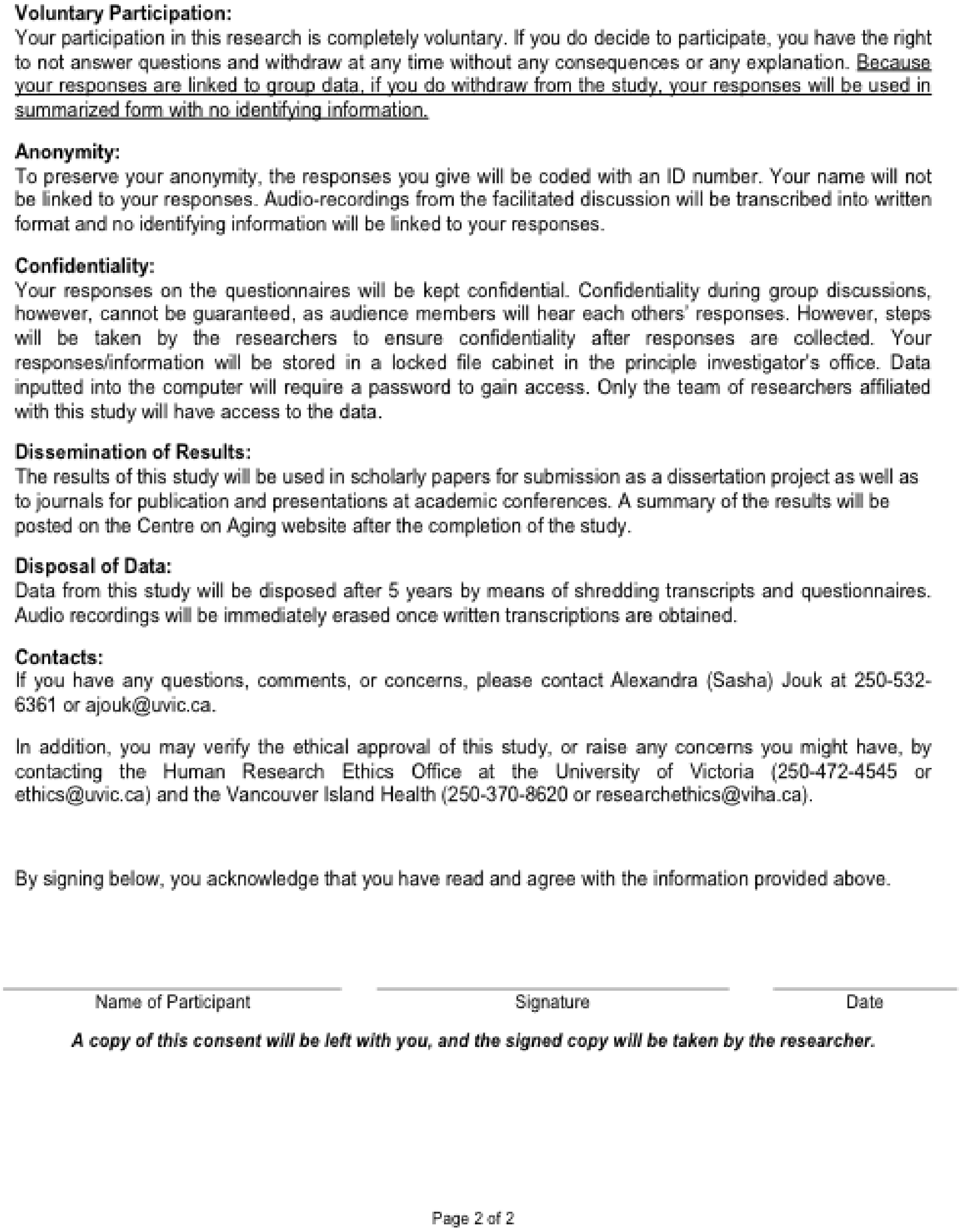
Inconvenience:
You may feel inconvenienced by having to devote time to attend this session. It is our intention, however, that providing you with an educational experience will offset any inconveniences.

Risks:
The risks posed to you by participating in this research are very minimal. Eye strain, fatigue, and emotional distress are possible. In the event that you should experience emotional distress, the lead researcher will recommend you consult with your family physician.

Benefits:
Your participation in this research will benefit the current state of knowledge in the rapidly emerging field of older driver mobility and safety. Specific benefits may include raised awareness of driving-related issues for the individual/s you care for and possible shifts in perceptions and beliefs about driving in the older adult population. You can also keep a hard-copy of the toolkit if you desire. It is available online as well at http://www.coag.uvic.ca/resources_research_Down-the-Road.html.

Over →

Appendix F: Study 2 Consent Form
Back Side



Voluntary Participation:
Your participation in this research is completely voluntary. If you do decide to participate, you have the right to not answer questions and withdraw at any time without any consequences or any explanation. Because your responses are linked to group data, if you do withdraw from the study, your responses will be used in summarized form with no identifying information.

Anonymity:
To preserve your anonymity, the responses you give will be coded with an ID number. Your name will not be linked to your responses. Audio-recordings from the facilitated discussion will be transcribed into written format and no identifying information will be linked to your responses.

Confidentiality:
Your responses on the questionnaires will be kept confidential. Confidentiality during group discussions, however, cannot be guaranteed, as audience members will hear each others' responses. However, steps will be taken by the researchers to ensure confidentiality after responses are collected. Your responses/information will be stored in a locked file cabinet in the principle investigator's office. Data inputted into the computer will require a password to gain access. Only the team of researchers affiliated with this study will have access to the data.

Dissemination of Results:
The results of this study will be used in scholarly papers for submission as a dissertation project as well as to journals for publication and presentations at academic conferences. A summary of the results will be posted on the Centre on Aging website after the completion of the study.

Disposal of Data:
Data from this study will be disposed after 5 years by means of shredding transcripts and questionnaires. Audio recordings will be immediately erased once written transcriptions are obtained.

Contacts:
If you have any questions, comments, or concerns, please contact Alexandra (Sasha) Jouk at 250-532-6361 or ajouk@uvic.ca.

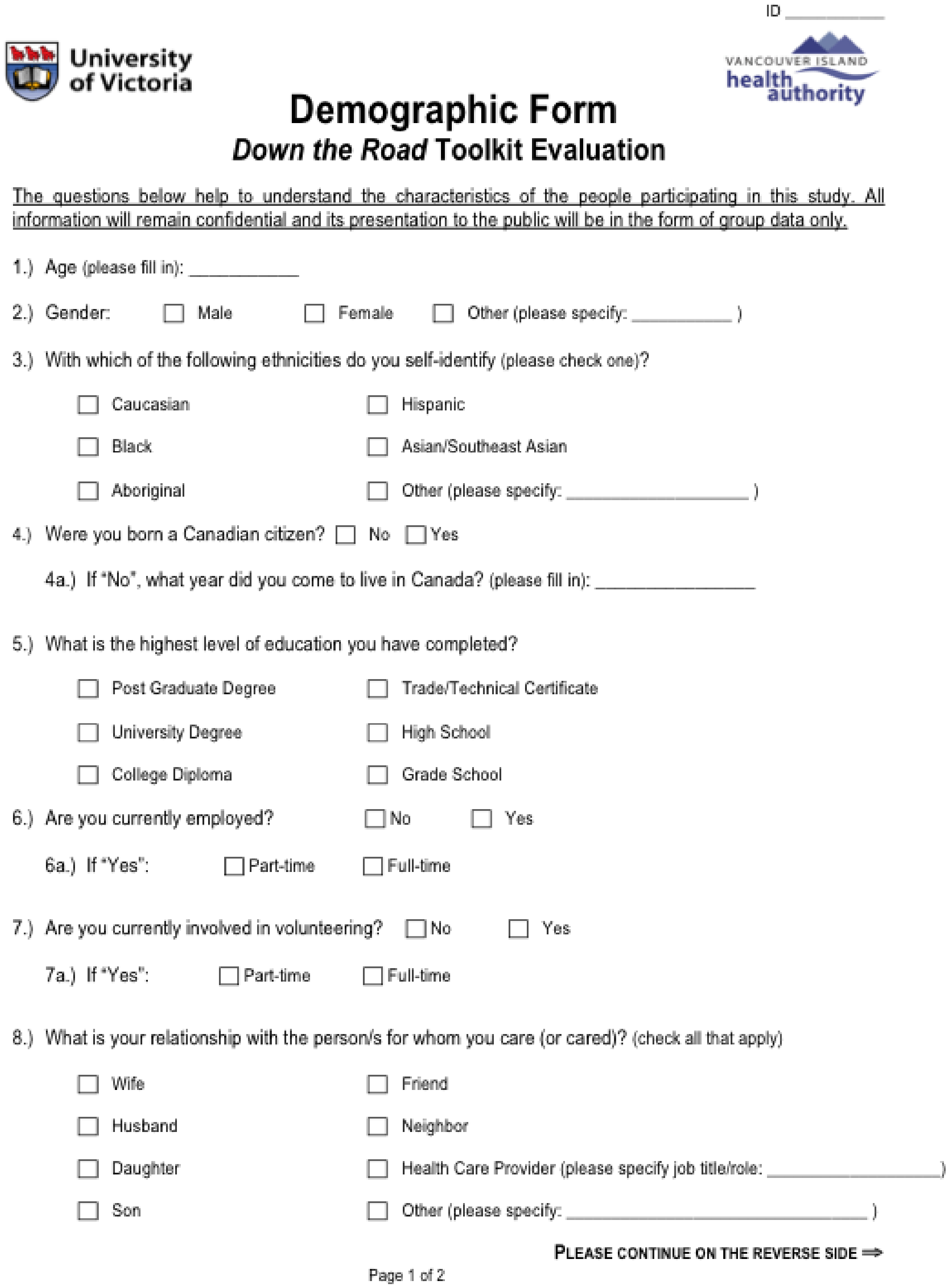
In addition, you may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Human Research Ethics Office at the University of Victoria (250-472-4545 or ethics@uvic.ca) and the Vancouver Island Health (250-370-8620 or researchethics@viha.ca).

By signing below, you acknowledge that you have read and agree with the information provided above.

Name of Participant	Signature	Date

A copy of this consent will be left with you, and the signed copy will be taken by the researcher.

Appendix G: Study 2 Demographic Form
Front Side



ID ___________

University of Victoria

VANCOUVER ISLAND health authority

Demographic Form
Down the Road Toolkit Evaluation

The questions below help to understand the characteristics of the people participating in this study. All information will remain confidential and its presentation to the public will be in the form of group data only.

1.) Age (please fill in): ___________

2.) Gender: ☐ Male ☐ Female ☐ Other (please specify: __________)

3.) With which of the following ethnicities do you self-identify (please check one)?

☐ Caucasian
☐ Black
☐ Aboriginal
☐ Hispanic
☐ Asian/Southeast Asian
☐ Other (please specify: __________________)

4.) Were you born a Canadian citizen? ☐ No ☐ Yes

4a.) If "No", what year did you come to live in Canada? (please fill in): ______________

5.) What is the highest level of education you have completed?

☐ Post Graduate Degree
☐ University Degree
☐ College Diploma
☐ Trade/Technical Certificate
☐ High School
☐ Grade School

6.) Are you currently employed? ☐ No ☐ Yes

6a.) If "Yes": ☐ Part-time ☐ Full-time

7.) Are you currently involved in volunteering? ☐ No ☐ Yes

7a.) If "Yes": ☐ Part-time ☐ Full-time

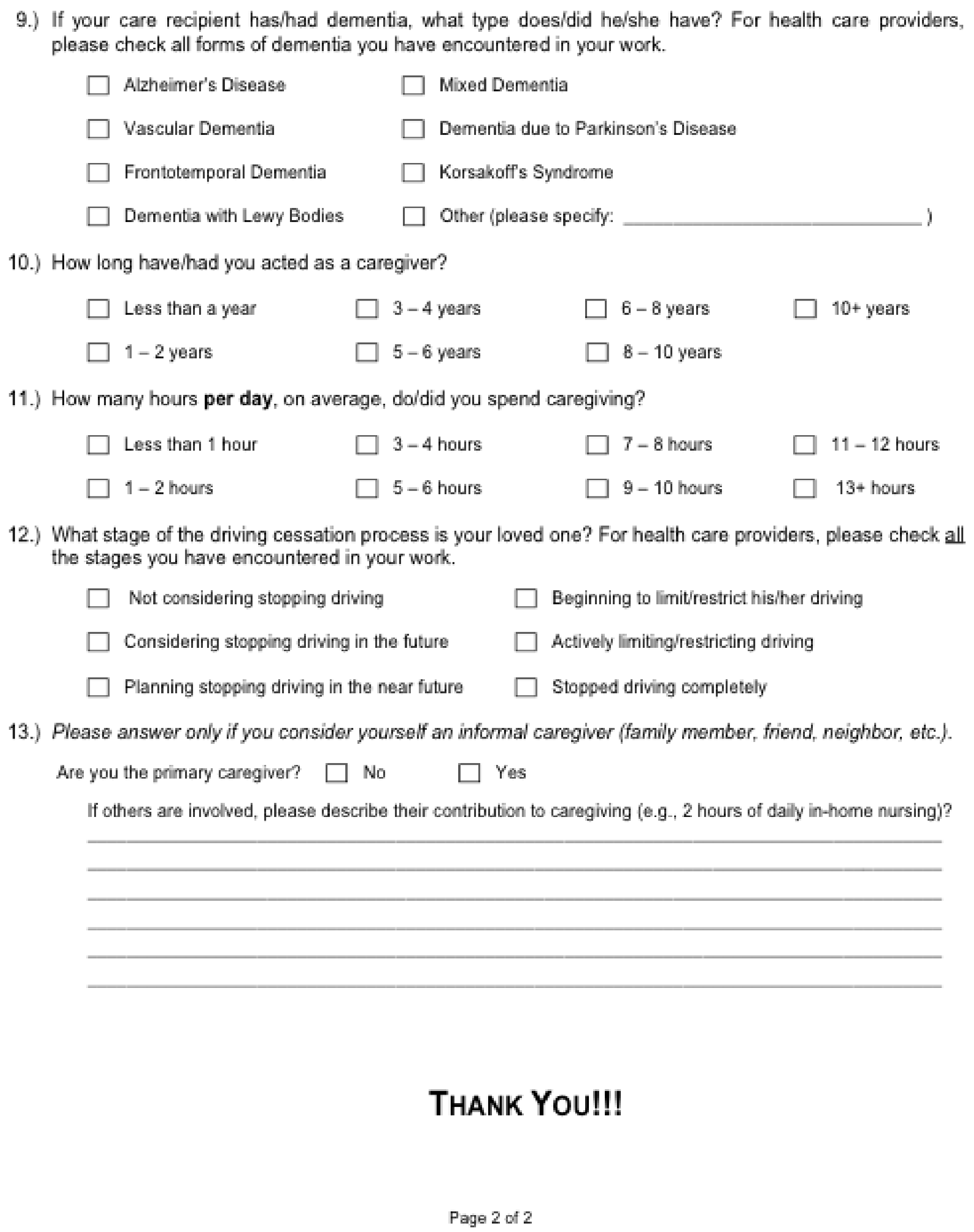
8.) What is your relationship with the person/s for whom you care (or cared)? (check all that apply)

☐ Wife
☐ Husband
☐ Daughter
☐ Son
☐ Friend
☐ Neighbor
☐ Health Care Provider (please specify job title/role: ________________)
☐ Other (please specify: ____________________________)

PLEASE CONTINUE ON THE REVERSE SIDE ⇒

Page 1 of 2

Appendix G: Study 2 Demographic Form
Back Side



9.) If your care recipient has/had dementia, what type does/did he/she have? For health care providers, please check all forms of dementia you have encountered in your work.

- ☐ Alzheimer's Disease
- ☐ Vascular Dementia
- ☐ Frontotemporal Dementia
- ☐ Dementia with Lewy Bodies
- ☐ Mixed Dementia
- ☐ Dementia due to Parkinson's Disease
- ☐ Korsakoff's Syndrome
- ☐ Other (please specify: ______________________________)

10.) How long have/had you acted as a caregiver?

- ☐ Less than a year
- ☐ 1 – 2 years
- ☐ 3 – 4 years
- ☐ 5 – 6 years
- ☐ 6 – 8 years
- ☐ 8 – 10 years
- ☐ 10+ years

11.) How many hours **per day**, on average, do/did you spend caregiving?

- ☐ Less than 1 hour
- ☐ 1 – 2 hours
- ☐ 3 – 4 hours
- ☐ 5 – 6 hours
- ☐ 7 – 8 hours
- ☐ 9 – 10 hours
- ☐ 11 – 12 hours
- ☐ 13+ hours

12.) What stage of the driving cessation process is your loved one? For health care providers, please check all the stages you have encountered in your work.

- ☐ Not considering stopping driving
- ☐ Considering stopping driving in the future
- ☐ Planning stopping driving in the near future
- ☐ Beginning to limit/restrict his/her driving
- ☐ Actively limiting/restricting driving
- ☐ Stopped driving completely

13.) *Please answer only if you consider yourself an informal caregiver (family member, friend, neighbor, etc.).*

Are you the primary caregiver? ☐ No ☐ Yes

If others are involved, please describe their contribution to caregiving (e.g., 2 hours of daily in-home nursing)?

____

____

____

____

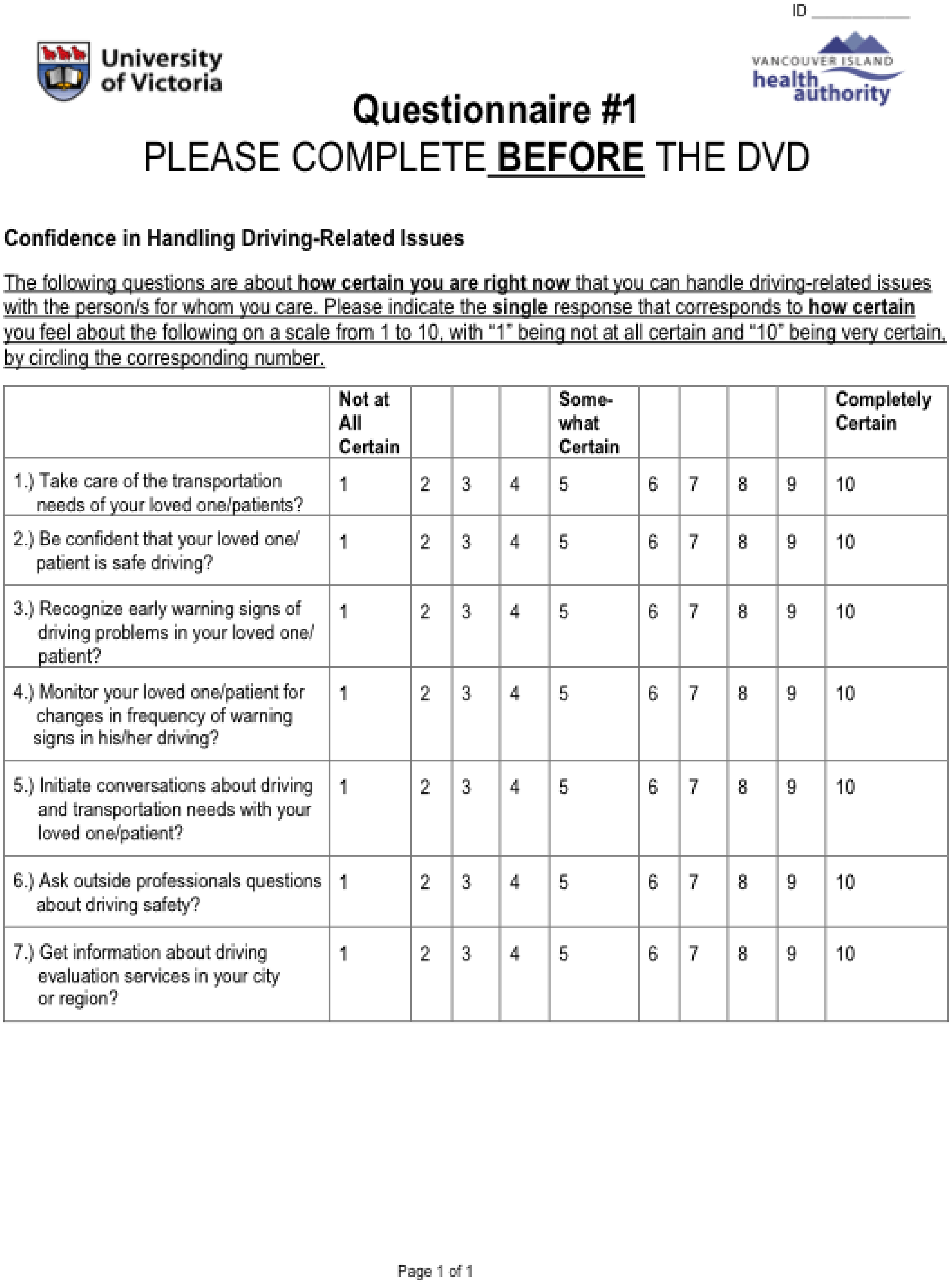
____

____

THANK YOU!!!

Page 2 of 2

Appendix H: Study 2 Pre-DVD Questionnaire



ID ___________

University of Victoria

VANCOUVER ISLAND health authority

Questionnaire #1

PLEASE COMPLETE **BEFORE** THE DVD

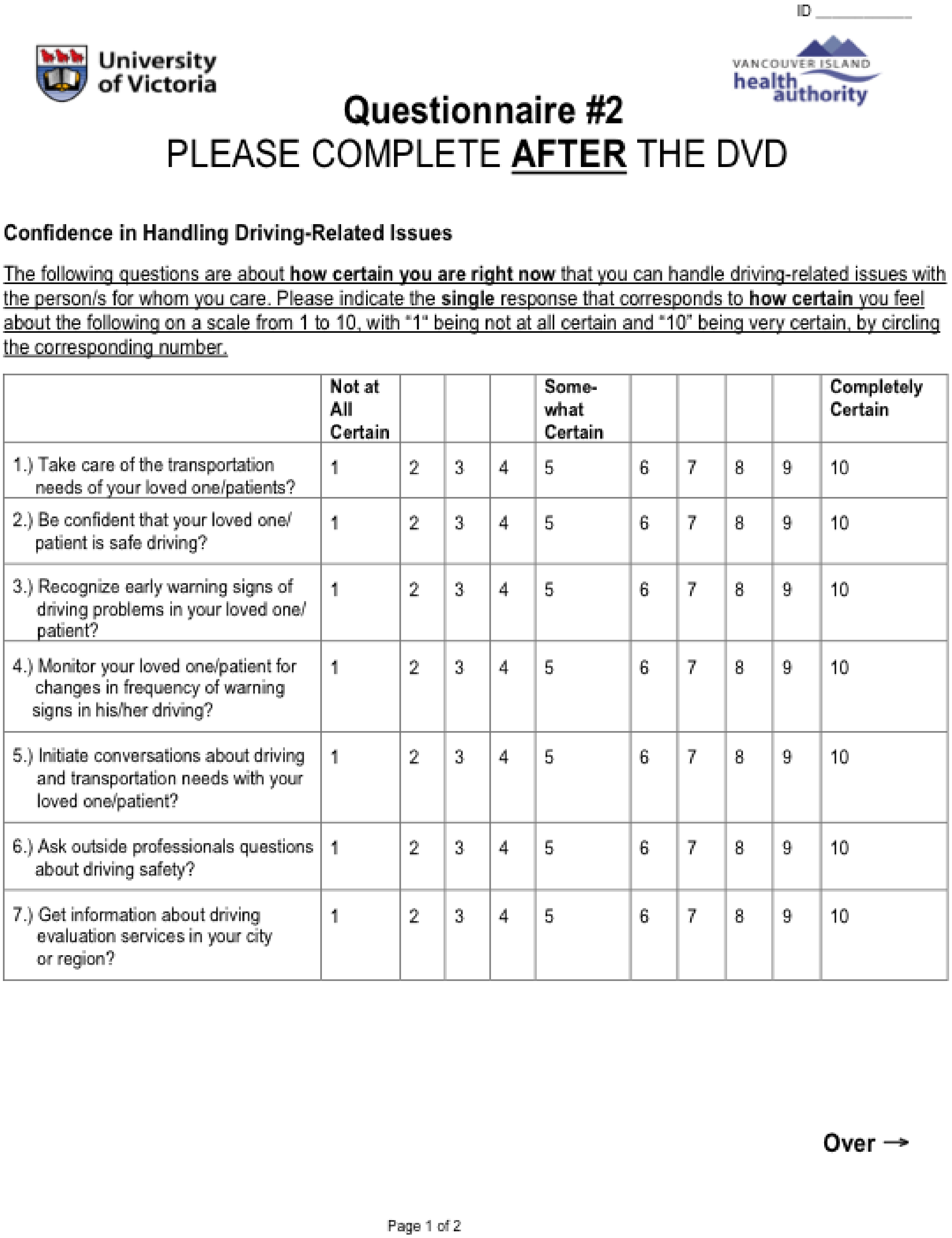
Confidence in Handling Driving-Related Issues

The following questions are about **how certain you are right now** that you can handle driving-related issues with the person/s for whom you care. Please indicate the **single** response that corresponds to **how certain** you feel about the following on a scale from 1 to 10, with "1" being not at all certain and "10" being very certain, by circling the corresponding number.

	Not at All Certain				**Some-what Certain**					**Completely Certain**
1.) Take care of the transportation needs of your loved one/patients?	1	2	3	4	5	6	7	8	9	10
2.) Be confident that your loved one/ patient is safe driving?	1	2	3	4	5	6	7	8	9	10
3.) Recognize early warning signs of driving problems in your loved one/ patient?	1	2	3	4	5	6	7	8	9	10
4.) Monitor your loved one/patient for changes in frequency of warning signs in his/her driving?	1	2	3	4	5	6	7	8	9	10
5.) Initiate conversations about driving and transportation needs with your loved one/patient?	1	2	3	4	5	6	7	8	9	10
6.) Ask outside professionals questions about driving safety?	1	2	3	4	5	6	7	8	9	10
7.) Get information about driving evaluation services in your city or region?	1	2	3	4	5	6	7	8	9	10

Page 1 of 1

Appendix I: Study 2 Post-DVD Questionnaire
Front Side



ID ___________

University of Victoria

VANCOUVER ISLAND health authority

Questionnaire #2
PLEASE COMPLETE **AFTER** THE DVD

Confidence in Handling Driving-Related Issues

The following questions are about **how certain you are right now** that you can handle driving-related issues with the person/s for whom you care. Please indicate the **single** response that corresponds to **how certain** you feel about the following on a scale from 1 to 10, with "1" being not at all certain and "10" being very certain, by circling the corresponding number.

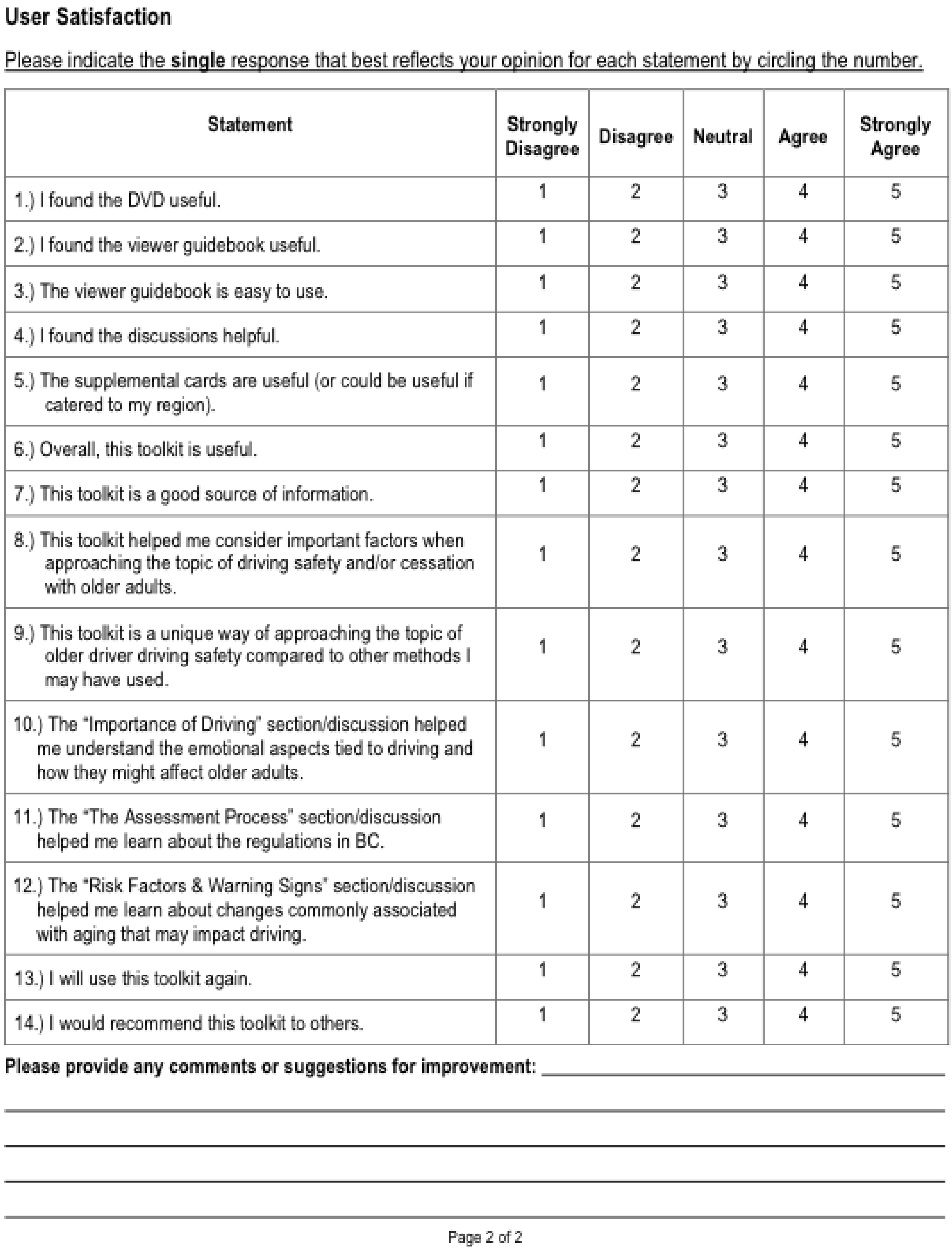
	Not at All Certain				**Some-what Certain**					**Completely Certain**
1.) Take care of the transportation needs of your loved one/patients?	1	2	3	4	5	6	7	8	9	10
2.) Be confident that your loved one/ patient is safe driving?	1	2	3	4	5	6	7	8	9	10
3.) Recognize early warning signs of driving problems in your loved one/ patient?	1	2	3	4	5	6	7	8	9	10
4.) Monitor your loved one/patient for changes in frequency of warning signs in his/her driving?	1	2	3	4	5	6	7	8	9	10
5.) Initiate conversations about driving and transportation needs with your loved one/patient?	1	2	3	4	5	6	7	8	9	10
6.) Ask outside professionals questions about driving safety?	1	2	3	4	5	6	7	8	9	10
7.) Get information about driving evaluation services in your city or region?	1	2	3	4	5	6	7	8	9	10

Over →

Page 1 of 2

Appendix I: Study 2 Post-DVD Questionnaire

Back Side



User Satisfaction

Please indicate the **single** response that best reflects your opinion for each statement by circling the number.

Statement	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
1.) I found the DVD useful.	1	2	3	4	5
2.) I found the viewer guidebook useful.	1	2	3	4	5
3.) The viewer guidebook is easy to use.	1	2	3	4	5
4.) I found the discussions helpful.	1	2	3	4	5
5.) The supplemental cards are useful (or could be useful if catered to my region).	1	2	3	4	5
6.) Overall, this toolkit is useful.	1	2	3	4	5
7.) This toolkit is a good source of information.	1	2	3	4	5
8.) This toolkit helped me consider important factors when approaching the topic of driving safety and/or cessation with older adults.	1	2	3	4	5
9.) This toolkit is a unique way of approaching the topic of older driver driving safety compared to other methods I may have used.	1	2	3	4	5
10.) The "Importance of Driving" section/discussion helped me understand the emotional aspects tied to driving and how they might affect older adults.	1	2	3	4	5
11.) The "The Assessment Process" section/discussion helped me learn about the regulations in BC.	1	2	3	4	5
12.) The "Risk Factors & Warning Signs" section/discussion helped me learn about changes commonly associated with aging that may impact driving.	1	2	3	4	5
13.) I will use this toolkit again.	1	2	3	4	5
14.) I would recommend this toolkit to others.	1	2	3	4	5

Please provide any comments or suggestions for improvement: