The Experience of Driving Cessation in Dementia: Examples from Ontario and Alberta

Dale Séguin

Thesis submitted to the Faculty of Graduate and Postdoctoral Studies

In partial fulfillment of the requirements for the

M.Sc. degree in Interdisciplinary Health Sciences

Interdisciplinary School of Health Sciences

Faculty of Health Sciences

University of Ottawa

© Dale Séguin, Ottawa, Canada, 2014

Abstract

Background: The rise in the total number of seniors will lead to a considerable increase in the prevalence of persons with dementia (PWD), the number of senior drivers and the amount of drivers with dementia. Understanding how this life event is experienced by PWD and their caregivers is paramount to policy development and planning. **Methods:** Descriptive qualitative study using secondary data. There were 25 participants over the age of 65, whose monthly phone call conversations were analyzed using analytic induction, to find links and create a theoretically based hypothesis regarding the experience of driving cessation. A standardized questionnaire was used to guide the telephone data collection. **Results:** PWD may experience emotions of anger when they don't understand why they are no longer allowed to drive. When PWD understand why they are no longer allowed to drive, they seem to accept and self-regulate their driving cessation. Cognitive tests and physicians instructing PWD they have to cease driving, are not perceived to be helpful in this understanding. Public transportation and alternate means of personal transportation are potentially associated with the acceptance of driving cessation. **Conclusions:** PWD might not understand the link between cognitive assessments, their memory, and their driving performance. A systems level approach to improved access to transportation and on-road driving tests might make it easier for PWD to understand and accept the lifestyle changes that come with driving cessation.

Keywords: Dementia; Alzheimer's disease; Driving Cessation; Coping; Transportation; Physicians; Driver's License

Contexte: L'augmentation du nombre total de personnes âgées va mener à un accroissement considérable de la prévalence de personnes atteintes de démence (PAD), du nombre de conducteurs âgés et le montant de conducteurs atteints de démence. Comprendre comment cet événement est vécu par les PAD et leurs aidants naturels est primordiale pour la planification et l'élaboration de politiques. **Méthodes:** Étude qualitative descriptive utilisant des données secondaires. Il y avait 25 participants âgés de plus de 65 ans, dont les conversations d'appel téléphonique ont étés analysées à l'aide de la méthode d'induction analytique. Des liens ont ainsi été créés afin d'élucider une hypothèse théorique concernant la transition de l'arrêt de la conduite. Un questionnaire standardisé a été utilisé pour guider la collecte de données par téléphone. **Résultats:** Les PAD peuvent éprouver des émotions de colère quand ils ne comprennent pas pourquoi ils ne peuvent pas continuer à conduire. Lorsque les PAD comprennent, ils semblent accepter et autoréguler leur arrêt de conduite. Les tests cognitifs et les médecins qui informent aux PAD qu'ils doivent cesser de conduire, ne les aident pas à comprendre. Le transport en commun et autres moyens de transport personnels sont potentiellement associés à l'acceptation de l'arrêt de la conduite. **Conclusions:** Les PAD ne comprennent pas tous le lien entre les évaluations cognitives, leur mémoire, et leur performance au niveau de la conduite automobile. Une approche systémique visant l'amélioration à l'accès au transport en commun et l'accès à des tests de conduite sur la route pourront peut-être aider les PAD à comprendre et accepter les changements de mode de vie associés avec l'arrêt de la conduite automobile.

Mots-clés: Démence; Maladie d'Alzheimer; Arrêt de conduite; Adaptation; Transport; Médecins; Permis de conduire

Acknowledgements

I would first like to acknowledge, with sincere gratitude, my debt of thanks to my brilliant supervisor, Dr. Linda Garcia, for her guidance and patience. I understand that I have not taken a traditional path to accomplish a graduate degree. For this, I have asked a lot from you, and yet your support has been unyielding. For the past few years, you have been a voice of reason and a role model. I have learned a great deal and I realize just how much I have changed since I first stepped in your research lab.

To my thesis committee members and examiners, Dr. Frank Molnar, Dr. Tracey O'Sullivan, Dr. Heidi Sveistrup, and Dr. Mary Egan, thank you for all of your help and direction.

I am also grateful to Dr. Lynn McCleary, who was cordial enough to offer her time, insight and advice during the course of this study. I appreciate all of the work you did to help me complete this thesis in a timely fashion. Indeed, it is a 'good thesis'.

I would like to offer additional thanks to Dr. Neil Drummond and the DementiaNET study group, for their endorsement, input and for the data used for this study. This research was supported by grants from the Canadian Institute of Health Research (CIHR).

To my family, specifically my parents and my brother, thank you for your encouragement and loving support throughout my undergraduate studies, the pursuit of a Master's degree and the first year of a Medical degree. I cannot thank you enough and I most definitely would not be the person I am today without you all.

Lastly, to my beautiful grand-father and grand-mother, for the wisdom you have given me throughout the years. You have both given me the ultimate motivation to work late nights in order to complete this thesis. I only hope to make you proud.

Table of Contents

Abstract ii

Acknowledgements iii

List of Tables v

List of Figures vi

List of Appendices vii

Interdisciplinary relevance viii

Abbreviations ix

CHAPTER 1: INTRODUCTION 1
1.1 Effect of dementia on driving performance 3
1.2 How do people stop driving? 5
1.3 Difficult transition 7
1.4 Strategies that families use in smoothing the transition of driving cessation 8
1.5 Theoretical framework 11
1.6 Researcher bias 13

CHAPTER 2: RESEARCH OBJECTIVES & QUESTIONS 14

CHAPTER 3: METHODOLOGY 15
3.1 Study designs 15
3.2 Recruitment 15
3.3 Data collection 16

CHAPTER 4: ANALYSIS 18
4.1 Analysis 18

CHAPTER 5: RESULTS 25
5.1 First coding process – 5 participants 27
5.2 Second coding process – 10 total participants 31
5.3 Third coding process – 19 total participants 34
5.4 Coding of the relationships – 25 total participants 41
5.5 Development of the final hypotheses 42
5.6 Refuting, reformulating, and accepting the hypotheses 44

CHAPTER 6: DISCUSSION 48
6.1 Hypothesis 48
6.2 Model of driving cessation 53

CHAPTER 7: LIMITATIONS 56

CHAPTER 8: CONCLUSIONS 57

CHAPTER 9: REFERENCES 58

List of Tables

Table 1 Summary of the driving cessation process ………………..………………………..…….. 78

Table 2 Participant demographics …………………………….……………………..….… 82

Table 3 First 20 codes – 5 participants ……..…………………………………….……..... 83

Table 4 21 codes – 5 participants ……………………………………………………..……… 84

Table 5 18 codes – 5 participants ……………………………….……….....…………. 86

Table 6 Relationship codes – 10 total participants …………………………………..……… 88

Table 7 18 codes – 10 participants ………………….……………………….....…………… 89

Table 8 Description of essential codes for the process of driving cessation …………………... 91

Table 9 Relationship codes for the process of driving cessation ……………………………… 93

Table 10 Most prominent relationship codes ……….…………………………..…………... 94

Table 11 Results of the redefined, accepted or refuted hypotheses ……………….…………... 96

Table 12 Results of the redefined, accepted or refuted 11th hypothesis ………….…….…..…... 99

List of Figures

Figure 1 A conceptual model of the driving cessation process …………………………........ 102

Figure 2 The process of analytic induction …………………………………………...……. 103

Figure 3 Coding hierarchy at 21 codes – 5 participants ...…………………..………...………. 104

Figure 4 Coding hierarchy – 18 codes – 5 participants ...…………………………………….. 105

Figure 5 Coding hierarchy – 18 codes – 10 participants ………...……………………...…… 106

Figure 6 Coding hierarchy for the process of driving cessation ………..…………………….. 107

List of Appendices

APPENDIX A. ADDITIONAL TABLES …………………………..…………..…..……… 108

Table 13 Reviewed coding changes – 10 participants ………………...……...……... 109

Table 14 Reviewed coding changes – 18 participants …………………………...…… 111

Table 15 Examples of relationship codes – 25 participants ………………..………. 117

APPENDIX B. ETHICS APPROVALS ……………………………………………………… 127

Ethics approval from the University of Ottawa …………………………………...….. 128

Ethics renewal from the University of Ottawa ……………………………………….. 129

Ethics approval from the Bruyère Research Institute ……………………..………. 130

Interdisciplinary relevance

Although this study is specific to the topic of driving cessation in persons with dementia, it utilizes an interdisciplinary stress-coping model to explain its findings. This model demonstrates how the results can be applied to multiple disciplines, such as medicine, occupational therapy, healthcare policy, driver licensing policies, and municipal transportation services. This research also discusses the emotions involved in the process and experience of driving cessation for PWD and their caregivers. The importance of acceptance and understanding are key points considered throughout this investigation. The impact of public and personal transportation on the acceptance of driving cessation is also a very real factor for these individuals. While dementia is a syndrome of physiological and cognitive change, its impact is very psychosocial and emotional, as highlighted by this thesis. Interventions can best be designed if interdisciplinary. However, most of the time, the initial realization that driving must cease is brought to the PWD`s attention through the physician. Further research could look into how physicians can best disclose to PWD that they are no longer allowed to drive, and, through a team based approach, help the PWD adapt and manage the lifestyle changes that will undoubtedly ensue with driving cessation.

Abbreviations

CG	Caregiver
PWD	Person(s) with dementia

CHAPTER 1: INTRODUCTION

In 2011, Canadians aged 65 and older consisted of 14.8% of the Canadian population (Statistics Canada, 2013). There was a 14.1% growth rate between 2006 and 2011, where the number of seniors aged 65 and older had reached nearly 5 million (Statistics Canada, 2013). It is estimated that by 2036, 1 in 4 of the Canadian population will be seniors aged 65 and older (Statistics Canada, 2013). This rise in the aging population will be due to the fact that baby boomers (individuals born between 1946 and 1964) will reach the age of 65 between 2010 and 2031 (Statistics Canada, 2013). Hence, since the longevity and total number of seniors is on the rise, and assuming no cures are found, the prevalence of people who will be affected with dementia will escalate considerably. In Canada, more then 747, 000 people currently have cognitive impairment, including Alzheimer's disease (AD) and related forms of dementia. Without the discovery of a cure or a preventative method, by 2031, approximately 1.4 million people will live with cognitive impairment, AD or a related dementia (Alzheimer Society of Canada, 2012). To put into perspective the financial burden that this may have on our healthcare system, in 2012, the direct and indirect costs of dementia were $33 billion per year. By 2040, it is estimated that the costs will increase to $293 billion per year (Alzheimer Society of Canada, 2012).

This rise in the senior population will lead to an increase in the number of senior drivers. In fact, senior drivers account for the quickest growing demographic of all drivers (Hu, Ivan, Ravishanker, & Mooradian, 2012). In 2009, approximately 60% of Canadians between the ages of 65-69 drive. Comparatively, 45% of those between the ages of 70-74 drive, as well as 20% of the elderly over 75 years old. In total, 3.25 million people aged 65 and over have had a driver's license, which represents approximately 33% of all seniors (Sivak & Schoettle, 2012).

The number of senior drivers in Ontario will have increased from nearly 500,000 in 1986 to approximately 2,500,000 in 2028 (Hopkins, Kilik, Day, Rows, & Tseng, 2004). In 2009, 1.20 million people aged 65 and over in Ontario had a driver's license, which represents 83% of all the seniors in the province (Statistics Canada, 2012). Furthermore, the number of seniors dependent on their own vehicles will be on the rise as seniors become increasingly active. This dependency will be even more apparent in the baby boomer population, who will all have become seniors by the year 2029 (Dobbs, 2008). Male and female baby boomers have shown to have more active lifestyles and a higher driving exposure (Dobbs, 2008). Driving has also become more universal as more women, including baby boomers, have obtained drivers licenses (Rosenbloom, 2004).

Since the total number of senior drivers is on the rise, it is only logical to assume that the number of drivers with dementia is also on the rise. In 2009, approximately 28% of all seniors aged 65 years and over, who had a diagnosis of dementia, had a driver's license. However, it is important to note that only 20.8% had driven a vehicle a month before the study (Statistics Canada, 2012). In Ontario, the number of drivers with dementia has gone from nearly 15,000 in 1986 to 34,000 in 2000. The best estimate is that this total will grow to be near 100,000 people by 2028 (Hopkins et al., 2004). If this is generalizable, it would imply that for approximately 3.4 million persons with dementia (PWD) in North America (Ferri et al., 2005), there are over 1.5 million who continue to drive (Byszewski, Molnar, & Aminzadeh, 2010). The majority of drivers with dementia continue to drive whilst their cognitive deficits are mild and they are still in the early phases of the disease (Adler & Kuskowski, 2003), but some even continue to drive when their cognitive deficits worsen (Bedard, Molloy, & Lever, 1998).

1.1 Effect of dementia on driving performance

Important deficits associated with dementia include impairments in attention, perception, judgment, motor skills and memory (Chapman, Williams, Strine, Anda, & Moore, 2006). Driving performance and skills incorporate various complex behaviors and cognitive abilities, such as decision making, selected and divided attention, visuospatial interpretation, and visuomotor integration (Calhoun et al., 2002). These factors are impaired by dementia. Motor (Anstey, Windsor, Luszcz, Andrews, 2006; Foley, Masaki, Ross, & White, 2000; Jette & Branch, 1992; Marottoli et al., 1993) and visual (Foley, Heimovitz, Guralnik, & Brock, 2002; Forrest, Bunker, Songer, Coben, & Cauley, 1997; Freeman, Munoz, Turano, & West, 2005; Gilhotra, Mitchell, Ivers, & Cumming, 2001) deficits, as well as cognitive deficits are important factors for poor driving performance and ultimately driving cessation (Dobbs, 2008). Dobbs, Zirk, & Daly (2009) later expand on this by explaining that a decline in driving performance is a “certainty” due to the progressive nature of dementia. Even though motor and sensory decline have little evidence linking them to vehicle accidents, there is substantial evidence in the literature linking cognitive deficits as a risk factor for accidents (Adler & Kuskowski, 2003; Daigneault, Joly, & Frigon, 2002; Owsley et al., 1998; Stutts, Stewart, & Martell, 1998). As such, there may be safety concerns among a PWD’s caregiver or physician pertaining to their driving performance, or a concern of the PWD themselves, regarding their declining driving skills.

With a few exceptions (Lafont, Laumon, Helmer, Dartigues, & Fabrigoule, 2008; Trobe, Waller, Cook-Flanagan, Teshima, & Bieliaukas, 1996), most studies have reported an increased risk for unsafe driving (Langford et al., 2007; Man-Son-Hing, Marshall, Molnar, & Wilson, 2007) and vehicle accidents associated with drivers with dementia (Carr, 1997; Carr, Duchek, & Morris, 2000; Cooper, Tallman, Tuokko, & Beattie, 1993; Drachman & Swearer, 1993;

Dubinsky, Williamson, Gray, & Glatt, 1992; Fox, Bowden, Bashford, & Smith, 1997; Johansson, Bogdanovic, Kalimo, Winblad, & Viitanen, 1997; Tuokko, Tallman, Beattie, Cooper, & Weir, 1995). While senior drivers will have the same risk of getting in a car crash as do 16 to 20 year olds, seniors have a much higher chance of a serious injury or death (Cerreli, 1998). It remains unclear if this is because seniors are more likely to get hurt due to frailty, or if their cognitive deficits lead them to be involved in more serious car accidents (Cerreli, 1998). Approximately 30-50% of people with cognitive impairment will have a car crash during the first three years of diagnosis, and 80% will continue to drive after an accident (Dobbs et al., 2009).

PWD are more conscious of sensory motor deficits, than cognitive deficits (Lafont et al., 2008). As a consequence, they may not have good insight into the risk cognitive deficits can impose and may not be likely to stop driving on their own (Dobbs et al., 2009; Lafont et al., 2008). Approximately 50% of PWD do not stop driving until 3 years after their diagnosis, when the deficits typically become more pronounced (Carr, 1997); this may lead to public safety issues. A study by Carr and Ott (2010) showed that drivers with dementia are two times more at risk of being involved in a collision, and the risk seems to increase as driving continues after the diagnosis. Similarly, Diller et al. (1999) reported that PWD have a three-fold increase in at-fault crash rates when compared to individuals without dementia matched for demographics, such as age and gender. This increase was even greater than that for fault crashes due to alcohol. A high incidence of non-reporting of at-risk drivers with dementia can have an important impact on public and healthcare issues. The primary reasons physicians may opt not to report unsafe drivers are: the lack of confidence assessing the driving ability of their patients; expensive on-road testing; the potential of reporting to lead to termination of the physician-patient relationship; and the mandatory policing role of the physician (Rapoport et al., 2007). Furthermore, there is a lack

of physician knowledge on reporting policies (Cable, Reisner, Geres, and Thirumavalavan, 2000), as well as a lack of standardized evidence-based guidelines (Rapoport et al., 2007).

Lastly, a consistent body of literature finds that dementia is a major reason for driving cessation (Talbot et al., 2005; Foley et al., 2000). For the study by Lafont et al. (2008), where dementia was not associated with an increase in self-reported crashes, it is possible that the non-association may have been due to most of the participants having already reduced or stopped driving. However, in this same study, future driving was associated with crashes because some participants did not yet know that they were starting to exhibit a declining performance and that they would soon have to cease driving.

Dickerson (2014) explains that if a person with a cognitive or physical impairment believes they are physically and mentally capable of driving, then they will drive with a limited risk of safety problems. Such a person is likely to make the proper decision to limit their driving, such as avoiding driving during rush hour, since they comprehend the significance of a restraint on the safety and performance of their driving (Dickerson, 2014). On the other hand, it is the incompetent drivers who believe they are mentally capable of driving, that are at highest risk of making poor choices with regards to driving (Dickerson, 2014).

1.2 How do people stop driving?

PWD may stop driving for various reasons, either voluntarily or involuntarily. A longitudinal study by Molnar et al. (2013) indicates that older drivers progressively diminish their distance and frequency of driving before they cease driving altogether. Alternatively, PWD may cease driving because their caregiver or family physician suggest that it is necessary (Adler & Kuskowski, 2003; Trobe et al., 1996); after a hospitalization or for a medical condition (Carr,

Shead, & Storandt, 2005); or after their first car accident (Dobbs et al., 2009). A study by Carr et al. (2005) revealed multiple reasons why their participants ceased driving. In their study, 76% of their participants ceased driving on the basis of memory and thinking problems, 32 % because of disorientation, 22% due to unsafe driving, 15% after an accident, 10% because of a physical problem, 4% after losing their license, 1% felt they were too old, and 9% stopped for other reasons. The previously cited study by Lafont et al. (2008) also found that PWD who had visual deficits would tend to cease driving. Dellinger, Sehgal, Sleet, & Barrett-Connor (2001) state that approximately 12.5% of the elderly ceased driving due to problems with renewing their license.

The majority of PWD cease driving after it is requested by a family member, however, most of the time PWD and a physician were implicated in the decision (Trobe et al., 1996). Adler and Kuskowski (2003) reported that the decision to cease driving is normally abrupt and not planned. There is an unwillingness to plan for driving cessation, as most PWD steer clear from discussions regarding driving cessation, until it is unavoidable (Liddle et al., 2012; Meuser, Berg-Weger, Chibnall, Harmon, & Stowe, 2013). Older drivers, as well as PWD, may be unwilling to participate in discussions regarding driving cessation as it is seen as an emotional issue (Liddle et al., 2012), with possible negative outcomes, and one that requires identity and behavioral changes (King et al., 2011).

Adler and Kuskowski (2003) explain that PWD value the input of their family over the Department of Motor Vehicles or the input of their physicians. Yet, many PWD will report that their physicians made the decision (Adler & Kuskowski, 2003). Another study by Adler (2010) concluded that most spouses said that they made the final decision to cease driving. Furthermore, many PWD and their caregivers would like some guidance, understandable assessments, consistent advice, and support from their family and physicians with regards to this decision

(Adler, 2010; Liddle et al., 2012). When driving has been an important part of a PWD's adult life, they seem less likely to instinctively cease driving on their own and appear more likely to arrive at a crisis point (Liddle et al., 2012).

1.3 Difficult transition

Driving cessation is a major life transition. It is tied with a person's identity and roles in society and within their family (Adler, 2010; Menec, 2003). In many cultures, being able to drive is a sign of independence and social status. Without access to alternate means of transportation, there is a risk of social isolation, which can impede daily functions and limit out-of-home activities (Azad, Byzewski, Amos, & Molnar, 2002; Herrera et al., 2011). Some PWD think of driving as a basic human right; therefore, revoking one's driver's license could compromise the emotional well-being of the individual (Snyder, 2005). Some may not accept the reality of the situation and will continue to drive even after being advised to cease driving by their physician or family (Lafont et al., 2008; Wang, Kosinski, Schwartzberg, & Shanklin, 2003). For many PWD and their caregivers, it is precisely when the car keys get taken away that the impact of the diagnosis becomes understood, and this moment is remembered as a life-changing transition (Snyder, 2005). As such, the transition of driving cessation can be traumatic and cause mental health consequences, such as reduced happiness (Menec, 2003), feelings of helplessness (Gardezi et al., 2006), increased depressive symptoms (Fonda, Wallace, & Herzog, 2001; Ragland, Satariano, & MacLeod, 2005; Windsor, Anstey, Butterworth, Luszcz, & Andrews, 2007), a decreased self-esteem (Ragland et al., 2005), and a feeling they are a burden (Finlayson & Kaufert, 2002). Additional negative outcomes for the psychosocial well-being of PWD include a decline in out-of-home activity (Marotolli et al., 2000), and reduced social integration due to a limited interaction with friends (Liddle et al., 2012; Mezuk & Rebok, 2008). This transition is

also a risk factor for placement in a nursing home or long-term care facility (Freeman, Gange, Munoz, & West, 2006) if there is a lack of alternate transportation, or simply a lack of use of available services.

1.4 Strategies that families use in smoothing the transition of driving cessation

PWD may be confronted with adversity while they create new routines and transition to using alternative means of transportation during the process of driving cessation (Perkinson et al., 2005). Therefore, it is important to minimize the impact of driving cessation by becoming familiar with the various strategies that are available to ease the transition. Perkinson et al. (2005) recommended the following strategies to limit or discontinue driving: assist the family in dealing with driving and dementia; use outside authority figures, such as physicians, social workers, or the Ontario Ministry of Transportation to convince the person not to drive; plant the seeds of reason during the early stages of dementia; provide feedback on the person's driving skills; provide concrete evidence as to the reasons why they should cease driving; remove the opportunity to drive; recognize the significance of driving by letting the driver keep their license or get an identification card; find a substitute activity; and find alternate sources of transportation. Carr et al. (2005) also stressed the importance of counseling towards driving retirement, as well as plans for alternate means of transportation as strategies to use prior to driving cessation.

As mentioned above, there will be a need to increase efforts in offering alternative methods of transportation to the elderly, not only for their inclusion in society, but also because of the more active lifestyle of aging baby boomers. The new population of seniors will be healthier, active and have more disposable income (Mercado, Paez, & Newbold, 2007). They are also known to prefer control over their lives (Healthy Aging and Wellness Working Group,

2006). However, after the loss of their driver's license, most people with dementia become increasingly dependent on their family and friends for transportation (Croston, Meuser, Berg-Weger, Grant & Carr, 2009; Dobbs, Harper, & Wood, 2009; Taylor & Tripodes, 2001). Additionally, few PWD and their caregivers are use supports during the process of driving cessation (Croston et al., 2009), as they do not augment their use of public transportation, taxis or other similar services (Taylor & Tripodes, 2001). It is possible that this is due to the fact that there are limited options regarding alternate means of transportation (Dobbs et al., 2009; Perkinson et al., 2005). As well, alternative transportation, mainly public transportation, is likely inconvenient, unacceptable, and unsafe (Buys et al., 2012; Curl, Stowe, Cooney, & Proulx, 2013; Liddle, McKenna, & Broome, 2005). Buys, Snow, van Megen and Miller (2012) suggest that many older adults are simply unwilling to use alternate means of transportation, such as public transportation. This may be due to years' worth of routine and a greater availability of personal transportation (Buys et al., 2012).

Nevertheless, there exist alternate strategies for conserving the mobility of seniors (Sterns, Burkhardt & Eberhard, 2003), but PWD and their families must first be made aware of these services. Compared to healthy seniors, it may be challenging for PWD to seek help, which might be due to a lack of insight in who to ask for help or knowing where to look. As such, it is typically the PWD`s family or caregiver that will seek help (Hinton, Franz, & Friend, 2004). Liddle et al. (2012), report that PWD and their family members receive inconsistent advice with regards to driving cessation, consistent with the literature emphasizing the urgency for trained physicians and health professionals to get involved (Byszewski et al., 2003; Meuser, Carr, Berg-Weger, Niewoehner, & Morris, 2006; O'Neill, 2010). At a minimum, physicians should be aware of driving assessment programs and transportation services available in their community

(Adler, 2010). Licensing authorities could distribute information booklets and other materials about services and resources (Langford et al., 2007), and they could partner with community agencies that offer or advocate for transportation services that are "available, affordable, accessible, adaptable and acceptable" (Beverly Foundation, 2002).

The majority of public systems or transportation services are organized by municipalities; however, it is the responsibility of the Ministry of Transportation to oversee the services offered within its jurisdiction (Mercado et al., 2007). In Ontario, alternative transportation includes fixed route public transit, paratransit or transport services on demand (Mercado et al., 2007). Once PWD have had their driver's license revoked, there are few alternate sources of transportation that are available to them (Taylor & Tripodes, 2001). Taxi and van services are available for those who live in areas not serviced by public transit (OC Transpo, 2012), but they can be very costly. As well, most PWD may not be capable of taking the bus on their own, either because of a lack of physical mobility or a lack of memory (Freund, 2000). This may inhibit them from being capable of using public transit. In this case, transportation is a service offered via paratransit, which are door-to-door transportation services for individuals who are unable to take public transit (OC Transpo, 2012).

By easing the transition of driving cessation, it may be possible to alleviate the health consequences, as well as diminish the number of PWD who continue to drive after being asked to stop, thereby potentially lowering the number of car accidents. While Perkinson et al. (2005) suggest strategies for smoothing the transition, these suggestions were not taken from the perspective of PWD, or by proxy, from their caregiver. Perkinson et al.'s study brings important information regarding strategies for driving cessation; however, it does not distinguish between participant ideas of what they could have used, as opposed to the services they did use.

1.5 Theoretical framework

A conceptual model of the driving cessation process (Figure 1) will be used to frame the study. Choi, Adams, and Mezuk (2012) designed this framework based on the stress-coping paradigm and "situate driving cessation within the context of exogenous stressors, individual vulnerabilities and coping strategies, and environmental hazards and buffers over the lifespan" (Choi et al., 2012). Stress-coping models of health suggest that there exist differences between individuals and their environmental contexts in the ability to positively cope with a new societal role or mobility limitation (Davey, 2007). Prior to the creation of this model, very few driving cessation research studies had attempted to base their research within a conceptual framework that incorporated the causes and consequences of driving cessation at the individual and community level (Choi et al., 2012). A framework, such as the one created by Choi et al. (2012), can help us understand how older drivers, or specifically PWD, go through the process of driving cessation, paying specific attention to the potential causes and consequences (Choi et al., 2012).

As illustrated in Figure 1, the stress-coping model distinguishes two types of stressors: primary and secondary stressors. Primary stressors relate to health and functional declines. In driving cessation, cognitive impairment is a primary stressor that is directly associated with dementia (Chapman, Williams, Strine, Anda, & Moore, 2006). These primary stressors can also give rise to secondary internal and external stressors for PWD and their caregivers (Pearlin, Mullan, Semple, & Skaff, 1990). For example, in relation to driving cessation, secondary internal stressors could involve personal trouble or anxiety about driving (Choi et al., 2012). Secondary external stressors are when PWD are asked or forced to stop driving. This could be through either formal authorities, such as physicians or the government, or informal networks, which includes family members and friends (Dobbs & Carr, 2005). The manner in which this model

differentiates internal and external stressors helps explain the PWD's reasons for driving cessation. Furthermore, PWD who are mostly pressured by external stressors will cease driving involuntarily, whereas PWD who are influenced by internal stressors are more likely to stop driving on their own (Choi et al., 2012). Adler and Rottunda (2006) have named this first group the 'reluctant accepters', and have described those who voluntarily cease driving as 'proactives'.

The outcomes in the stress-coping paradigm are directly affected by the stressors; however, these effects may be reduced by coping methods and buffers. There exist two types of coping strategies: emotion-focused coping and problem-focused coping (Lazarus & Folkman, 1984), which can be used to adjust to the various stressors of driving cessation (Choi et al., 2012). The productive use of emotion-focused coping can comprise the denial of the need to drive (Ragland, Satariano, & MacLeod, 2004); and the acceptance of having to self-regulate or cease driving (Adler & Rottunda, 2006). On the other hand, the unproductive use of emotion-focused coping can consist of the avoidance or denial of their inability to drive, despite their cognitive impairments, which may even postpone driving cessation among PWD (Choi et al., 2012). Alternatively, the use of problem-focused coping may consist of self-regulatory driving, where PWD cope by only driving in good weather and lighting conditions (Ross et al., 2009), therefore avoiding difficult or stressful driving conditions and delaying driving cessation. Finally, the use of alternative transportation is another type of problem-focused coping. Adler & Rottunda (2006) state that older adults prefer receiving transportation help from their family and friends, rather than using public transportation.

This model of coping with driving cessation (Choi et al., 2012) will be used to frame and understand the results of this study. The model will help clarify the different stressors involved and the coping methods used for PWD who ceased driving voluntarily or involuntarily.

1.6 Researcher bias

My educational background consists of a completed Bachelor's degree in Health Sciences, where I also spent time as a volunteer in a research lab focussed on dementia. This educational background as well as the experience learned while being a medical student has influenced my understanding and perspectives with regards to dementia and its impact on PWD and their caregivers.

Additionally, given the fact that two of my grandparents have dementia, and given the active role I have taken in their care, I believe I have a biased but realistic perspective of what it is like to be a caregiver and the consequences of dementia. In conclusion, the coding and data analysis was done through a lens that was influenced by my personal experiences and views on the matter, my undergraduate degree and my individual experience interacting with other students and researchers in the lab.

CHAPTER 2: RESEARCH OBJECTIVES & QUESTIONS

The purpose of the current study is to explore the experience of driving cessation from the perspective of PWD and their caregivers.

1. What is the reaction to the loss of the driver's license?

    1.1 What are the experiences and processes of individuals with dementia and their caregivers during the driving cessation transition?

2. What are the strategies (i.e. coping strategies) that families and PWD use in smoothing the transition?

    2.1 Are there facilitators or obstacles involved in the transition of driving?

CHAPTER 3: METHODOLOGY

3.1 Study designs

The current study is part of a larger investigation looking at transitions, outcomes and dementia. The larger study utilized a longitudinal design, with inquiry into different life transitions, as they occur, placing emphasis on the participants living with dementia or their caregivers. Nine transitions were included in the larger study. These included: 1) initial problem identification and health system contact; 2) first requiring support from external agencies for instrumental or basic activities of daily living; 3) driving cessation; 4) change in financial autonomy; 5) acute hospital admission; 6) change in informal support; 7) relocation to new community-based living accommodation; 8) relocation to long-term care; and 9) entry to palliative or end of life care. Each person may experience these life transitions differently and at various times. The project was built to respond to participants when they are going through a significant transition or even multiple events at once. The current investigation is a descriptive qualitative study, using secondary data analysis, and focusing specifically on the transition of driving cessation.

3.2 Recruitment

Ethics approval was obtained for data collection in all three cities: Calgary, Edmonton, and Ottawa. The participants for this project were recruited from various sources, such as geriatric outpatient clinics, dementia assessment specialists, family practices, and local Alzheimer Societies in Calgary, Edmonton, and Ottawa. Individuals were eligible for inclusion if they were over 65 years of age; had a confirmed diagnosis of dementia; were not living in a nursing home; were judged to be capable of recounting their past experiences or had an informal caregiver who was able to recount these experiences; were fully able to give informed consent or

assent to participate in research; had an informal caregiver available who gave consent for proxy and for themselves.

3.3 Data Collection

Participants were then each randomly assigned a number for anonymity. In order to obtain information about participants' experiences with driving cessation, a research associate made a brief telephone contact, each month, with the participants (PWD and caregivers), in order to identify if a transition had taken place, or was in the process of occurring. A standardized questionnaire was used to guide the telephone data collection and interviews were audio-recorded for the purpose of data analysis. Integral factors of transition experiences have been identified from previous research to include: awareness, engagement, change, difference, critical points of events, time span, service demand, availability, utilization, expectations, experience, knowledge, and environments. These factors were included in the questions used to investigate the transition of driving cessation.

- What brought this issue to your attention? (triggers)
- How long has this been going on? (time span)
- What do you think/feel about it? (awareness, hazard assessment and engagement)
- Have you done anything because of it? (engagement)
- Has anything changed? (change)
- Is anything different now compared to before? (difference)
- What are the important turning points or events that have happened? (critical events)
- Have you requested services relating to this transition? (demand, availability)
- What services have you received? (utilization)
- What waiting time did you experience for the services? (demand, utilization)

- In the next 6 months what do you expect will happen in relation to this issue? (expectations)
- What have you learned because of this transition? (experience, knowledge)
- Were environmental factors (legal, ethical, social, or physical) important during this transition? (environments)

In addition to these, additional questions were asked to the caregivers and/or the PWD.

Caregivers:

- What was the reason your family member had to stop driving?
- How did you feel when your family member was told to stop driving?
- Have your family, friends, doctor or other health workers helped you to find other methods of transportation?
- (If yes) What has been your experience with your family member using these other methods of transportation?

PWD (when judged appropriate by the caregiver):

- What was the reason you had to stop driving?
- Do you think the assessment that you are unfit-to-drive was arrived at fairly?
- Have you actually stopped driving?
- Were you satisfied with the manner in which this news was disclosed to you?
- Have your family, friends, doctor or other health workers helped you to find other methods of transportation?
- (If yes) What has been your experience using these other methods of transportation?

CHAPTER 4: ANALYSIS

4.1 Analysis

When I first became involved in the larger study as a research volunteer, the interviews had already been conducted and were in the process of being transcribed. I helped complete the data transcription for the larger study. The data was transcribed, inputted into NVIVO software for use in the qualitative analysis (Bazeley & Jackson, 2013) and re-checked to assure the accuracy of the transcriptions. Following this process, three researchers, including myself, coded the data into 9 different transitions:

1) Initial problem identification and help-seeking, contact with health services, and the peri-diagnostic period, including diagnostic processes
2) First requiring support from external agencies for instrumental (IADL) or basic activities of daily living (ADL)
3) Driving cessation
4) Loss of financial autonomy
5) Acute hospital admission
6) Change in informal support
7) Relocation to new community living accommodation
8) Relocation to long-term care
9) End of life

The current thesis focused on the third transition, driving cessation. The data was analyzed in order to explore the experiences and processes of individuals with dementia and their caregivers as they accessed services during the driving cessation transition. It was designed not only to find out what the reaction was to the loss of the driver's license, but also to determine the strategies families used in smoothing the transition. The data was analyzed using analytic

induction (Hammersley, 2012), in order to find links and create a theoretically based hypothesis about the process of driving cessation from the perspective of PWD and their caregivers.

Analytic induction is a method of data analysis that was originally reported by Florian Znaniecki in 1934 (Ratcliff, 1994). According to Znaniecki, analytic induction can be defined as a social scientific method where determination of causation can be a goal of the method, as well as the inclusion of many exceptions (i.e. deviant cases) that add to the knowledge (Ratcliff, 1994). In contrast to Znaniecki's view of analytic induction, Martyn Hammersley's (2012) interpretation of analytic induction does not start with a hypothesis. Rather, his method uses 'induction' to develop a hypothesis by reviewing multiple cases of the outcome to be explained and by detecting what these cases have in common (Hammersley, 2012). More specifically, analytic induction builds up a hypothesis with the intent of confirming the links between the constructs and the categories. Ratcliff (1994) adds to this by explaining that the constructs developed must be interrelated through extensive, logical classifications and theories. Furthermore, analytic induction was created to develop and test an explanation or a hypothesis (Hammersley, 2010). Analytic induction can test a hypothesis by seeking out deviant cases with a goal of developing an explanation or a hypothesis that can be maximally generalized and applicable to all of the relevant cases (Hammersley, 2010). In this regard, the hypothesis developed is more exhaustive since it is reformulated to fit each case, rather than simply producing statements of what is most probable. As such, analytic induction tries to find the important conditions that have to be included for a specific outcome to occur. The model in Figure 2 demonstrates how the process of analytic induction is completed; the steps for analytic induction as per Goetz and LeCompte (1981), as well as Hammersley (2012), are as follows:

1) Initially specify the outcome to be explained, which in the current case is driving cessation for PWD
2) Collect data where PWD have ceased driving or are in the driving cessation transition
3) Scan the data to identify categories and attributes
4) Create typologies for categories
5) Determine the relationships that exist between categories
6) Create several hypotheses from the relationships discovered
7) Use the hypothesis that you find best represents the data
8) Collect more data
9) Seek examples that contradict that hypothesis
10) If an example is found that does not fit the hypothesis, then either reformulate that hypothesis or redefine the outcome
11) Continually refine hypotheses until all examples are accounted for and explained

However, since the data had already been collected at the time of this study, step 2 was changed to "review the data collected where the outcome is present" and step 8 was removed entirely. Instead of collecting more data, cases that were not used to develop the original hypothesis were sought out to contradict the hypothesis. Bogdan and Biklen (1982) remark that this is the opposite of "funneling"; where a more comprehensive hypothesis is produced, instead of a restricted result, since selected sampling of specific cases can broaden the hypothesis. In this study, 5 cases were randomly sampled to represent the data from which the original hypotheses were developed. With 20 cases remaining, specific cases were sought out to contradict the hypothesis. For each deviant case, the hypothesis was either reformulated or the outcome was redefined to account for this specific case (Hammersley, 2012). Additionally, after each

reformulation, every case was re-examined, including the original 5 cases, to confirm that they fit the reformulated hypothesis (Hammersley, 2012). Finally, the data analysis was concluded once a final hypothesis could explain and account for all of the cases (Hammersley, 2012).

Analytic induction is the appropriate data analysis method for this study since it is capable of developing and testing an explanation or a hypothesis. Compared to similar data analysis methods, such as grounded theory and constitutive ethnography, analytic induction accounts for deviant cases by reformulating the outcome rather than adding more variables in further analyses (Ratcliff, 1994; Mehan, 1979). Although constitutive ethnography proposes causal relationships and similarly develops a framework that accounts for all relevant data, including deviant cases, it compares the data used for the hypothetical framework with upcoming data (Ratcliff, 1994). In comparison with grounded theory, analytic induction is not only capable of generating an explanation for a specific outcome, but it can also reformulate or redefine the outcome to account for all deviant cases (Hammersley, 2010). Analytic induction is a lengthy, hard, and time consuming process, where the researcher is forced to study each case in the same way, and where the researcher must always consider the alternate hypotheses and explanations (Hammersley, 2012). In this regard, to be able to develop a hypothesis that can be maximally generalized, the researcher is forced to be consistent and inclusive.

Analytic induction is an applicable data analysis method in health research as long as the research is systematic, rigorous and consistent (Bloor & Wood, 2006). Research is rigorous when it is transparent, explicit, and the appropriate methods are used in conjunction with the objectives of the study (Ryan, 2005). Simply, this means that researchers must be able to clearly explain how the research was conducted (Ryan, 2005). Furthermore, Becker (1958) stated that researchers should explain in their report how they arrived to their final hypothesis. The purpose

of this is to promote the adequacy of the analytic induction process and give evidence towards the final hypothesis (Becker, 1958). Additionally, readers will be able to judge if they would have come to similar conclusions, considering the researcher's data and perspective (Becker, 1958).

Sandelowski (1986) proposed a framework for assessing the rigour of qualitative research, which included four factors: credibility; auditability; confirmability; and fittingness or transferability (Guba, 1981; Lincoln & Guba, 1985). These factors were alternative to those used in assessing the rigour of quantitative research, which were: truth value, consistency, neutrality, and applicability (Sandelowski, 1986). The first factor, the truth value or the internal validity of the data, is measured by determining how well the data collection and data analysis methods work (Guba & Lincoln, 1989). However, since some threats to internal validity may not translate to qualitative research, it was proposed that credibility should replace truth value or internal validity (Guba & Lincoln, 1989). The credibility of the data analysis depends on how well the categories and themes represent the data. The study is rigorous and credible as long as all relevant data is included in the study and all irrelevant data is excluded. This means that categories with minimal relevant information should not be included in the study, instead categories should be formed on the richness of the data. The second factor, consistency, is replaced with auditability due to the fact that the concept of reliability is not suitable as a measure of consistency in qualitative research (Morse, 1998; Guba & Lincoln, 1981). Similar to what was previously mentioned by Becker (1958), a study is rigorous and auditable when other researchers are able to follow the methods used by the researcher and are able to reach similar conclusions (Ryan-Nicholls & Will, 2009). Next, due to the unsuitability of using objectivity as a measure of neutrality in qualitative research, it was recommended that confirmability be used as

the criterion of rigour instead (Guba & Lincoln, 1981). Since qualitative researchers interact with the data, rather than distance themselves from what is being studied, the concept of confirmability pertains to the findings of the study, as opposed to the objective or subjective perspective of the researcher. Therefore, confirmability is a measure of how well the findings are held up by the data collected (Lincoln & Guba, 1985). Finally, Guba and Lincoln (1989) suggest the use of fittingness or transferability as a measure of the applicability of qualitative research, rather than the use external validity. As a criterion for the measurement of applicability, transferability or fittingness can be utilized by comparing the sample population to the demographic data and by describing the context and assumptions that were trivial to the research.

Furthermore, strategies can be used to maintain the credibility and fittingness of qualitative research (Sandelowski, 1986), such as developing theories or explanations that keep into consideration the typical and atypical cases (Ryan-Nicholls & Will, 2009). Another strategy is assuring the representativeness of the data, including the coding categories and excerpts used to present the data (Ryan-Nicholls & Will, 2009). Guba and Lincoln (1981) suggest another strategy for ensuring the credibility and fittingness of qualitative research; this strategy is using multiple skilled qualitative researchers to review the analytic induction process and to independently assess data transcripts. Agreement and consensus can be attained via a thorough discussion among the raters of the data, which can produce consistent and valid research data (Ryan-Nicholls & Will, 2009).

Multiple research assistants, including DS, transcribed the data from the monthly phone call conversations. DS and two research assistants grouped the transcribed data into the 9 different transitions. Afterwards, DS reviewed the transition of driving cessation and assigned codes to topics discussed by the participants. These codes were reviewed by two additional

researchers, LG and LM. Following the process described in Chapter 5, DS, LG and LM discussed the codes and a consensus was reached. Categories were identified and agreed by the three researchers. The relationship codes[1] were then created by DS, re-checked by LG and LM, and an agreement was attained. Finally, the hypotheses were created by DS, reviewed by LG and LM, and agreed upon by all three researchers.

[1] In qualitative research, the term "relationship" describes the identified association between existing codes.

CHAPTER 5: RESULTS

There are 80 participants in the larger study and 35 participants had data relating to driving. From these 35 participants, data from 9 participants were not used since they had not yet ceased driving or their transcript on driving cessation did not have enough information. As well, one eligible retired driver was removed from the study since it was later deemed that he was not fit to give consent and did not have a caregiver who could give consent by proxy. Therefore, data from 25 participants were analyzed as having gone through the process of driving cessation.

Originally, after reading the transcripts, it was felt that the data could be coded as "driving cessation transition", "pre-existing driving cessation" or "thinking about driving cessation", and only the data pertaining to 22 PWD who ceased driving during the study were to be analyzed. This was due to the original proposal for the study, which required that the participants have ceased driving during the study. However, many of the participants who were included in the group that had apparently ceased driving during the study, have or may have actually ceased driving prior to the study. It was therefore impossible to determine when certain participants had actually ceased driving. The research data acknowledges that participants stopped driving, but it does not confirm that participants coded as having ceased driving during the study, actually stopped driving during the study (as opposed to having ceased driving prior to the study). Therefore, as a result of this methodological difficulty and in light of the fact that driving cessation is indeed a process, it was decided by the research team to code for all participants who went through the process of driving cessation. Hence, three additional participants, from the group of "pre-existing driving cessation" were also coded, which brings the total of participants to the aforementioned number of 25. This gives a good outlook on the experience from participants who were in the transition of driving cessation during the study and

participants who were thinking back on the process of driving cessation. A summary of the process of driving cessation for each participant can be seen in Table 1. This table can be used to justify that it is a heterogeneous group of participants and that each participant adds a different experience and perspective to the process. Table 1 also groups these summaries into groups of participants who ceased driving prior to the study, during the study, or were in the transition of driving cessation.

Table 2 specifies participant demographics, such as location, sex, age, caregiver age, and past employment. From Table 2, we can see that the 25 participants include 4 PWD who answered questions on their own, 7 pairs of the PWD and their caregiver, and 14 caregivers who answered on their own. There are 4 participants from Calgary, 6 participants from Edmonton, and 15 participants from Ottawa. There are 9 females and 16 males. The average age for PWD is 80 (range of 65 to 94) and the average age of their caregivers is 66 (range of 35 to 87). As well, it is worth noting that 9 of the caregivers are sons or daughters, versus 16 of which are spouses. This group of participant is also relatively more educated than your average group of seniors (Statistics Canada, 2001), where 10 participants (40%) have a post-secondary education, 11 participants (44%) have a secondary school education, and 4 participants (16%) have a primary or elementary school education. This higher educational attainment may be an artifact of the recruitment methods used, where it is possible that their educational level had an influence on them seeking help, or that participants self-identified a need for education and support.

In the remainder of this chapter, the detailed process of inductive analysis will be explained from coding a few participants to the coding of all 25 participants, the identification of relationships amongst codes and the development of temporary and final hypotheses.

5.1 First coding process – 5 participants

The data analysis was started by coding 5 participants chosen randomly for driving cessation. The participants included in the first round of coding included numbers 2009, 3001, 3013, 3016, and 3023. It is important to note that participant codes starting with "1" are from Calgary, "2" are from Edmonton, and "3" are from Ottawa. After having coded the interview transcripts corresponding to driving cessation for these 5 participants, there were a total of 20 codes (Table 3) created and agreed upon by 3 researchers (DS, LG, and LM). Concepts were captured by title alone; knowing that further analysis would help refine the definitions. After further review of these 20 codes, new codes were then created and verified by the 2 additional researchers (LG and LM), for a total of 21 codes (Table 4). Many of the existing codes were deleted, combined or replaced with a different title. For example, the code "easier over time" was changed to the code "come to terms with driving cessation"; the code "planning week differently" was changed to the code "caregiver burden"; and the code "PWD deciding to stop on their own" was changed to the code "reasons for driving cessation – self-regulated cessation". These changes were made to better define the codes. This helps make strict distinctions between the different codes and a more refined coding system helped identify the important categories and ease the creation of a theoretical hypothesis that describes the process of driving cessation.

A restructuring of the codes was formed to create a categorical structure or a coding hierarchy to the coding system (Figure 3). Categories or parent codes were created to group codes that are related with one another and build up towards a hypothesis that captures the present cases. This coding hierarchy was also developed to aid with visual interpretation of the codes and help create hypotheses that can be confirmed or refuted by further analysis. For instance, the code "alternate transportation" became the parent code for "no alternate methods",

"personal transportation", and "public transportation". The code "emotional reaction" became the parent code for "anger" and "blaming the tests". The code "notification" was created to group together the codes "government" and "physician". Finally, the code "reasons for driving cessation" became the parent code for the codes: "failed driving tests", "poor cognitive assessment", "self-regulated cessation", and "vehicle accident".

A definition or descriptions of each code, including the parent and child codes[2], were added to clarify each code and the coding process as a whole (Table 5). This helped with reviewing the codes once the second and third researchers (LG and LM) revised the codes. Figure 4 presents the new coding structure, which can be compared to the coding structure in Figure 3. As well, the new definitions for each code aided in reducing the number of codes to 18 (Table 5), as a few of the existing codes were deemed either less important or simply irrelevant to the study. For example, it is relatively known in the literature on driving cessation that it is a hard and difficult process (see section 1.3), therefore coding for the few participants who specifically mention the weight of the transition, was deemed of lesser importance. Also, only one participant mentioned having attended a therapy group, as such we deleted the code "therapy group" since it could not joined with another code. Finally, the fact that driving cessation is a difficult transition is well discussed in the literature on driving cessation, thus we removed the few codes relating to how participants had difficulty getting used to not being able to drive.

To clarify and distinguish some of the different reasons for driving cessation, it was decided that participants who self-regulated their driving cessation had to have decided to cease driving on their own. This was to separate these participants from other participants who had

[2] A hierarchy is formed by creating parent and child codes, where the parent code aggregates or includes similar child codes under its own definition. Therefore, a single parent code may have multiple child codes.

decided to self-regulate their driving cessation after a physician had suggested that they stop driving. Despite that distinction, participants who self-regulated their driving cessation also included participants who ceased driving after having chosen not to complete a driving test.

> *"CG1027: When his license was ready to expire, we have a new doctor, and he needed a medical for that, so the doctor required that, because he was taking Aricept, he required him to go to [DriveABLE]. So he decided, and I think that it cost about 300 dollars. He said that wasn't important to him. That was not fair. So … he gave it up."*

These participants may have decided to pass on a driving test due to financial reasons or personal reasons. These circumstances are applicable since, in this situation, they were not recommended to stop driving; rather, they made the conscious decision to cease driving on their own.

It is important to note that at this first stage of coding, both participants who ceased driving on their own were women. It is the men who used their good driving record and many years of driving experience as a reason for why memory is not involved in driving. Based on the analytic induction method, once the codes had been formed for the first round of randomly sampled participants, relationships codes were then created. Therefore, for the 18 codes, 13 relationships were formed. However, only 3 out of the 5 cases were able to form any relationships amongst the codes. The other 2 cases did not form any relationships due to a lack of codes. Since the relationships of only 3 of the 5 participants were used to create the hypotheses, it is difficult to form a hypothesis that is representative of the total data. That being said, with the codes and relationships that were created, potential hypotheses were formed and could have been reformulated further along in the data analysis. The following are the hypotheses that were created, including the reasons as to whether they were removed or kept for consideration, following discussion between 2 researchers (DS and LG).

Hypothesis #1: The emotional reaction (anger) is dependent on whether the PWD believes that memory is linked with driving; this is independent of the person that notified them.

This hypothesis was later removed since the words “dependent” and “independent” are strong quantitative terms and in fact, it is not possible to determine whether or not there is an association. If there were no relationships in the data between the emotional reaction and the notification of the need to cease driving, it might suggest that there is no association between these two codes.

Hypothesis #2: Women will have less trouble self-regulating their driving cessation.

This hypothesis was based on the 2 cases that did not have any relationships. It is possible that women might not have been driving as long as most men their age. An assumption may be made that they might have less trouble adapting to the use of public transportation or using personal transportation (i.e. family and/or friends).

Hypothesis #3: PWD who fail a driving test and who have poor driving cessation comprehension may ultimately blame the driving test and feel angry.

This hypothesis reflects the fact that it is possible that the emotional reaction to be angry and to blame the driving test may be a coping strategy to deal with the loss of driving. It may also just be that for the PWD, it does not make sense, which feels unjust and leads to anger.

Hypothesis #4: Personal transport as a means of alternate transportation may add to the caregiver burden; whereas public transportation may alleviate some of this burden.

It was noted that another direction could be to look at how alternate transportation can smooth the transition. As well, it could be interesting to look into whether the use of a mixture of personal transportation and public transportation is less of a burden, versus those who simply use personal transportation.

It should be noted that these 4 hypotheses were based on the relationships formed amongst the 18 codes. However, since 2 out of the 5 cases did not have any relationships, the hypotheses numbered 1, 3, and 4 were only based on 3 cases.

5.2 Second coding process – 10 total participants

Typically, during the analytic induction process, once the first sample of participants has been coded and the hypotheses have been formed, the most prominent hypothesis is used to analyze the remaining cases. However, since there was not enough information to build a solid hypothesis for the continued use of analytic induction, 5 additional cases were randomly chosen and coded in the same manner as the previous 5 cases. Ideally, once the first 10 cases were coded and stronger hypotheses were formed, then the remaining cases could have been coded with the intent of confirming, refuting or reformulating the hypothesis. The 5 cases that were randomly sampled for the second batch of coding are numbered: 1027, 2015, 3019, 3021, and 3025.

From the 5 extra cases, no additional codes were created and none were modified. As such, all of the existing codes were used as a coding structure for these cases. As well, 12 new

relationships were formed and some of the existing relationships grew in number, bringing the total number of relationships up from 13 to 25 (Table 6). Based on the added relationships, two new hypotheses were formed:

Hypothesis #5: A good driving record as justification can be followed by a lack of driving cessation comprehension, which may lead to an emotional reaction of anger or blaming the tests.

Asked if it was a fair assessment that he/she was not fit to drive anymore, participant 3023 responded:

> *"Definitely not. It is not fair whatsoever, because like I say, I could drive. Memory as far as I am concerned has nothing to do with driving a vehicle. It is 70 years of practice, you know, you don't have to think even, you just drive."*

Hypothesis #6: PWD will self-regulate their driving cessation either since they recognize a decline in driving ability; have chosen not to complete a driving assessment; and/or they have personal transportation to supplement their own driving.

Taking in consideration all 6 of the hypotheses, the previous hypotheses numbered 2, 3, and 4, may still be valid. The 5th and 6th hypotheses were reviewed by a second researcher (LG) and it was agreed by both researchers that the 6th hypothesis was too general and simple. As well, the 6th hypothesis might not be relevant as it would not help create a final hypothesis that would be useful, as deemed by the objectives and goals of this study. On the other hand, the 5th hypothesis was at the foreground of all the hypotheses since it intuitively made sense and is more thoroughly captured by specific excerpts in the data.

Two researchers (DS and LG) once again reviewed and debated the codes. This is done to assure the credibility and fittingness of the qualitative data and analytic induction process. After the first 10 participants were coded and the codes were reviewed, there were still 18 codes (Table 7). Figure 5 presents the new coding structure, which again can be compared to the previous coding structures in Figures 3 and 4. For some cases, the codes were changed to a more appropriate code, for which the justification and explanation of each of these is found in Appendix A: Table 13.

As a result, an emphasis is now placed on the acceptance of driving cessation. This new emphasis reflects that driving cessation is an ongoing process and that most participants have not completely come to terms with the fact that they are no longer allowed to drive. As well, for the vast majority of the participants, it was not an immediate compliance to driving cessation. Therefore, the codes "immediate compliance" and "come to terms with driving cessation" were changed to the code "accepting driving cessation".

The findings also revealed the source of the different types of personal transportation. Some participants were driven by their caregivers, whereas others may have been driven by their friends or extended family. Of course, it is possible that participants had access to both types of personal transportation. As such, the code "personal transportation" was given two child codes or sub-categories: "caregivers" and "friend or extended family". In addition to these changes, the results showed that participants either understood why they were no longer allowed to drive, or they did not understand. This distinction could have an impact on the relationships and hypotheses that could be formed. Accordingly, the code "driving cessation comprehension" was sub-coded into two child codes: "understanding why driving no longer allowed" and "not understanding why driving no longer allowed". Lastly, it was determined that the few

participants who were hoping to get their license back simply did not understand why driving must cease. Therefore, the code “hoping to get the license back” was deleted and the case was coded as “not understanding why driving must cease”.

At last, after the data for the first 10 participants was coded using the analytic induction process, there were a total of 18 codes, comprising of 6 parent codes, 15 child codes, and 4 codes which did not have a parent or child code (Table 7, Figure 5). It is worth noting that parent codes were not included in the total number of codes. As well, since the code “personal transportation” was both a parent and a child code, it was also not included in the total number of codes. Therefore, the 14 remaining child codes and the 4 additional codes make up the 18 total codes.

5.3 Final coding process – 18 total participants

To maintain the rigor of the study, the remaining 8 cases were coded so that the final codes of all 18 cases could be agreed upon by the 3 researchers (DS, LG, and LM) prior to developing the final relationships and hypotheses that include all of the cases. Once a hypothesis was chosen to continue the analytic induction process, all of the cases were used separately to confirm, refute or reformulate the final hypothesis. For the last batch of coding, the participant codes are: 1003, 2006, 2021, 3002, 3003, 3011, 3015, and 3031.

During the last round of coding, the findings reveal that some PWD did not decide to stop driving on their own, and instead were responding to the wishes of their family. Therefore, these participants were not considered to have self-regulated their driving cessation; rather they ceased driving in a similar fashion to those who stopped at the request or demand of a physician. As such, the code “family advised to cease driving” was created as a child code to the code “reasons for driving cessation”. Additionally, other participants were forced to cease driving because they

could no longer physically drive. This may have been due to a stroke, a surgery, or a disability that impedes with the PWD's ability to drive. It may also have been the government or a physician that advised the PWD that they can no longer drive due to their disability. For this reason, the code "physical limitations" was also created as a child of the code "reasons for driving cessation".

Once the coding of the 18 participants was completed, the entire text of the driving cessation transition was re-read and codes were added, modified or deleted as needed. The justification and explanation of each of these is found in Appendix A: Table 14. This was done so as to maintain the rigor of the coding structure and to make sure that no additional codes were missed. As well, after the review of the codes, there were 4 more participants who went through the process of driving cessation and 3 participants who ceased driving prior to the study. As previously mentioned at the beginning of this chapter, the data from these 3 participants was also coded and used in the data analysis. Again, all of the codes were reviewed by the second and third researcher (LG and LM). The new and final coding structure can be seen in Table 8.

The findings show that all of the participants, who used their good driving record as a justification that they should be able to continue to drive, also did not understand why they were no longer allowed to drive. Therefore, it was appreciated that their good driving record may have been the cause for not understanding. As such, all of the sources coded as "good driving record as justification" were moved as a new child code of "not understanding why driving not allowed" and a grandchild code of "driving cessation comprehension". Additionally, since the term 'accidents' can be interpreted as avoidable and may even be seen as predictable, the code "vehicle accident" was changed to "vehicle collision". As a substitute, the term 'collision' does not make the assumption whether it was avoidable or not.

It was also agreed upon that to be able to create a hypothesis that is applicable and generalizable to the entire set of data, codes of 1 or 2 instances should be removed. The purpose of this is to help determine which codes are the most useful and important for creating a theoretically based hypothesis. For example, the codes "caregiver-PWD relationship" and "caregiver burden" were removed. These changes can be viewed in Appendix A: Table 14.

At the end of the final coding process, there were 25 participants, where 16 participants were male and 9 were female. There are 6 major codes, of which 5 are also parent codes. In total, there are 24 codes, with the 18 essential codes described in Table 8. The final coding structure can be visualized in Figure 6, and compared to the previous coding structures in Figures 3-5. Ultimately, the findings of this study show that PWD cease driving due to many reasons. Some PWD self-regulated or voluntarily ceased driving and were satisfied with their decision. Relief was observed to have been a common response to having made the decision:

> *"CG2021: It was down to maybe once every 2 weeks and as of probably September he has decided on his own, even though he still has the license that he will not be driving the car, so…"*
> *[…]*
> *"Interviewer: Right he did. And how is that going?"*
> *"CG2021: Very well, he's comfortable with it and we're doing very well with the public transit."*

Comparatively, some PWD were forced to cease driving after a poor cognitive assessment or a failed driving test. Not to mention, some PWD simply don't understand how a cognitive assessment can determine that they are not capable of driving.

> "*CG3031: She made him pass some written exams you know."*
> *"PWD3031: I thought I did quite well with that, but I can't see how it has anything to do with driving … Been driving since I was 18 … I'm a very careful driver, I always give signals, I do everything right."*
> *"CG3031: Dear, they gave you exams for that, you didn't pass."*
> *"PWD3031: They didn't give me driving exams."*
> *"CG3031: No it's not driving, it's spatial; it's on paper. The A1, B2, that's the spatial one."*

"PWD3031: How can they tell with that you can't drive?"

Additionally, some PWD may cease driving after their family advised that they stop, or after they have had a vehicle collision.

"PWD026 : Et puis j'avais mon auto, puis en arrivant, il m'est arrivé un petit accident, donc j'ai vendu mon auto."
"Interviewer: Toute seule. Ce n'est pas le ministère qui vous a dit –"
"PWD026 : Ah, non, non, non."
"Interviewer: Donc vous n'avez pu vos permis, mais c'est vous-même."
"PWD026 : Oui, oui, j'ai non je ne conduis pu, je ne conduis pu sur la ville."
"CG026 : Elle a eu un accrochage. Elle est trop énervée, pis elle est trop nerveuse pour conduire."

[Translated]
"PWD3026: And I had my car, and on arrival, I had a small accident, so I sold my car."
"Interviewer: All alone. It wasn't the department who told you –"
"PWD3026: Ah, no, no, no."
"Interviewer: So you don't have your license anymore, but it was yourself –"
"PWD3026: Yes, I don't drive anymore; I don't drive in the city anymore."
"CG3026: She had a collision. She's too anxious, and she is too nervous to drive."

Other times, PWD explained that they ceased driving since they were determined to avoid hurting other people:

"PWD3013: Je savais que je pouvais plus conduire. Je me disais je ne sais pas conduire je ne peux plus conduire et j'ai tout de suite donné mon auto à son frère en fin de semaine."
"Interviewer: juste comme ça?"
"PWD3013: Bien oui. J'avais plus mon permis de conduire je suis allée le porté. Quand je me suis dit, non dans cette situation là je suis allé porter mon permis. Parce que je ne voulais pas prendre de chance de frapper quelqu'un."

[Translated]
"PWD3013: I knew I could no longer drive. I told myself I don't know how to drive, I can't drive anymore, and I immediately gave my car to her brother on the weekend."
"Interviewer: Just like that?"
"PWD3013: Well yes. I didn't have my license anymore; I went to give it in. When I told myself, no in this situation, I went to give in my license; because I did not want to take any chance of hitting someone."

Lastly, some PWD were forced to cease driving due to physical limitations, while others ceased driving due to the overwhelming costs of the driving tests (i.e. DriveABLE). Whether or not they were capable of driving, some participants could simply not afford to take a driving test, and therefore felt it was unfair to cease driving.

> *"CG1008: And if he insists upon driving he has to go and get this other one, and it cost 400 dollars, so I mean, who can afford to do that? It, it's a 400 dollar test and he probably would have to take it yearly, it would be the same cost every year, so, you know, we sort of talked about it and it isn't necessary for him to drive, I mean I know how to drive."*

The results also show that PWD are notified that they have to cease driving, either by a physician or by the government, such as the Ministry of Transportation. As such, some PWD will blame their physician for making the decision that they could no longer drive:

> *"CG1032: That was when he lost his license. That was it. He could not understand that. It didn't matter how much I talked to him, or how much Dr. CH talked to him. He was mad at Dr. CH ... and he must have forgotten that it was Dr. CH that did the first test. He said to Dr. CH: 'I went to see somebody here, and some bloody idiot took my license away.'"*

Once the PWD has been notified that they have to cease driving, the results show that the PWD either understands or does not understand why they are no longer allowed to drive. For example, many PWD do not believe memory is necessary for a person to be capable of driving a vehicle.

> *"PWD3023: Well he was picking holes, 'now look what you done here; now look what you done here.' Now what do you expect, I answered the questions to the best of my ability ... Anyway, I mean, memory has nothing to do with driving. You know what I mean, nothing to do. Memory, driving a vehicle is 70 years of consistent driving, so it's automatic. Memory has nothing to do with driving a vehicle ... you don't have to think even, you just drive."*

Half of the PWD who did not understand, also used their good driving record as justification that they should be able to continue to drive. On top of all this, participants explained having experienced emotional reactions, such as anger and blaming the tests, as well as the acceptance

of driving cessation. Finally, the study captured the use and availability of different types of alternate transportation. Personal transportation, including caregivers, extended family and friends, and public transportation were a prominent point of discussion for many PWD, where 2 participants were also found to have had no access to alternate methods of transportation.

The breakdown of these findings, including parent codes, child codes, number of sources, and number of references (one source may have multiple references for the same code) can be seen as follows:

1. Reasons for driving cessation (21 sources, 35 references)
    a. Self-regulated cessation (8 sources, 9 references)
    b. Poor cognitive assessment (7 sources, 10 references)
    c. Failed driving tests (3 sources, 6 references)
    d. Family advised to cease driving (2 sources, 3 references)
    e. Vehicle Collision (2 sources, 2 references)
    f. Physical limitations (1 sources, 1 references)
2. Notification (10 sources, 22 references)
    a. Physician (10 sources, 16 references)
    b. Government (3 sources, 4 references)
3. Driving Cessation Comprehension (17 sources, 34 references)
    a. Understanding why driving not allowed (9 sources, 10 references)
    b. Not understanding why driving not allowed (8 sources, 15 references)
        i. Good driving record as justification (4 sources, 4 references)
4. Emotional Reaction (7 sources, 21 references)
    a. Anger (5 sources, 13 references)

    b. Blaming test (4 sources, 7 references)

5. Accepting driving cessation (17 sources, 28 references)
6. Alternate transportation (22 sources, 73 references)
    a. Personal transportation (17 sources, 47 references)
        i. Caregivers (14 sources, 21 references)
        ii. Friends or extended family (5 sources, 13 references)
    b. Public transportation (15 sources, 24 references)
    c. No alternate transportation methods (2 sources, 2 references)

Lastly, while there were 16 male and 9 female participants in our study, we've also noted a few gender differences with regards to the results. First of all, there were 9 participants who understood why driving was no longer allowed. Of these 9 participants, 3 were male and 6 were female. On the other hand, there are 8 participants who did not understand why driving was no longer allowed. Of these 8 participants, 7 were male and 1 was female. Thus, in total, there were 16 male participants in the study: 7 participants did not understand why driving was no longer allowed; 3 understood why driving was no longer allowed; and 6 did not produce sufficient data to answer this question. As well, there are 9 female participants in the study: 6 participants understood why driving was no longer allowed; 1 did not understand why driving was no longer allowed; and 2 did not produce sufficient data to answer this question. Therefore, this may suggest that men have a harder time understanding why they have been told not to drive, once affected by dementia.

While it may be more difficult for men to understand why they have been told not to drive, 11 out of our 17 participants who accepted driving cessation, were male. That being said,

the description of the code "accepting driving cessation" states that the text associated with this code "may not always consist of participants who comprehend the reasons for driving cessation." Therefore, participants may accept that they can no longer drive even if they do not understand. As well, there may not be sufficient data to answer whether or not the participant understands why they are no longer allowed to drive. This would explain why out of the 17 participants who have accepted driving cessation, only 10 have answered if they understand why they were no longer allowed to drive (6 female and 4 male). Out of these 10 participants, 8 understood why driving was no longer allowed, of which 6 were female and 2 were male. This means that while 11 men accepted driving cessation, only 2 men understood why they were no longer allowed to drive (2 did not understand and 7 did not produce sufficient data to answer this question). More importantly, out of the 6 women who accepted driving cessation, they all understood why they were no longer allowed to drive.

5.4 Coding of the relationships – 25 participants

After the coding was completed and the categories had been formed, the relationships between the codes were further analyzed with the intent of strengthening the categories, understanding the links that exist between different codes, and continuing to build on the existing coding hierarchy. This was the last step prior to forming hypotheses that were refuted and reformulated until a final hypothesis was developed that could include all 25 cases. Relationships codes were created when there were multiple codes for a specific portion of text. Every permutation of relationship codes were created when there were overlapping codes, except when two codes were in close proximity but were clearly not related. Furthermore, once all of the text on driving cessation had been coded for relationships between the different codes and child codes, these relationships were then reviewed by the second and third researchers (LG and LM)

so as to obtain a consensus on the final relationship codes. After the relationship codes were agreed upon, there are a total of 46 relationships. The coding breakdown, including the total of sources and references for each relationship code can be seen in Table 9. As well, examples of each relationship can be viewed in Appendix A: Table 15. Finally, Table 10 can help visualize which relationships codes are the most prominent in the data. In this table, the rows and columns represent the 6 major codes. The middle of the table presents the relationships formed between two child codes, with the exception that the acceptance of driving cessation does not have a child code. The most prominent relationships are in bold, as they represent relationships coded by 6-8 sources. The relationships in italic (3-5 sources) should also be considered. The relationships in bold and italic are discussed in the following sections, for their involvement in the development of the final hypotheses.

5.5 Development of the final hypotheses

Once the relationship codes had been finalized, the final hypotheses could then be determined. These hypotheses will attempt to account for the entire data on driving cessation, with a final result that is generalizable to most of the participants who ceased driving prior to or during the study.

After reviewing the relationship codes, Table 9 and Table 10 demonstrate which relationships are the most prominent. These tables show that 8 PWD understood why driving was not allowed and also accepted driving cessation. Furthermore, 7 PWD accepted driving cessation and self-regulated their driving cessation. Hence, this also explains why there are relationship codes that show that 7 PWD understood and self-regulated their driving cessation. Finally, the results acknowledge that there are 6 PWD that understand, accept and have self-regulated their driving cessation. Therefore, a 7th hypothesis can be formed:

Hypothesis #7: It is important for persons with dementia to understand why driving is no longer allowed for them to be able to accept driving cessation, which are both potentially associated with the self-regulation of driving cessation.

There are 6 PWD who ceased driving due to a poor cognitive assessment and that were also notified by a physician that they were no longer allowed to drive. As well, 3 of these 6 PWD did not understand why they were told to stop driving. Therefore, it may be assumed that there is a link between a participant's poor cognitive assessment and those participants also not understanding why they are not allowed to continue driving. As such, in this study, there were 4 PWD who had a poor cognitive assessment and also did not understand why driving was not allowed. More so, 3 of these same 4 PWD also used their good driving record as justification that they should be able to continue to drive.

Likewise, there are 6 PWD in this investigation that were notified by a physician that they were no longer allowed to drive, and that also did not understand why they were not allowed to continue driving. Moreover, 2 of these PWD used their good driving record as justification that they are capable of driving, and 2 of them also explained experiencing emotions of anger. Furthermore, there are 3 PWD who had a poor cognitive assessment, were notified by a physician, and did not understand why they were told to cease driving. Therefore, an 8th hypothesis can be drawn:

Hypothesis #8: A poor cognitive assessment, as a reason for driving cessation, is potentially associated with the notification by a physician that driving must cease. Subsequently, a poor cognitive assessment and the notification of driving cessation by a physician are potentially both associated with a lack of understanding why driving is no longer allowed; where persons with dementia may also use their history of a good driving record as justification that they should be able to continue driving.

5.6 Refuting, reformulating, and accepting the hypotheses

As per Hammersley (2012), the final phase of the analytic induction process is the acceptance, refusal or reformulation of the hypotheses. As such, the hypotheses are based on a specific outcome to be explained (i.e. self-regulated driving cessation), from which only the participants where the outcome occurs should be subject to either an acceptance, a refusal, or a reformulation of the hypothesis. This final step has led to the creation of a final hypothesis that can explain data from all or a majority of the participants. As such, the data from each participant in the study were looked at individually to determine whether the hypotheses should be accepted, refuted or redefined until all cases were accounted for or explained. Table 11 summarizes the results of this process.

From Table 11 we can observe whether the hypothesis should be confirmed, thrown away or redefined to better fit the data. For hypothesis #7: 10 cases were judged to fit the hypothesis; 2 cases suggested a reformulation of the hypothesis; 2 cases refute the hypothesis; and 13 cases were either not applicable or did not provide an answer. The two cases that refute the hypothesis do so since both participants did not understand why they were no longer allowed to drive, and yet they both accepted driving cessation. This opposes the hypothesis that it is important to first understand why driving is no longer allowed to then accept the cessation of driving, and

potentially self-regulate driving cessation. The two cases that suggested a reformulation of the hypothesis both brought to attention the fact that alternate transportation is linked with accepting driving cessation and self-regulated cessation. More specifically, 5 PWD accepted driving cessation and also used their caregivers as a source of alternate transportation. As well, 4 PWD accepted driving cessation and used public transportation, 3 of which also self-regulated their driving cessation. Therefore, the 7th hypothesis can be redefined as such:

Hypothesis #9: It may be important for persons with dementia to understand why driving is no longer allowed for them to be able to accept driving cessation, which are both potentially associated with the self-regulation of driving cessation. Moreover, personal and public transportation may help persons with dementia accept driving cessation.

As for hypothesis #8, Table 11 shows that 7 cases were judged to have accepted the hypothesis; 2 cases suggested a redefined hypothesis; 2 cases refuted the hypothesis; and 16 cases either were not applicable or did not provide an answer. The two cases that refuted the hypothesis were both notified by a physician that they were no longer allowed to drive after a poor cognitive assessment; however they both understood why they were no longer allowed to drive. That goes against the hypothesis that a poor cognitive assessment and the notification of driving cessation by a physician may both be associated with a lack of understanding why driving is no longer allowed. From the two cases that offered a redefined hypothesis, one participant failed a driving test, was notified by a physician and did not understand why driving was no longer allowed. The other participant ceased driving due to a physical limitation (stroke), which led to a poor cognitive assessment and the notification by a physician that driving must cease, as well as them not understanding why driving was no longer allowed. As such, the 8th

hypothesis and these two cases both suggest that cognitive impairment in general, rather than simply a poor cognitive assessment, is potentially associated with the notification by a physician and PWD not understanding why were no longer allowed to drive. The 8th hypothesis can be redefined as follows:

Hypothesis #10: A poor cognitive assessment or a failed driving assessment, due to cognitive impairment, and as a reason for driving cessation, is potentially associated with the notification by a physician that driving must cease. Subsequently, cognitive impairment and the notification of driving cessation by a physician are both potentially associated with a lack of understanding why driving is no longer allowed; where persons with dementia may also use their history of a good driving record as justification that they should be able to continue to drive.

A final and major hypothesis can be formed by combining the ideas behind the 9th and 10th hypotheses. This final and 11th hypothesis is as follows:

Hypothesis #11: When PWD do not understand why they are no longer allowed to drive, they may experience emotions of anger. On the other hand, when PWD understand why they are no longer allowed to drive, they seem to accept and self-regulate their driving cessation. Public transportation and caregivers as a means of personal transportation are potentially associated with the acceptance of driving cessation. Furthermore, physicians notifying PWD that they have to cease driving does not seem to help them understand, nor do results of cognitive assessments help PWD understand why they are no longer allowed to drive.

Each individual participant was reviewed once more, to see if they could accept, refute or reformulate the 11th hypothesis. The results of this process can be viewed in Table 12, where we can see that this final hypothesis is judged to fit the data of 22 participants in the study. The data from the remaining 3 participants were not applicable since they either did not have enough information or it was unclear if they understood or accepted driving cessation.

CHAPTER 6: DISCUSSION

6.1 Final hypothesis

The overall goal of this study was to better understand and form a theoretically based hypothesis about the experience of driving cessation from the perspective of PWD and their caregivers. Understanding the process and the significance of driving cessation is necessary for the creation of adequate driving cessation programs (Liddle, McKenna, & Bartlett, 2007). Accordingly, by exploring the experience of driving cessation from the perspective of PWD and their caregivers, the findings from this study may provide insight and help understand this difficult process. Hereby, one hypothesis emerged from the qualitative methodologies of this study:

> *When PWD do not understand why they are no longer allowed to drive, they may experience emotions of anger. On the other hand, when PWD understand why they are no longer allowed to drive, they seem to accept and self-regulate their driving cessation. Public transportation and caregivers as a means of personal transportation are potentially associated with the acceptance of driving cessation. Furthermore, physicians notifying PWD that they have to cease driving does not seem to help them understand, nor do results of cognitive assessments help PWD understand why they are no longer allowed to drive.*

This hypothesis was found to hold for 22 cases within the study and it is worth noting that there were no disconfirming cases. Liddle et al. (2012) describe the adjustment process of driving cessation as one that is concentrated on information seeking and requiring support towards decision-making. It is a process where PWD have to discover and use alternative means

of transportation, as well as adjust to new routines (Liddle et al., 2012). Ultimately, driving cessation is an adaptation process towards accepting the loss of identity and role in society (Liddle et al., 2012). This supports the hypothesis that cognitive assessments and physician notifications are not sufficient to prompt or assure PWD that driving must cease. Trying to convince a PWD that they cannot drive may not be effective. PWD may not see the connection between a cognitive assessment, their memory, and their driving performance.

As the literature emphasizes the necessity for trained physicians and health professionals (Adler, 2010; Byszewski et al., 2003; Meuser, Carr, Berg-Weger, Niewoehner, & Morris, 2006; O'Neill, 2010), it is important to consider how to improve health professionals' understanding of the dementia experience and its impact on PWD and their caregivers. It may be possible to improve the communication and dialogue that occurs between physician and PWD when they are told they are no longer allowed to drive. With reports stating that PWD and their caregivers are receiving inconsistent advice with regards to driving cessation (Liddle et al., 2012), it is conceivable that this inconsistency has an impact on why PWD do not understand why they are no longer allowed to drive. Likewise, many PWD will report that their physicians made the decision for them to cease driving (Adler & Kuskowski, 2003), and as seen in this study, some PWD will be angry and blame their physician for this decision. Other PWD simply do not understand how a cognitive assessment can determine that they are not capable of driving or they do not believe memory is necessary for driving a vehicle. Given these findings, a health systems approach could improve the quality of care received by PWD by focusing on helping PWD understand the link between a cognitive assessment and their driving performance. For instance, a broader systemic approach could concentrate on improving access to on-road driving tests (i.e DriveABLE), rather than focus on driving tests performed on computers, which may be difficult

for the current cohort of healthy seniors. Improved access to on-road testing should also include reduced costs, allowing a larger proportion of PWD who may be capable of driving, from affording the expenses of taking the test.

Furthermore, the period of early planning for driving cessation may be an opportune time to introduce support programs (Liddle et al., 2014) and help with acceptance of driving cessation; therefore smoothing the process (Liddle et al., 2014). Further research might be needed to determine how physicians may improve this transition for PWD and their caregivers. The evidence from the current study suggests that it may not help individuals understand why they can no longer drive by having physicians simply tell them that this is the case. An alternative solution could be for physicians or other health professionals to explain suitable and accessible alternatives to driving. For example, using taxis or taking the bus might be less stressful and less expensive than financing a car, insurance, gas and so on. Intervention programs could be developed to help physicians communicate the lifestyle changes that PWD will have to go through when they cease driving.

A systems level approach should also look at expanding the accessibility and adaptability of alternate transportation. Developing support and training programs targeting retired drivers prior to driving cessation can help PWD and their caregivers understand which services are available to them and possibly augment the self-efficacy and acceptance of alternate transportation (Buys et al., 2012; Curl et al., 2013; Liddle, Reaston, Pachana, Mitchell, & Gustafsson, 2014). The final hypothesis of this study also suggests that alternative transportation could be directed towards increasing the acceptance of driving cessation. Alternative transportation may help minimize the impact on lifestyle if properly approached. This means offering bus services that are accessible and acceptable for all PWD and their caregivers. The

physical demands of using public transportation may make it hard for PWD and their caregivers to use the bus (Buys et al., 2012). As well, paratranspo services might only be offered for the PWD and not for the caregiver, as PWD may not always be deemed to need assistance or an attendant. However, many PWD would not or cannot travel without their caregiver.

Another avenue of exploration might be to see whether healthcare professionals focus too much on trying to explain to PWD why driving must cease, rather than deal with the emotions of acceptance, by targeting lifestyle changes as an emotion-focused coping strategy. Lifestyle changes, early planning and the use of alternate means of transportation could help PWD understand and accept why they've been told to cease driving. This importance of understanding and accepting driving cessation is also acknowledged by Liddle et al. (2012).

Some strategies could be suggested for helping improve PWD's comprehension of why they have been told to cease driving. In 2010, the Alzheimer Society of Canada published a study with the aim of determining the health and economic burden of dementia in Canada over the next 30 years. This study evaluated potential intervention strategies and examined health care policies, to form recommendations moving forward. This report analysed Wagner's chronic care model (Wagner, 1998) and appreciated its suitability to offer improved care and management of individuals with dementia (Alzheimer Society of Canada, 2010). Specifically, it mentions how an early diagnosis can help the PWD and their caregivers in the self-management of the disease, through education in risk reduction, intervention options, and coping mechanisms (Alzheimer Society of Canada, 2010). This approach places emphasis on team based care and support, which follows the design and principles of the chronic care model (Wagner, 1998). Consequently, by adhering to Wagner's model of disease management, we are able to offer improved care for PWD. As such, with an early diagnosis, improved self-management of the disease, and defined

roles for health professionals and community resource providers, it may be possible to help more PWD and their caregivers understand why, after a certain time, driving must cease. This may also impact the overall acceptance of driving cessation, lead to less emotional reactions of anger, and aid more PWD with the self-regulation of their driving cessation.

As with our investigation, the study by Liddle et al. (2012) recognized that some PWD decided to cease driving and were satisfied with their decision. While they also noted that these instances do not depict the process of driving cessation for all PWD, those who decided to cease driving demonstrate how the process of driving cessation can be a different experience for each individual (Berg-Weger, Meuser, & Stowe, 2013; Liddle et al., 2012). As mentioned in our results, and similar to the study by Liddle et al. (2012), some participants ceased driving due to a single decisive event, while others explained they were determined to avoid hurting other people. As well, satisfaction and relief seemed to be familiar to PWD who decided to cease driving (Liddle et al., 2012).

Driving cessation may also trigger other transitions for PWD. Having already mentioned the costs of driving tests and financing a car, it is worth noting that the socioeconomic status of PWD and their caregivers may also have an impact on their financial autonomy and the resources available to them (i.e. transportation, living at home). Social isolation or a lack of transportation options may lead PWD to move into a retirement home or a long-term care facility. This also brings to attention the possibility that PWD may have had multiple transitions simultaneously. Therefore, their anger could be a culmination of multiple factors, including not understanding why they were no longer allowed to drive. Future research might look into this possibility and how it impacts the experience of dementia and driving cessation.

Lastly, previous studies report that in healthy aging (Chipman, Payne, & McDonough, 1998) and in dementia (Herrmann et al., 2006; Seiler et al., 2012), women are more likely to cease driving than men. Stewart, Moore, Marks, May, and Hale (1993) stated that women are more likely to voluntarily stop driving than men. In our study, of our 8 participants with self-regulated driving cessation, there are 4 male and 4 female participants. As such, our data does not produce sufficient evidence to concur or disagree with these reported findings on driving cessation. However, our study might be relevant for explaining these previous reports. The described gender difference in reference to driving cessation might be explained by women having an easier time understanding why they are no longer allowed to drive, which has led to more women understanding and accepting driving cessation in our investigation. Moreover, the hypothesis put forth in the current study may explain these differences. In the current generation of seniors, driving cessation may be less of a lifestyle change for women with dementia, as it would for men (Burkhardt, Berger, & McGavock, 1996; Rosenbloom & Winsten-Bartlett, 2002; Siren, Hakamies-Blomqvist, & Lindeman, 2004). That being said, the personal transportation of husbands with dementia also has a significant impact on their spouses and needs to be addressed.

6.2 Driving cessation model

The conceptual model of the driving cessation process (Choi et al., 2012), used to motivate this thesis, was instrumental in understanding the results. For PWD, cognitive impairment is the primary stressor relating to driving cessation. Secondary internal stressors could be attributed to nervousness about driving. Secondary external stressors are when formal authorities (i.e. physicians, government) or informal networks (i.e. family members, friends) inform a PWD that they are no longer allowed to drive. As Choi et al. (2012) have explained, PWD who are mostly influenced by external stressors are forced to stop driving involuntarily,

compared to PWD who are mostly pressured by internal stressors, and are more likely to cease driving on their own. Although some participants did voluntarily cease driving after it was suggested by a formal authority, the majority of the participants in this study followed the path expressed in the model by Choi et al (2012). This may also supports the hypothesis that it is harder for PWD to understand why they are no longer allowed to drive when they are being told by an external stressor (i.e. physician) and forced to stop driving involuntarily.

In this model, the quality of life of each PWD is distinctively affected by the internal or external stressors, but can also be ameliorated by buffers and coping methods. The buffers are interventions that promote a sense of control (Choi et al. 2012), such as support programs that aim to increase the acceptance of alternate transportation and thus the acceptance of driving cessation. The two types of coping methods are emotion-focused coping and problem-focused coping (Lazarus & Folkman, 1984). The effective use of emotion-focused coping can include the acceptance of having to self-regulate or cease driving (Adler & Rottunda, 2006). As per the hypothesis put forth in this study, understanding why they are no longer allowed to drive may be important for PWD to be able to accept driving cessation. Additionally, personal and public transportation may assist with the acceptance of driving cessation. On the contrary, the ineffective use of emotion-focused coping by PWD could involve the denial of their inability to drive. Ultimately, instead of only using problem-focused coping strategies, physicians and healthcare professionals could also concentrate on emotion-focused coping strategies centred on the acceptance of driving cessation and lifestyle change. PWD already report having ceased driving because they were nervous or did not want to hurt other people. Therefore, by incorporating the use of emotion-focused coping, it might be easier for PWD to understand and accept the lifestyle changes that come with alternate ways of transportation.

Aside from emotion-focused coping, problem-focused coping might consist of self-regulated driving (Rose et al., 2009) or the use of alternative transportation (Choi et al., 2012). By self-regulating their driving cessation, some PWD only drive in good driving conditions, such as good weather and in the daytime (Ross et al., 2009). Using alternative transportation can also strengthen the PWD's independence and help keep an active lifestyle. Thus, emotion-focused coping and problem-focused coping are most befitting when used in conjunction with one another.

Finally, the spatial and temporal context of the driving cessation model should also be discussed (Choi et al., 2012). The spatial context (i.e. the living arrangements) of PWD may predispose them to an avail of personal or public transportation, depending on their proximity to their desired destinations. On the other hand, their living arrangements may also limit the range of transportation opportunities at their disposal. For example, living in a rural neighbourhood that is underserved by public transit or living too far from relatives, may restrict the services at their disposition. Besides their proximity to alternate transportation, living in walking distance to friends or a supermarket can also have an important impact on how a PWD accepts driving cessation and the lifestyle changes that are associated. Transportation policy (temporal context) should also be improved to offer more accessible and affordable alternate means of transportation. Lastly, of note, are the high costs of driving tests for PWD, which some participants have attributed to having impeded on their financial ability to continue driving.

CHAPTER 7: LIMITATIONS

For this study, there are a few limitations to consider. Since this investigation used a volunteer sample of participants that were available for monthly phone calls, participants who were too busy, burdened with the role of caregiver, or did not speak English or French would have been incapable of participating. The relatively frequent contact with research participants could reduce loss to follow up, which is one of the more serious limitations of a cohort study (Kristman, Manno, & Cote, 2004). An important disadvantage to having used monthly phone calls is the possibility that the monthly contact will have been used as a support intervention and risk influencing the natural course of the dementia experience (Sackett, 1979). As well, data collected may be less valid if the caregiver or PWD were recounting experiences that occurred a long time ago and therefore their retelling of this event may be less accurate.

The fact that 60% of the participants were from Ottawa may have an influence on the results. For example, the bus and transportation system in Ottawa differs from the transportation systems in Edmonton and Calgary. As well, the three researchers who conducted interviews (one in each city) had different interview styles which may had an impact on the data collected.

The researchers performing the analysis did not conduct the interviews themselves. Typically, using analytic induction means that the researcher will code and analyze the data while the collection is ongoing, so as to direct the data and follow up on leads or relevant information prior to a re-sampling of the data. However, for this study, the open coding was performed after the data had been collected and the re-sampling of participants occurred within the pool of data that had already been collected. Finally, Katz (1983) explains that the end result could be viewed as well-defined definitions, instead of a comprehensive theory.

CHAPTER 8: CONCLUSIONS

From this investigation, we were able to develop a hypothetical explanation for the experience of driving cessation, with no disconfirming cases. We were able to establish that public transportation and alternate means of personal transportation (i.e. caregivers, friends) are potentially associated with the acceptance of driving cessation. PWD may experience emotions of anger when they do not understand why are not allowed to drive. Nonetheless, when PWD understand why are not allowed to drive, they seem to accept and self-regulate their driving cessation. This answers the study objective of learning the reaction to the loss of the driver`s license and it has been identified as a potential area of interest for future research. Essentially, it could be important to conceive studies that look to comprehend how PWD understand and accept driving cessation. It would be worthwhile to construct strategies with this focus, since it may contribute to a smoother transition and it may lead to more PWD self-regulating their driving cessation.

Likewise, the results reveal that cognitive tests and physicians instructing PWD that they have to cease driving, do not seem to help them understand. In this regard, further research is needed to determine how physicians might be able to improve this transition for PWD and their caregivers. PWD may not understand the connection between a cognitive assessment, their memory, and their driving performance. A health systems level approach might be needed to improved access and adaptability of alternative means of transportation, as well as augment the access of on-road driving tests. This might help PWD understand why they were no longer allowed to drive; accept driving cessation; and adjust to the lifestyle changes that are associated.

CHAPTER 9: LIST OF REFERENCES

Adler, G. (2010). Driving decision-making in older adults with dementia. *Dementia, 9*(1), 45-60.

Adler, G. & Kuskowski, M. (2003). Driving cessation in older men with dementia. *Alzheimer's Disease and Associated Disorders, 17*(2), 68-71.

Alzheimer Society of Canada (2010). Rising Tide: the impact of dementia on Canadian society. Retrieved on May 5th 2014 from the Alzheimer Society of Canada Web Site: http://www.alzheimer.ca/durham/~/media/Files/national/Advocacy/ASC_Rising_Tide_Full_Report_e.pdf

Alzheimer Society of Canada (2012). "A new way of looking at the impact of dementia in Canada", Retrieved on October 21st 2012 from the Alzheimer Society of Canada Web Site: http://www.alzheimer.ca/~/media/Files/national/Media-releases/asc_factsheet_new_data_09272012_en.pdf

Anstey, K.J., Windsor, T.D., Luszcs, M.A., & Andrews, G.R. (2006). Predicting driving cessation over 5 years in older adults: psychological well-being and cognitive competence are stronger predictors than physical health. *Journal of the American Geriatrics Society,* 54(1), 121-126.

Azad, N., Byszewski, A., Amos, S., & Molnar, F. (2002). A survey of the impact of driving cessation on older drivers. *Geriatrics Today: J. Canadian Geriatric Society, 5*, 170–174.

Bazeley, P. & Jackson, K. (2013). *Qualitative data analysis with NVivo*. Sage Publications Ltd.

Becker, H.S. (1958). Problems of inference and proof in participant observation. *American Sociological Review, 23*, 652-660.

Bedard, M., Molloy, D.W., & Lever, J.A. (1998). Factors associated with motor vehicle crashes in cognitively impaired older adults. *Alzheimer Disease and Associated. Disorders, 12*(3), 135-139.

Berg-Weger, M., Meuser, T.M., & Stowe, J. (2013). Addressing individual differences in mobility transition counseling with older adults. *Journal of Gerontological Social Work, 56*, 201-218.

Beverly Foundation (2002). The 5 A's of senior-friendly transportation: Supplemental transportation programs for seniors (STPs), Retrieved October 15th, 2012, from the http://beverlyfoundation.org/resource-library/#stp

Bloor, M. & Wood, F. (2006). *Keywords in qualitative methods: A vocabulary of research concepts*. Sage Publications, London.

Bogdan, R.C. & Biklen, S.K. (1982). *Qualitative research for education*. Boston: Allyn & Bacon.

Burkhardt, J., Berger, A. & McGavock, A. (1996). The mobility consequences of the reduction or cessation of driving by older women. pp. 441-453 in Women's Travel Issues: Proceedings from the Second National Conference, October 1996. U.S. Department of Transportation.

Buys, L., Snow, S., van Megen, K., & Miller, E. (2012). Transportation behaviours of older adults: An investigation into car dependency in urban Australia. *Australasian Journal of Ageing, 31,* 181-186.

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 post-evaluation on knowledge, confidence gained, and satisfaction. *Journal of American Geriatrics Society, 51*, 1484-1489.

Byszewski, A.M., Molnar, F.J., & Aminzadeh, F. (2010). The impact of disclosure of unfitness to drive in persons with newly diagnosed dementia: Patient and caregiver perspectives, *Clinical Gerontologist, 33*, 152-163.

Cable, G., Reisner, M., Gerges, S., & Thirumavalavan, V. (2000). Knowledge, attitudes, and practices of geriatricians regarding patients with dementia who are potentially dangerous automobile drivers: A national survey. *Journal of the American Geriatrics Society, 48*(1), 14-17.

Calhoun, V.D., Pekar, J.J., McGinty, V.B., Adali, T., Watson, T.D., & Pearlson, G.D. (2002). Different activation dynamics in multiple neural systems during simulated driving. *Human Brain Mapping, 16*(3), 158-167.

Carr, D.B. (1997). Motor vehicle crashes and drivers with DAT. *Alzheimer Disease Associated Disorders, 12*(3), 135-139.

Carr, D.B., Duchek, J., & Morris, J.C. (2000). Characteristics of motor vehicle crashes of drivers with dementia of the Alzheimer type. *Journal of the American Geriatrics Society, 48*(1), 18–22.

Carr, D.B. & Ott, B.R. (2010). He older adult driver with cognitive impairment: “It’s a very frustrating life”. *JAMA, 303*, 1632-1641.

Carr, D.B., Shead, V., & Storandt, M. (2005). Driving cessation in older adults with dementia of the Alzheimer’s type. *The Gerontologist, 45*(6), 824-827.

Cerreli, E. (1998). *Crash data and rates for age-sex groups of drivers*. Washington, DC: National Highway Traffic Safety Admin.

Chapman, D.P., Williams, S.M., Strine, T.W., Anda, R.F., & Moore, M.G. (2006). Dementia and its implications for public health. *Preventing Chronic Disease, 3*, 1–13.

Chipman, M.L., Payne, J., & McDonough, P. (1998). To drive or not to drive: The influence of social factors on the decisions of elderly drivers. *Accident Analysis and Prevention*, *30*, 299-304.

Choi, M., Adams, K.B., & Mezuk, B. (2012). Examining the aging process through the stress-coping framework: application to driving cessation in later life. *Aging & Mental Health, 16*(1), 75-83.

Cooper, P.J., Tallman, K., Tuokko, H., & Beattie, B.L. (1993). Vehicle crash involvement and cognitive deficit in older drivers. *Journal of Safety Research, 24*, 9-17.

Croston, J., Meuser, T.M., Berg-Weger, M., Grant, E.A., & Carr, D.B. (2009). Driving retirement in older adults with dementia. *Topics in Geriatric Rehabilitation, 25*, 154-162.

Curl, A.L., Stowe, J.D., Cooney, T.M., & Proulx, C.M. (2013). Giving up the keys: How driving cessation affects engagement in later life. *Gerontologist*, doi:10.1093/geront/gnt037

Daigneault, G., Joly, P., & Frigon, J.Y. (2002). Executive functions in the evaluation of accident risk of older drivers. *Journal of Clinical and Experimental Neuropsychology, 24*, 221-238.

Davey, J.A. (2007). Older people and transport: Coping without a car. *Ageing and Society, 27*, 49-65.

Dellinger, A.M., Sehgal, M., Sleet, D.A., & Barrett-Connor, E. (2001). Driving cessation: What older former drivers tell us. *Journal of the American Geriatrics Society, 49*, 431-435.

Dickerson, A.E. (2014). Driving with dementia: Evaluation, referral, and resources. *Occupational Therapy in Health Care, 28*(1), 62-76.

Diller, E., Cook, L., Leonard, D., Dean, J.M., Reading, J., & Vernon, D. (1999). *Evaluating drivers licensed with medical conditions in Utah, 1992-1996*, No. DOT HS 809 023, National Highway Traffic Safety Administration, Washington, DC.

Dobbs, A.R. (1997). Evaluating the driving competence of dementia patients. *Alzheimer Disease and Associated Disorders, 11*(1), 8-12.

Dobbs, B,M. (2008). Aging baby boomers: A blessing or challenge for driver licensing authorities. *Traffic Injury Prevention, 9*, 379-386.

Dobbs, B.M., Carr, D. (2005). Screening and assessment of medically at-risk drivers. *Public Policy & Aging Report, 15*(2), 6–12.

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*, 73-86.

Dobbs, B., Zirk, H., & Daly, S. (2009). Tackling a tough issue: Strategies for identifying, assessing and supporting drivers with dementia in the primary care setting. *The Canadian Review of Alzheimer's Disease and Other Dementias, 12*(1), 13-21.

Downs, M., Small, N., & Froggatt, K. (2006). Explanatory models of dementia: Links to end-of-life care. *International Journal of Palliative Nursing, 12*(5), 209-213.

Drachman, D.A. & Swearer, J.M. (1993). Driving and Alzheimer’s disease: The risk of crashes. *Neurology, 43*, 2448-2456.

Dubinsky, R.M., Williamson, A., Gray, C.S., & Glatt, S.L. (1992). Driving in Alzheimer’s disease. *Journal of American Geriatrics Society, 40*, 1112-1116.

Ferri, C.P., Prince, M., Brayne, C., Brodaty, H., Fratiglioni, L., Ganguli, M. … Scazufca, M. (2005). Global prevalence of dementia: A Delphi consensus study. *Lancet*, *366*, 2112–2117.

Finlayson, M. & Kaufert, J. (2002). Older women’s community mobility: a qualitative exploration. *Canadian Journal on Aging, 21*, 75-84.

Foley, D.J., Heimovitz, H.K., Guralnik, J.M., & Brock, D.B. (2002). Driving life expectancy of persons aged 70 years and older in the United States. *American Journal of Public Health, 92*, 1284-1289.

Foley, D.J., Masaki, K.H., Ross, G.W., & White, L.R. (2000). Driving cessation in older men with incident dementia. *Journal of American Geriatrics Society, 48*, 928-930.

Fonda, S.J., Wallace, R.B., & Herzog, A.R. (2001). Changes in driving patterns and worsening depressive symptoms among older adults. *Journal of Gerontology: B: Psychological Sciences and Social Sciences, 56*(6), S343-351.

Forrest, K.Y., Bunker, C.H., Songer, T.J., Coben, J.H., & Cauley, J.A. (1997). Driving patterns and medical conditions in older women. *Journal of American Geriatrics Society, 45*, 1214-1218.

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

Freeman, E.E., Gange, S.J., Munoz, B., & West, S.K. (2006). Driving status and risk of entry into long-term care in older adults. *American Journal Public Health, 96*(7), 1254–1259.

Freeman, E.E., Munoz, B., Turano, K.A., & West, S.K. (2005). Measures of visual function and time to driving cessation in older adults. *Optometry Vision Science, 82*, 765-773.

Freund, K. (2000). Independent transportation network: Alternative transportation for the elderly. *TR News, 206*, 3–12.

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

Gilhotra, J.S., Mitchell, P., Ivers, R., & Cumming, R.G. (2001). Impaired vision and other factors associated with driving cessation in the elderly: the Blue Mountains Eye Study. *Clinical and Experimental Ophthalmology, 29*, 104-107.

Goetz, J., & LeCompte, M. (1981). Ethnographic research and the problem of data reduction. *Anthropology and Education Quarterly, 12*, 51-70.

Guba, E.G. (1981). Criteria for assessing the trustworthiness of naturalistic inquiries. *Educational Communication and Technology Journal*, *29*(2), 75-92.

Guba, E.G. & Lincoln, Y.S. (1989). *Fourth generation evaluation*. Sage Publications, Newbury Park, CA.

Guba, E.G. & Lincoln, Y.S. (1981). *Effective evaluation*. Jossey-Bass, San Francisco, CA.

Hammersley, Martyn (2010). A historical and comparative note on the relationship between analytic induction and grounded theorising. *Forum: Qualitative Social Research, 11*(2), Art. 4. Can be found at: http://www.qualitative-research.net/index.php/fqs/article/view/1400/2994

Hammersley, Martyn (2012). What is analytic induction? University of Southampton Presentation, Can be viewed at: http://www.ncrm.ac.uk/TandE/video/RMF2012/whatis.php?id=186d59f

Healthy Aging and Wellness Working Group (2006). Healthy aging in Canada: A new vision, a vital investment from evidence to action. A background paper prepared for the Federal/Provincial/Territorial Committee of Officials (Seniors), 76 p.

Herrera, A.P., Meeks, T.W., Dawes, S.E., Hernandez, D.M., Thompson, W.K., Sommerfeld, D.H., Allison, M.A., & Jeste, D.V. (2011). Emotional and cognitive health correlates of leisure activities in older Latino and Caucasian women. *Psychology, Health, and Medicine, 16*, 661-664.

Herrmann, N., Rapoport, M.J., Sambrook, R., Hebert, R., McCracken, P., & Robillard, A. (2006). Predictors of driving cessation in mild-to-moderate dementia. *CMAJ*, *175*(6), 591-595.

Hinton, L., Franz, C., & Friend, J. (2004). Pathways to a dementia diagnosis: Evidence for cross-ethnic differences. *Alzheimers Disease Associated Disorders, 18*(3), 134–144.

Hopkins, R.W., Kilik, L., Day, D.J., Rows, C., & Tseng, H. (2004). Driving and dementia in Ontario: a quantitative assessment of the problem, *Canadian Journal of Psychiatry*, *49*(7), 434-438.

Hu, S., Ivan, J., Ravishanker, N., & Mooradian, J. (2012). Temporal modeling of highway cash counts for senior and non-senior drivers, *Accident Analysis & Prevention, 50*, 1003-1013.

Jette, A.M. & Branch, L.G. (1992). A ten-year follow-up of driving patterns among community-dwelling elderly. *Human Factors, 34*, 25-31.

Johansson, K., Bogdanovic, N., Kalimo, H., Winblad, B., & Viitanen, M. (1997). Alzheimer's disease and apolipoprotein E epsilon 4 allele in older drivers who died in automobile accidents. *Lancet, 349*, 1143-1144.

Katz, J. (1983). A theory of qualitative methodology. In R.M. Emerson (Ed.), Contemporary field research: A collection of readings (pp. 127-148). Prospect Heights, Ill.: Waveland.

King, M.D., Meuser, T.M., Berg-Weger, M., Chibnall, J.T. Harmon, A.C., & Yakimo, R. (2011). Decoding the Miss Daisy Syndrome: an examination of subjective responses to mobility change. *Journal of Community Health Nursing, 25*, 65-74.

Kristman, V., Manno, M., & Cote, P. (2004). Loss to follow-up in cohort studies: How much is too much? *European Journal of Epidemiology, 19*(8), 751-760.

Lafont, S., Laumon, B., Helmer, C., Dartigues, J.F., & Fabrigoule, C. (2008). Driving cessation and self-reported car crashes in older drivers: The impact of cognitive impairment and

dementia in a population-based study. *Journal of Geriatric Psychiatry and Neurology, 21*(3), 171-182.

Langford, J., Braitman, K., Charlton, J., Eberhard, J., O'Neill, D., Staplin, L., & Stutts, J. (2007). *Communiqué from the Panel.* TRBWorkshop, Washington, DC.

Lazarus, R.S. & Folkman S. (1984). *Stress, appraisal, and coping*. New-York: Springer.

Liddle, J., Bennett, S., Allen, S., Lie, D.C., Standen, B., & Pachana, N.A (2012). The Stages of driving cessation for people with dementia: needs and challenges. *International Psychogeriatrics*, *25*(12), 2033-2046.

Lidle, J., McKenna, K., & Bartlett, H. (2007). Improving outcomes for older retired drivers: The UQDRIVE program. *Australian Occupational Therapy Journal, 54*, 303-306.

Liddle, J., McKenna, K., & Broome, K. (2005). *Older road users: From driving cessation to safe transportation.* Canberra: Australian Transport Safety Bureau.

Liddle, J., Reaston, T., Pachana, N., Mitchell, G., & Gustafsson, L. (2014). Is planning for driving cessation critical for the well-being and lifestyle of older drivers? *International Psychogeriatrics, 26*(7), 1111-1120.

Lincoln, Y.S. & Guba, E.G. (1985). *Naturalistic inquiry*. Beverly Hills, CA: Sage.

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*, 878–884.

Marottoli, R.A., Ostfeld, A.M., Merrill, S.S., Perlman, G.D., Foley, D.J., & Cooney, L.M Jr. (1993). Driving cessation and changes in mileage driven among elderly individuals. *Journal of Gerontology: Social Sciences, 48*, 255-260.

Menec, V.H. (2003). The relation between everyday activities and successful aging: a 6-year longitudinal study. *Journal of Gerontology: B: Psychological Sciences and Social Sciences, 58*, S74-S82.

Mercado, R., Paez, A., & Newbold, K. B. (2007). *Policy spheres and elderly transportation needs*, retrieved September 20th, from: http://www.science.mcmaster.ca/geo/faculty/paez/additional_info/Transport_Policy_Ontariov1.1.pdf

Meuser, T.M., Berg-Weger, M., Chibnall, J.T., Harmon, A.C., & Stowe, J. (2013). Assessment of readiness for mobility transition (ARMT): A tool for mobility transition counselling with older adults. *Journal of Applied Gerontology, 32*, 484-507.

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

Molnar, L.J., Eby, D.W., Charlton, J.L., Langford, J., Koppel, S., Marshall, S., & Man-Son-Hing, M. (2013). Driving avoidance by older adults: Is it always self-regulation? *Accident Analysis and Prevention, 57*, 96-104.

Morse, J.M. (1998). Designing funded qualitative research. In: Denzin, N.K., & Lincoln, Y.S. (Eds) *Strategies of qualitative inquiry.* Sage Publications, Thousand Oaks CA, pp. 56-85.

OC Transpo (2012). *Para Transpo: Transportation for people with disabilities*, Retrieved October 5th 2012, from http://www.octranspo1.com/community-events/para_transpo

OC Transpo (2012). *Taxi coupon program*, Retrieved October 5th 2012, from http://www.octranspo1.com/riding-with-oc-transpo/taxi_coupon

O'Neill, D. (2010). Practice parameter update: Evaluation and management of driving risk in dementia: Report of the Quality Standards Subcommittee of the American Academy of Neurology. *Neurology, 75*, 1659; author reply 1659-1660.

Owsley, C., Ball, K., McGwin, G. Jr., Sloane, M.E., Roenker, D.L., White, M.F., & Overley, E.T. (1998). Visual processing impairment and risk of motor vehicle crash among older adults. *JAMA, 279*, 1083-1088.

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

Ragland D.R., Satariano, W.A., & MacLeod, K.E. (2005). Driving cessation and increased depressive symptoms. *Journal of Gerontology: A: Biological Sciences & Medical Sciences, 60*(3), 399–401.

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.

Rapoport, M., Herrmann, N., Molnar F., Man-Son-Hing, M., Marshall, S., Shulman, K., & Naglie, G. (2007). Sharing the responsibility for assessing the risk of the driver with dementia. *CMAJ, 177*(6), 599-601.

Ratcliff, D.E. (1994). Analytic induction as a qualitative research method of analysis. The University of Georgia, 1-4.

Ross, L.A., Clay, O., Edwards, J.D., Ball, K., Wadley, V.G., Vance, D.E., … Joyce, J. (2009). Do older drivers at-risk for crashers modify their driving over time? *Journal of Gerontology: Psychological Sciences, 64B*, 163-170.

Rosenbloom S. (2004). The mobility of the elderly: There's good news and bad news. In Transportation in an aging society: A decade of experience conference. *Transportation Research Board Conference Proceedings, 27*, 3-21.

Rosenbloom, S. & Winsten-Bartlett, C. (2002). Asking the right question: Understanding travel needs of older women who do not drive. *Transportation Research Records: Journal of the Transportation Research Board, 1808,* 78-82*.* Transportation Research Board of the National Academies, Washington, D.C.

Ryan, G.W. (2005). What are standards of rigor for qualitative research? Paper Prepared for the NSF Workshop on Interdisciplinary Standards for Systematic Qualitative Research, Washington, DC: May. URL: http://www.wjh.harvard.edu/nsfqual/Ryan%20Paper.pdf

Ryan-Nicholls, K., & Will, C. (2009). Rigour in qualitative research: mechanisms for control. *Nurse Researcher, 16*(3), 70-85.

Sackett, D.L. (1979). Bias in analytic research. *Journal of Chronic Diseases, 32*, 51-63.

Sandelowski, M. (1986). The problem of rigour in qualitative research. *Advances in Nursing Science, 8*(3), 27-37.

Seiler, S., Schmidt, H., Lechner, A., Benke, T., Sanin, G., Ransmayr, G., … Schmidt, R. (2012). Driving cessation and dementia: results of the prospective registry on dementia in Austria (PRODEM). *Plos One, 17*(12), 1-6.

Siren, A., Hakamies-Blomqvist, L., & Lindeman, M. (2004). Driving cessation and health in older women. *The Journal of Applied Gerontology, 23*(1), 58-69.

Sivak, M. & Schoettle, B. (2012). Recent changes in the age composition of drivers in 15 countries. *Traffic Injury Prevention, 13*(2), 126-132.

Snyder, C.H. (2005). Dementia and driving: autonomy versus safety, *Journal of the American Academy of Nurse Practitioners*, *17*(10), 393-402.

Statistics Canada (2013). *National Seniors Day… by the numbers*, retrieved on May 5th 2014 from: http://www42.statcan.gc.ca/smr08/2013/smr08_178_2013-eng.htm

Statistics Canada (2012). *Profile of senior's transportation habits*, retrieved September 18th 2012, from:_ http://www.statcan.gc.ca/pub/11-008-x/2012001/article/11619-eng.htm

Statistics Canada (2011). *The Canadian Population in 2011: Age and Sex*, retrieved on May 5th 2014 from: http://www12.statcan.ca/census-recensement/2011/as-sa/98-311-x/98-311-x2011001-eng.cfm

Statistics Canada (2001). *Profile Series: Seniors in Canada.* Catalogue No. 85F0033MIE, retrieved July 23rd 2014, from: http://publications.gc.ca/Collection/Statcan/85F0033M/85F0033MIE2001008.pdf

Sterns, H.L., Burkhardt, J.E., & Eberhard, J.W. (2003). Moving along the mobility continuum. *Generations, 27*(2), 8-13.

Stewart, R.B., Moore, M.T., Marks, R.G., May, F.E., & Hale, W.E. (1993). Driving cessation and accidents in the elderly: An analysis of symptoms, diseases, cognitive dysfunction and medications. *AAA Foundation for Traffic Safety*, Washington, DC.

Stutts, J.C., Stewart, J.R., & Martell, C. (1998). Cognitive test performance and crash risk in an older driver population. *Accident Analysis and Prevention, 30*, 337-346.

Talbot, A., Bruce, I., Cunningham, C.J., Coen, R.F., Lawlor, B.A., Coakley, D., Walsh, J.B., O'Neill, D. (2005). Driving cessation in patients attending a memory clinic. *Age Ageing, 34*, 363-368.

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

Trobe, J.D., Waller, P.F., Cook-Flannagan, C.A., Teshima, S.M., & Bieliauskas, L.A. (1996). Crashes and isolations among drivers with Alzheimer disease. *Archives of Neurology, 53*(5), 411-416.

Tuokko, H., Tallman, K., Beattie, B.L., Cooper, P., & Weir, J. (1995). An examination of driving records in a dementia clinic. *Journal of Gerontology: B: Psychology Sciences and Social Sciences, 50*, S173-S181.

Wagner, E.H. (1998). Chronic disease management: What will it take to improve care for chronic illness? *Effective Clinical Practice, 1*, 2-4.

Wang, C.C., Kosinski, C.J., Schwartzberg, J.G., & Shanklin, A.V. (2003). Physician's guide to assessing and counseling older drivers. Chicago: American Medical Association. Retrieved October 15th, 2012, from Highway Traffic Safety Administration Web site: http://www.nhtsa.dot.gov/people/injury/olddrive/OlderDriversBook/pages/Contents.html

Windsor, T.D., Anstey, K.J., Butterworth, P., Luszcz, M.A., & Andrews, G.R. (2007). The role of perceived control in explaining depressive symptoms associated with driving cessation in a longitudinal study. *Gerontologist, 47*, 215-223.

Tables

Table 1: Summary of the driving cessation process

Period of driving cessation	Summary of driving cessation process
Ceased driving during the study	The PWD went to DriveABLE to have a computer test and a driving test done, where they said that he shouldn't be driving. His caregiver does not agree with the assessment and is not happy with their service. Afterwards, he was no longer driving but still had his license until the government asked for a cognitive re-assessment. The caregiver is capable of driving and neither takes the bus.
	The PWD took a driving test, at which point the test results concluded that it was unsafe. He and his wife decided that he would stop driving and that she would drive. For him to continue driving he would have to pass an annual driving test, with a cost of 400$, which is too expensive. Their transportation is more limited during winter since the caregiver has trouble driving during those conditions.
	The PWD ceased driving in 2011 after his doctor requested he go to DriveABLE. He stopped driving on his own because he said it wasn't important to him and he didn't want to pay ~300$ for the test. The caregiver thinks it's not fair and the PWD was upset that they would charge him to take the test. The caregiver can also drive close by, but does not like to. They have Access Calgary[3], but have to renew it to continue.
	The PWD was told he could no longer drive because of his dementia and that he wouldn't be able to find his way home. He has not driven for 2-3 weeks, after being a truck driver for 20 years. He did not get tested at DriveABLE. His wife is his source of transportation; she drives him to appointments, etc. He explains that the transition wasn't easy, it ruined his life, but he's accepted it.
	The PWD was tested at DriveABLE and then received a letter from Service Alberta informing him that he had failed the assessment. The letter said he could have a physician perform a test, to support his efforts to drive again. He did not pass a test by a referred physician. His wife was surprised that he did not pass his first test after driving around with him the day before and not noticing any problems. The PWD said they would try to trick him during the 2 hour road test and he doesn't want to go back. He has accepted that he can no longer drive; although he is angry at times and talks about it a lot and how he would get his license back. His wife didn't realize how much he drove and now the driving is a burden on her. Their only other means of transportation is taking a cab to group therapy.
	The PWD is doing some limited driving. He drives once every 2 weeks and has decided on his own that he will cease driving, even though he still has a license. The caregiver does not drive, and they both take public transit and the Light Rail Train quite frequently. Three months later, the caregiver states that they're both doing well with taking public transit now that the PWD has quit driving. He's very comfortable with taking public transit; he could go on his own but hasn't had the opportunity to.
Ceased driving prior to the study	Before the PWD turned 80, his wife noticed some changes in his driving, and he's always been a good driver since he was 18. He started making mistakes and losing patience, for a man who's very patient. When he was 80, he was diagnosed with Alzheimer's and his doctor took his license away. Afterwards, he became bad tempered, shouting, and swearing, for a man who never shouted. He was really mad at the doctor and never understood why he lost his license. He has never forgotten or gotten over losing his license, and he'll bring it up once a week; it was the biggest blow to him out of everything. At the beginning, he was very aggravated when his wife

[3] Access Calgary is a public transportation service offered to those with disabilities.

	would drive and would hold the hand brake, but now he's accepted it and gets in happily.
	The PWD lost his driver's license after having a minor stroke. His son is a source of transportation but he's also busy with his own life. They pay somebody in their building to come and drive them when they cannot get a family member to go with them. The caregiver is worried because her doctor is far away. They also have DriveAgain as private help. Since she has trouble walking because of her hip and knee, a woman from the Arthritis Society helped fill out papers for Para Transpo. Their application was refused when they applied for him, but now they're hoping that they can go together if she gets Para Transpo.
	The PWD ceased driving after his family convinced him to stop, at which point he sold his car. Once he hit 80 and his license expired he did not pass a drivers' test. Now he forgets that he can't drive and still thinks he has his car. They were used to leaving the house, but now they only leave on occasion. His wife has been looking for other transportation services for 2 years and hasn't found any help. The PWD did have Para Transpo, but not his wife. After he stopped driving, his wife lost her independence as well. Afterwards, they both got access to Para Transpo. She likes it, but the wait time of half an hour to 3/4 of an hour is too long. If they want a ride there and back, they're only allotted 2 hours to do their groceries, etc.
	The PWD gave up driving a long time ago because she was nervous and she did not drive much. The caregiver has gotten her access to Para Transpo because she had trouble walking with her ankle. However, the PWD refuses to go out and is no longer active.
	In June 2009 the PWD had a stroke and they took away his license when he was still in the hospital. In Nov. 2009, he no longer drives, however he does not think the assessment was fair and they were not being honest with him when they asked him questions in the hospital. He was told by the hospital physician that he could no longer drive until he's recovered and had a re-assessment. He was not satisfied with how the information was disclosed to him, and is now in the middle of completing the tests for his re-assessment. He just bought a new car and his niece can drive him since she lives in the same building. He also has a friend who can drive him and he can use the bus if he has to. He has a monthly bus pass; he likes the service, but not the wait time. In March 2010, the PWD states that he goes everywhere by bus, without any trouble, now that his niece has a job and can't always drive him.
	About 3 years ago the PWD' wife was no longer comfortable with him driving, so he stopped. He no longer drives and doesn't care either. "A lot of things he doesn't care, all he wants are TV and food."
	About a week ago, the PWD knew she could no longer drive, at which point she stopped driving and gave her car to her husband's brother. She didn't want to take the chance of hurting someone on the road, so she decided to hand in her driver's license. Now she takes taxies and a family member drives her when she can. At the moment, OC Transpo doesn't service her area very well.
	It's been half a year since the PWD stopped driving at which point she gave her car to her daughter (caregiver). After two cognitive assessments it was suggested that she stopped driving. She did stop and still thinks it was a fair decision. She was starting to get nervous driving. She can now use the bus/shuttle at her residence and has access to OC Transpo.
	The PWD stopped driving around 3-4 years ago. She had an accident and because of her age, they made her re-test, which she failed. It was very difficult for her; she never got used to using taxies. Her daughter (caregiver) has an account with a taxi company,

	but she wouldn't use them because she thought it was a waste of money and preferred taking the bus.
	The PWD was no longer driving because her family sent her to driving school. Afterwards, her physician told her that she didn't have to go there anymore because she couldn't have a driver's license anymore. She left the car in the garage for a while, but she doesn't have it anymore. She misses it but her family will take her out when she needs to go. She states that she wouldn't have quit driving on her own because she enjoyed it too much. However, she trusted her doctors and also received a letter from the government, so she had no choice. She thinks it was fair and she's satisfied because she doesn't want to get into trouble or hurt anyone on the road.
	The PWD no longer drives since their physician sent a letter to the government saying they may want to re-test her. It was decided that the PWD wouldn't test again since her caregivers drive her. The PWD was still capable of driving; however the decision was made for her for precautionary reasons. The decision was recommended by her specialist and family physician. She does not understand why she had to stop and does not believe it was right for someone to make that decision. She believes to have always been a good driver. OC Transpo does not service her area very well.
	The PWD no longer drives after a physician sent a letter to the ministry of transportation. The PWD discusses his cognitive evaluation and how the physician "picked holes" in all of his wrong answers. The PWD does not believe memory has anything to do with driving. As well, he does not believe it was a fair assessment and that they could say he was not fit to drive. Caregiver mentions the need for someone to drive them.
	The PWD passed a driving test before she got into an accident and then decided on her own to stop driving. The caregiver says she was too nervous to drive. It's been 5-6 years since she stopped driving. She had two cars in her garage but decided to sell them both since they were no longer using them.
	After failing a cognitive assessment, a physician said the PWD could no longer drive. He does not understand how a cognitive test has anything to do with driving. He had been using a car to go short distances, for shopping, appointments, etc. The PWD has Para Transpo and taxi services at a discount. His wife (caregiver) no longer drives either.
Unable to determine	The caregiver or the family takes the PWD to his appointments and DATS[4] takes him to his programs.
Transition in progress during the study	The PWD still drives but the caregiver prefers driving. The caregiver says that he doesn't like to drive but the PWD says he manages well. He's currently using Para Transpo, mostly to go to his day program. They both really enjoy the Para Transpo services.
	The PWD has just received a one year license without having to pass a test. She's required to pass a test once she's 80 to renew it again. However, she has decided on her own not to renew her license once it expires. She no longer drives as it is, even with the new license.
	The PWD is used to doing all of the driving, but he gets right into the passenger seat when he knows they're taking the highway or driving far. He started 2-3 years ago slowly letting his wife drive because he was getting lost. She wouldn't help him so that he would realize it himself, and that has helped with him giving up most of the driving. His wife considered using DATS, however she says they can be late sometimes and he is not the kind of person to get dressed and wait around for half an hour. She prefers

[4] DATS is a service in Edmonton that stands for Disabled Adults Transit Service.

	driving him. A month ago he passed a test at DriveABLE, and does drive a little, ~2km from home.
	The caregiver says the PWD has no problem driving when she's with him. She won't go on long trips by herself because she might get lost, but can drive no problem when her husband is with her. In the last month she hasn't been behind the wheel.

Table 2: Participant demographics

Data from	Location	Sex	Age	CG Age	Education level	Past Employment
CG	Calgary	Male	65	64	Post-secondary	School teacher
CG	Calgary	Male	76	66	Primary school	School bus driver
CG	Calgary	Male	84	84	Secondary school	Sales engineering
CG	Calgary	Male	82	81	Primary school	Engineer 32 years on-hand training – 10 years security officer
PWD	Edmonton	Male	82	80	Secondary school	Retail service manager
PWD & CG	Edmonton	Male	70	75	Post-secondary	Medical doctor
CG	Edmonton	Male	72	66	Post-secondary	Chemical engineer, coal mine research – teacher at technical school
CG	Edmonton	Female	86	87	Post-secondary	Elementary school teacher
CG	Edmonton	Male	67	65	Post-secondary	Chartered accountant
CG	Edmonton	Male	78	77	Secondary school	Sales representative
CG	Ottawa	Female	78	71	Post-secondary	Secretary
CG	Ottawa	Male	79	74	Primary school	Entrepreneur/Upholsterer
CG	Ottawa	Male	94	87	Post-secondary	Real estate agent
CG	Ottawa	Female	81	45	Post-secondary	Nurse
PWD	Ottawa	Male	76	40	Secondary school	Cartographer for Fed. Govt.
CG	Ottawa	Male	68	35	Post-secondary	Engineer
PWD	Ottawa	Female	87	45	Secondary school	Ski instructor
PWD & CG	Ottawa	Female	77	58	Secondary school	Advertising copy writer
CG	Ottawa	Female	90	61	Primary school	Secretary – homemaker – actress
PWD	Ottawa	Female	80	63	Secondary school	Restaurant worker – hairdresser
PWD & CG	Ottawa	Female	81	43	Secondary school	National Research Council – Administrative Assistant
PWD & CG	Ottawa	Male	88	80	Secondary school	Army, customs and excise, Ottawa Airport
PWD & CG	Ottawa	Male	77	74	Post-secondary	Lawyer
PWD & CG	Ottawa	Female	84	50	Secondary school	Piano teacher
PWD & CG	Ottawa	Male	89	83	Secondary school	Bedroom decorator – business of wallpapers

Table 3: First 20 codes – 5 participants

Code
Anger
Blaming test
Caregiver – PWD relationship
Difficult getting used to
Driving cessation comprehension
Easier over time
Failed driving tests
Good driving record as justification
Government
Hoping to get the license back
Immediate compliance
No alternate methods
Personal transportation
Planning week differently
Physician
Poor cognitive assessment
Public transportation
PWD deciding to stop on their own
Vehicle accident
Weight of the transition

Table 4: 21 codes – 5 participants

Code	Description
Alternate transportation – no alternate methods	This text relates to PWD and their caregivers not having access or using any alternate means of transportation. However, this does not include samples of text where the PWD's spouse has taken on more of the driving.
Alternate transportation – personal transport	This text relates to the availability or a PWD's use of personal transportation. For example, "personal transportation" may refer to the PWD's spouse or caregiver taking on more of the driving responsibility. Personal transportation may also refer to a friend or extended family member who will drive the PWD.
Alternate transportation – public transport	This text related to the availability or the use of public transportation. For example, "public transportation" may refer to a bus, train, taxi, or/and public para-transportation.
Caregiver – PWD relationship	This text relates to the link between the caregiver and the PWD. For example, this may refer to the caregivers support; how they interact and communicate with one another; the feelings felt towards one another; or the dependency of the PWD or the caregiver.
Caregiver burden	This text relates to the burden of care on the PWD's caregiver. It may refer to stress or dependence, and this text may describe instances such as having to take on more of the driving responsibility, or not being able to get around as easily as prior to the PWD losing their driver's license.
Come to terms with driving cessation	This text relates to the PWD or their caregiver accepting the need for driving cessation. However, this text may not always consist of participants who comprehend the reasons for driving cessation.
Difficult getting used to	This text refers to the participants for whom the transition of driving cessation is a difficult transition. For many participants it may not be easier to get used to no longer driving.
Driving cessation comprehension	This text refers to the process of understanding why the PWD are no longer allowed to drive. These codes may contain participants who lack insight into the reasoning for driving cessation. For example, it may contain situations of a lack of comprehension after failing a test or after an accident. It may also contain participants who understand why are no longer allowed to drive.
Emotional reaction – anger	This text relates to a PWD or their caregiver's anger towards any aspect of driving cessation.
Emotional reaction – blaming test	This text relates to the PWD or their caregiver placing the blame on a driving test or a cognitive assessment, as the reason for having lost their driver's license.
Good driving record as justification	This text relates to a PWD using a history of good driving, and possibly accident free, as a reason for why they should not have lost their license.
Hoping to get the license back	This text relates to a PWD thinking that they will be able to regain their driver's license. It is a possible emotion-focused strategy. For example, this may be achieved by re-taking the test or by the belief that they will get better and receive a higher score on a driver's test or cognitive assessment.
Immediate compliance	This text relates to a PWD who has ceased driving immediately after receiving word that their license was suspended or that they could no longer drive.
Notification – government	This text relates to the moment when the PWD finds out through the government that they can no longer drive (driver's license was suspended).

	Typically this occurs by receiving a letter from the Ministry of Transportation.
Notification – physician	This text relates to the moment when a physician has explained to the PWD that they can no longer drive. This may refer to their family physician or a specialist.
Reasons for driving cessation – failed driving tests	This text relates to a precursor to driving cessation. In this situation, the PWD can no longer drive since their license was suspended after failing a driving test.
Reasons for driving cessation – poor cognitive assessment	This text relates to a precursor to driving cessation. In this situation, the PWD can no longer drive since their license was suspended after the PWD had a poor cognitive assessment. A poor cognitive assessment can force a physician to send a letter to the Ministry of Transportation.
Reasons for driving cessation – self-regulated cessation	This text relates to a precursor to driving cessation. In this situation, the PWD has self-regulated their driving cessation.
Reasons for driving cessation – vehicle accident	This text relates to a precursor to driving cessation. In this situation, the PWD no longer drives after they have had a vehicle accident. Afterwards, the license may either be suspended or the PWD will self-regulate their driving cessation.
Therapy group	This text relates to participants who attended a therapy group as a type of support group.
Weight of the transition	This text relates to the participants who described the transition of driving cessation as anything from an easy transition to a difficult transition..

Table 5: 18 codes – 5 participants

Code	Description
Alternate transportation – no alternate methods	This text relates to PWD and their caregivers not having access or using any alternate means of transportation. However, this does not include samples of text where the PWD's spouse has taken on more of the driving.
Alternate transportation – personal transport	This text relates to the availability or a PWD's use of personal transportation. For example, "personal transportation" may refer to the PWD's spouse or caregiver taking on more of the driving responsibility. Personal transportation may also refer to a friend or extended family member who will drive the PWD.
Alternate transportation – public transport	This text related to the availability or the use of public transportation. For example, "public transportation" may refer to a bus, train, taxi, or/and public para-transportation.
Caregiver – PWD relationship	This text relates to the link between the caregiver and the PWD. For example, this may refer to the caregivers support; how they interact and communicate with one another; the feelings felt towards one another; or the dependency of the PWD or the caregiver.
Caregiver burden	This text relates to the burden of care on the PWD's caregiver. It may refer to stress or dependence, and this text may describe instances such as having to take on more of the driving responsibility, or not being able to get around as easily as prior to the PWD losing their driver's license.
Come to terms with driving cessation	This text relates to the PWD or their caregiver accepting the need for driving cessation. However, this text may not always consist of participants who comprehend the reasons for driving cessation.
Driving cessation comprehension	This text refers to the process of understanding why the PWD are no longer allowed to drive. These codes may contain participants who lack insight into the reasoning for driving cessation. For example, it may contain situations of a lack of comprehension after failing a test or after an accident. It may also contain participants who understand why are no longer allowed to drive.
Emotional reaction – anger	This text relates to a PWD or their caregiver's anger towards any aspect of driving cessation.
Emotional reaction – blaming test	This text relates to the PWD or their caregiver placing the blame on a driving test or a cognitive assessment, as the reason for having lost their driver's license.
Good driving record as justification	This text relates to a PWD using a history of good driving, and possibly accident free, as a reason for why they should not have lost their license.
Hoping to get the license back	This text relates to a PWD thinking that they will be able to regain their driver's license. It is a possible extension of a lack of driving cessation comprehension. For example, this may be achieved by re-taking the test or by the belief that they will get better and receive a higher score on a driver's test or cognitive assessment.
Immediate compliance	This text relates to a PWD who has ceased driving immediately after receiving word that their license was suspended or that they could no longer drive.
Notification – government	This text relates to the moment when the PWD finds out through the government that they can no longer drive (driver's license was suspended). Typically this occurs by receiving a letter from the Ministry of Transportation.

Notification – physician	This text relates to the moment when a physician has explained to the PWD that they can no longer drive. This may refer to their family physician or a specialist.
Reasons for driving cessation – failed driving tests	This text relates to a precursor to driving cessation. In this situation, the PWD can no longer drive since their license was suspended after failing a driving test.
Reasons for driving cessation – poor cognitive assessment	This text relates to a precursor to driving cessation. In this situation, the PWD can no longer drive since their license was suspended after the PWD had a poor cognitive assessment. A poor cognitive assessment can force a physician to send a letter to the Ministry of Transportation.
Reasons for driving cessation – self-regulated cessation	This text relates to a precursor to driving cessation. In this situation, the PWD no longer drives since they have decided to stop driving on their own. Exception: this text does not include samples of participants who have decided to self-regulate their driving cessation after a physician has suggested they stop driving.
Reasons for driving cessation – vehicle accident	This text relates to a precursor to driving cessation. In this situation, the PWD no longer drives after they have had a vehicle accident. Afterwards, the license may either be suspended or the PWD will self-regulate their driving cessation.

Table 6: Relationship codes – 10 total participants

First code	Second code	Sources	References
Alternate transportation – personal transportation	Alternate transportation – public transportation	1	1
Alternate transportation – personal transportation	Caregiver burden	1	1
Alternate transportation – personal transportation	Come to terms with driving cessation	1	1
Alternate transportation – personal transportation	Reasons for driving cessation – self-regulated cessation	1	1
Caregiver – PWD relationship	Come to terms with driving cessation	1	1
Come to terms with driving cessation	Reasons for driving cessation – self-regulated cessation	1	1
Driving cessation comprehension	Come to terms with driving cessation	1	1
Driving cessation comprehension	Emotional reaction – anger	1	1
Driving cessation comprehension	Emotional reaction – blaming test	1	1
Emotional reaction – anger	Come to terms with driving cessation	1	1
Emotional reaction – anger	Emotional reaction – blaming test	1	1
Emotional reaction – angers	Good driving record as justification	1	1
Good driving record as justification	Driving cessation comprehension	2	2
Notification – physician	Come to terms with driving cessation	1	2
Notification – physician	Driving cessation comprehension	2	2
Notification – physician	Emotional reaction – anger	1	1
Notification – physician	Immediate compliance	1	1
Notification – physician	Notification – government	1	1
Notification – physician	Reasons for driving cessation – self-regulated cessation	1	1
Reasons for driving cessation – failed driving tests	Driving cessation comprehension	1	2
Reasons for driving cessation – failed driving tests	Emotional reaction – blaming test	1	1
Reasons for driving cessation – failed driving tests	Notification – government	1	1
Reasons for driving cessation – poor cognitive assessment	Driving cessation comprehension	1	1
Reasons for driving cessation – poor cognitive assessment	Notification – physician	2	2
Reasons for driving cessation – vehicle accident	Reasons for driving cessation – failed driving tests	1	1

Table 7: 18 codes – 10 participants

Parent Code	Child Code	Description
Accepting driving cessation		This text relates to the PWD or their caregiver accepting the need for driving cessation. However, this text may not always consist of participants who comprehend the reasons for driving cessation.
Alternate transportation	No alternate methods	This text relates to PWD and their caregivers not having access or using any alternate means of transportation. However, this does not include samples of text where the PWD's spouse has taken on more of the driving.
	Personal transportation	This text relates to the availability or a PWD's use of personal transportation. For example, "personal transportation" may refer to the PWD's spouse or caregiver taking on more of the driving responsibility. Personal transportation may also refer to a friend or extended family member who will drive the PWD.
	Public transportation	This text relates to the availability or the experience with the use of public transportation. For example, "public transportation" may refer to a bus, train, taxi, or/and public para-transportation.
Caregiver – PWD relationship		This text relates to the link between the caregiver and the PWD. For example, this may refer to the caregivers support; how they interact and communicate with one another; the feelings felt towards one another; or the dependency of the PWD or the caregiver.
Caregiver burden		This text relates to the burden of care on the PWD's caregiver. It may refer to stress or dependence, and this text may describe instances such as having to take on more of the driving responsibility, or not being able to get around as easily as prior to the PWD losing their driver's license.
Driving cessation comprehension	Not understanding why driving not allowed	This text refers to the process of understanding why the PWD is no longer allowed to drive. These codes contain participants who lack insight into the reasoning for driving cessation and do not understand why are no longer allowed to drive. Situations of a lack of comprehension may occur after failing a test or after an accident.
	Understanding why driving not allowed	This text refers to the process of understanding why the PWD is no longer allowed to drive. These codes contain participants who understand why they are no longer allowed to drive. Comprehension may occur due to self-regulated driving cessation.
Emotional Reaction	Anger	This text relates to a PWD or their caregiver's anger towards any aspect of driving cessation.
	Blaming test	This text relates to the PWD or their caregiver placing the blame on a driving test or a cognitive assessment, as the reason for having lost their driver's license.
Good driving record as justification		This text relates to a PWD using a history of good

		driving, and possibly accident free, as a reason for why they should not have lost their license.
Notification	Government	This text relates to the moment when the PWD finds out through the government that they are no longer allowed to drive (driver's license was suspended). Typically this occurs by receiving a letter from the Ministry of Transportation.
	Physician	This text relates to the moment when a physician has explained to the PWD that they are no longer allowed to drive. This may refer to their family physician or a specialist.
Reasons for driving cessation	Failed driving tests	This text relates to a precursor to driving cessation. In this situation, the PWD is no longer allowed to drive since their license was suspended after failing a driving test.
	Poor cognitive assessment	This text relates to a precursor to driving cessation. In this situation, the PWD is no longer allowed to drive since their license was suspended after the PWD had a poor cognitive assessment. A poor cognitive assessment can force a physician to send a letter to the Ministry of Transportation.
	Self-regulated cessation	This text relates to a precursor to driving cessation. In this situation, the PWD no longer drives since they have decided to stop driving on their own. Exception: this text does not include samples of participants who have decided to self-regulate their driving cessation after a physician has suggested they stop driving.
	Vehicle accident	This text relates to a precursor to driving cessation. In this situation, the PWD no longer drives after they have had a vehicle accident. Afterwards, the license may either be suspended or the PWD will self-regulate their driving cessation.

Table 8: Description of essential codes for the process of driving cessation

Grand-parent code	Parent code	Child code	Description
Accepting driving cessation			This text relates to the PWD or their caregiver having accepted the need for driving cessation. However, this text may not always consist of participants who comprehend the reasons for driving cessation.
Alternate transportation	No alternate methods		This text relates to PWD and their caregiver not having access or using any alternate means of transportation. However, this does not include text where it is the PWD's spouse who has taken on the driving responsibility.
	Public transportation		This text relates to the availability or the experience with the use of public transportation. For example, public transportation may refer to a bus, train, taxi, and/or public para-transportation.
	Personal transportation	Caregivers	This text relates to a PWD's spouse or caregiver taking on more of the driving responsibility.
	Personal transportation	Friends or Extended Family	This text relates to the availability or a PWD's use of a friend or extended family member who will drive the PWD.
Driving cessation comprehension	Understanding why driving not allowed		This text refers to the process of understanding why the PWD is no longer allowed to drive. These codes contain participants who understand why they are no longer allowed to drive.
	Not understanding why driving not allowed		This text refers to the process of understand why PWD are no longer allowed to drive. These codes contain participants who lack insight into the reasoning for driving cessation and do not understand why they are no longer allowed to drive.
	Not understanding why driving not allowed	Good driving record as justification	This text relates to a PWD using a history of good driving, and/or the possibility of an accident free record, as a reason for why they should not have lost their driving license.
Emotional Reaction	Anger		This text relates to a PWD or their caregiver's anger towards any aspect of the driving cessation process.
	Blaming test		This text relates to the PWD or their caregiver placing the blame on a driving test or a cognitive assessment, as the reason for having lost their driver's license.
Notification	Government		This text relates to the moment when the PWD finds out through the government, that they are no longer allowed to drive (driver's license was suspended). Typically this occurs by receiving a letter from the Ministry of Transportation.
	Physician		This text relates to the moment when a physician has explained to the PWD that they are no longer allowed to drive. Typically, the physician will also send a letter to the Ministry

		of Transportation. This may refer to their family physician or a specialist.
Reasons for driving cessation	Failed driving tests	This text relates to a precursor to driving cessation. In this situation, the PWD is no longer allowed to drive since their license was suspended after failing a driving test.
	Family advised to cease driving	This text relates to a precursor to driving cessation. In this situation, the PWD has been advised by his family to stop driving. Therefore, the PWD has ceased driving after being asked to stop by his family, similar to those who cease driving due to being told by a physician.
	Physical limitations	This text relates to a precursor to driving cessation. In this situation, the PWD can no longer drive due to physical limitations. They can no longer physically drive and were either told to cease driving or they may not have gone to renew their license for this reason.
	Poor cognitive assessment	This text relates to a precursor to driving cessation. In this situation, the PWD is no longer allowed to drive since their license was suspended after a poor cognitive assessment. A poor cognitive assessment can force a physician to send a letter to the Ministry of Transportation.
	Self-regulated cessation	This text relates to a precursor to driving cessation. In this situation, the PWD no longer drives since they have decided to stop driving on their own. Exception: this text does not include participants who have decided to self-regulate their driving cessation after a physician has suggested they stop driving.
	Vehicle collision	This text relates to a precursor to driving cessation. In this situation, the PWD no longer drives after they have had a vehicle collision. Afterwards, the license may either be suspended or the PWD will self-regulate their driving cessation.

Table 9: Relationship codes for the process of driving cessation

First code			Second code			Sources	References
Parent code	Child code	Grand-child code	Parent code	Child code	Grand-child code		
Accepting driving cessation			Reasons for driving cessation	Self-regulated cessation		7	7
Alternate transportation	Personal transportation	Caregivers	Accepting driving cessation			5	5
Alternate transportation	Personal transportation	Caregivers	Alternate transportation	Public transportation		2	2
Alternate transportation	Personal transportation	Caregivers	Driving cessation comprehension	Understanding why driving not allowed		1	1
Alternate transportation	Personal transportation	Caregivers	Driving cessation comprehension	Not understanding why driving not allowed		1	1
Alternate transportation	Personal transportation	Caregivers	Driving cessation comprehension	Not understanding why driving not allowed	Good driving record as justification	1	1
Alternate transportation	Personal transportation	Caregivers	Emotional Reaction	Anger		2	3
Alternate transportation	Personal transportation	Caregivers	Reasons for driving cessation	Self-regulated cessation		1	1
Alternate transportation	Personal transportation	Friends or extended family	Accepting driving cessation			1	1
Alternate transportation	Personal transportation	Friends or extended family	Alternate transportation	Public transportation		1	1
Alternate transportation	Public transportation		Accepting driving cessation			4	6
Alternate transportation	Public transportation		Reasons for driving cessation	Self-regulated cessation		3	4
Driving cessation comprehension	Not understanding why driving not allowed		Accepting driving cessation			2	4
Driving cessation comprehension	Understanding why driving not allowed		Accepting driving cessation			8	8
Driving cessation comprehension	Understanding why driving not allowed		Emotional Reaction	Anger		1	1
Driving cessation comprehension	Not understanding why driving not allowed		Emotional Reaction	Anger		3	5
Driving cessation comprehension	Not understanding why driving not allowed	Good driving record as justification	Emotional Reaction	Anger		2	2
Driving cessation comprehension	Not understanding why driving not allowed		Emotional Reaction	Blaming test		2	3
Driving cessation comprehension	Not understanding why driving not allowed	Good driving record as justification	Emotional Reaction	Blaming test		1	1
Driving cessation comprehension	Understanding why driving not allowed		Reasons for driving cessation	Self-regulated cessation		7	8
Emotional Reaction	Anger		Accepting driving cessation			2	3
Emotional Reaction	Anger		Emotional Reaction	Blaming Test		3	4
Notification	Government		Accepting driving cessation			1	1
Notification	Physician		Accepting driving cessation			2	3
Notification	Physician		Alternate transportation	Personal transportation	Caregivers	1	1
Notification	Physician		Driving cessation	Not understanding why driving		6	6

		comprehension	not allowed			
Notification	Physician	Driving cessation comprehension	Not understanding why driving not allowed	Good driving record as justification	2	2
Notification	Physician	Driving cessation comprehension	Understanding why driving not allowed		1	1
Notification	Physician	Emotional Reaction	Anger		2	3
Notification	Physician	Notification	Government		1	1
Notification	Physician	Reasons for driving cessation	Self-regulated cessation		1	1
Reasons for driving cessation	Failed driving tests	Accepting driving cessation			1	1
Reasons for driving cessation	Failed driving tests	Emotional Reaction	Blaming test		2	3
Reasons for driving cessation	Failed driving tests	Driving cessation comprehension	Not understanding why driving not allowed		2	4
Reasons for driving cessation	Failed driving tests	Driving cessation comprehension	Not understanding why driving not allowed	Good driving record as justification	1	2
Reasons for driving cessation	Failed driving tests	Notification	Government		1	1
Reasons for driving cessation	Failed driving tests	Notification	Physician		1	1
Reasons for driving cessation	Family advised to cease driving	Accepting driving cessation			1	1
Reasons for driving cessation	Family advised to cease driving	Driving cessation comprehension	Not understanding why driving not allowed		1	1
Reasons for driving cessation	Poor cognitive assessment	Accepting driving cessation			2	2
Reasons for driving cessation	Poor cognitive assessment	Driving cessation comprehension	Not understanding why driving not allowed		4	6
Reasons for driving cessation	Poor cognitive assessment	Driving cessation comprehension	Not understanding why driving not allowed	Good driving record as justification	3	3
Reasons for driving cessation	Poor cognitive assessment	Driving cessation comprehension	Understanding why driving not allowed		1	1
Reasons for driving cessation	Poor cognitive assessment	Notification	Physician		6	7
Reasons for driving cessation	Vehicle Collision	Reasons for driving cessation	Failed driving tests		1	1
Reasons for driving cessation	Vehicle Collision	Reasons for driving cessation	Self-regulated driving cessation		1	1

Table 10: Most prominent relationship codes[5]

	Accepting driving cessation	Alternate transportation	Driving cessation comprehension	Emotional reaction	Notification	Reasons for driving cessation
Accepting driving cessation						1. ***<u>Accepting / Self-regulated cessation</u>***
Alternate transportation	1. *<u>Public transportation / Accepting</u>* 2. *<u>Caregivers / Accepting</u>*	1. Caregivers / Public transportation	1. Caregivers / Understanding 2. Caregivers / Not understanding	1. Caregivers / Anger		1. *<u>Public transportation / Self-regulate cessation</u>*
Driving cessation comprehension	1. **<u>Understanding / Accepting</u>** 2. Not understanding / Accepting			1. *<u>Not understanding / Anger</u>* 2. Not understanding / Blaming test 3. Good driving record / Anger		1. **<u>Understanding / Self-regulated cessation</u>**
Emotional reaction	1. Anger / Accepting			1. *Anger / Blaming test*		
Notification	1. Physician / Accepting 2. Government / Accepting	1. Physician / Caregivers	1. **<u>Physician / Not understanding</u>** 2. Physician / Understanding 3. Physician / Good driving record	1. Physician / Anger	1. Physician / Government	1. Physician / Self-regulated cessation
Reasons for driving cessation	1. Poor cognitive assessment / Accepting 2. Failed driving test / Good driving record		1. *<u>Poor cognitive assessment / Not understanding</u>* 2. *<u>Poor cognitive assessment / Good driving record</u>*	1. Failed driving test / Blaming test 2. Failed driving test / Not understanding	1. **<u>Poor cognitive assessment / Physician</u>**	1. Vehicle collision / failed driving tests 2. Vehicle collision / Self-regulated cessation

[5] Normal: 1-2 sources
<u>Italic</u>: 3-5 sources
<u>Bold</u>: 6-8 sources

Table 11: Results of the redefined, accepted or refuted hypotheses

	Hypothesis #7				Hypothesis #8				
Participant	Accept	Reformulate	Refute	N/A	Accept	Reformulate	Refute	N/A	Comments
1003			✓					✓	The PWD does not understand why driving not allowed, and yet accepts driving cessation
1008				✓	✓				The PWD ceased driving after a poor cognitive assessment, notified by a physician, but they've accepted driving cessation. It is unclear if he understands why he is no longer allowed to drive.
1027	✓	Possibly piece in the fact that there are 5 sources where caregivers are linked to accepting driving cessation						✓	The PWD ceased driving on his own, accepts driving cessation, but it is unclear if he understands why he is no longer allowed to drive.
1032				✓	✓				The PWD ceased driving after a poor cognitive assessment. He doesn't understand, he was angry, and didn't accept it for a long time.
2006	✓							✓	The PWD was told he could no longer drive and his wife drives him around. It ruined his life, but he's accepted it.
2009				✓	✓	Failing a driving test is also linked to physicians and not understanding			The PWD failed a "driving" test, notified by a physician, and did not understand why he was told he could no longer drive.
2015	✓							✓	The PWD had slowly self-regulated his driving cessation by letting his spouse drive. He's accepted driving cessation.
2016				✓				✓	Transition in progress. The PWD hasn't driven in a while and lets her

									husband drive.
2021	✓							✓	The PWD has decided to cease driving and has accepted driving cessation.
2032				✓				✓	Minimal data.
3001	✓							✓	The PWD has decided to cease driving and not renew their license when it expires.
3002				✓				✓	The PWD lost their driver's license after a minor stroke. Not clear if the PWD understands or has accepted driving cessation.
3003				✓				✓	The PWD no longer drives after being advised by his family. He does not understand.
3010	✓	Possibly piece in the fact that public transportation is linked to accepting and self-regulated driving cessation						✓	The PWD gave up driving a long time ago due to nervousness. Has access to para-transportation.
3011				✓	✓	Physical limitations, such as a stroke, may lead to poor cognitive assessments			The PWD no longer drives due to a stroke, notified by the physician, and does not understand why he is not allowed to drive.
3012				✓				✓	The PWD ceased driving after being advised by his family. He's accepted it; unclear if he understands.
3013	✓							✓	The PWD decided to cease driving to not take the chance of hurting someone.
3015	✓						✓		The PWD ceased driving after a poor cognitive assessment. She understands and accepts.
3016				✓				✓	The PWD had a vehicle collision, was forced to re-test and failed the driving test. The

									transition was difficult.
3019	✓						✓		The PWD ceased driving after a poor cognitive assessment; notified by a physician. She understands and accepts.
3021				✓	✓				The PWD received a letter from their physician and government. It was decided that the PWD wouldn’t test again since her caregivers drive. She does not understand or accept.
3023			✓		✓				The PWD ceased driving after a poor cognitive assessment, notified by a physician. He does not understand, yet has accepted it.
3025				✓				✓	The PWD still drives but the caregiver prefers driving.
3026	✓							✓	The PWD passed a driving test, got into collision and then decided to cease driving. She was too nervous to drive.
3031				✓	✓				The PWD failed a cognitive assessment, was told by a physician that they could no longer drive. The PWD does not understand.

Table 12: Results of the redefined, accepted or refuted 11th hypothesis

	Hypothesis #11				
Participant	Accept	Reformulate	Refute	N/A	Comments
1003	✓				The PWD does not understand why driving must cease, was angry, the cognitive test at DriveABLE did not help, and he now accepts driving cessation. His spouse drives him.
1008	✓				The PWD ceased driving after a poor cognitive assessment, notified by a physician, but they've accepted driving cessation. His spouse drives him. It is unclear if he understands why driving must cease.
1027	✓				The PWD ceased driving on his own, accepts driving cessation, but it is unclear if he understands why driving must cease. The PWD has public and personal transportation.
1032	✓				The PWD ceased driving after a poor cognitive assessment. He doesn't understand, he was angry, and didn't accept it for a long time.
2006	✓				The PWD was told he could no longer drive and his wife drives him around. It was a difficult transition, it ruined his life, but he's accepted it.
2009	✓				The PWD failed a "driving" test, notified by a physician, and did not understand why he could no longer drive. The PWD is angry at times.
2015	✓				The PWD had slowly self-regulated his driving cessation by letting his spouse drive. He's accepted driving cessation.
2016	✓				Transition in progress. The PWD hasn't driven in a while and lets her husband drive.
2021	✓				The PWD has decided to cease driving, takes public transit frequently, and has accepted driving cessation.
2032				✓	Minimal data.
3001	✓				The PWD has decided to cease driving and not renew their license when it expires.
3002				✓	The PWD lost their driver's license after a minor stroke. Not clear if the PWD understands or has accepted driving cessation.
3003	✓				The PWD no longer drives after being advised by his family. He does not understand and forgets that he can't drive. CG has also lost their independence.
3010	✓				The PWD gave up driving a long time ago due to nervousness. Has access to para-transportation.
3011	✓				The PWD no longer drives due to a stroke, notified by the physician, and does not understand why driving must cease.
3012				✓	The PWD ceased driving after being advised by his family. He's accepted it; unclear if he understands.
3013	✓				The PWD decided to cease driving to not take the chance of hurting someone. They have access to taxies and personal transportation on occasion.
3015	✓				The PWD ceased driving after a poor cognitive assessment. She understands and accepts it since she was getting nervous driving. The PWD has access to

					public transportation. It might be viewed that this case refutes the hypothesis that cognitive tests and physicians telling them to cease driving does not help with understanding; however, this participant was already nervous driving before the cognitive tests and didn't need much convincing.
3016	✓				The PWD had a vehicle collision, was forced to re-test and failed the driving test. The transition was difficult. She didn't like taking taxies and preferred the bus.
3019	✓				The PWD ceased driving after a poor cognitive assessment; notified by a physician. She understands and accepts. She wouldn't have quit driving on her own but she had no choice to stop and didn't want to get in trouble or her anyone on the road. As with 3015, this case might refute the hypothesis that a physician notification doesn't help understand; however, there is a certain aspect of emotion-focused coping when she trusts her physician and doesn't want to hurt anyone.
3021	✓				The PWD no longer drives since their physician sent a letter to the government saying they may want to re-test her. It was decided that the PWD wouldn't test again since her caregivers drive her. She does not understand or accept that someone made that decision for her. Public transportation does not service the area well.
3023	✓				The PWD ceased driving after a poor cognitive assessment, notified by a physician. He does not understand and believes that memory has nothing to do with driving. He does not believe it was a fair assessment and that they could say he was not fit to drive.
3025	✓				The PWD still drives but the caregiver prefers driving. They both also enjoy public transportation.
3026	✓				The PWD passed a driving test before she got into a vehicle collision and then decided to cease driving. She was too nervous to drive.
3031	✓				After failing a cognitive assessment, a physician told the PWD that they could no longer drive. He does not understand how a cognitive test has anything to do with driving.

Figures

Figure 1: A conceptual model of the driving cessation process (Choi et al., 2012).

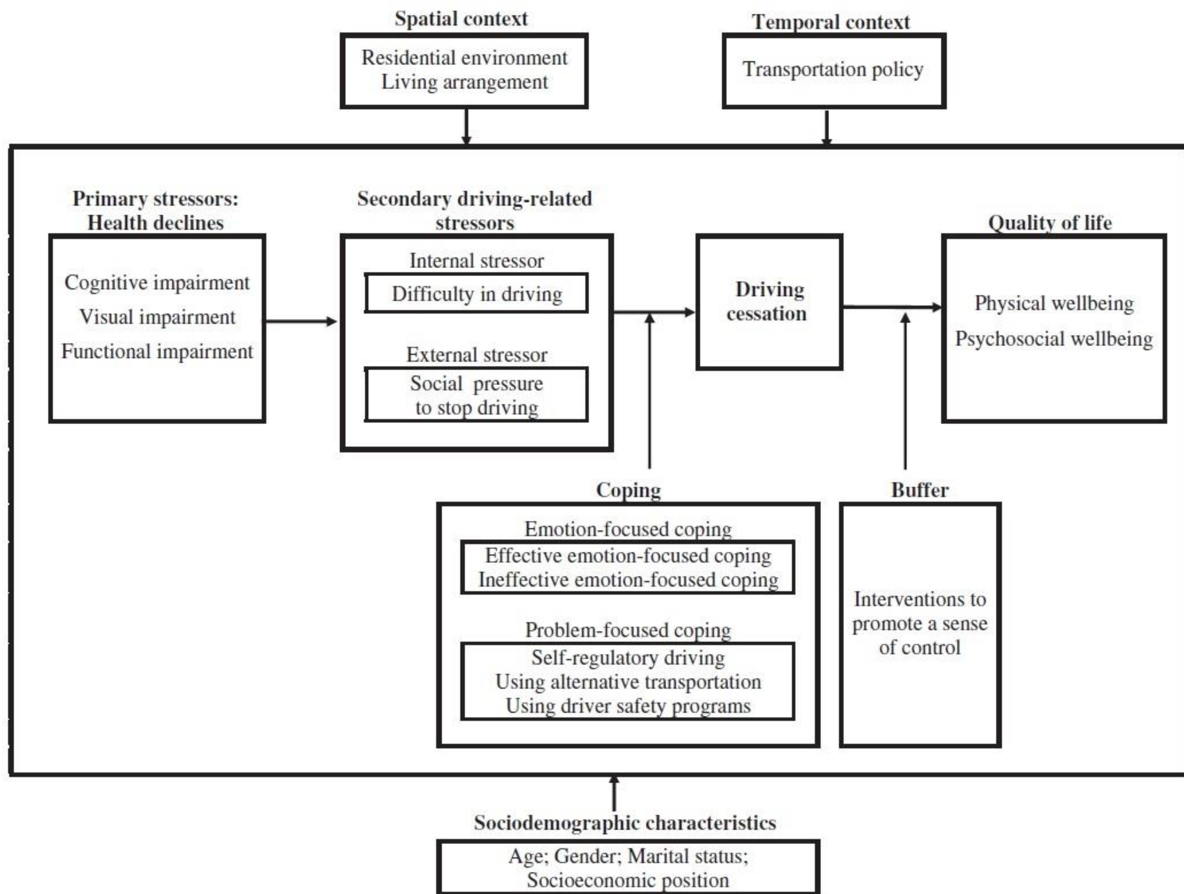


Figure 2: The process of analytic induction (Hammersley, 2012).

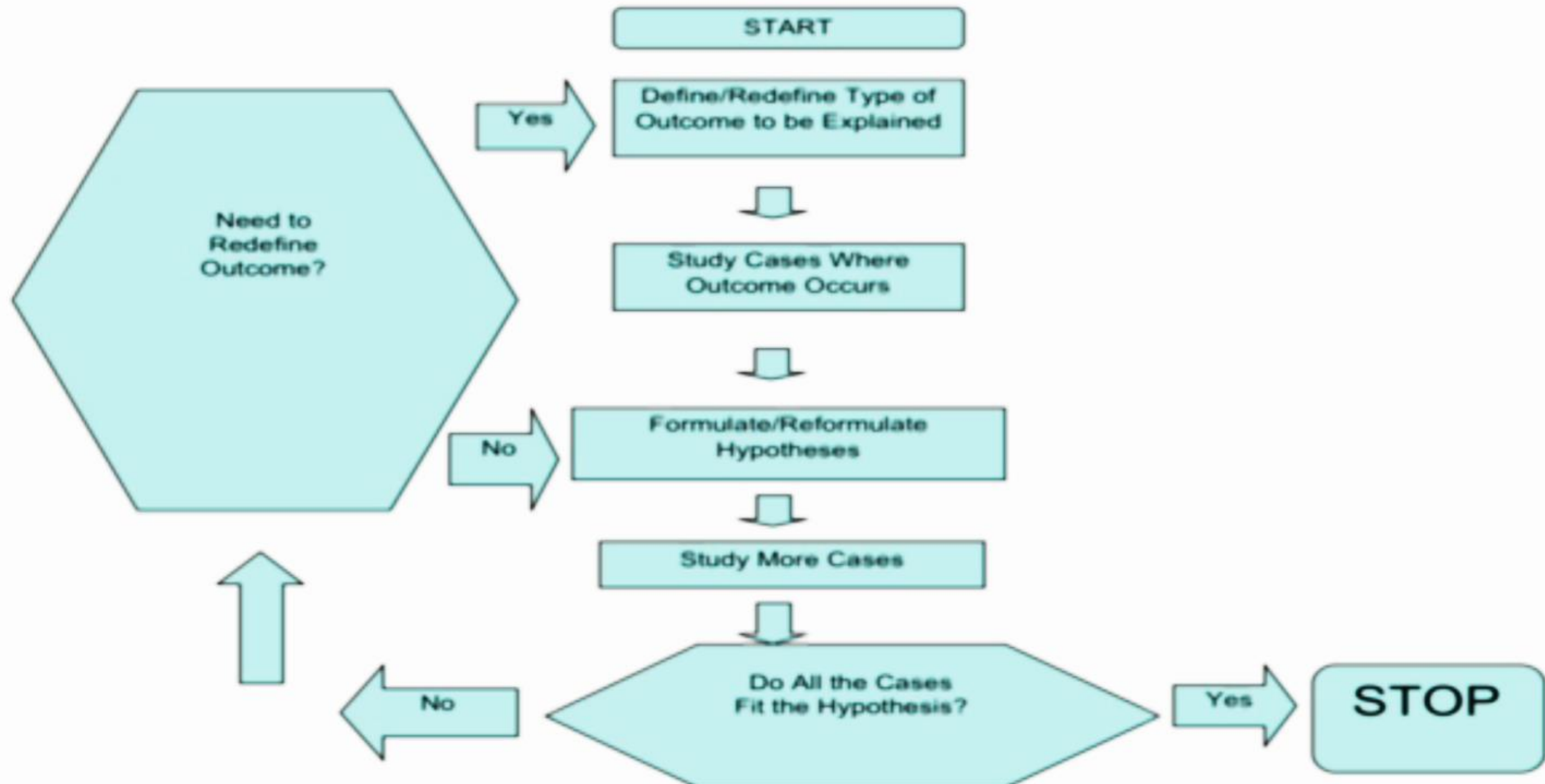


Figure 3: Coding hierarchy at 21 codes.

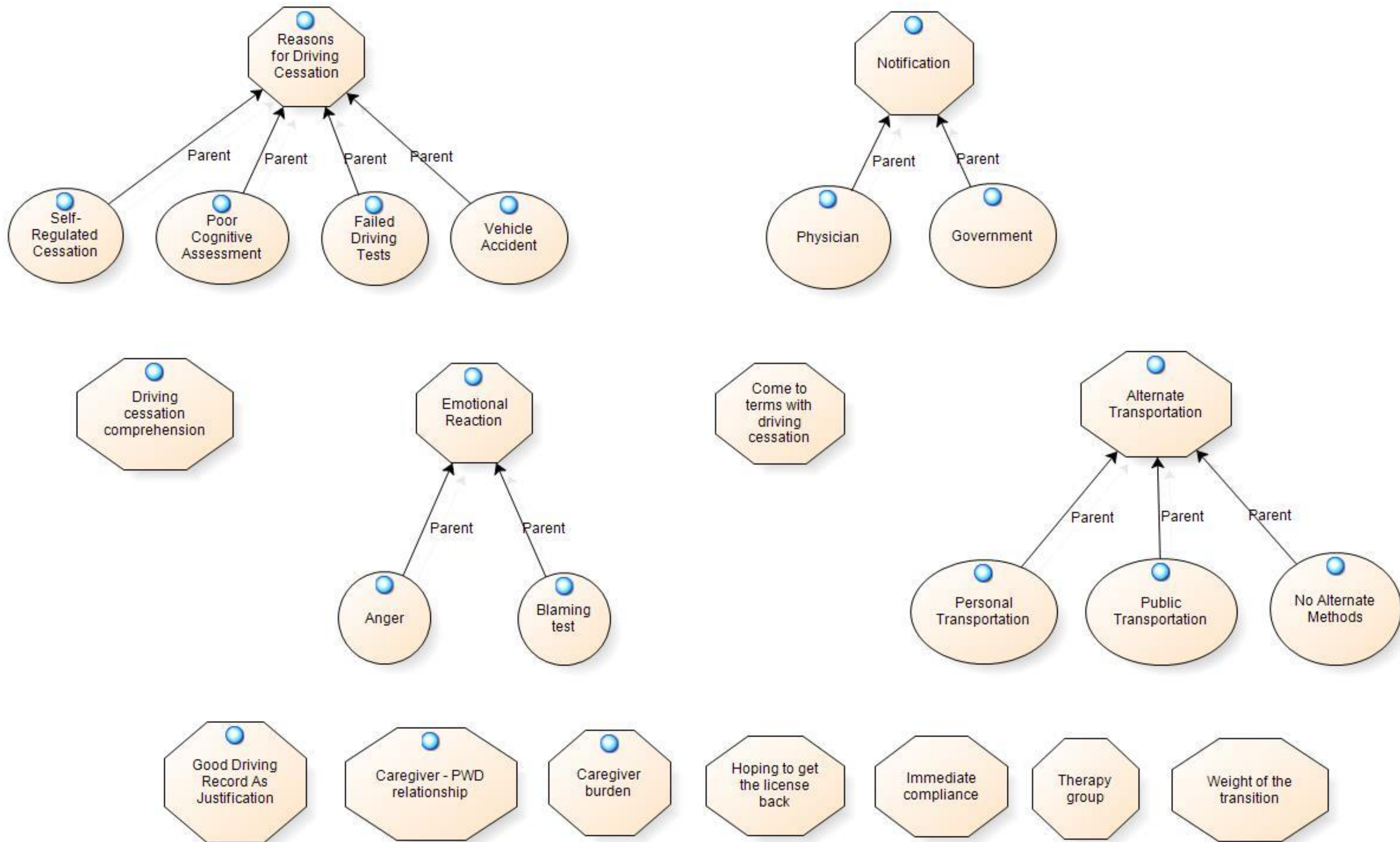


Figure 4: Coding hierarchy – 18 codes – 5 participants.

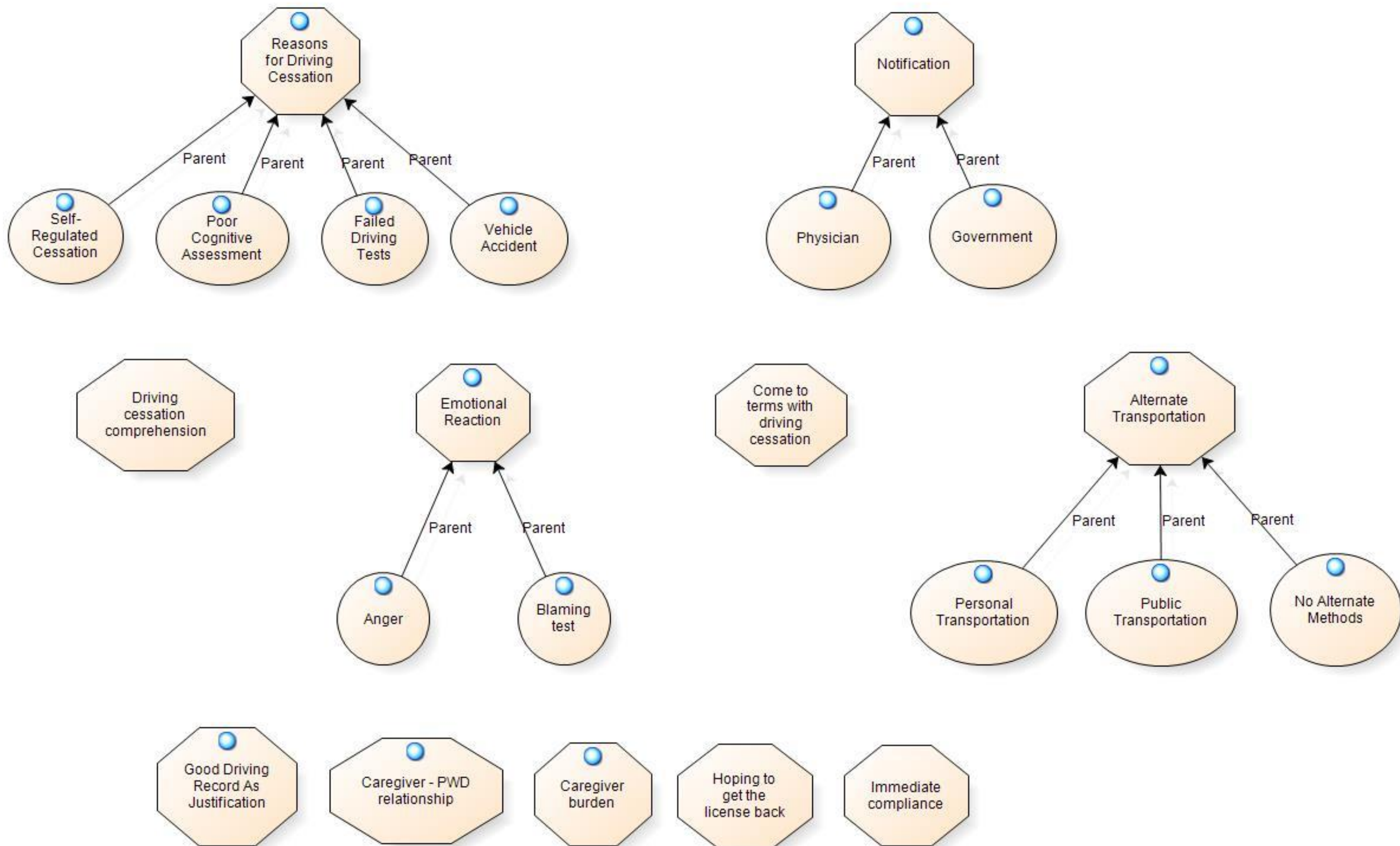


Figure 5 : Coding hierarchy – 18 codes – 10 participants.

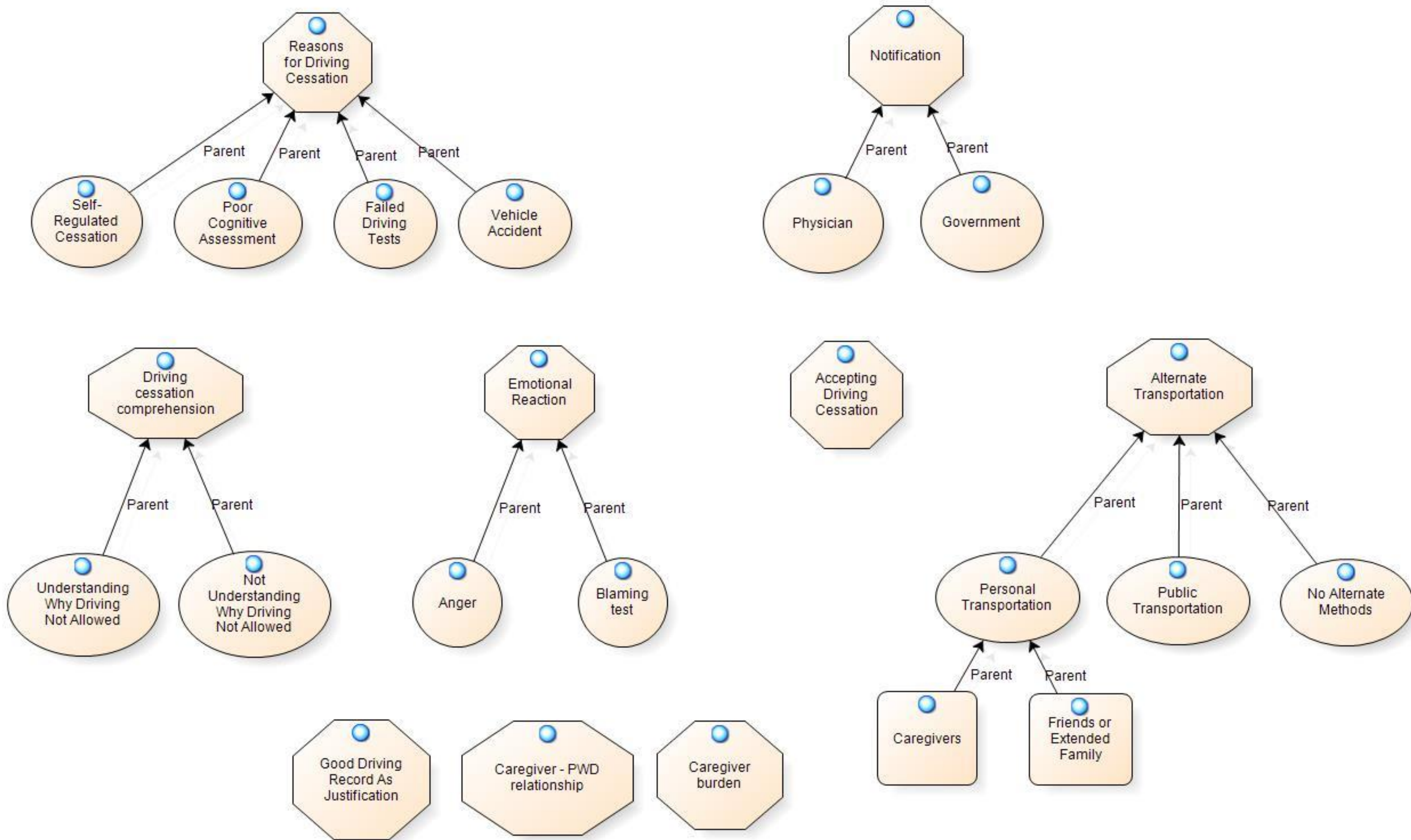
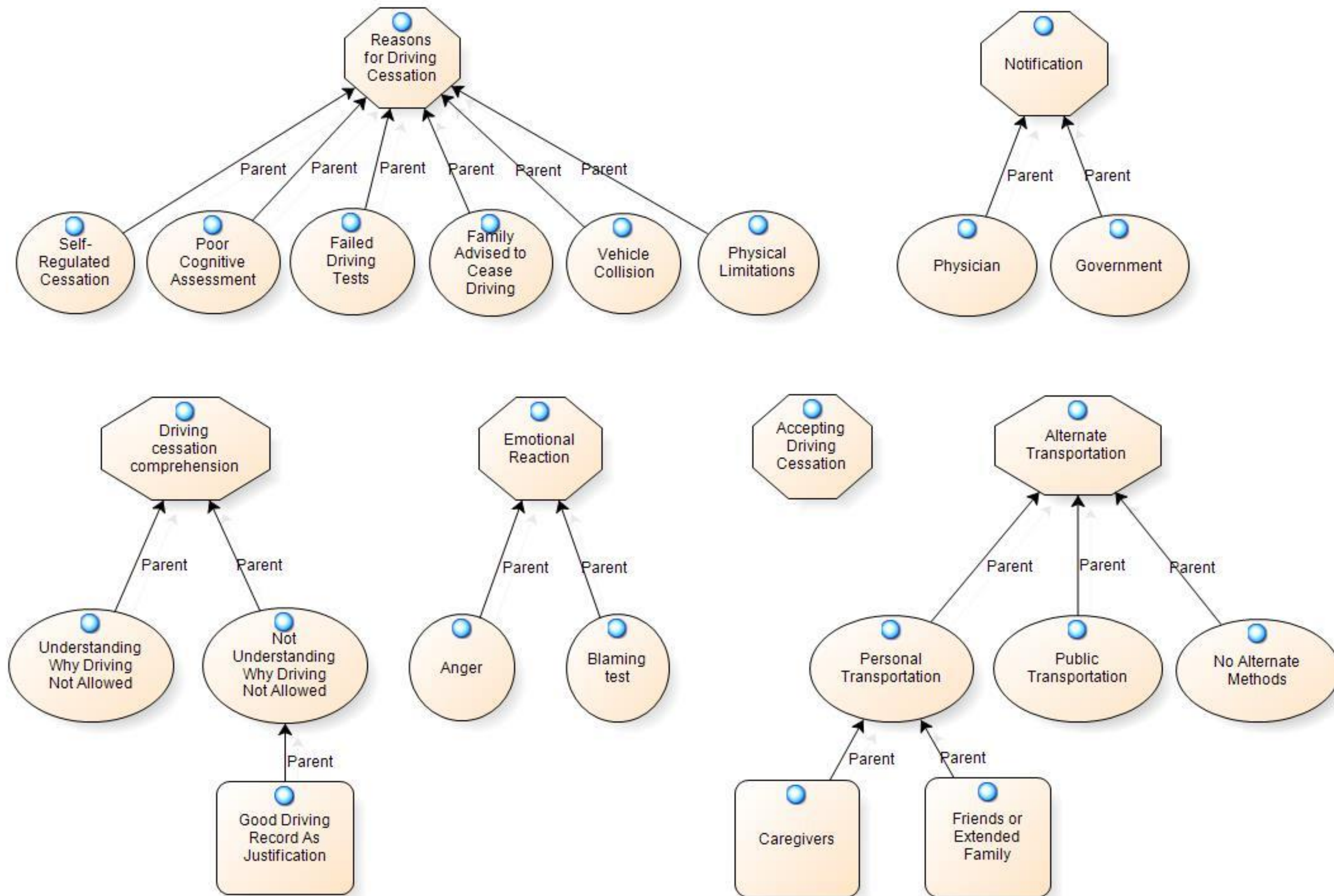


Figure 6: Coding hierarchy for the process of driving cessation.



Appendixes

APPENDIX A. ADDITIONAL TABLES

Table 13: Reviewed coding changes – 10 participants

Old code	New code	Excerpt	Reasoning
Alternate transportation – personal transportation	Alternate transportation – no alternate methods	*"CG3023: No, but we need somebody to drive us."* *"Interviewer: No services requested at this time?"* *"CG3023: Only drivers we need drivers."*	This switch was made since the case explained that they needed drivers and thus had no alternate methods of transportation.
Alternate transportation – public transportation	Alternate transportation – personal transportation	*"Interviewer: And you drive? Do you have the opportunity DATS being used or like that?"* *"CG2015: You know, I do, but I talked to other people and they can be on time, they can be half an hour late. He is not the sort of person that's going to dress and get ready and sit and wait for half an hour ... So it's just easy for me to drive him. It's only like 12 minutes from our house."*	This portion of text explained that there were opportunities to use public transportation, however it was easier for the caregiver to drive, therefore the current method of transportation was personal transport.
Come to terms with driving cessation	Alternate transportation – personal transportation	*"PWD2009: Well, just not doing the driving. It's as simple as that; I just can't do anything about it."* *"Interviewer: Are you still going to all the places you went to before?"* *"PWD2009: Well, always [CG] driving me somewhere, or a friend doing it, but it's not me driving anymore."*	This was done since this section of the transcript explained that the spouse was the current methods of transportation and it was not related to the PWD "coming to terms" with driving cessation.
Immediate compliance	Accepting driving cessation	*"CG2009: Yes, and so I called out family doctor, and he said he would, he knew about those tests, nut he would have Dr. SS[6] do it. We called her, and she did it, and he couldn't pass that test."* *"Interviewer: So he went back to DriveABLE again or to another company?"* *"CG2009: No, he didn't do anything. He just accepted that he couldn't drive."* *"PWD3019: Driving school that is it. I had been there for a while and then at the end they had me driving all over the place. Something happened I can't remember now. I had to go down to the doctor's office or something. So I cancelled one appointment and he says you don't have to go there because he said you can't have a driver's license anymore anyways. And that kind of started it. Well it had already kind of*	These participants had accepted that they could no longer drive and therefore there was no need for a separate code for "immediate compliance".

[6] Note: All of the physician names were assigned random initials.

		started from my doctor. And this kind of put the finishing touches to it. So from then on, I didn't touch the car. They would say we took it away from you for your own good. So when I heard that, I said 'I am not touching it', so I left the car in the garage for quite a while."	
Hoping to get the license back	Driving cessation comprehension – not understanding why driving not allowed	*"Interviewer: And did he talk about it a lot?"* *"CG2009: Yes. He did talk about it a lot. He talked about getting his driver's license back … At the beginning of his therapy group that he is going to now, when he was first going, he voiced to me in the car, that he hoped that this would help him get his driver's license back."*	The code "hoping to get the license back" was deleted and the case was added to the code "not understanding why driving not allowed" since the piece of transcript was already coded as "driving cessation comprehension".

Table 14: Reviewed coding changes – 18 participants

Old code	New code	Excerpt	Reasoning
N/A	Driving cessation comprehension – not understanding why driving not allowed	*"Well, I feel anger a little bit. It just wasn't far. I just didn't, I've just driven all my life, and I really had a good driving record. I just think this is… anyways, you know, that's but I still can't drive but I have tried to fly my airplane, but I sure miss that a lot."*	Each code for "good driving record as justification" were also coded as "not understanding why driving not allowed", except for this reference. As well, 3 other references of this same participant are coded as "not understanding why driving not allowed".
Caregiver-PWD relationship	N/A	*"Interviewer: And he's obliging, or understanding and kind of accepting the changes? CG2009: Oh yeah. There is a good relationship between us. Interviewer: The openness. CG2009: The openness and the relationship. He's not diminished in my eyes, he is not. But, we still, I still enjoy living with him, and that's you know, I can't imagine, well, I can't imagine anything yet that would spoil that."*	The code "caregiver-PWD relationship" was deleted. The text that was used to create this code is also used for other codes in the data analysis process; as such, this portion of text will continue to be relevant in the study.
Caregiver burden	N/A	*"Interviewer: And how does this change you and your husband's life with him not driving? Has it put more burdens on you? CG2009: Yes, it has. Interviewer: Does he tend to not go to places that he would have gone to before? CG2009: I don't have any indication of that. I must admit when it first started, I was really astonished at how much, I didn't realize how much he drove. I mean how much he took off my shoulders, I guess; because I had to take, you know, do all the driving, like taking the dog to the groomer for instance. That was a job he did and so on, and um, it's working out fine, but it's more for me to do for sure."*	The code "caregiver burden" was also deleted. The code had two references, and although the description of the code was well understood, it was reasoned that due to the low instances in the data, the code would be less important moving forward. Additionally, the aspect of burden is present within the data, mostly through the codes "accepting driving cessation", "alternate transportation", and "emotional reaction" where the burden of driving cessation can be affected or limited.
Personal transportation	Public transportation	*"Interviewer: And you drive him? Do you have the opportunity DATS*	After being reviewed, it was questioned whether this excerpt

– caregivers	& Personal transportation – caregivers	*being used or like that?"* *"CG2015: You know, I do but I talked to other people and they can be on time, they can be half an hour late. He is not the sort of person that's going to dress and get ready and sit and wait for half an hour."* *"Interviewer: Okay and also taking the [transit system] home and take a long time to get home."* *"CG2015: Yes, yes."* *"Interviewer: So you just find it just…"* *"CG2015: So it's just easier for me to drive him. It's only like 12 minutes from our house."*	should be coded as "personal transportation". However, the text states that alternate public transportation is available, but it is easier for the caregiver to drive due to having to wait for the disabled public transportation service (DATS). Therefore, it should be coded as "personal transportation". On the other hand, it should also be coded as "public transportation" since this service is available to them, even if they do not use it. As such, the code "public transportation" was added.
Reasons for driving cessation – self-regulated cessation	Reasons for driving cessation – poor cognitive assessment	*"Interviewer: The reason you had to stop driving was because of the doctors. You would have never stopped on you own right?"* *"PWD3019: I don't think I would have because I enjoyed the car, I enjoyed driving."*	The code "self-regulation cessation" does not include samples of participants who have decided to self-regulate their driving cessation after a physician has suggested they stop driving. This participant explained that they would need for a physician to tell them to cease driving and could not do it on their own. Therefore, this case re-coded as "poor cognitive assessment" since a portion of text was already coded as "poor cognitive assessment".
Accepting driving cessation	N/A	*"CG1003: Everything went in, your test went in. DriveABLE's result had to go in, and [PWD], they refused to uh, they said that [PWD] would have to have a total – they didn't refuse us, they said the only way that they would allow him to take a road test, to do the test with them was if he had a complete re-cognitive assessment done. Which means we would have to go back through Dr. L and all these other things, and I just sort of let it go? I thought by the time we fight all this it could be that perhaps [PWD] shouldn't be driving."*	CG1003 has a portion of text coded under "accepting driving cessation". To make this text more understandable, additional text was coded to add detail and depth to the code for this participant.
Driving	N/A	*"Interviewer: And you had, you've*	Participant PWD2009 had a

cessation comprehension – not understanding why driving not allowed – good driving record as justification		*been going to DriveABLE over the years, right? Every 6 months or every year to have testing done?"* *"PWD2009: No, I'm not going to go back there ever again."* *"Interviewer: But, before this incident, you've had it done before?"* *"PWD2009: Um, very… I have been a very good drive, but I didn't think it was a good examination."* *"Interviewer: Okay, so after you went through the DriveABLE, and then did you see your family doctor and discuss the result?"* *"PWD2009: Well yeah, and my family actually, Dr. MM, you know, agreed with me basically, you know, could have been a lot better, you now, I just don't know how I could drive around for 2 hours, and at the end of it, I get this thing, as a test, and after all these years of driving just being thrown out of the window. I thought that was crazy."*	small portion of text coded as "good driving record as justification" and an additional portion of text has been added to extend this code.
None	Driving cessation comprehension – understanding why driving not allowed	*"Interviewer: And so he is slowly turning the driving over to you?"* *"CG2015: Well, he started maybe 2 or 3 years ago, and it was because he was getting lost."* *"Interviewer: And was he aware that he…"* *"CG2015: I think at that time he was because I wouldn't help him. I wanted him to see what was going on. And I think that did help, with him giving up most of the driving."*	The code "understanding why driving not allowed" was added to an existing portion of text for participant CG2015. This code was added since the caregiver did not help the PWD when they were driving because they wanted them to "see what was going on", or in other terms, understand why they could no longer drive.
None	Alternate transportation – personal transportation – caregivers	*Excerpt: "Interviewer: And is she driving at all?"* *"CG2016: No, we always go together. She can drive, she helps me drive in our long trips and that, but I don't let her drive for a long trip for fear that she might get lost but her driving is still, no problem at her driving when I'm with her."* *"Interviewer: And has she driven in the last month?"*	Participant CG2016 did not yet have a specific code within the transition of driving cessation. However, a portion of transcript has now been coded as "alternate transportation – personal transportation – caregivers".

		"CG2016: Not by herself, no." *"Interviewer: And with you, has she been behind the wheel in the last month?"* *"CG2016: No, I was driving."*	
None	Alternate transportation – public transportation & Alternate transportation – personal transportation – caregivers	*"Interviewer: Ok, and you take him, you're still driving?"* *"CG2032: I drive, yes."* *"Interviewer: Yeah, so DATS takes him to his program but otherwise you or your family drive him to appointments."* *"CG2032: Yes."*	Participant CG2032 did not yet have a code within the transition of driving cessation until this portion of text was coded as "alternate transportation – public transportation" and "alternate transportation – personal transportation – caregivers"
Reasons for driving cessation – self-regulated cessation	Accepting driving cessation & Driving cessation comprehension – understanding why driving not allowed & Reasons for driving cessation – self-regulated cessation	*"Interviewer: She got her driver's license?"* *"CG3001: Yup, no test required this time. She'll have to go back in a year I think, it's only a one year, and I think a one year or maybe two year license. If she's 79 this year and next year, she'd be 80."* *"Interviewer: Yeah, next year I think that's when they have to do a test."* *"CG3001: And when that comes, she's not going to renew."* *"Interviewer: Nope, no. Did she decide that?"* *"CG3001: Yeah."* *"Interviewer: Oh good for her."* *"CG3001: Oh yeah, she doesn't drive anyway."*	This was done since the caregiver explains that the PWD will not seek to renew their license when they turn 80. The reasons for why the participant no longer drives are not explained, and may be due to the fact that they no longer drive or simply do not use the vehicle. In any case, both of the additional codes are applicable.
Reasons for driving cessation	None	"*CG3002: Yes, yes. No, nothing happened thank god."* *"FAMILY: A couple of year ago my sister…"* *"Interviewer: How did you feel when he was told to stop driving?"* *"CG3002: Well I felt stuck"*	There was no child code to explain what the reason was for driving cessation. The interviewer asks the caregiver for the reason for driving cessation; however the caregiver does not answer the question. When the interviewer then asks "how did you feel when he was told to stop driving?" we do not know who told the PWD to cease driving. Therefore, we cannot code this text as "reasons for driving

			cessation" since there is no specific reason given.
None	Public transportation	*[translated] "CG3003: For me it is very hard, I lost my independence. Then I couldn't go anywhere. I had to ask others to drive me. And there was no Para Transpo at that time; my husband had it, but not me. It's hard to lose it because we are forced to ask others [to drive us]."*	Participant CG3003 had a portion of text already coded for "public transportation" where they mention the usage of Para Transpo. An added piece of text prior to the code has now also been coded to give more depth to the conversation regarding Para Transpo.
None	Alternate transportation – public transportation & Reasons for driving cessation – self-regulated cessation	*"Interviewer: Does she drive?" "CG3010: No." "Interviewer: Did she drive?" "CG3010: A long time ago. She was nervous so she did not drive much, she just gave it up. And we have got her para transport because she had problems walking with her ankle. She just refuses to go out so."*	This had previously been determined to hold no significance if coded, however it was reviewed that the text adds depth to the codes, even if it is not the most descriptive
Alternate transportation – public transportation	Alternate transportation – personal transportation – friends or extended family & Alternate transportation – public transportation	*"PWD3011: Yup. I go everywhere by bus. That [niece] can't take me. She works on and off."*	Participant PWD3011 had a portion of text that was coded as "public transportation". This text is situated at the end of the conversation regarding how the participant's niece can serve as an option for alternate transportation. The participant then explains that his niece works and can no longer drive him. As such, the code "alternate transportation – personal transportation – friends or extended family" was added as it completes a coded conversation regarding the participant's niece.
None	Accepting driving cessation & Reasons for driving cessation – family advised to cease driving	*"Interviewer: Is he still driving?" "CG3012: No." "Interviewer: Did he ever drive?" "CG3012: Oh yeah. He drove out – they moved to Canada in 2007, a year or so before they moved here, about a year or two, my mom started to, didn't feel comfortable with him driving anymore, so he stopped."*	Participant CG3012 previously did not have a specific code within the transition of driving cessation.

		"Interviewer: There's a question on that actually, that I'll ask you. For a lot of people the cessation of driving is a huge transition." *"CG3012: Oh he doesn't care. You'll see. A lot of things he doesn't care, all he wants it TV and food."*	
Reasons for driving cessation – self-regulated cessation	Accepting driving cessation & Driving cessation comprehension – understanding why driving not allowed & Reasons for driving cessation – self-regulated cessation	*[translated]* *"PWD3013: I knew I could no longer drive. I told myself I don't know how to drive, I can't drive anymore, and I immediately gave my car to her brother on the weekend."* *"Interviewer: Just like that?"* *"PWD3013: Well yes. I didn't have my license anymore; I went to give it in. When I told myself, no in this situation, I went to give in my license. Because I did not want to take any chance of hitting someone."*	This was done since the participant clearly explains that they understand why they are no longer allowed to drive and they have accepted this.
None	Notification - physician	*"Interviewer: And did he talk about it a lot?"* *"CG2009: Yes. He did talk about it a lot. He talked about getting his driver's license back. Um, here for a time when he was, um, at the beginning of his therapy group with Dr. SS that he is going to now, when he first was going, he voiced me in the car, going over that he hoped that this would help him get his driver's license back."* *"Interviewer: Okay and has anybody talked to him that if there is a chance for his driver license, getting it back or is it permanent?"* *"CG2009: No, it is permanent. Dr. SS said that there isn't any way that he would be able to get it back."* *"Interviewer: Okay. And he has been told this?"* *"CG2009: Not for sure he understood what was being told, but I think at some point she must have told him he wasn't."*	Participant CG2009 has a pre-existing code for "notification – physician". Now, an additional portion of text has been coded as "notification – physician", since it clarifies what has been said by the physician to the PWD.

Table 15: Examples of coding relationships – 25 participants

Relationship code	Excerpt	Reasoning
Reasons for driving cessation – failed driving tests / Emotional reaction – blaming test	*"CG1003: He did a road test. But you know the things that they put in there that they said he failed. Any one of us could fail that. Dr. JD, this spring, because he's had some other issues come up, said: 'you know, I don't think they give a person a fair chance. I think once they've decided they shouldn't have it, they just don't really look at the whole thing.' The things that they failed [PWD] on, I could have failed on."*	This relationship code was created to capture those who failed a driving test and consequently blamed the test.
Emotional reaction – anger / Emotional reaction – blaming test	*"CG1003: Ok, it was August of last year that we had an in home evaluation from the seniors' health, from <name>, and he suggested at that time that <name> should have a driving test, through this DriveABLE. And so that took place in the first part of October, I believe it was. That the first, the part on the computer was done. And then they said that he didn't have that, and I fought that, and I fought that with our family doctor. And our family doctor agreed that <name> should have the driving test. As you are very aware, I am not happy with DriveABLE, and we're finding out that a lot of people aren't happy with DriveABLE."* *"CG1027: More upset because they wanted to charge him to take the test."*	This relationship code was created to code for participants who were angry specifically at a driving test, and go on to blame the driving test.
Driving cessation comprehension – not understanding why driving not allowed / Accepting driving cessation	*"CG1003: Yes, so we're leaving it alone. At this point, yeah."* *"Interviewer: So, how is [PWD], how has he been dealing with this issue for the past several months?"* *"CG1003: It's become an acceptance. Is it understood, or happy? No, but he just goes along."*	This relationship code was created to capture those who do not understand why they are no longer allowed to drive, but have accepted it.
Notification – physician / Reasons for driving cessation – self-regulated cessation	*"Interviewer: And probably can't drive now."* *"CG1027: Well no, when his license was ready to expire, we have a new doctor, and he needed a medical for that, so the doctor required that, because he was taking Aricept, he required him to go to this, this Drive"* *"Interviewer: DriveABLE."* *"CG1027: Right. So he decided, and I think that it cost about 300 dollars. He said that wasn't important to him. That was not fair. So…"* *"Interviewer: So he decided to give up. He just gave up."* *"CG1027: He gave it up, yeah."*	This relationship code was created to link those who self-regulated their driving cessation after a physician notified them that they would have to be re-tested, either due to their age or medication status. This does not include those who self-regulated their driving cessation after having a poor cognitive assessment from a physician.
Alternate	*"CG1027: I don't' like to drive, I do some driving, just*	This relationship code

transportation – personal transportation – caregivers / Alternate transportation – public transportation	*around here. We have us, Access Calgary, until the end of February. Then I have to fill out some more, I filled more forms."* *"Interviewer: And you drive him? Do you have the opportunity DATs being used or like that?"* *"CG2015: You know, I do but I talked to other people and they can be on time, they can be half an hour late. He is not the sort of person that's going to dress and get ready and sit and wait for half an hour."* *"Interviewer: Okay, and also the taking the [transit system] home and take a long time to get home."* *"CG2015: Yes, yes."* *"Interviewer: So you find it just…"* *"CG2015: So it's just easy for me to drive him. It's only like 12 minutes from our house."*	was created to code for participants who can drive, but feel more comfortable using public transportation instead, or for participants' caregivers who drive because they do not or cannot use public transportation.
Driving cessation comprehension - understanding why driving not allowed / Reasons for driving cessation – self-regulated cessation	*"Interviewer: When you stopped driving, what were you told about why you had to stop driving, or did you do…"* *"PWD2006: It was mainly the dementia. But um, basically, felt that I would go out and couldn't find my way home again so."* *Interviewer: Okay and you went to the DriveABLE and were tested? No? Okay. So what do you feel about not driving anymore?* *"PWD2006: It just ruined my life. I was a truck driver for 20 years for demolition [company]. I drove from here to Whitehorse and there was one time that we had a job in [name of city], I drove from here to [name of city] and turned around and drove back."*	This relationship code was created to link together cases where participants understand why they are no longer allowed to drive and therefore have decided to self-regulate their driving cessation.
Alternate transportation – personal transportation – caregivers / Accepting driving cessation	*"Interviewer: Okay and so how did you get around now?"* *"PWD2006: I got a wife that is perfect driver."* *"Interviewer: Okay, good."* *"PWD2006: Fortunately."* *"Interviewer: And do you have a need to go out every day driving or?"* *"PWD2006: No."* *"Interviewer: No? So just more for doctor's appointment and things like that?"* *"PWD2006: Yes."* *"Interviewer: So you feel that even you are discouraged and disappointed that you accept the fact that you can't drive anymore?"* *"PWD2006: Oh yes, but … it wasn't easy."* *"Interviewer: No, no, it wouldn't be."* *"PWD2006: When your wife was driving and it's something to swallow."* *"Interviewer: Good thing you have your wife."*	This relationship code was created to highlight those who have accepted driving cessation due in part to having access to alternate transportation through their caregivers (i.e. spouse or other family members)

<table>
<tr><td></td><td>"PWD2006: That's right."</td><td></td></tr>
<tr><td>Reasons for driving cessation – failed driving tests / Notification – government</td><td rowspan="2">"Interviewer: And he went to the DriveABLE assessment, and they failed him. And how did you find out about this?"<br>"CG2009: From the Alberta service… service Alberta. They sent him a registered letter, and he had signed the paper saying that DriveABLE could inform him of the results of the test, and they sent us a registered letters, sent him a registered letter, saying that he had failed it. That was an explanation that If he had another test… with a doctor who would support this…"<br>"Interviewer: That would challenge you…"<br>"CG2009: Yes, and so I called our family doctor, and he said he would, he knew about those tests, but he would have Dr. SS do it. We caller her, and she did it. And um, he couldn't pass that test."</td><td rowspan="2">Both of these relationship codes were created to link together participants who ceased driving after they were notified that they were no longer allowed to drive.</td></tr>
<tr><td>Reasons for driving cessation – failed driving tests / Notification – physician</td></tr>
<tr><td>Reasons for driving cessation – failed driving tests / Accepting driving cessation</td><td>"Interviewer: And he went to the DriveABLE assessment, and they failed him. And how did you find out about this?"<br>"CG2009: From the Alberta service… service Alberta. They sent him a registered letter, and he had signed the paper saying that DriveABLE could inform him of the results of the test, and they sent us a registered letters, sent him a registered letter, saying that he had failed it. That was an explanation that If he had another test… with a doctor who would support this…"<br>"Interviewer: That would challenge you…"<br>"CG2009: Yes, and so I called our family doctor, and he said he would, he knew about those tests, but he would have Dr. SS do it. We caller her, and she did it. And um, he couldn't pass that test."
"Interviewer: So he went back to DriveABLE again or to another company?"<br>"CG2009: No, he didn't do anything. He just accepted that he couldn't drive."
"Interviewer: And how long ago was this?"<br>"CG2009: Um, it was the 9th… he got the test before his birthday, which was January 26th, but we got the results around the 10th of February."
"Interviewer: And then he just quit driving altogether?"<br>"CG2009: Yes."</td><td>This relationship code was created to highlight participants who have accepted that they are no longer allowed to drive due to having previously failed a driving test.</td></tr>
<tr><td>Notification – physician / Driving cessation comprehension – not understanding why driving not</td><td>"Interviewer: And did he talk about it a lot?"<br>"CG2009: Yes. He did talk about it a lot. He talked about getting his driver's license back. Um, here for a time when he was, um, at the beginning of his therapy group with Dr. SS that he is going to now, when he first was going, he voiced me in the car, going over</td><td>This relationship code was created to code for participants who do not understand why they are no longer allowed to drive, even after being</td></tr>
</table>

<table>
<tr>
<td>allowed</td>
<td>that he hoped that this would help him get his driver's license back."
"Interviewer: Okay and has anybody talked to him that if there is a chance for his driver license, getting it back or is it permanent?"<br>"CG2009: No, it is permanent. Dr. SS said that there isn't any way that he would be able to get it back."
"Interviewer: Okay. And he has been told this?"<br>"CG2009: Not for sure he understood what was being told, but I think at some point she must have told him he wasn't."</td>
<td>told by a physician.</td>
</tr>
<tr>
<td>Reasons for driving cessation – failed driving tests / Driving cessation comprehension – not understanding why driving not allowed</td>
<td>"CG2009: Actually I was surprised that he didn't pass the test. Very surprised. Up until the day before he didn't pass the test, we were driving around Edmonton, and he was doing the driving. I was very surprised that he did not pass it."
"Interviewer: So there wasn't any evidence to you beforehand?"<br>"CG2009: No, there wasn't. And so I was very hopeful that the test that Dr. SS would do on him and with her supporting the application that, that could happen. But she made it clear to both of us that he had failed it miserable, really."</td>
<td>This relationship code was created to code for participants who ceased driving after having failed a driving test and also did not understand why they were no longer allowed to drive.</td>
</tr>
<tr>
<td>Reasons for driving cessation – failed driving tests / Driving cessation comprehension – not understanding why driving not allowed – good driving record as justification</td>
<td rowspan="2">"Interviewer: And you had, you've been going to DriveABLE over the years, right? Every 6 months or every year to have testing done?"<br>"PWD2009: No, I'm not going to go back there ever again."
"Interviewer: But before this incident, you've had it done before?"<br>"PWD2009: Um, very… I have been a very good driver, but I didn't think it was a good examination."
"Interviewer: Okay, so after you went through the DriveABLE, and then did you see your family doctor and discuss the result?"<br>"PWD2009: Well yeah, and my family physician actually, Dr. MM, you know, agreed with me basically, you know, could have been a lot better, you know, I just don't know how I could drive around for 2 hours, and at the end of it, I get this thing, um, as a test, and after all these years of driving just being thrown out of the window. I thought that was crazy."
…
"Interviewer: So how long has it been, when did you</td>
<td>This relationship code was created to highlight participants who have failed a driving test and do not understand why they are no longer allowed to drive, based on their history of a good driving record.</td>
</tr>
<tr>
<td>Driving cessation comprehension – not understanding why driving not allowed – good driving record as justification / Emotional reaction – anger</td>
<td>These two relationship codes were both created since it can be concluded that the participant might be angry and thus be blaming the test since they do not understand why they are no longer allowed to drive. This may be due to the</td>
</tr>
</table>

<table>
<tr>
<td>Driving cessation comprehension – not understanding why driving not allowed – good driving record as justification / Emotional reaction – blaming test</td>
<td>stop driving?”
“PWD2009: I forgot.”
“Interviewer: Okay, so it has been a little bit of time.”
“PWD2009: Yeah, I haven’t driven for a while. I don’t have the license thing… got grounded up.”
“Interviewer: And what are your thoughts of not having your license anymore?”
“PWD2009: Well, I feel angry a little bit. It’s just wasn’t fair… I just didn’t, I’ve just driven all my life, and I really had a good driving record. I just think this is… anyways, you know, that’s but I say, I still can’t drive, but I have tried to fly my airplane, but I sure miss that a lot.”</td>
<td>participant having a history of a good driving record.</td>
</tr>
<tr>
<td>Emotional reaction – anger / Accepting driving cessation</td>
<td>“Interviewer: Is it getting easier over time?”
“PWD2009: Yeah it is, just um, you know, just getting started to think back over the year, how many patients I had that I had to go through all these things too, but now I am in the receiving end. But, I wish I was still in there, that’s all.”
“Interviewer: So each day is getting a little bit better for you, but you are still angry.”
“PWD2009: Well, I’m angry up to a point, but I still have my grand piano sitting there that I can play every day. And I really enjoy that big time.”</td>
<td>This relationship code was created to code for participants who are angry and yet have also accepted that they can no longer drive or are no longer allowed to drive.</td>
</tr>
<tr>
<td>Accepting driving cessation / Reasons for driving cessation – self-regulated cessation</td>
<td rowspan="4">“Interviewer: Okay, and does he drive much?”
“CG2015: Very little.”
“Interviewer: And how far would he go from home?”
“CG2015: Maybe 2km.”
“Interviewer: Okay. And when you go out on a highway or to the lake, you do the driving?”
“CG2015: I do the driving.”
“Interviewer: And does he automatically get into the passenger’s seat?”
“CG2015: Yeah, yeah.”
“Interviewer: Okay, so he is kind of slowly lending… did he do all the driving before?”
“CG2015: Pretty much.”
“Interviewer: And so that he is slowly turning the driving over to you?”
“CG2015: Well, he started maybe 2 or 3 years ago, and it was because he was getting lost.”
“Interviewer: And was he aware that he…”
“CG2015: I think at that time he was, because I wouldn’t help him. I wanted him to see what was going on. And I think that did help, with him giving up most of the driving.”</td>
<td>This relationship code was created to code for participants who self-regulated their driving cessation after having accepted that they could no longer drive.</td>
</tr>
<tr>
<td>Alternate transportation – personal transportation – caregivers / Driving cessation comprehension – understanding why driving not allowed</td>
<td rowspan="2">These two relationship codes were created to highlight the caregivers who have helped PWD understand why they were no longer allowed to drive and/or self-regulate their driving cessation.</td>
</tr>
<tr>
<td>Alternate transportation – personal transportation – caregivers / Reasons for driving cessation – self-regulated cessation</td>
</tr>
<tr>
<td>Driving cessation comprehension –</td>
<td>This relationship code was created to code for</td>
</tr>
</table>

understanding why driving not allowed / Accepting driving cessation		participants who have accepted driving cessation once having already understood why they were no longer allowed to drive.
Alternate transportation – public transportation / Accepting driving cessation Alternate transportation – public transportation / Reasons for driving cessation – self-regulated cessation	*"Interviewer: Transportation is he still doing some limited driving?"* *"CG2021: Yes."* *"Interviewer: Would it be on once or twice a week?"* *"CG2021: It was down to maybe once every 2 weeks and as of probably in September he had decided on his own, even though he still has the license, that he will not be driving the car, so…"* *…* *"Interviewer: So there's nobody coming into the home. Transportation, you're doing the driving."* *"CG2021: No, we're taking public transit."* *"Interviewer: Oh, because he quit his driving in September. Right, he did. And how is that going?"* *"CG2021: Very well, he's very comfortable with it and we're doing very well with the public transit."*	These relationship codes were created to code for participants who have accepted and self-regulated their driving cessation in part due to the availability and use of public transportation.
Reasons for driving cessation – family advised to cease driving / Driving cessation comprehension – not understanding why driving not allowed	*[translated]* *"CG3003: He says 'I've got my car, we'll go in the car.' I told him you do not have your car anymore, you've sold it. 'How come I don't have a car anymore? I still have my license.' They did not remove the car; it was the whole family who said you should not drive anymore. So he said 'ok, I'll sell my car.' After, he lost his license, he has not passed a test, and you know, after 80 years old you have to pass every 2 years. And it really gave him a wallop. If you understand, we used to go out. If I needed our son, we went out. But it's over, it was completely at once."*	This relationship code was created so as to code for the few participants who were asked to stop driving by their family, and yet do not understand why they were told they could no longer drive.
Alternate transportation – personal transportation – friends or extended family / Alternate transportation – public transportation	*[translated]* *"CG3003: For me it is very hard, I lost my independence. Then I couldn't go anywhere. I had to ask others to drive me. And there was no Para Transpo at that time; my husband had it, but not me. It's hard to lose it because we are forced to ask others [to drive us]."* *"Interviewer: How was the experience relative to the use of new means of transportation?"* *"CG3003: Para Transpo is good but it takes a half or ¾ of an hour. If we were to return, two hours, there was no time to do what we wanted. It's really good however; it's a nice thing for people like us who don't have the means. I have my sister in law who comes*	This relationship code was created to code for participants who rely on friends or family members since they do not have access to public transportation. It also codes for participants who use public transportation because they cannot ask their friends or extended family to drive them on a consistent basis.

	once a week to drive us. I appreciate it a lot, but we cannot just call anyone whenever we want. We take Para Transpo for the majority of thing. I think it's really good."	
Reasons for driving cessation – family advised to cease driving / Accepting driving cessation	*"CG3012: Oh yeah. He drove out – they moved to Canada in 2007, a year or so before they moved here, about a year or two, my mom started to, didn't feel comfortable with him driving anymore, so he stopped."* *"Interviewer: There's a question on that actually, that I'll ask you. For a lot of people the cessation of driving is a huge transition."* *"CG3012: Oh he doesn't care. You'll see. A lot of things he doesn't care, all he wants are TV and food."*	This relationship code was created to capture participants who accepted driving cessation after their family advised that they cease driving.
Reasons for driving cessation – poor cognitive assessment / Driving cessation comprehension – understanding why driving not allowed Reasons for driving cessation – poor cognitive assessment / Accepting driving cessation	*"Interviewer: Ok, so what was the reason you had to stop driving?"* *"PWD3015: Oh they did, after the 2 assessments that I had of the house … it was suggested that –* *"Interviewer: You stop."* *"PWD3015: You stop, yeah."* *"Interviewer: Ok, did you think the assessments were fair? Did you think that was a fair decision for them to [make]?* *"PWD3015: Yes I did."* *"Interviewer: Did you. And you have actually stopped driving?"* *"PWD3015: Uh huh, because I was getting nervous driving."*	These relationship codes were created to highlight participants who had a poor cognitive assessment, that understand and accept that they can no longer drive.
Reasons for driving cessation – vehicle collision / Reasons for driving cessation – failed driving tests	*"Interviewer: Now did she ever drive?"* *"CG3016: Yup."* *"Interviewer: And when did she give that up?"* *"CG3016: Um, gave that up, I'm guessing about 3 years ago, 4 years ago, it would've been a long time."* *"Interviewer: Was that hard for her?"* *"CG3016: Yup, she had a little fender bender and because of her age, they made her re-test and she failed her test, so it was…"* *"Interviewer: Very difficult."* *"CG3016: It was very difficult, she never really did get used to the idea of using taxis."*	This relationship code was created to code for the few participants who had to stop driving after having failed a driving test, which is required after having a vehicle collision.
Reasons for driving cessation – poor cognitive assessment / Notification physician	*"Interviewer: And you were still driving at the time?"* *"PWD3019: I wasn't driving much at that time because…"* *"CG3019: We sent you to driving school."* *"PWD3019: Driving school that is it. I had been there for a while and then at the end. They had me driving and all over the place. Something happened I can't remember now. I had to go down to the doctor's office or something, at the clinic where Dr. W. was. So I cancelled once appointment and he says you don't*	These two relationship codes were both created to code for participants, who had to cease driving due to a poor cognitive assessment, were then notified by their family physician or a specialist, and thus accepted that they could no longer

<table>
<tr>
<td>Notification – physician / Accepting driving cessation</td>
<td>have to go there because he said you can't have a driver's license anymore anyways. And that kind of started it. Well it had already kind of started from my doctor. And this kind of put the finishing touches to it. So from then on I didn't touch the car. I just left it. They would say we took it away from you for your own good. So when I heard that I said I am not touching it, so I left the car in the garage for quite a while. But anybody would take me out if I had to go and everything was working out fine. But I missed the car so much. I still do, but that is ok. I don't have it anymore."</td>
<td>continue to drive.</td>
</tr>
<tr>
<td>Notification – physician / Driving cessation comprehension – understanding why driving not allowed</td>
<td rowspan="2">"Interviewer: The reason you had to stop driving was because of the doctors. You would have never stopped on your own right?"<br>"PWD3019: I don't think I would have because I enjoyed the car, I enjoyed driving."
"Interviewer: Doctors advice. And did you find that it was a fair assessment."
"PWD3019: Well when they told me it was for my own good, I felt like I should just forget about it. Leave it alone. And that gave me my answer right away."
"Interviewer: Ok so you trusted their judgement."
"PWD3019: Well I got a letter from the government and the rest of it so I had no choice. I couldn't say I am not going to do this because I had to."
"Interviewer: Were you satisfied with the manner in which the news was disclosed?"<br>"PWD3019: Well yeah I was satisfied. Well I was looking after my own health too. And I didn't want to wreck someone else's car. You know I didn't want to get into trouble."</td>
<td>This relationship code was created to highlight participants who understood why they were not allowed to drive after having received a notification from their physician.</td>
</tr>
<tr>
<td>Notification – physician / Notification government</td>
<td>This relationship code was created so as to capture participants whose physician notified the government.</td>
</tr>
<tr>
<td>Alternate transportation – personal transportation – caregivers / Driving cessation comprehension – not understanding why driving not allowed</td>
<td>"Interviewer: Do you drive?"<br>"PWD3021: I did drive recently, somebody arranged for me not to be able to drive anymore, not to have my car anymore."
"CG3021DAUGHTER2: No, Dr. K sent a letter to the provincial government saying you may want to test her again, and it was decided that you just wouldn't test again, it was just easier, I mean, we drive you where you need to go anyway. So…"<br>"PWD3021: So I had no trouble driving right up to the</td>
<td>These three relationship codes were each created to code for participants who do not drive since it is easier for their caregivers to drive, and yet these participants are angry and do not understand why they are no longer allowed to</td>
</tr>
</table>

<table>
<tr>
<td>Alternate transportation – personal transportation – caregivers / Driving cessation comprehension – not understanding why driving not allowed – good driving record as justification</td>
<td rowspan="5">very end, I could drive beautifully, I was always a good driver, I must say.”
“Interviewer: Okay, so that was just recently, until the last 6 months or so.”
“CG3021DAUGHER2: Yeah, it was uh, when was it, October, November time frame.”
“PWD021: But I never reached a point where I was a poor drive.”
“CG3021: No I’m sure not, no, no, no, I’m sure of that. It was just more of a better safe than sorry kind of thing.”
“Interviewer: Okay, actually this is one of the bid transitions so let’s get into that now then. What do you think that the reason that you stopped driving was?”
“PWD3021: I think just because they told me I should stop driving! But I don’t know why, I was doing everything right, I knew how to drive, I was always a good driver, and I say that very honestly. I was a good, good driver.”</td>
<td rowspan="2">continue to drive.</td>
</tr>
<tr>
<td>Alternate transportation – personal transportation – caregivers / Emotional reaction – anger</td>
</tr>
<tr>
<td>Notification – physician / Emotional reaction – anger</td>
<td rowspan="2">These two relationship codes were created to distinguish participants who, after receiving a notification from their physician, are angry that they are no longer allowed to drive, since they believe to have always been a good driver.</td>
</tr>
<tr>
<td>Notification – physician / Driving cessation comprehension – not understanding why driving not allowed – good driving record as justification</td>
</tr>
<tr>
<td>Reasons for driving cessation – poor cognitive assessment / Driving cessation comprehension – not understanding why driving not allowed</td>
<td>These two relationship codes were both created to expand on participants who were no longer allowed to drive due to a poor cognitive assessment, yet still believed to be good drivers and as such do not</td>
</tr>
</table>

Reasons for driving cessation – poor cognitive assessment / Driving cessation comprehension – not understanding why driving not allowed – good driving record as justification		understand why they were no longer allowed to drive.

APPENDIX B. ETHICS APPROVALS

Ethics approval from the University of Ottawa

Date (mm/dd/yyyy): 01/21/2010

Université d'Ottawa University of Ottawa
Service de subventions de recherche et déontologie Research Grants and Ethics Services

This is to confirm that the University of Ottawa Research Ethics Board identified above, which operates in accordance with the Tri-Council Policy Statement and other applicable laws and regulations in Ontario, has examined and approved the application for ethical approval for the above named research project as of the Ethics Approval Date indicated for the period above and subject to the conditions listed the section above entitled "Special Conditions / Comments".

During the course of the study the protocol may not be modified without prior written approval from the REB except when necessary to remove subjects from immediate endangerment or when the modification(s) pertain to only administrative or logistical components of the study (e.g. change of telephone number). Investigators must also promptly alert the REB of any changes which increase the risk to participant(s), any changes which considerably affect the conduct of the project, all unanticipated and harmful events that occur, and new information that may negatively affect the conduct of the project and safety of the participant(s). Modifications to the project, information/consent documentation, and/or recruitment documentation, should be submitted to this office for approval using the "Modification to research project" form available at:

Please submit an annual status report to the Protocol Officer 4 weeks before the above-referenced expiry date to either close the file or request a renewal of ethics approval. This document can be found at: http://www.rges.uottawa.ca/ethics/application_dwn.asp

If you have any questions, please do not hesitate to contact the Ethics Office at extension or by e-mail at:

Signature:

Catherine Paquet
Assistant Director (Ethics)
For Daniel Lagarec
Chair of the HSS REB

Ethics renewal from the University of Ottawa

Date (mm/dd/yyyy): 01/19/2011

Université d'Ottawa — Bureau d'éthique et d'intégrité de la recherche
University of Ottawa — Office of Research Ethics and Integrity

This is to confirm that the University of Ottawa Research Ethics Board identified above, which operates in accordance with the Tri-Council Policy Statement and other applicable laws and regulations in Ontario, has examined and approved the application for ethical approval for the above named research project as of the Ethics Approval Date indicated for the period above and subject to the conditions listed the section above entitled "Special Conditions / Comments".

During the course of the study the protocol may not be modified without prior written approval from the REB except when necessary to remove subjects from immediate endangerment or when the modification(s) pertain to only administrative or logistical components of the study (e.g. change of telephone number). Investigators must also promptly alert the REB of any changes which increase the risk to participant(s), any changes which considerably affect the conduct of the project, all unanticipated and harmful events that occur, and new information that may negatively affect the conduct of the project and safety of the participant(s). Modifications to the project, information/consent documentation, and/or recruitment documentation, should be submitted to this office for approval using the "Modification to research project" form available at:

Please submit an annual status report to the Protocol Officer 4 weeks before the above-referenced expiry date to either close the file or request a renewal of ethics approval. This document can be found at: http://www.rges.uottawa.ca/ethics/application_dwn.asp

If you have any questions, please do not hesitate to contact the Ethics Office at extension by e-mail at:

Signature:

Germain Zongo
Protocol Officer for Ethics in Research
For Daniel Lagarec, Chair of the Sciences and Health Sciences REB

Ethics approval from the Bruyère Research Institute

www.bruyere.org

Bruyère pour des soins continus.
Bruyère Is Continuing Care.

Hôpital Élisabeth-Bruyère Hospital
43, rue Bruyère St.
Ottawa ON K1N 5C8
Tél./Tel.: 613-562-6262
Téléc./Fax: 613-562-6367

Hôpital Saint-Vincent Hospital
60, rue Cambridge St. N.
Ottawa ON K1R 7A5
Tél./Tel.: 613-562-6262
Téléc./Fax: 613-782-2785

Institut de recherche Élisabeth-Bruyère
Élisabeth Bruyère Research Institute
43, rue Bruyère St.
Ottawa ON K1N 5C8
Tél./Tel.: 613-562-6045
Téléc./Fax: 613-562-4266

Résidence Saint-Louis Residence
879, chemin Hiawatha Park Road
Ottawa ON K1C 2Z6
Tél./Tel.: 613-562-6262
Téléc./Fax: 613-683-5001

Résidence Élisabeth-Bruyère Residence
75, rue Bruyère St.
Ottawa ON K1N 5C8
Tél./Tel.: 613-562-6262
Téléc./Fax: 613-562-4223

Centre de médecine familiale Bruyère
Bruyère Family Medicine Centre
75, rue Bruyère St.
Ottawa ON K1N 5C8
Tél./Tel.: 613-241-3344
Téléc./Fax: 613-241-1971

Centre de médecine familiale Primrose
Primrose Family Medicine Centre
35, rue Primrose St.
Ottawa ON K1R 0A1
Tél./Tel.: 613-230-7788
Téléc./Fax: 613-230-7778

Fondation Bruyère Foundation
43, rue Bruyère St.
Ottawa ON K1N 5C8
Tél./Tel.: 613-562-6319
Téléc./Fax: 613-562-6023

Affilié à / Affiliated with

uOttawa

December 17, 2009

Dr. Linda Garcia
Professor and Chair
Honours Bachelor in Health Sciences
University of Ottawa

RE: **Dementia Services and Health Outcomes during Transitions**
(Bruyère Continuing Care REB Project [redacted]

Final Approval

Dear Dr. Garcia,

Thank you for your response to our conditional approval (letter dated October 21, 2009) which we received December 17, 2009. The OHREB extension of approval date and their approval of the French tools have been duly noted. The application has now satisfied all ethical requirements

As such, the Bruyère Continuing Care Research Ethics Board (REB) is pleased to give ethical approval for one year (December 17, 2009 to December 17, 2010) to proceed with the above titled study.

Any complaints made by participants must be reported to the REB.

Changes to the protocol must be submitted to the REB for approval.

You are also expected to provide a written request for annual renewal or written notification of the termination of the study by the end of the approved year, as stated above.

We wish you the best of luck with this study.

Sincerely

Dr. Lisa Sweet, C. Psych.
Chair of the Research Ethics Board
Bruyère Continuing Care

c.c.: Jennifer Hesketh, Project Coordinator, EBRI