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Reporting Practices, Knowledge and Opinion of Policy Regarding Drivers with Dementia Among Arkansas Neurologists and Geriatricians

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Reporting Practices, Knowledge and Opinion of Policy Regarding Drivers with Dementia
Among Arkansas Neurologists and Geriatricians

Reporting Practices, Knowledge and Opinion of Policy Regarding Drivers with Dementia
Among Arkansas Neurologists and Geriatricians

A dissertation submitted in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy in Public Policy

by

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Abstract

Background: States have various policies regarding a physician's ability or responsibility to report at-risk drivers with dementia to the Department of Motor Vehicles (DMV). Some states have mandatory reporting policies, others have optional reporting policies and some have no policy regarding this issue. Arkansas has no reporting policy regarding drivers with dementia to the DMV. Therefore, physicians in Arkansas face the risk of liability if they report a patient against their will to the DMV in good faith. Neurologists and geriatricians are often in a position to diagnose and treat individuals with dementia. **Research Questions:** The following three research questions were developed in an effort to identify how the problem of drivers with dementia is defined among these two types of specialists in Arkansas: (1) What knowledge do Arkansas neurologists and geriatricians have of state policy regarding reporting of at-risk drivers with dementia to the DMV; (2) What are Arkansas neurologists' and geriatricians' opinions regarding various policy options for reporting of such drivers to the DMV; and (3) What are the reporting practices of Arkansas neurologists and geriatricians of drivers with dementia to the DMV? **Methods:** A survey was distributed to Arkansas neurologists and geriatricians to explore the reporting practices, knowledge and opinion of policy regarding drivers with dementia among these practitioners. **Results:** There was considerable uncertainty among respondents, regarding the process of assessing and reporting at-risk drivers with dementia in Arkansas. Support for optional reporting policy was very strong. Mandatory reporting policy was less favored by those surveyed. Respondents reported that conversations with patients and family members regarding the cessation of driving is often contentious and ongoing. **Conclusions:** Findings have implications for both policy and practice. It is recommended that the Arkansas legislature develop and adopt an optional reporting policy. There is also a need for physician education

regarding state reporting policy, as well as training in the assessment of fitness to drive for patients with dementia.

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Chapter 1: Introduction

State policies differ in how at-risk drivers with dementia are identified and tested to determine whether they are safe to drive (AMA, 2013). Some states, such as California, mandate that physicians automatically report a person with particular diagnoses (including dementia) to the Department of Motor Vehicles (DMV) (Reuben & St. George, 1996). Other states have optional (or permissive) reporting laws, in which a doctor may report a person with dementia to the DMV if they are concerned, however they are not obligated to make a report (AMA, 2013). In some states, such as Arkansas, a physician has no obligation to report a person with dementia to the DMV if they are concerned about their driving. Furthermore, making such a report could be considered a violation of patient-physician confidentiality (Bacon, Fisher, Morris, Rizzo, & Spanaki, 2007). As a result, doctors in these states are often faced with the inability to report a driver of concern without putting themselves at legal risk.

Research Questions

Doctors in Arkansas have no legally acceptable process for reporting a driver with dementia to the DMV, without putting themselves at risk for a lawsuit for violation of patient-physician confidentiality (Bacon et al., 2007). The following research questions seek to identify how the problem of drivers with dementia is defined among specialists in this state: (1) What knowledge do Arkansas neurologists and geriatricians have of state policy regarding reporting of at-risk drivers with dementia to the DMV; (2) What are Arkansas neurologists' and geriatricians' opinions regarding various policy options for reporting of such drivers to the DMV; and (3) What are the reporting practices of Arkansas neurologists and geriatricians of drivers with dementia to the DMV?

Significance of the Research

Recent trends suggest that overall, older adults are driving more frequently and more miles per year (AMA, 2009). Even though older adults often voluntarily reduce their mileage, crash rates per mile increase after age 65 (Li, Braver, & Chen, 2003). When looking at per mile crash rates, older adults are close to those found with teenage drivers (Mayhew, Simpson, & Ferguson, 2006). In addition to this, due to frailty, older adults are more likely to die in an accident than are teenage drivers (Mayhew, et al., 2006). Car accidents are the leading cause of injury related deaths among those aged 65-74 years old (AMA, 2009).

As Baby Boomers age and the elderly population grows, it will become increasingly imperative that issues surrounding Alzheimer's disease and other neurodegenerative conditions be addressed. The National Alzheimer's Association reports that "one in eight people aged 65 and older has Alzheimer's disease" (Alzheimer's Association, 2009, p. 10). Alzheimer's disease and other dementias not only negatively impact one's memory, but may also rob an individual of other cognitive abilities including attention, mental processing speed and spatial reasoning (National Institute of Neurological Disorders and Stroke, 2013). As a result of such cognitive decline, one's ability to safely drive becomes a major concern. Individuals with Alzheimer's disease have been shown to have a heightened risk for motor vehicle accidents (Dubinsky, Stein, & Lyons, 2000). Around 30% of individuals with dementia are current drivers (Carr, Duchek, Meuser, & Morris, 2006).

Another significant concern is the occurrence of individuals with dementia getting lost while driving. Television and newspapers often relay stories of people with dementia getting into accidents or becoming lost while driving. One study reviewed 207 media reports of drivers with dementia becoming lost over ten years (Hunt, Brown, & Gilman, 2010). Findings from this study concluded that of these 207 drivers, 32 were discovered dead while 116 were found alive

(although 35 of these were injured). Finally, patients with Alzheimer's disease and other types of dementia are often unaware of their driving deficits, which can lead to a refusal to stop driving despite physician or family concerns (Cottrell & Wild, 1999). These combined issues related to dementia and driving have led to widespread concerns regarding public safety.

Dementia Defined

The term "dementia" is not actually a single, identifiable disease. Instead, it is a word that represents an assortment of symptoms, caused by disorders that affect the brain (National Institute of Neurological Disorders and Stroke, 2004). The Diagnostic and Statistical Manual of Mental Disorders describes disorders in the category of "dementia" as exhibiting "multiple cognitive deficits (including memory impairment) that are due to the direct physiological effects of a general medical condition, to the persisting effects of a substance, or to multiple etiologies" (American Psychiatric Association, 2000, p. 147). The four most common types of dementia (Alzheimer's disease, vascular dementia, lewy-body dementia and frontotemporal dementia) are all neurodegenerative in nature (National Institute of Neurological Disorders and Stroke, 2004). Patients with a neurodegenerative disease will inevitably and progressively lose cognitive and/or motor function (Byrne, et al., 2011). Alzheimer's disease is the most widespread neurodegenerative disorder and the most commonly diagnosed form of dementia (Gallagher, Mhaolain, Sperling, & Lawlor, 2011). Aside from the four most common types of dementia, there are also some (less common) forms of dementia that are not neurodegenerative and may actually be reversible (Alzheimer's Association, 2013).

Statement of Problem

Older drivers may have an increased risk for being involved in accidents or driving errors. The effects of cognitive decline may increase this risk. As a result, the issue of revoking

driving privileges in older adults with cognitive impairments has become a topic of public health and policy concern. In particular, there are questions regarding what role physicians could or should play in this process and how states might regulate their role.

In states with mandated reporting laws, doctors must report a person with dementia to the DMV, following diagnosis. This leads to concerns about unnecessary breaches of patient confidentiality. A second ethical concern with such policies is that a patient's ability to drive may be prematurely revoked, leading to a loss of independence. Doctors in states with mandatory reporting laws who choose *not* to report medically at-risk drivers could potentially face charges of physician negligence should their patient get into an accident (Berger, Rosner, Kark, & Bennett, 2000).

In states with permissive reporting policies, doctors may report drivers with dementia to the DMV when concerned. This type of policy allows physicians discretion in determining the appropriate time to report a driver to the DMV. The patients' autonomy and privacy may be extended with this type of policy. If they choose to report patients with dementia to the DMV, doctors in states with permissive reporting policies have legal protection from any criminal or civil liability that may arise (AMA, 2013). They are also provided immunity from charges of negligence for failure to report.

Significance of the Research Questions

Learning how this issue is defined by specialists in Arkansas, may offer understanding as to why it has not yet reached the state governmental agenda. Insight may be gained as to how or why private problems eventually come to be viewed as public problems. In states, such as Arkansas, where there is no policy in place, the issue of physician reporting of drivers with dementia to the DMV, is still a private problem. It has not yet surfaced as an issue for

consideration by the state government. In the book *Public Policymaking*, James Anderson describes the difference between a private problem and a public problem (1994). A private problem is viewed as a condition that is perceived as being one's own responsibility, whereas a public problem involves circumstances that are viewed as deeming government action (Anderson, 1994, p. 85).

Anderson also describes public problems as “those which affect a substantial number of people and have broad influence, including consequences for persons not directly involved” (Anderson, 1994, p. 87). As outlined in previous sections of this dissertation, the issue of drivers with dementia does indeed affect a significant number of people and has potential consequences for public safety. Other states have already adopted various reporting policies, shifting the issue from what Anderson would describe as a private problem to a public one.

John Kingdon (2011) offers a model to explain why certain items reach the governmental agenda, while others do not. Kingdon states that active participants and three processes (problem recognition, policy considerations and political realities) influence governmental agenda setting (Kingdon, 2011, p.16-18). While researching this policy issue, various attempts were made to learn whether the matter of physician reporting and subsequent testing of drivers with dementia had ever reached the Arkansas legislative agenda. A thorough search of the Lexis Nexis database with the assistance of a librarian from the Little Rock, Arkansas law library turned up nothing in the history of this policy area in Arkansas. A search of the Arkansas State Legislature website of “all documents” since 1987 resulted in no findings as well. Discussions with local geriatricians, Department of Motor Vehicle staff and car insurance agencies based in Arkansas led to the conclusion that this policy issue has never been on the Arkansas legislative agenda. Therefore, it is not clear whether “problem recognition” has taken place in Arkansas.

Furthermore, we do not know the perspectives of specialists in Arkansas about various policy options. This will be useful because learning about the perspectives of state specialists will provide new knowledge regarding policy preferences.

Public policymaking is not an objective process. Stakeholders have perceptions that lead them to define a problem a certain way, and conflicting definitions may be present (Rocheffort & Cobb, 1994). The way that a problem is defined affects which solutions are considered. The topic of physician reporting of drivers with dementia to the DMV may be considered from the perspective of various social or ethical concepts, some of which conflict with each other. The problem may be perceived by community members as a public safety concern. The problem could also be perceived by caregivers and patients as a threat to autonomy or privacy. Finally, physicians may share these perceptions and also define the problem as a risk for liability. Over time, states have trended towards adoption of optional reporting policy (Aschkenasy et al., 2006). This may indicate that these conflicting definitions are somewhat reconciled through the flexibility offered in optional reporting policy. This research helps to identify how the problem of reporting drivers with dementia is defined by neurologists and geriatricians in Arkansas, which definitions are dominant, and where definitions conflict.

The answers to these research questions will provide information on how the problem of drivers with dementia is defined among neurologists and geriatricians in Arkansas. Learning how this issue is defined by these specialists, may offer insight as to why it is not yet framed as a “public problem” and why it has not yet reached the governmental agenda. New knowledge regarding policy preferences for state specialists will also be discovered. Some policy researchers assert that government officials will not consider a problem until there is a viable solution proposed (Rocheffort & Cobb, 1994). Thus the findings for this research may suggest

ways in which to build political support for policies like optional or mandatory reporting. According to Kingdon, the generation of policy proposals is an important step towards getting an issue on the governmental agenda (Kingdon, 2011).

Outline of the Following Chapters

Chapter Two describes findings from past literature. Consideration is given to various ethical principles involved in this topic, as well as resulting ethical dilemmas. Next there is a review of how dementia affects driving ability. An assessment of driving ability considers findings related to the following: 1) Patient self-assessment of their driving ability, 2) caregiver assessment of driving ability in a patient with dementia, and 3) physician assessment of driving ability. Following this, there is a review of various neuropsychological methods for testing driver safety. State level responses to the issue of drivers with dementia are considered as follows: 1) California's 3-Tier Model for identifying and testing drivers, 2) state variances in what conditions are reportable to the DMV, 3) state trends for changes in reporting policy over time and 4) the process of policy development in the state of Oregon. Various national and professional organizations have taken formal policy positions regarding the issue of physician reporting of drivers with dementia to the DMV. These include the American Academy of Neurology, the American Medical Association, the AARP, and the Alzheimer's Association. Political implications are discussed, that may result due to the differences in policy position among these organizations. Finally, there is a review of research that has considered physician knowledge of policy, opinion of policy and reporting practices.

Chapter Three describes the research design for this study. Hypotheses were drawn from the Literature Review, which led to the creation of the survey questions. A description is given for questions designed to provide demographic information on respondents. Next, questions

used to elicit responses about physician knowledge of policy, opinions towards policy and reporting practices are explained. Also in this chapter, is a description of the strategies that were used to identify and recruit participants for the survey. Methods of distribution for the surveys and collection of the data is detailed. Finally, the use of an open ended question is outlined.

Chapter Four outlines the results of the dissertation research. The results are reported as follows: 1) Demographic characteristics, 2) physician knowledge of state policy, 3) physician opinion of state policy, 4) physician reporting practices, 5) intergroup differences (regarding opinion, reporting practices and knowledge of policy) and 6) data from the open ended question is reported. Numbers and percentages are provided for demographics, knowledge, opinions and reporting practices of respondents. Intergroup differences were determined through Chi-Square statistical analyses. This data is described and displayed in tables, indicating differences between the following groups: 1) Neurologists versus geriatricians, 2) urban versus rural physicians, 3) physicians who saw more or fewer patients over the last six months, and 4) physicians who had been in practice more or fewer years. Finally, there is an analysis of responses to the open ended question. First, respondents were asked “In the last six months, have you had a patient with dementia who refused to restrict or stop driving against your advice?” Those who responded “yes” to this question were asked to give an open ended response, detailing the typical trajectory and outcome of such a situation. Categories of predominant themes and subthemes identified in these open ended responses are described with frequencies displayed in a table.

Chapter Five considers the implications of the research findings. The research questions are revisited and connected with corresponding findings regarding physician reporting practices, knowledge and opinion of policy regarding drivers with dementia. Overall numbers and

percentages of responses are provided, with consideration given to findings with relatively high frequencies. Data reflecting significant differences among various demographics are explored. Findings are compared to past research. Potential ethical dilemmas are considered and compared among states with no policy, optional and mandatory reporting policy. The strengths and limitations of the research are discussed. Finally, recommendations are made for future research, practice and policy.

Chapter 2: Literature Review

Conceptualization of the topic of drivers with dementia is often started with discussion of the ethical dilemmas that the physician must face (Jang et al., 2007; Adler & Rottunda, 2011; Brooks et al., 2011). Patients with dementia will eventually lose the ability to drive safely. Physicians who specialize in dementia are in a position to competently assess when it is time for them to stop driving. There are neuropsychological testing instruments that have been found to be most effective in identifying when a patient is at risk for having a motor vehicle accident (Ball et al., 2006; Clay et al., 2005).

National organizations that represent patients with dementia, such as the AARP and the Alzheimer's Association, have expressed concern regarding mandatory reporting policies (AARP, 2012; Alzheimer's Association, 2012). Professional associations that represent physicians, such as the American Academy of Neurology and the American Medical Association, have formally endorsed policy that allows doctors to report, while offering protections from liability (American Academy of Neurology, 2012; Berger, Rosner, Kark, & Bennett, 2000). In line with these preferences, over time, states have tended towards adoption of optional reporting policies, rather than mandated reporting policy (Aschkenasy, Drescher, & Ratzan, 2006).

Some studies have considered the three research questions of this dissertation research (Brooks et al., 2011; Cable, Reisner, Gerges, & Thirumavalavan, 2000; Drickamer & Marottoli, 1993; Jang et al., 2007; Kelly, Warke, & Steele, 1999; King, Benbow, & Barrett, 1992; Marshall & Gilbert, 1999; McLachlan, 1997; Miller et al., 1993; Redelmeier, Venkatesh, & Stanbrook, 2008; Snellgrove & Hecker, 2002; Turnipseed, Vierra, DeCarlo, & Panacek, 2008). This literature review will also consider studies that have looked at physician knowledge and opinions

of policy regarding physician reporting of drivers with dementia. In addition, there will be a review of past research that looks at physician reporting practices. There are significant gaps, however, in this literature which has therefore led to the design of this dissertation research.

Past literature regarding issues to do with drivers with dementia will be covered in the following sections of this chapter: 1) Ethical principles and dilemmas, 2) dementia and driving ability, 3) assessment of driving ability, 4) state level response, 5) policy positions of national and professional organizations, 6) physicians and policy, and 7) demographic data.

Ethical Principles and Dilemmas

Ethical principles are concepts that are commonly considered within the context of an ethical problem. Beauchamp and Childress (2001) have identified four key ethical principles to help guide professional decision making: Autonomy, nonmaleficence, beneficence and justice. *Autonomy* is the right that one has to self-determination as long as others are not harmed. *Nonmaleficence* is the duty to avoid causing unnecessary harm. *Beneficence* is the duty to offer benefit whenever possible. The principle of *justice* refers to the equal treatment of people, regardless of sex, race, ethnicity, age or socioeconomic status. These four ethical principles outline important considerations for professional responsibilities and patient rights.

There are other various principles that are often referenced in the context of ethical decision making. For the sake of this paper, we will also consider the ethical principle of *privacy*, which is the right that one has to restrict access to personal information. This last ethical principle is especially salient in the healthcare setting, where communication about medical information is restricted by the Health Insurance Portability and Accountability Act (HIPPA) of 1996 (U.S. Department of Health and Human Services, 2013).

An ethical dilemma occurs when behaviors related to two or more ethical principles come into conflict with one another. Consider a scenario in which a patient is diagnosed with dementia and the physician is unsure about the patient's ability to continue to drive safely. The patient, however, firmly believes that their ability to drive safely remains intact. While the patient has a right to privacy, justice and autonomy, the physician also has a responsibility to practice nonmaleficence and beneficence. The ethical question at hand, is whether a diagnosis should be reported when there is a potential threat to public safety?

Doctors are increasingly able to diagnose patients while they are still in the early stages of dementia. The trajectories for different types of dementias vary widely and it can be difficult to identify the exact moment when a person should stop driving. While a person in the early stages of dementia may retain driving skills, studies have shown that even those with mild dementia have often lost the ability to drive safely (Hunt et al., 1997). There is extensive research that indicates that patients with dementia will, over time, lose the ability to drive safely (Man-Son-Hing, Marshall, Molnar, & Wilson, 2007).

Driving is a key component to many older adults' autonomy. When they can no longer drive, older adults may lose the ability to independently get to the grocery store or doctor's office. Older adults often experience a decline in general health and physical performance following driver cessation (Edwards, Lunsman, Perkins, Rebok, & Roth, 2009). Other studies have indicated that depressive symptoms worsen following driver cessation and that this is often the case, despite the presence of a spouse who drives (Fonda, Wallace, & Herzog, 2001). This is notable because it suggests that there is value in the act of driving, rather than simply having direct access to transportation. It is important, therefore, that physicians carefully consider the point at which this privilege is taken away so as to avoid a premature loss of autonomy.

With consideration to the ethical principle of justice, some would say that a diagnosis alone should not result in a report to the DMV. Instead, a report should be based upon a measured loss of ability, so as to ensure that discrimination does not occur. Dementia is, however, neurodegenerative in nature and those suffering from the disease will inevitably lose the ability to drive (The Hartford, 2009). Individuals with dementia and their caregivers are often unable to objectively determine when it is time to stop driving (Wild & Cottrell, 2003). While a practitioner may not wish to cause a patient harm by violating their privacy, this must be weighed with the reality that a driver with dementia may pose a serious public safety risk. Physicians, patients and caregivers play different roles in these circumstances that often lead them to define the problem in conflicting ways. According to Rochefort and Cobb (1994) these conflicting definitions may affect which solutions each individual considers most viable. Policymakers must consider the best way to balance the principles of justice, autonomy, privacy, nonmaleficence and beneficence with consideration to individual rights versus public safety.

Dementia and Driving Ability

Dementia is a broad label for “loss of memory and other mental abilities severe enough to interfere with daily life” (Alzheimer’s Association, 2014, p. 1). There are various types of dementia. Alzheimer’s disease is the most common type of dementia, and is the cause of 60-80% of the cases of dementia (Alzheimer’s Association, 2014). Symptoms include not only difficulty with memory, but also poor judgment and disorientation which can lead to problems when driving (Alzheimer’s Association, 2014). In a review of well designed, controlled studies, patients with moderate Alzheimer’s disease were found to be at an increased risk for a crash (Dubinsky et al., 2000). Findings from Ott and Daiello (2010) indicate that driving deficiency in patients with Alzheimer’s disease is affected by changes that occur in regional cortical function.

The authors warn, however, that the pathology of Alzheimer's disease may differ from that of other types of dementia, and therefore affect driving ability differently than other forms of dementia. In a driver simulation study, patients with Alzheimer's disease were compared to a control group of similar age (Rizzo, McGehee, Dawson, & Anderson, 2001). One-third of the patients with Alzheimer's disease crashed at an intersection while trying to avoid a collision, whereas none of the control group experienced a crash during the simulation. The authors attributed the crashes to differences in visuospatial capacity, attention, ability to process visual motion cues and cognitive decline (Rizzo et al., 2001)

There has been some investigation into the driving abilities of patients with Frontotemporal dementia, which is the second only to Alzheimer's disease as the cause of primary dementia (Simone, Kaplan, Patronas, Wasserman, & Grafman, 2007). Symptoms of Frontotemporal dementia frequently involve striking changes in personality and behavior (Alzheimer's Association, 2014). In a driver simulation study, researchers found that patients with Frontotemporal dementia ran more stop signs and had more speeding violations than their control counterparts (Simone et al., 2007). Authors of this study also found that speeding and collisions in the simulator were related to agitation and aggressive behavior in patients with Frontotemporal dementia. These findings indicate that various types of dementia may lead to distinctive deficits that affect driving ability differently. Neuropsychological testing, along with neuroimaging and review of clinical history can help physicians identify which type of dementia the patient has (Jacova, Kertesz, Blair, Fisk, & Feldman, 2007).

Assessment of Driving Ability

Assessment of driving ability in patients with dementia may be done informally by a physician or through the employment of neuropsychological testing measures. The following

sections will discuss issues surrounding patient and caregiver assessment, as well as physician assessment and neuropsychological testing methods.

Patient Self-Assessment of Driving Ability

Research has shown that “normal” or healthy elderly drivers (without dementia) have reasonable insight into their own driving abilities (Wild et al., 2003). There may, however, be a tendency for individuals in the general aging population to deny problems with driving when they are faced with driving evaluation and potential loss. In one study, aging drivers (65 or older) who were referred for a driving evaluation underwent testing in a driving simulator (Freund, Colgrove, Burke, & McLeod, 2005). These individuals were presumably referred for driving evaluation due to an expressed concern about driving ability. The study showed that, regardless of the presence of cognitive impairment, these drivers rated their driving ability significantly higher than what their performance in reality showed.

Anosognosia is defined as “a loss of insight into one’s own cognitive and functional deficits” (Starkstein, Jorge, Mizrahi, Adrian, & Robinson, 2007, p. 455). Loss of insight caused by anosognosia may lead patients with dementia to overestimate their cognitive and physical abilities. In one study, researchers found that patients with dementia often rated their own performance on cognitive screening tests well above their actual abilities and results (Graham, Kunik, Doody, & Snow, 2005). The authors of this study hypothesized that this tendency to misjudge one’s own abilities could contribute to dangerous behaviors. This was later confirmed in a study that found that patients with dementia of the Alzheimer’s type were reported to take part in dangerous behaviors at a higher frequency than healthy aging individuals (Starkstein et al., 2007). In this analysis, dangerous behaviors were defined as those that had a “high risk of physical harm.” Graham et al. (2005) also hypothesized that overestimating one’s own cognitive

ability could decrease the likelihood of compliance with doctor treatment plans. Treatment plans for dementia patients often include directions to restrict or discontinue driving. It has been found that some patients with Alzheimer's disease voluntarily restrict their driving practices. Those who do not restrict their driving, however, often have an associated "deficit of awareness" (Cottrell & Wild, 1999). A second study found that drivers with dementia of the Alzheimer's type who took an on-road test, scored significantly worse than the control group of healthy elderly drivers (Wild & Cotrell, 2003). The individuals in this study with Alzheimer's disease rated their own driving abilities considerably higher than the driving assessor had rated them.

Not all dementia patients, however, suffer from anosognosia. There is considerable variance among patients with Alzheimer's disease as to how much insight they have into their own ability to drive safely (Wild et al., 2003). While some preserve insight into their abilities and deficits throughout the disease process, others may begin suffering from anosognosia at varying stages of the disease. When anosognosia is present, however, it is more often in the later stages of dementia (Harwood, Sultzer, & Wheatley, 2000). The trajectory of decline with insight, however, has not been found to be linear. One study concluded that association between anosognosia and cognitive impairment "follows a trilinear pattern with preserved insight in the middle stages of the dementia, followed by a progressive loss of insight, and finally by a plateau of severe insight impairment in the latest stages of dementia" (Zanetti et al., 1999, p. 105). These findings suggest that not all patients with dementia will exhibit anosognosia, nor can doctors necessarily predict when it will occur. Onset will vary on a case-by-case basis.

Caregiver Assessment of Driver Ability

Caregivers or family members are often involved in the decision for a patient with dementia to discontinue driving. Caregivers, however, may not have the capacity to objectively

recognize driving deficits in their loved one. Some researchers have concluded that caregivers were more accurate than the patient with Alzheimer's disease in identifying the level of ability to drive (Wild et al., 2003). However, the caregivers in this study often did not report a number of present problematic behaviors identified on the road. A later study also found that while caregivers usually reported the patient's driving ability more accurately than the patients themselves, the caregivers often rated the patient's ability above what it was in reality in the on-road assessment (Brown et al., 2005).

It may not be surprising that when a caregiver believes that their loved one should stop driving, the patient does not necessarily concur. One study found that although a caregiver may decide that their loved one should no longer be driving, there was often a significant amount of time that passed from that point, before the person with Alzheimer's disease ceased to drive (Cotrell et al., 1999). Findings of this study found that this period of time varied from one half month to four years. A second study found that caregivers were often aware of unsafe driving behaviors and made multiple unsuccessful attempts to stop the patient from driving (Adler, Rottunda, Bauer, & Kuskowski, 2000).

These studies suggest that patients with dementia may continue to drive for some time, despite the caregivers wish for the patient to stop. This indicates a need for intervention outside of the family. Adler, Rottunda, and Kuskowski (1999) found that 18% of drivers with dementia and 32% of caregivers believed that it was the physician's responsibility to determine when to stop driving. An additional finding from this study was that 46% of drivers with dementia stated that they would be reluctant to cease driving based solely on a doctor's advice, however 88% said that they would be willing to undergo a state driving exam if requested by a physician

(Adler et al., 1999). These findings highlight the importance that doctors have the ability to refer to the DMV for further referral and assessment regarding driver safety.

Physician Assessment of Driver Ability

There is some question as to whether physicians have the ability to accurately identify deficits in drivers with dementia. In one study, a neurologist specializing in dementia was able to regularly identify patients with driving deficits, when the patient and caregiver were not (Brown et al., 2005). This study, however, used only one clinician and therefore the results cannot be generalized. Another study, published the same year found that physicians trained in dementia assessment were most accurate in identifying unfit drivers when compared to practitioners without specialized training (Ott et al., 2005). These findings suggest that physicians in the field of dementia are most capable in identifying unfit drivers with dementia when compared with the actual patient, caregiver or general practitioners.

Methods of Neuropsychological Testing for Driver Safety

Extensive research has been conducted on the various testing methods used to determine driving ability in individuals with dementia. Three of these testing methods will be considered for the purpose of this paper: (1) The Repeatable Battery for the Assessment of Neuropsychological Status (RBANS), (2) Trails Making Test (TMT) A and B, and (3) the Useful Field of View (UFOV) test. The following section describes the purpose of each test and research findings supporting their use in assessing drivers with dementia.

The repeatable battery for the assessment of neuropsychological status. The Repeatable Battery for the Assessment of Neuropsychological Status (RBANS) measures: (1) immediate memory, (2) visuospatial/constructional ability, (3) language, (4) attention and (5) delayed memory in its test subjects (Lezak, Howieson, & Loring, 2004). The RBANS can

effectively detect the presence of dementia, even when not indicated by the commonly used Mini Mental State Examination (MMSE) (Randolf, Tierney, Mohr, & Chase, 1997). The RBANS may be used to distinguish between various types of neuropsychological disorders and also to indicate the level or severity of cognitive decline (Lezak et al., 2004). The RBANS is valuable in the detection of specific cognitive deficits associated with Alzheimer's disease (Duff, Clark, O'Bryant, Mold, Schiffer, & Sutker, 2008). If utilized in driver testing, the RBANS could help establish a firm diagnosis and indicate whether deficits are likely to interfere with driving ability.

Trails making test A and B. Trails Making Test (TMT) A and B are two separate tests that measure: (1) scanning and visuomotor tracking, (2) divided attention, and (3) cognitive flexibility (Lezak et al., 2004). While discussing TMT Part A and B, Lezak et al., (2004) explain that “when the number of seconds taken to complete Part A is relatively much less than that taken to complete Part B, the patient probably has difficulties in complex – double or multiple – conceptual tracking” (p. 372). Research has shown the usefulness of TMT A and B in identifying at-risk drivers. One study found that individuals who took 147 seconds or more to complete TMT B were 2.01 times more likely to be at fault in a motor vehicle accident (Ball et al., 2006). While TMT A and B have been found to be useful in identifying drivers who are likely to perform poorly in on-road testing, these tests on their own are not sufficient to determine licensing decisions (National Highway and Traffic Safety Administration [NHTSA] 2009). The TMT A and B should therefore be used in conjunction with other neuropsychological exams when testing drivers with dementia.

The useful field of view test. The Useful Field of View (UFOV) User Guide states that the test measures a subject's “speed of visual processing under increasingly complex task demands” (Useful Field of View User Guide, p. 4). The booklet also asserts that the test may be

used to help assess an individual's ability to drive. Many studies have been published on the effectiveness of the UFOV test in determining driving ability for older patients. In one review, eight different studies that reported a relationship between UFOV and driving ability were analyzed to see if this relationship was valid and constant among all eight studies (Clay et al., 2005). In this review, Clay et al., (2005) conclude that the UFOV can reliably predict driving performance and safety of older drivers. While there is a clear relationship between UFOV and driving performance, it is not always possible to use this tool to accurately predict who will have an accident (Bedard, Weaver, Darzins, & Porter, 2008). There is still a significant risk of issuing a false positive or false negative. Therefore, this screening tool might be best utilized as an indicator for the need for an on-road exam.

State Level Response

States vary in the ways that they have responded to the issue of physician reporting of drivers with dementia to the DMV. Mandatory reporting policy in California has been established for around 25 years (Cable et al., 2000), which is longer than many other states. A 3-Tier Assessment System was developed to test driver safety with individuals upon renewal of their driver's license. While this testing system was not applied specifically following a medical referral of subjects, it is still useful to consider within the context of physician reporting in a state that has mandatory reporting policy. In the *Physician's Guide to Assessing and Counseling Older Drivers*, the American Medical Association (AMA) describes each state's policy regarding doctor's ability or responsibility to report medically unfit drivers (AMA, 2009). States vary in which conditions are identified as being reportable by physicians to the DMV. There have been overarching trends in policy change over time and while there is little information regarding the

trajectory of these changes, there is significant documentation of policy change in state of Oregon.

California's 3-tier model. As described earlier, states vary on how reporting to the DMV of unfit drivers takes place. California law mandates that doctors report a diagnosis of Alzheimer's disease to the DMV. A second variance may be seen in how state DMVs examine ability to drive, once a referral from the doctor has been made or when an individual comes in for license renewal. States have struggled with creating a system that identifies individuals who can no longer drive safely while simultaneously preserving mobility independence for those who still can. California recently tested a 3-Tier Assessment System (3TAS), which was a pilot program for six driver's license offices and one driver safety office in the state. Individuals, regardless of age, entered this system upon driver's license renewal.

California's 3TAS system was developed in response to various research findings, described in the pilot test's process analysis (Schwarzenegger, Bonner, & Valverde, 2010). The summary of those findings reported that the elderly population have relatively low crash rates overall but when considered on a per mile basis, the crash rates for older drivers are relatively high. There are, however, relatively low rates of traffic citations and violations in the elderly population. Seniors make fewer and shorter drives and often alter driving behavior to avoid difficult driving environments, such as driving at night, on the highway or during rush hour. These alterations, however, require an awareness of limitations, which individuals with dementia may not have. From this research, three key points were emphasized for direction of the 3TAS system. These points were that "(1) an assessment system designed to identify driving-relevant functional limitations should apply to a broad spectrum of drivers, regardless of age, (2) that such a system must involve multiple domains of assessment, including vision, cognition, and

physical function, and (3) that such a system should incorporate a substantial educational and/or therapeutic component, so that drivers may retain the driving privilege as long as they can safely do so” (Schwarzenegger et al., 2010, p. 2). The 3-Tiered Assessment System was developed on these three key points.

When an individual entered a pilot program office to renew their driver’s license, they entered at Tier 1. The 3-Tiered Assessment System (3TAS) was designed so that an individual was first tested at Tier 1. If they passed at Tier 1 then their license was renewed. If they failed at Tier 1 then they went on to be tested at Tier 2. If they failed at Tier 2 then they went on to be tested at Tier 3. If they failed at Tier 3 then their license was revoked.

At Tier 1 the participant was required to take two vision tests and a memory recall test. Front-line staff members also visually observed the customer in an effort to identify any physical or functional limitations. If the individual was required to go on to Tier 2, then they were administered an 18-question written test, along with a Perceptual Response Test and computer-based test of visual function. If a Tier 3 assessment was necessary, then the individual underwent an on-road driving exam. Educational materials were given to the person, in accordance with what particular challenges they faced in regards to driving as an individual. For example, information might have been distributed regarding macular degeneration, with suggestions for specific ways to adapt as a driver. Individuals who had been reported by a doctor through the mandated referral system went through only the third Tier of the system. Some health conditions were treatable and therefore the individual’s ability to drive had the potential to be restored. In these instances a referral was made to an Occupational Therapist for driving rehabilitation. When a person failed Tier 3 and was required to resign their driver’s license, information on local transportation alternatives were provided to them.

When assessed alongside two comparison groups, the 3-Tier system showed no evidence of improving crash rates among drivers aged 70 and older (Camp, 2013). Subsequently, the researcher recommended against implementation of the 3-Tier system for the state of California. What is not made clear in this study, however, is what the outcome was for those subjects who were referred due to medical diagnosis by their physician. In the future, it would be useful to learn whether this system of evaluation is successful in reducing crash rates among drivers with dementia.

A separate finding from the study, indicated that the 3-Tier system led to delays of driver's license renewal, restrictions on driving privilege and reduced licensure for drivers 70 and older (Camp, 2013). The author points out that it is unclear whether this may have led to heightened safety for those individuals who were restricted or kept from licensure. Also interesting was that variation in tester administration was identified as a possible limitation to the study. This highlights the importance of training and consistency among those who administer driving exams at the DMV.

State variances in reportable conditions. States vary in the medical conditions that are mandated or allowed to be reported by physicians to the DMV. Some states such as Colorado (which has a permissive reporting policy), offer a very broad definition of conditions that are reportable. The reporting procedures for Colorado state that "Physicians are encouraged but not required to report patients who have a medical condition that may affect their ability to safely operate a motor vehicle" (AMA, 2009, p. 77). Maryland (also a permissive reporting state) allows for discretionary reporting to the DMV of individuals who have "disorders characterized by lapses of consciousness" (AMA, 2009, p. 97). In California, where reporting is mandatory, the definition of "lapse of consciousness" is explained in greater detail. The law specifies that

“this definition includes Alzheimer’s disease and those related disorders that are severe enough to be likely to impair a person’s ability to operate a motor vehicle” (AMA, 2009, p. 75).

Nevada’s policy identifies epilepsy or seizure disorders as specific medical conditions that involve a lapse of consciousness and are therefore mandated for report (AMA, 2009). It is of note that many of these policies are vague in identifying the exact medical conditions that may/should be reported by physicians to the DMV.

State trends for change in reporting policy. Over the years, there has been a trend among states to shift from having no policy to having permissive policies for doctors who wish to report medically unfit drivers to the DMV (Aschkenasy et al., 2006). In 1986, seven states had mandatory policies, 12 permissive and 32 had no policy regarding the reporting of medically impaired drivers, whereas in the year 2000, six states had mandatory reporting policies, 25 permissive and 20 had none (Aschkenasy et al., 2006). These numbers indicate that many states that formerly had no policy, have opted for permissive reporting policies over time.

In the *Physician’s Guide to Assessing and Counseling Older Drivers*, the American Medical Association (AMA) offers information on state policies regarding doctor’s ability and responsibility to report medically unfit drivers (AMA, 2009). This information was published in 2009 and provides the reader with the ability to consider additional trends that have occurred since 2000. It appears that, for the most part, states have maintained their policies over this time period. One exception, however, is Indiana, where the state revised its legislative code in 2005 to protect physicians reporting patients of concern to the DMV, as long as they did so in “good faith” (Office of Code Revision, 2010). Previous to 2005, Indiana did not have a policy regarding physician report to the DMV for medically unfit drivers.

Policy development in Oregon. In 1999 Oregon's state legislature organized the Older Driver Advisory Committee to consider the effects of aging on driving ability (Snyder & Bloom, 2004). The committee developed a list of medical conditions that physicians would be mandated to report to the Department of Motor Vehicles. This list included cognitive impairments such as dementia. The committee collaborated with physicians, specialists and the general public in making this decision. At the time, some committee members expressed concern that physicians could face liability for choosing to not report patients to the DMV. Despite these concerns, in 2001 a bill was passed that established mandatory physician reporting of patients with dementia in the state of Oregon (Snyder et al., 2004). Later that year, an 80 year old man collided head on with a car, killing a woman, her son and critically injuring her daughter. The woman's family filed a lawsuit against the elderly driver's physician, asserting that that the doctor should have reported a medical impairment to the DMV (Snyder et al., 2004). After consulting key stakeholders and reviewing other state laws, in 2003 the Oregon state legislature passed a bill revising their policy to provide immunity to physicians who choose not to report at-risk drivers (Snyder et al., 2004).

It was through this series of events that Oregon came to have a permissive physician reporting policy for drivers with dementia. In many ways, this process exemplifies why permissive reporting is less burdensome on patients, physicians and the legal system. In Oregon a doctor can delay reporting a patient with dementia to the DMV until there is a clear safety threat. In this way, a doctor only breaches patient-physician confidentiality in cases of "good faith," and in the event that they do make a report, they are immune from liability.

Policy concerns often show up on what is referred to as the "systemic" agenda before legislators become involved and the issue is brought to the governmental agenda. The systemic

agenda is less formal and involves discussion among key stakeholders (Kingdon, 2011). An issue may or may not gain any traction and rise from the systemic agenda to the governmental agenda. Kingdon (2011) identifies three processes of agenda setting: problems, policies and politics. An emergency or event may create a problem which leads to a policy gaining traction in the governmental agenda. In the case of Oregon, the accident and lawsuit developed into such a problem. Kingdon identifies policies as being a second process involved in agenda setting. The topic of optional reporting had been considered previously in Oregon, but was not originally accepted. Following the accident, this policy alternative gained viability. Finally, Kingdon describes politics as an influence in agenda setting. The topic of reporting drivers with dementia to the DMV does not have any general benefit to legislators who may want to please their constituency. In the event of an accident, however, if the issue were to gain publicity, it could become politically risky for legislators to avoid addressing the issue. Such an event could lead legislators to place the issue on the governmental agenda. In Arkansas, there has been no publicity surrounding such a crisis or event, to bring attention or publicity to the issue of drivers with dementia. There have been informal discussions among healthcare providers, regarding the difficulties that they face when working with a patient with dementia who refuses to stop driving (Gergerich, 2013). While the topic appears to have reached the systemic agenda in the state, it has not yet risen to the governmental agenda.

Interestingly, in the *Physician's Guide to Assessing and Counseling Older Drivers*, the state of Oregon is categorized as having a "mandatory" reporting policy. Oregon physicians, however, are provided with immunity from civil liability if they choose not to make a report (Oregon DMV, 2014). When states with a "mandatory" reporting policy, add physician

protection from civil liability, it in effect becomes a state with “permissive” reporting policy. This, however, is not always clear.

Currently, there is no information regarding the effectiveness of mandatory or optional reporting policies, in reducing crash rates. In a study by Snyder and Ganzini (2009), however, implementation of Oregon’s permissive policy led to a loss of driving privileges in a small number of older adults with cognitive impairment between the years 2003-2006. Further research is needed to determine whether reporting policies are effective in decreasing crash rates.

Policy Positions of National and Professional Organizations

Various interest groups have taken a formal position regarding mandatory and optional state reporting policies. Some of these interest groups represent diagnosing physicians, such as the American Academy of Neurology (AAN) and the American Medical Association (AMA). Other interest groups, such as the AARP and the Alzheimer’s Association, represent individuals who may potentially be reported by physicians for driver testing.

The American Academy of Neurology. Neurologists are doctors who specialize in disorders of the brain and nervous system. These specialists often work with patients who suffer from conditions such as dementia, movement disorders and epilepsy. The American Academy of Neurology (AAN) is an international association composed of over 25,000 neurologists and neuroscience professionals (American Academy of Neurology, 2012). The AAN appears to have been quite assertive regarding the topic of drivers with dementia. The group supports optional physician reporting of patients with dementia to the Department of Motor Vehicles. The AAN has developed advocacy toolkits, to encourage policy change in those states that do not have optional reporting policies in place (American Academy of Neurology, 2007). Perhaps the AAN has taken the lead with the issue of dementia and driving, due to the familiarity that neurologists

must have regarding driving limits for patients with epilepsy. Epileptics often regain the ability to drive safely after a period of time. Alzheimer's disease and most other types of dementia are neurodegenerative and patients will inevitably and permanently lose the ability to drive safely with time. The official position of the AAN is that they:

...support optional reporting of individuals with medical conditions that may impact one's ability to drive safely, especially in cases where public safety has already been compromised, or it is clear that the person no longer has the skills needed to drive safely...The AAN supports clarification of physician-immunity policies, to make it apparent that a physician should be granted immunity both for reporting and not reporting a patient's condition when such action is taken in good faith, when the patient is reasonably informed of his or her driving risks, and when such actions are documented by the physician. (American Academy of Neurology, 2006, pp. 6-7)

The American Medical Association. In 1997 the AMA Council on Ethical and Judicial Affairs stated that "in those situations where clear evidence of substantial driving impairment implies a strong threat to patient and public safety, and where physicians' advice to discontinue driving privileges is disregarded, physicians have an ethical duty to notify the DMV of the medical conditions which would impair safe driving" (Berger et al., 2000, p. 670). The Council went on to emphasize that this is the physician's duty, even when mandated laws are not in place. After this statement was made, many AMA members objected, citing the liability that they could potentially face for breaching patient confidentiality in states that had no protections. In 1998 the Council reconsidered the issue and reported that physicians and states should work together to "create statutes that promote the best interests of patients and the community, and safeguard physicians from liability in good faith reporting" (Berger et al., 2000, p. 671). It appears that the AMA supports mandatory reporting policies with protections for breaching confidentiality, yet they emphasize that the choice between optional or mandatory reporting should be left up to state medical societies.

The AARP. The AARP is a non-profit organization with over 37 million members that serves the interests of people age 50 and older (AARP, 2012). Studies have shown that these drivers have the lowest crash rate of all age groups (AARP, 2012). This is in part because many older adults limit their own driving behaviors. The AARP states that driver safety is not tied to age, but is instead related to function (such as cognitive, visual or physical impairment). The AARP cautions policymakers to avoid unnecessary restrictions on elderly drivers. They state that driver's license renewal should be done in person and at regular intervals without increased frequency of testing based solely on age. Instead, the AARP emphasizes that driver testing be done on the basis of function. The AARP encourages physicians to "voluntarily report patients who pose a threat to their own safety or the public yet ignore a physician's advice to stop driving" (AARP, 2011, p. 5). The AARP also supports physician immunity from liability when they report at-risk drivers to the DMV in good faith. While the AARP warns against the potential for ageism, the organization supports optional physician reporting of individuals with dementia to the DMV. They do not, however, take an official stance on mandatory physician reporting.

The Alzheimer's Association. The Alzheimer's Association is a global nonprofit that serves those affected by Alzheimer's disease and other types of dementia through education, advocacy and research (Alzheimer's Association, 2012). The Alzheimer's Association has formally stated that it does not support mandatory reporting of drivers with dementia "because it can have unintended consequences, including an unwillingness for individuals to seek early diagnosis; risk to the relationship between the physician and patient; and even an unwillingness of physicians to appropriately diagnose Alzheimer's disease" (Alzheimer's Association, 2011, p. 2). The Alzheimer's Association recommends that doctors "order" a patient to stop driving

when they can no longer do so safely. However, there is no mention of optional reporting to the DMV when this time comes. Instead, they suggest that doctors communicate with their patient in the early stages of the disease and convey that they can expect to eventually lose the ability to drive safely. They also suggest that a patient's family disable or remove a vehicle, if they continue to drive against the doctor's advice. Based upon statements made by the Alzheimer's Association National Board of Directors, it is not clear whether they would support optional physician reporting of drivers with dementia to the DMV. They do, however, clearly oppose mandated reporting policies.

The AMA, AAN and AARP could play a significant role in getting the issue of physician reporting on the state policy agenda. These three groups would likely find common interest in optional reporting policy. It is significant, however, that the Alzheimer's Association does not offer direct support for optional reporting policy. This could indicate a potential conflict between interest groups. The Alzheimer's Association represents both patients with dementia and their caregivers. In states where doctors may not report patients with dementia to the DMV, the burden often falls on the caregiver to convince the patient to discontinue driving. This burden to the caregiver could provide an incentive for the Alzheimer's Association to consider support for optional reporting policy in the future.

Physicians and Policy

In order for a policy to be effective, key players must be aware of their role in its implementation. Physicians must know whether they are required to report medically unfit drivers, what the process of reporting is and to whom they are expected to report. In an effort to determine the best policy option, it is important to seek the opinions of those directly affected. Finally, physician practices may vary, depending on state policy, their knowledge of policy

and/or their opinion of reporting policy. The following sections will discuss physician knowledge and opinion of reporting policy, as well as their reporting practices.

Physician Knowledge of Policy

Research has shown that physician knowledge of state or regional policies and processes for reporting is often inadequate (Brooks et al., 2011; Cable et al., 2000; Kelly et al., 1999; Snellgrove et al., 2002). South Carolina is a state that does not require physicians to report medically at-risk drivers. The state also does not offer protection from liability for those who do. In a recent pilot study, physicians in a large South Carolina hospital system were surveyed in an effort to determine their knowledge of state policy regarding report of medically at-risk drivers (Brooks et al., 2011). Around 60% responded that they were unsure of reporting policies and 14% of the time participants reported an incorrect understanding of state policy (Brooks et al., 2011).

The response rates for the sample in this pilot survey were quite small (15.6%). It would be particularly useful to obtain a broad state sample in an effort to determine knowledge of policy. Responses in a single hospital system may not be reflective of what may be found at the state level. Because policies are state-wide, broadening the sample to include practitioners throughout the state would be useful. Additionally, it would be interesting to gather state-wide data on physician knowledge in a state that does not have a reporting policy, and subsequently compare them to those in a state that does not have mandatory or a state with permissive policies in place. From this, it could be determined whether there are differences in knowledge among practitioners in states with varying policies.

In the United Kingdom (UK), patients with certain diagnoses that affect driving ability are required to notify the Driver and Vehicle Licensing Agency (DVLA) as well as their auto

insurance company (Alzheimer's Society, 2013). It is a physician's responsibility to alert the patient of their duty to notify the DVLA and insurance company (King et al., 1992). In the event that a patient disregards their physician's advice to report themselves, the doctor is then expected to alert the DVLA of the infraction. The law provides that this physician action is *not* considered a breach of patient confidentiality. King et al. (1992) surveyed a random sample of doctors in the Mersey region of the UK. They found that 41% of hospital doctors said that they would take no action if a patient refused to inform the DVLA, because to do so would be "a breach of confidentiality" (King et al., 1992). This finding may indicate a lack of policy understanding on the part of the UK physicians. However, it may instead indicate an unwillingness of physicians to report such drivers, due to valuing patient confidentiality over the legal responsibility to report.

A later study in the UK surveyed 50 physicians from a geriatric day hospital, acute elderly care and rehabilitation wards in the region (Kelly et al., 1999). Only 26 of the survey respondents were aware that patients should report to the DVLA and just one doctor knew that a report should be made to both the DVLA and the insurance company (Kelly et al., 1999). Although doctors in the UK are provided the legal means to make a report to licensing authorities, these findings indicate that physicians are often unaware of their ability to do so.

In Australia, General Practitioners are required to report medically unfit drivers to the Licensing Authority. Snellgrove and Hecker (2002) surveyed practicing General Practitioners in South Australia to determine their knowledge of this responsibility in regards to patients specifically with dementia. Only 12% of respondents answered incorrectly when asked if they were legally responsible for reporting unfit drivers with dementia to the Licensing Authority. A large majority (93%) correctly reported that if a patient with dementia disregarded their advice to

stop driving, they could breach confidentiality to report the person to the Licensing Authority (Snellgrove et al., 2002). It is interesting that such high levels of correct policy recognition are found in a region that has clear mandatory reporting guidelines.

In a nationwide sample of geriatricians in the U.S., researchers found that 31.8% of geriatricians were unaware of state policy guidelines regarding how to report at-risk drivers with dementia (Cable et al., 2000). However, when responses from California geriatricians were considered separately, it was found that only 9.8% of these geriatricians were unaware of reporting procedures. The authors point out that California has firmly established mandatory reporting policies, which at the time had been present for over ten years (Cable et al., 2000). The long standing nature of policy in this state may provide physicians with the needed clarity to practice accordingly.

Physician Opinion of Policy

Some studies have indicated that doctors believe a conflict of interest occurs when they must report unsafe drivers to licensing authorities, and that this results in damage to the physician-patient relationship (Jang et al., 2007; Marshall & Gilbert, 1999). Reporting policies vary among Canadian provinces. In Saskatchewan, Canada it is mandatory that physicians report medically unfit drivers to licensing authorities. Of Saskatchewan physicians deemed likely to assess medical fitness to drive, almost 60% of respondents claimed that the physician patient relationship was negatively affected by reporting (Marshall et al., 1999).

A second study, that surveyed family physicians in various provinces of Canada, also found that a majority of respondents felt that reporting unsafe drivers resulted in a conflict of interest and had negative consequences on the physician-patient relationship (Jang et al., 2007).

Despite this finding, most respondents in this study (72%) expressed the opinion that doctors should be mandated to report unsafe drivers to licensing authorities.

One Canadian survey compared opinions towards mandated reporting for neurologists practicing in regions that had permissive reporting policies versus those practicing in regions that had mandated reporting policies (McLachlan, 1997). Those neurologists practicing in regions with mandated reporting were more likely to support mandated reporting policy. In Australia, where reporting is mandated, 83% of general practitioners surveyed, supported mandatory reporting of at-risk drivers with dementia to licensing authorities (Snellgrove et al., 2002). In South Carolina, however, where neither mandatory nor permissive policy is in place, only 48% of physicians supported mandated reporting of at-risk drivers (Brooks et al., 2011).

Physician Reporting Practices

Physician reporting practices of medically at-risk drivers have been shown to vary depending on a number of different factors including the region's reporting policy, the physician's specialty, whether the area is rural or urban and the disease that the patient suffers from. Most of the studies considered in this literature review, measure physician reporting practices through self-report (Drickamer et al., 1993; Marshall et al., 1999; McLachlan, 1997; Snellgrove et al., 2002; Turnipseed et al., 2008). One group of researchers, however, studied patients admitted to a Canadian trauma center due to life threatening motor vehicle accidents in which they were the driver (Redelmeier, Venkatesh, & Stanbrook, 2008). The researchers considered whether the patients had reportable conditions that were overlooked during previous physician visits. The study found that, of the patients that had a reportable condition, 85% had been seen by a physician in the year previous to the crash but only 3% had been reported to the Ministry of Transportation (as is mandated by law in Ontario). This study is of particular interest

because it does not rely on anticipated actions or self-report. It may, therefore, offer a more accurate measure of reporting practices. It is also interesting that so few eligible patients were reported in a region whose laws mandate physician reporting.

Some studies seem to indicate that report rates are quite low, regardless of whether the region has mandated or permissive reporting policies (Mclachlan et al., 1997; Jang et al., 2007). Mclachlan's study found that Canadian neurologists practicing in regions with mandatory reporting laws were no more likely to report patients with dementia, stroke or other neurological conditions to the licensing authorities, than neurologists practicing in regions with permissive reporting laws (Mclachlan, 1997). Jang et al. also concluded that "the only significant difference between physicians from provinces with mandatory versus discretionary reporting was that physicians from mandatory reporting provinces are more likely to report an unsafe driver who agrees to stop driving" (Jang et al., 2007, p. 535). These findings suggest that physician reporting practices are not necessarily associated with the region's reporting policy.

Certain physician characteristics might play a part in reporting practices as well. Physicians who responded to a survey by Jang et al. (2007) were asked to report the percentage of patients that they served who were older than age 65. Findings indicated that physicians serving a higher percentage of older adults were more likely to report medically at-risk drivers. This would suggest that geriatric specialists might be more likely to report unfit drivers to the licensing authorities.

When comparing studies involving various practitioner specialties, it appears that geriatricians may be more likely to report patients with dementia to the DMV (Cable et al., 2000; Drickamer et al., 1993; Miller et al., 1993; Turnipseed et al., 2008). In their nationwide survey, Miller et al. found that more than 60% of geriatricians had never referred a patient to licensing

authorities (Miller et al., 1993). In a later nationwide survey of geriatricians, Cable et al. found that a large majority of geriatricians (92%) indicated that they would “contact the appropriate authority to recommend that driving privileges of their patients with dementia be revoked if they believed that the patient was a danger to others on the road” (Cable et al., 2000, p. 15). In a survey of California emergency physicians (where reporting is mandated), when asked how often they would report patients described as having symptoms of dementia, 83% responded “never” (Turnipseed et al., 2008). In Connecticut, where there are permissive reporting laws, only 14% of general practitioners and specialists had reported patients to the DMV (Drickamer et al., 1993).

Some studies suggest that rural physicians may be less likely to report at-risk patients to licensing authorities. One study found that general practitioners in Australia “tend to inform the Licensing Authority or the police in rural regions as a last resort” (Snellgrove & Hecker, 2002, p. 211). Marshall and Gilbert (1999) found that doctors practicing in rural regions claimed that the availability of restricted licensing made them more likely to report patients to licensing authorities. Restricted licenses would allow for patients to drive under limited circumstances (for example during the day time or good weather conditions only), rather than confiscating their driver’s license altogether (Marshall et al., 1999).

Finally, the type of disease that a patient suffers from, might lead to varying physician reporting practices. In McLachlan’s study of Canadian neurologists, he found that patients suffering from seizures were reported “almost always” or “most of the time” by half of respondents, while dementia was reported “almost always” or “most of the time” by only 26% of respondents (McLachlan, 1997). Similarly, Drickamer and Marottoli (1993) found that different health conditions were more likely to encourage physician discussion of driving with their

patient. The most commonly cited maladies listed as leading to discussions about driving were seizures (52%), visual difficulty (51%), loss of consciousness (46%) and cognitive impairment (38%) (Drickamer et al., 1993).

Demographic Data

The majority of the studies described in this review, relied on basic descriptive data – reporting, for example, the percentages of physicians that held one opinion or practice over another. Some of the studies, however, made an effort to determine differences of opinion among physicians with various demographic characteristics (Adler & Rottunda, 2011; Snellgrove & Hecker, 2002). As was mentioned earlier, variances in opinion of reporting policy was found between physicians practicing in urban and rural regions (Snellgrove et al., 2002).

Adler and Rottunda (2011) surveyed 239 physicians who reported working with patients suffering from dementia in North Carolina and South Carolina. Family practitioners, geriatricians, internists neurologists, ophthalmologists, psychiatrists, physical medicine and rehabilitation physicians licensed in both states, were chosen from state licensure registries at random to be included in the study. Various demographic features were considered (age, gender, race, specialty, years in practice and number of patients seen in the last six months). This was done in an effort to learn whether these characteristics were associated with a heightened likelihood of addressing driving issues with their patients with dementia. Physicians who perceived their role as physician as “very important” regarding driving decisions and discussions, were more likely to address driving issues with their patients (Adler et al., 2011). Those with more years of medical practice were also more likely to address driving issues. The study did not show that physicians were any more likely to address driving with their patients, based on their practice specialty. However, participants for this study had been chosen, based on

the indication that they worked with older adults with dementia. Knowledge of state policy was somewhat associated with likelihood of reporting patients to the DMV. While this is an interesting finding, the authors did not distinguish between findings in North Carolina versus South Carolina. This would have been useful, as South Carolina has no policy regarding physician report and North Carolina has an optional reporting policy.

Conclusions from Literature Review

Each type of state reporting policy (mandated, permissive or optional) comes with its own set of ethical considerations. There is concern for privacy, regarding disclosure of the patients' diagnosis to the DMV. Doctors are often wary of damaging the physician-patient relationship when considering whether to report (Jang et al., 2007). Health issues and depressive symptoms may worsen following driver cessation, therefore autonomy should be maintained for as long as reasonably possible (Edwards et al., 2009; Fonda et al., 2001). Autonomy may be maintained through use of driving restrictions, rather than outright cessation.

Drivers with Alzheimer's disease are likely to suffer from issues relating to visuospatial capacity, attention and cognitive decline (Rizzo et al., 2001), whereas drivers with Frontotemporal dementia often exhibit agitation and aggression when driving (Simone et al., 2007). With varying trajectories for different types of dementia, it is important that driving ability be accurately determined through use of appropriate measurement tools and on-road testing. The RBANS can detect dementia, distinguish between various types of dementia, and indicate the severity of decline. TMT A and B can be useful in identifying drivers who may have difficulty with on-road examinations but should not be used to determine licensing decisions. The UFOV can reliably predict driving performance but there are still concerns that a

false positive or negative could lead to premature loss of autonomy. On-road examinations offer the best indicator of driver safety.

Healthy older adults may have a tendency to rate their driving ability significantly higher than their actual performance (Freund, 2005). Drivers with Alzheimer's disease have also been shown to over-rate their own driving ability (Wild et al., 2003). While caregivers have been shown to report driving ability more accurately than the patient themselves, they too are likely to over-rate driving ability for a patient with dementia (Brown et al., 2005). Even when a caregiver believes that the patient should cease driving, there is often a lengthy period of time that passes before the patient actually stops (Cotrell et al., 1999). Physicians who practice in the field of dementia are the most appropriate entity to identify unfit drivers with dementia.

State policies vary widely in regards to physician ability or responsibility to report medically at risk drivers to the DMV. Many policies are vague in identifying the exact medical conditions that are reportable. Over time, states have trended away from having no policy, towards implementation of permissive policies for physicians to report patients to the DMV. What is unclear though, is whether some states have kept the "mandatory" reporting policy label, and simply added language that provides immunity from civil liability, should there be consequences from the physician's decision to either make or not make a report. This, in effect, makes the policy "permissive" or "optional."

Various national organizations have offered public policy positions regarding the issue of physician reporting of drivers with dementia. The American Academy of Neurology supports optional reporting with protections from civil liability for both reporting and not reporting when done so in good faith. The AMA supports mandatory reporting with protections from liability for breach of confidentiality. The AARP holds the view that physicians should have the ability

to report patients of concern, while having protection from liability for reporting in good faith. While the Alzheimer's Association has renounced mandatory reporting, it has not offered a formal position on optional reporting. The AARP and Alzheimer's Association's positions are grounded in avoiding unnecessary reporting or restrictions.

Following a review of the literature, it can be concluded that physician knowledge of reporting policies is often insufficient. Interestingly, findings might suggest that physician knowledge is superior in regions with mandatory reporting laws (Cable et al., 2000), but more research is needed to establish this pattern. It was also found that mandated reporting policy is more popular among physicians in regions that have adopted such policies (Mclachlan, 1997). Finally, physician reporting of medically at-risk drivers is surprisingly low (Drickamer et al., 1993; Turnipseed et al., 2008). It is also of note that reporting rates are similar between regions with mandated and permissive reporting policies (Jang et al., 2007; Mclachlan, 1997).

Many of the studies in this review surveyed general practitioners or various specialists. My dissertation research will focus solely on neurologists and geriatricians. One of the goals of using geriatricians and neurologists for this survey is to attempt to include those practitioners who regularly diagnose patients with dementia. The population chosen must be fairly inclusive if it is going to consist of practitioners that are regularly invested in diagnosis. The population chosen, however, will need to be exclusive if it is to be small enough to reach an optimal number of members for participation. When using small populations, greater proportions of the population must be completed to reduce the margin of error (Dillman, Smyth, & Christian, 2009). Risk for this type of error will be avoided through an effort to reach all practicing geriatricians and neurologists within the state of Arkansas. When possible, it is best to survey an entire population rather than a sample or fraction of that population.

One study surveyed geriatric, family and internal medicine residents and physicians within Texas medical programs, Dallas County and the Health Texas Provider Network, in an effort to identify level of comfort among providers, in the identification and management of dementia (Baloch et al., 2010). Findings from this study indicated that geriatricians more often screened for dementia and had higher levels of comfort in diagnosing patients with dementia.

A second multinational study, indicated that of those diagnosed with Alzheimer's disease, 52% received their diagnosis from a neurologist, 18% from a geriatrician, 13% from general practitioners, 8% from a psychiatrist and 4% from a psycho-geriatrician (Wilkinson et al., 2004). In this study, a neurologist was most likely to make a diagnosis in France, Spain and Italy, whereas a geriatrician or general practitioner was most likely to make the diagnosis in Australia, and a psychiatrist in the UK. Findings of this study also indicated that although 74% of patients first went to their general practitioner with symptoms of Alzheimer's disease, 70% of patients were not diagnosed by the physician with whom they first discussed their symptoms (Wilkinson et al., 2004).

To my knowledge, there has been no similar study conducted in the United States to identify the type of practitioner that most often diagnoses dementia. What is known, however, is that Arkansas has one of the highest numbers of geriatricians per capita in the United States (University of Arkansas for Medical Sciences, 2013). According to these studies an appropriate population sample would include both neurologists and geriatricians. Inclusion of general practitioners and psychiatrists could offer additional insight as well but would make the size of the target population larger and therefore more difficult to reach.

Dementia is a relatively common neurological disease that afflicts one in eight people over the age of 65 (Alzheimer's Association, 2009). While there are other disorders that affect

driving ability, my dissertation research focuses on dementia alone, due to its prevalence. It would be useful for future studies to consider how other specialists regard reporting policy, of patients that suffer from a particular malady that they commonly treat in their practice. It would also be useful for future studies to utilize more direct measures of physician reporting, rather than relying on self-report. Physicians might not respond honestly to questions if their answers reveal practices that are not in accordance with the law. It is interesting to note that in this review of literature, the knowledge and opinions of caregivers and patients regarding reporting policy were absent. While these reporting policies have legal implications for physicians, caregivers and patients face more personal consequences. This could be a significant line of investigation to consider as well.

Samples for some of the studies in this review were limited to a single facility or region (Brooks et al., 2011; Redelmeier et al., 2008). When looking at opinions within a single facility, reporting practices of practitioners within that facility are likely to be similar due to overarching agency policies or practices. In this dissertation research, however, there was a poll of all licensed neurologists and geriatricians for the entire State of Arkansas. The studies described in this review of literature often spanned regions that had different types of reporting policies. By surveying only the State of Arkansas, my research reflects the knowledge, opinions and reporting practices of neurologists and geriatricians in a single state that has neither a mandatory nor a permissive reporting policy. It would be useful for future studies to offer parallel data for states with mandatory or permissive reporting policies. This might indicate a difference in knowledge, opinions or reporting practices among states with different reporting policies. Another useful study would be to measure knowledge, opinions and reporting practices in Arkansas before and after a new policy is implemented (permissive or mandatory in this case). Previous studies have

suggested that a more clear policy in the state of Arkansas might lead to a shift in opinions and increased knowledge.

Chapter 3: Research Design

The following chapter outlines the research design for my dissertation. The first section details the hypotheses that were drawn from the literature review. These hypotheses led to the development of research questions which guided the choice of survey questions. Permission was granted, by Dr. Geri Adler, to use parts of the questionnaire from her previous study of physician attitudes, knowledge, and practice regarding drivers with dementia (Adler & Rottunda, 2011). Strategies for recruitment of participants are outlined, as well as methods for distribution of the surveys. Finally, there is an explanation of the process used to organize and analyze data from the open ended question in the survey.

Hypotheses

The goal of this research was to answer the following research questions: (1) What knowledge do Arkansas neurologists and geriatricians have of state policy regarding reporting of at-risk drivers with dementia to the DMV; (2) What are Arkansas neurologist and geriatricians' opinions regarding various policy options for reporting of such drivers to the DMV; and (3) What are the reporting practices of Arkansas neurologists and geriatricians of drivers with dementia to the DMV? In addition to this, a number of hypotheses were drawn from the literature review, regarding potential variances among respondents with different demographics.

Past research has indicated that physicians who serve a greater number of patients aged 65 and older, are more likely to report unsafe drivers (Jang et al., 2007). It was therefore hypothesized that 1) those serving more patients aged 65 and older would be more likely to report patients. It was further estimated that 2) those serving more patients aged 65 and older would be more likely to support mandatory reporting policy.

When comparing past studies, there are variances in reporting practices among different types of specialists (Cable et al., 2000; Drickamer et al., 1993; Miller et al., 1993; Turnipseed et al., 2008). Geriatricians generally act as primary care physicians for patients aged 65 and older (American Geriatric Society, 2014). Neurologists act as specialists and serve a wide range of age groups, affected by disorders of the brain, spinal cord or nerves. Jang et al. (2007) compared one survey of geriatricians with a separate survey of neurologists. This comparison showed that while 92% of the geriatricians said they would report unsafe drivers with dementia, only 44% of neurologists were in favor of mandatory reporting (Jang et al., 2007). It was therefore hypothesized that 3) geriatricians would be more likely to report patients, and that 4) geriatricians would be more likely to support mandatory reporting.

Past research has shown that rural physicians may be more hesitant to report medically unfit drivers (Marshall et al., 1999). It was therefore hypothesized that 5) those practicing in rural regions would be less likely to report. It was further estimated that 6) those practicing in rural regions would be less likely to support mandatory reporting policy.

Survey Questions

Questions in this survey were aimed at answering one of the three research questions, in addition to gathering demographic information from respondents. As mentioned earlier, the first question on the survey eliminated respondents who did not work with older adults with dementia. Demographic information gathered included the following: 1) Number of patients with dementia that the doctor has seen in the last six months, 2) region that the doctor practices in (rural or urban), and 3) number of years practicing in their current specialization. Finally, before mailing the survey, the researcher pre-identified the respondent as being either a

geriatrician or neurologist through use of the Survey Code in the top right corner of the first page of the survey.

Knowledge of state policy regarding reporting at-risk drivers with dementia was determined by asking the participant to rate three statements as Definitely True, Probably True, Probably False, or Definitely False. Opinion towards policy options were determined by asking the participant to rate their level of agreement with nine statements as Strongly Agree, Somewhat Agree, Somewhat Disagree, and Strongly Disagree.

Reporting practices were identified by first determining whether the doctor was having conversations about driving with their patients who have dementia and/or with family members. The participant was asked who typically initiates this conversation. The doctor was asked about their likelihood of asking a patient with dementia (and/or the family members) about driving. The respondent was asked to rank their likelihood of addressing the topic of driving under a list of six different circumstances. Level of likelihood was ranked as Very Likely, Somewhat Likely, Somewhat Unlikely or Very Unlikely. In the future this question should be reworded, as the phrase “likelihood of addressing the topic of driving” is vague, leaving it unclear as to what action that may entail. Finally, participants were asked whether they referred a patient with dementia for a driving assessment in the last six months. If the response to this question was yes, then they were asked how many referrals were made, and where they typically made these referrals. The survey utilized a single open ended question in an effort to learn about reporting practices when patients with dementia refuse to restrict or stop driving against doctor advice.

Strategy for Identifying State Geriatricians & Recruitment for Participation

Arkansas’ geriatricians and neurologists are both relatively small and accessible groups to survey. The Arkansas State Medical Board provides a regularly updated list of physicians,

categorized by board certification or specialization, along with contact information. This directory is available online (Arkansas State Medical Board, 2013). According to the website, the list was last updated October, 2013 to include those most recently issued their license.

For my dissertation research, geriatricians were defined as Medical Doctors (MDs) or Doctors of Osteopathy (DOs) who were listed in the Arkansas State Medical Board Directory as specializing in geriatric medicine, geriatric psychiatry or geriatrics. Neurologists were defined as MDs or DOs who were listed in the Arkansas State Medical Board Directory as specializing in neurology. In an effort to exclude neurologists that do not regularly diagnose patients with dementia, two steps were taken. First, the list of neurologists was cross checked with those who specialize specifically with children. Child specialists were taken off of the contact list. Second, the survey that the participants received began with the question, “Do you work with older adults (50+) with dementia in your practice?” Those who responded “no” were asked to discontinue the survey and return it blank.

Dillman et al. (2009) outlines a useful delivery sequence for distributing a mail based survey. This involves 1) a standard prenotice letter, 2) an invitation, the survey and return envelope four days after the letter, 3) a thank you/reminder post card seven days after the survey, 4) and finally a replacement survey and return envelope with a cover letter that includes the URL for an online survey option around two weeks after the post card. The authors claim that this method can yield response rates of 50-70%. Another suggestion offered is to personalize contacts with the participants when possible (Dillman et al., 2009). Each survey that was mailed for this dissertation research, used the practitioner’s full name and title.

There is always a risk for nonresponse error, in which the views of those who do not respond to the survey differ significantly from those who do respond. In an effort to minimize

nonresponse error, the researcher made a number of clinic site visits in an effort to notify potential participants and increase response rate, previous to sending the standard prenotice letter.

Distribution of Surveys and Collection of Data

Mailing labels were made for each physician, with the names and address supplied by the Arkansas State Medical Board database. An Excel file was created with the name of each physician. In this file, each physician was given a numeric code that was unique to them. This code started either with an “N” to indicate that they were a neurologist or a “G” to signal that they were a geriatrician. This code was also written in the top corner of the survey that was mailed to their name and location. When a survey was completed and returned, the researcher entered data under the unique code for that physician and also excluded that individual from the second mail out of surveys.

On Friday, March 28, 2014 the pre-notification letter was mailed to 97 neurologists and 99 geriatricians (for a total of 196 physicians) throughout the state of Arkansas. The pre-notification letter alerted the physicians that they would receive the Driving and Dementia Survey in the mail the next week. The pre-notification letter also stated the purpose of the research, as well as the name and contact information of the researcher.

The following Tuesday, April 1st, the first round of surveys was sent. The survey was accompanied by a cover letter and self-addressed, stamped envelope. Mailed items for seven physicians were returned as undeliverable. An attempt was made to find a second address for these. Of these seven, one physician eventually responded with a completed survey. As completed surveys were returned, responses were coded and entered into the Excel Word file.

One week after the surveys were sent, reminder/thank you post cards were mailed. These postcards made reference to the survey that they should have received the previous week.

Physicians were offered thanks for completing the survey (if they had already returned it) and if they had not returned the survey, they were encouraged to do so. Contact information of the researcher was provided in the event that the survey had been misplaced.

On April 22nd the second and final round of surveys were sent out. These surveys were accompanied with a cover letter and self-addressed stamped envelope. This cover letter also offered the option of taking the survey online. Of the 196 surveys mailed out, 62 completed surveys were returned. In addition to these, 19 came back with the indication that the physician did not work with older adults (50+) with dementia in their practice, which therefore disqualified them from being eligible to take the survey. Of those deemed ineligible, some revealed that they were retired or currently working in a specialization other than geriatrics or neurology. By subtracting those who were ineligible from the original number of surveys sent, the response rate was 62/177 or 35%. None of the participants completed a survey online.

Responses from the surveys were entered into an Excel Word file. Data from the Excel Word file was uploaded into SPSS for analysis. Percentage totals of returned questionnaires revealed the overall demographic characteristics of respondents, their level of knowledge of state policy regarding report of at-risk drivers with dementia, overall opinions towards policy options and reporting practices among Arkansas neurologists and geriatricians.

Chi-Square statistical analyses through use of SPSS was used to determine whether there were significant differences in opinion, practice and knowledge among various demographic characteristics. For all analyses, significance was set at a p value of .05 (unless otherwise

indicated in discussion). Lambda was utilized to report the strength of the relationship where significant differences existed.

Methods Used with the Open Ended Response

The single open ended survey question asks, “In the last six months, have you had a patient with dementia who refused to restrict or stop driving against your advice? If yes, what is the typical trajectory and outcome of such a situation?” The second portion of this question considers what physicians do when a patient refuses to restrict or stop driving against advice. This allows us insight into whether the physicians report without patient consent, or if they take a different course of action. It also allows for a description of the trajectory and outcomes for such situations. The use of an open ended question in this case, offer greater depth.

Responses to the open ended question were analyzed in seven phases as suggested by Marshall and Rossman (2011). These included 1) organization of data, 2) immersion in the data, 3) generation of categories and themes, 4) coding data, 5) offering interpretations through analytic memos, 6) consideration of alternative understandings and 7) written report of findings.

There were 36 open ended responses provided by respondents. First, the responses were typed into a Word document for review. Minor revisions were made, to clarify shorthand that is commonly used in the healthcare setting. For example, “pt” was rewritten as “patient.” The researcher read and reread the statements in an effort to become cognizant of the various responses. Throughout this process, observational notes were taken.

The open ended question requested a two pronged response: 1) Regarding the typical trajectory of a situation wherein a patient with dementia refused to restrict or stop driving against advice, and 2) the typical outcome of such a situation. In the future, for clarity, the question of trajectory and outcome should be asked separately. Distinction between the two were not always

clear in the responses, so additional time had to be spent classifying parts of each response as either trajectory or outcome.

Responses were first categorized according to which of these two questions they were answering. Following prolonged engagement with the data, responses for these categories were further sorted into themes. These themes were identified by noting patterns among responses. Themes uncovered regarding trajectory included: 1) Communication with family, and 2) communication with the patient. Subthemes were created in an effort to indicate the tone of the reported communication. Responses regarding outcome were further categorized into the following themes: 1) DMV/authority involvement, 2) removal or disabling of the car, 3) driving error or accident, 4) unknown or 5) institutionalization.

Chapter 4: Results

Data Analysis

Demographic Characteristics

Table 4.1 reports the number and percentage for demographic characteristics of survey participants. There were slightly more geriatricians (56%) than neurologists (44%) who responded to the survey. A large fraction of physicians (45%) had been practicing in their current specialization for more than 20 years, with 15% in practice for 16-20 years, 19% for 11-15 years, 6% 6-10 years and 15% in practice for 5 years or less. Most respondents held their practice in an urban region (77%) versus a rural area (23%).

Table 4.1 Demographic Characteristics of Survey Participants

	Raw Number*	Percent*
Number of patients with dementia seen in last 6 months		
< 50	16	33
50-99	11	23
100-149	6	13
150-199	2	4
200+	13	27
Specialty		
Geriatrician	35	56
Neurologist	27	44
Location of practice		
Rural	14	23
Urban	47	77
Years in practice for current specialization		
0-5	9	15
6-10	4	6
11-15	12	19
16-20	9	15
20 +	28	45

* (N = 62) Sample size varies because some respondents did not answer all of the questions.

Physician Knowledge of State Policy

Table 4.2 reports the numbers and percentages for responses to questions that measure knowledge of state policy. In the state of Arkansas, it is not mandatory for physicians to report drivers with dementia to the DMV. When asked whether it was mandatory in the state, 48% responded that mandatory reporting is “definitely false,” 34% said that it was “probably false,”

16% said “probably true,” and 2% “definitely true.” This indicates that around half (48%) of respondents answered correctly with confidence, while the other half (50%) were uncertain.

In the state of Arkansas, physicians do not have legal protection from being sued by patients that they report to the DMV. When asked to indicate whether they thought it was true that Arkansas physicians have legal protection from making such a report, 26% responded that this claim was “definitely false,” 56% said that it was “probably false,” 16% said “probably true,” and 2% said “definitely true.” This indicates that only 26% of physicians reported the correct answer with confidence while the majority (72%) were uncertain whether physicians in Arkansas have legal protection from being sued by patients reported to the DMV.

A person in Arkansas who receives a diagnosis of dementia is not required to inform their auto insurance company. When asked if people with dementia are required to report to their auto insurance company in the U.S., 34% of physicians said that this was “definitely false, 47% said that it was “probably false,” and 18% said “probably true.” None of those surveyed claimed that it was “definitely true.” A majority of respondents (66%) replied with uncertainty regarding expectations for patients to inform their auto insurance company of a diagnosis of dementia.

Table 4.2 Responses on Knowledge of State Policy

Statement made in survey	Number (Percent)		
	Answered Correctly	Answered Incorrectly	Unsure
It is mandatory for physicians to report drivers with dementia to the DMV in Arkansas	30 (48)	1 (2)	31 (50)
Physicians in Arkansas have legal protection from being sued by patients that they report to the DMV	16 (26)	1 (2)	44 (72)
A person in Arkansas who receives a diagnosis of dementia is required to inform their auto <u>insurance company</u>	21 (34)	0 (0)	40 (66)

* (N = 62) Sample size varies because some respondents did not answer all of the questions.

Physician Opinions

Table 4.3 presents the results for physicians' opinions on practice and policy for drivers with dementia. Most of those who responded to the survey (87%) indicated that physicians have a responsibility to make a medical assessment of a patient's ability to drive, whereas 13% disagreed with this statement. More respondents (61%) indicated that they felt that physicians have a responsibility to report an unsafe driver with dementia to the DMV, than those who disagreed with this statement (39%). More than half of respondents (55%) indicated that they did not support mandatory reporting by physicians of drivers with dementia to the DMV, with 38% "strongly" and 17% "somewhat" disagreeing with mandatory reporting policy. Fewer respondents (45%) agreed with mandatory reporting, with 27% "somewhat" and 18% "strongly" agreeing. A majority of those surveyed (87%) indicated that physicians would face a conflict of

interested when mandated to report patients with dementia to the DMV, with 8% “somewhat” and 5% “strongly” disagreeing with this claim. When asked whether physicians should have legal protection from being sued by patients that they report to the DMV, 89% “strongly” agreed, 8% “somewhat” agreed, and 3% “somewhat” disagreed.

Almost half of respondents (49%) “strongly” disagreed that physicians receive sufficient training to assess driver fitness in persons with dementia, with 30% “somewhat” disagreeing. Fewer felt that training was sufficient with 13% “somewhat” agreeing and 8% “strongly” agreeing that physician have sufficient training to assess driving fitness in persons with dementia. Over half (57%) of those surveyed “strongly” disagreed that a physicians’ legal responsibility regarding their role with an unsafe driver is clear in Arkansas, with 34% “somewhat” disagreeing. Fewer (2%) “somewhat agree” that legal responsibilities are clear and 7% “strongly agree.” More than half (59%) agreed that persons 65 and older should be required to take a specialized driver’s test when they renew their license, whereas 41% did not agree with specialized testing after age 65. When asked whether driving cessation has a significant impact on an older adults’ quality of life, 87% “strongly” agreed, 11% “somewhat” agreed and 2% “somewhat” disagreed.

Table 4.3 Physicians Opinions on Practice and Policy for Drivers with Dementia

Statement made in survey	Number (Percent) of responding physicians			
	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree
When a patient has dementia, the physician has a responsibility to make a medical assessment of their ability to drive	30 (50)	22 (37)	3 (5)	5 (8)
Physicians have a responsibility to report an unsafe driver with dementia to the DMV	21 (34)	17 (27)	15 (24)	9 (15)
It should be mandatory for physicians to report drivers with dementia to the DMV	11 (18)	16 (27)	10(17)	23 (38)
Physicians face a conflict of interest (patient confidentiality vs. public safety) when they are mandated to report patients with dementia to the DMV	24 (39)	30 (48)	5 (8)	3 (5)
Physicians should have legal protection from being sued by patients that they report to the DMV	54 (89)	5 (8)	2 (3)	0 (0)
Physicians have sufficient training in assessing driving fitness in persons with dementia	5 (8)	8 (13)	18 (30)	30 (49)
Physicians' legal responsibility regarding their role with an unsafe driver is clear in Arkansas	4 (7)	1 (2)	21 (34)	35 (57)
Persons 65 and older should be required to take a specialized driver's test when they renew their license	20 (33)	16 (26)	10 (16)	15 (25)
Driving cessation can have a significant impact on an older adults' quality of life	54 (87)	7 (11)	1 (2)	0 (0)

Physician Reporting Practices

Table 4.4 presents the results on questions designed to identify physician reporting practices for patients with dementia. A large majority of respondents (98%) reported that they had discussed driving ability with a patient diagnosed with dementia and 75% of physicians reported that they were the ones to initiate this conversation, whereas 5% responded that the patient was the one to typically initiate the conversation. An additional 5% responded both “the patient” and “I do.” Interestingly, 15% of respondents indicated that family was involved in this discussion. This was conveyed by writing something to the side of the survey, as it was not one of the prepared responses. Most physicians indicated being likely to ask a patient with dementia about driving with 69% reporting “very likely” and 26% “likely,” whereas 3% were “somewhat unlikely” and 2% “very unlikely.” A majority of respondents (98%) indicated that they had discussed driving ability with the family of a patient with dementia about their relative’s ability to drive. Around half (46%) reported that it was they who typically initiated the conversation, 46% reported that it was the family to typically initiate the conversation and 8% marked both “I do” and the “family.” The majority of respondents were likely to ask the family of a patient with dementia about their relative’s driving with 66% being “very likely” and 24% being “somewhat likely,” whereas 8% were “somewhat unlikely” and 2% “very unlikely.”

Survey participants were asked whether they would address driving under a variety of circumstances. When asked, half of respondents stated that they were “very likely” to address driving with a patient upon diagnosis of dementia, with 27% “somewhat likely,” 18% “somewhat unlikely” and 5% “very unlikely.” Upon an increase of dementia severity 74% were “very likely” to address driving, 23% “somewhat likely,” and 3% “somewhat unlikely.” If the patient became disoriented while driving, 95% were “very likely” to address driving and the

remaining 5% were “somewhat likely.” In the event that a patient got lost while driving, 98% of physicians were “very likely” to address driving and 2% were “somewhat likely.” Fewer physicians (85%) were “very likely” to address driving if their patient had a close call with driving but 13% were still “somewhat likely” to address driving under these circumstances. Finally, following a patient getting in a car accident, 92% were “very likely” to address driving with 6% “somewhat likely” and 2% “somewhat unlikely.”

Table 4.4. Reporting Practices: Addressing the Issue of Driving

Survey question	Number (Percent) of responding physicians			
	Very Likely	Somewhat Likely	Somewhat Unlikely	Very Unlikely
How likely are you to ask a patient with dementia about driving?	43 (69)	16 (26)	2 (3)	1 (2)
How likely are you to ask the family of a patient with dementia about their relative’s driving?	41 (66)	15 (24)	5 (8)	1 (2)
How likely are you to address driving Under the following circumstances?				
Upon diagnosis of dementia	31 (50)	17 (27)	11 (18)	3 (5)
Upon an increase of dementia severity	46 (74)	14 (23)	2 (3)	0 (0)
If the patient becomes disoriented while driving	59 (95)	3 (5)	0 (0)	0 (0)
If the patient gets lost while driving	60 (98)	1 (2)	0 (0)	0 (0)
If the patient has a close call while driving	53 (85)	8 (13)	1 (2)	0 (0)
If the patient gets involved in a car accident	57 (92)	4 (6)	1 (2)	0 (0)

* Sample size varies because some respondents did not answer all of the questions.

Table 4.5 reports the number and percentage of physicians who referred a patient with dementia for a driving assessment. Also included in Table 4.5 is whether the physician had experienced a patient with dementia who refused to restrict or stop driving against their advice. Over half (62%) of respondents indicated that they had referred a patient with dementia for a driving assessment in the past six months. While 38% of those surveyed did not report referring a patient for assessment, 48% referred 10 or fewer patients and 13% referred more than 10 patients for assessment in the past six months. Over half of respondents (62%) indicated that they had experienced a patient with dementia refusing to restrict or stop driving against their advice.

Table 4.5 Reporting Practices: Need for Assessment

Survey question	Number (Percent) of responding physicians	
	Yes	No
In the past six months, have you referred a patient with dementia for a driving assessment?	38 (62)	23 (38)
In the past six months, have you had a patient with dementia who refused to restrict or stop driving against your advice?	37 (62)	23 (38)

* Sample size varies because some respondents did not answer all of the questions.

Table 4.6 gives the location of referrals for those physicians who reported patients with dementia for a driving assessment. Physicians were most likely to refer to Occupational or

Physical therapists with the DMV being the next most likely referral site. Multiple sites were often indicated by a single respondent for this question.

Table 4.6 Reporting Practices: Location of Referral for Assessment

Location of Referral	Value [Number]*
The State DMV	13
Primary Care Physician	0
Occupational or Physical Therapist	16
Specialist in Driving	6
Other	9

* 38 respondents indicated that they had referred a patient with dementia for a driving assessment. Multiple sites were often indicated, therefore numbers are reported but not percentages.

Intergroup Differences

Chi-Square statistical analyses through use of SPSS was used to determine whether there were differences in opinions and reporting practices among the following groups. The following data are displayed in crosstabs: 1) Neurologists versus geriatricians, 2) urban versus rural physicians, 3) physicians who saw more or fewer patients over the last six months, and 4) physicians who had been in practice more or fewer years. Consideration was also given to differences in knowledge among neurologists versus geriatricians.

Intergroup differences in opinion. Table 4.7 reports the effect of specialization upon opinion towards policy for drivers with dementia. The dependent variable (opinion), was

condensed from four categories (strongly agree, somewhat agree, somewhat disagree and strongly disagree) to two (agree or disagree). Opinion was measured through responses to questions 7b, 7c, 7d and 7e.

Geriatricians were significantly more likely than neurologists to agree that “physicians have a responsibility to report an unsafe driver with dementia to the DMV” ($p < .001$). There was a moderately strong relationship between being a geriatrician and agreement with this statement ($\text{Lambda} = .412$). It was hypothesized that geriatricians would be more likely to report patients. While this finding does not indicate actual reporting practices, it does indicate that geriatricians believe that they have a responsibility to report.

Geriatricians were also significantly more likely than neurologists to agree that “it should be mandatory for physicians to report drivers with dementia to the DMV” ($p = .001$). The relationship between being a geriatrician and agreeing with this statement was moderate ($\text{Lambda} = .333$). This finding supports the hypothesis that geriatricians would be more likely to support mandatory reporting. Chi-Square analyses were not run for 7d or 7e because results are not valid where there are fewer than five observations in a cell.

Table 4.7 Effect of Specialization Upon Opinion

	Number (Percent)		Chi-Square Value	Chi-Square P-value	Lambda Value
	Neurologist	Geriatrician			
(7b) Physicians have a responsibility to report an unsafe driver with dementia to the DMV.					
Agree	9 (33)	29 (83)	15.756	<.001	.412
Disagree	18 (67)	6 (17)			
(7c) It should be mandatory for physicians to report drivers with dementia to the DMV.					
Agree	6 (22)	21 (64)	10.291	.001	.333
Disagree	21 (78)	12 (36)			
(7d) Physicians face a conflict of interest when they are mandated to report patients with dementia to the DMV.					
Agree	24 (89)	30 (86)	-	-	-
Disagree	3 (11)	5 (14)			
(7e) Physicians should have legal protection from being sued by patients that they report to the DMV.					
Agree	26 (96)	33 (97)	-	-	-
Disagree	1 (4)	1 (3)			

* A dash indicates where Chi-Square analyses were not valid due to there being fewer than five observations in a cell.

Table 4.8 reports the effect of practice location upon opinion towards policy for drivers with dementia. Chi-Square analysis was used to determine whether there were significant differences between doctors practicing in rural regions versus urban areas, in their opinion towards policy. It was hypothesized that those practicing in rural regions would be less likely to support mandatory reporting. There was not, however, a significant difference between rural and urban doctors in their opinions towards policy regarding drivers with dementia.

Table 4.8 Effect of Practice Location Upon Opinion

	Number (Percent)		Chi-Square Value	Chi-Square P-value	Lambda Value
	Urban	Rural			
(7b) Physicians have a responsibility to report an unsafe driver with dementia to the DMV.					
Agree	29 (62)	8 (57)	.094	.759	.000
Disagree	18 (38)	6 (43)			
(7c) It should be mandatory for physicians to report drivers with dementia to the DMV.					
Agree	20 (43)	6 (46)	.029	.864	.000
Disagree	26 (57)	7 (54)			
(7d) Physicians face a conflict of interest when they are mandated to report patients with dementia to the DMV.					
Agree	40 (85)	13 (93)	-	-	-
Disagree	7 (15)	1 (7)			
(7e) Physicians should have legal protection from being sued by patients that they report to the DMV.					
Agree	44 (96)	14 (100)	-	-	-
Disagree	2 (4)	0 (0)			

* A dash indicates where Chi-Square analyses were not valid due to there being fewer than five observations in a cell.

Table 4.9 reports the effect of the number of patients seen, upon physicians' opinions regarding policies for drivers with dementia. While Chi-Square analyses test for the significance of a relationship, it does not provide information about direction or strength of a relationship (Berman, 2007). Lambda was used to report the strength of the relationship where significant differences existed. The number of patients seen had a significant effect upon only one of statements of opinion. Those who had seen more than 100 patients in the last six months were significantly more likely to agree that "physicians have a responsibility to report an unsafe driver

with dementia to the DMV” ($p = .10$). The strength of this relationship was not strong ($\text{Lambda} = .153$). It was hypothesized that those who served more patients aged 65 and older would be more likely to report patients. While this finding does not indicate actual reporting practices, it does indicate that those serving more patients believe that they have a responsibility to report. It was hypothesized that those serving more patients 65 and older would be more likely to support mandatory reporting, however, this was not the case.

Table 4.9 Effect of Number of Patients Seen Upon Opinion

	Number (Percent)		Chi-Square Value	Chi-Square P-Value	Lambda Value
	< 100 Patients	100+ Patients			
(7b) Physicians have a responsibility to report an unsafe driver with dementia to the DMV.					
Agree	11 (41)	15 (71)	9.236	.010	.153
Disagree	16 (59)	6 (29)			
(7c) It should be mandatory for physicians to report drivers with dementia to the DMV.					
Agree	8 (32)	11 (52)	3.003	.223	.097
Disagree	17 (68)	10 (48)			
(7d) Physicians face a conflict of interest when they are mandated to report patients with dementia to the DMV.					
Agree	26 (96)	19 (90)	-	-	-
Disagree	1 (4)	2 (10)			
(7e) Physicians should have legal protection from being sued by patients that they report to the DMV.					
Agree	25 (96)	20 (95)	-	-	-
Disagree	1 (4)	1 (5)			

* A dash indicates where Chi-Square analyses were not valid due to there being fewer than five observations in a cell.

Table 4.10 reports the effect of the number of years in practice, upon physicians' opinions regarding policies for drivers with dementia. Chi-Square and Lambda analyses were not run due to cells having fewer than five observations. Even when categories were further collapsed into those who had practice <10 or 10+ years, many cells had fewer than five observations. Therefore it was not possible to determine whether the number of years a physician had been in practice had a significant effect upon physician opinion. Nor was it possible to determine whether the number of years in practice had a significant effect upon the opinion of survey respondents. While past research has not identified an effect for years of practice upon opinion, it is worth noting that (although there is no significance), a trend is visible in regards to the statement that "It should be mandatory for physicians to report drivers with dementia to the DMV." It appears that more "agree" with this statement, as they accumulate more years of practice.

Table 4.10 Effect of Years in Practice upon Opinion

Years in Practice	0-5	6-10	11-15	16-20	20+
(7b) Physicians have a responsibility to report an unsafe driver with dementia to the DMV.					
Agree	5	1	9	8	15
Disagree	4	3	3	1	13
(7c) It should be mandatory for physicians to report drivers with dementia to the DMV.					
Agree	1	1	8	5	12
Disagree	8	3	3	4	15
(7d) Physicians face a conflict of interest when they are mandated to report patients with dementia to the DMV.					
Agree	7	4	12	8	23
Disagree	2	0	0	1	5
(7e) Physicians should have legal protection from being sued by patients that they report to the DMV.					
Agree	8	4	12	9	26
Disagree	1	0	0	0	1

* Numbers reported are total amounts of those who responded as indicated

Intergroup differences in reporting practices. The effect of specialization upon reporting practices is offered in Table 4.11. Chi-Square statistical analyses were used to determine whether there were differences between neurologists versus geriatricians in their reporting practices. Reporting practices were determined through responses to question 10. It was hypothesized that geriatricians would be more likely to report patients. However, there was no significant difference between neurologists and geriatricians in their reporting practices. Past researchers that have suggested that there may be a difference among these specializations, considered evidence from nationwide samples. These physicians may have similar reporting practices because they are both practicing in the same state, with the same reporting policy.

Table 4.11 Effect of Specialization on Reporting Practices

	Number (Percent)		Chi-Square Value	Chi-Square P-Value	Lambda Value
	Neurologist	Geriatrician			
(10) In the past six months have you referred a patient with dementia for a driving assessment?					
Yes	19 (70)	19 (56)	1.345	.246	.000
No	8 (30)	15 (44)			

The effect of practice location upon reporting practices is offered in Table 4.12. Chi-Square statistical analyses were used to determine whether there were differences between rural and urban physicians in their reporting practices. Reporting practices were determined through responses to question 10. It was hypothesized that those practicing in rural regions would be less likely to report. There was no significant difference between rural and urban practicing physicians in their reporting practices when $p < .05$. However, at $p \leq .10$ there is a significant difference between urban and rural practitioners in their reporting practices. Urban physicians were more likely to have referred a patient with dementia for a driving assessment, whereas fewer rural respondents reported making such a referral. The strength of this relationship is not strong (Lambda = .056). Therefore, the hypothesis that rural practitioners would be less likely to report was somewhat supported.

Table 4.12 Effect of Practice Location on Reporting Practices

	Number (Percent)		Chi-Square Value	Chi-Square P-Value	Lambda Value
	Urban	Rural			
(10) In the past six months have you referred a patient with dementia for a driving assessment?					
Yes	32 (70)	6 (43)	3.297	.069 *	.056
No	14 (30)	8 (57)			

* Significance at $p \leq .10$

Table 4.13 shows the effect of number of patients seen upon reporting practices. Chi-Square and Lambda were used to determine whether the number of patients a doctor has seen has an effect upon reporting practices as indicated in question 10. It was hypothesized that those serving more patients 65 and older would be more likely to report patients. However, there was no significant difference in reporting practices between those who had seen more or fewer than 100 patients over the last six months.

Table 4.13 Effect of Number of Patients Seen Upon Reporting Practices

Number of patients seen	Number (Percent)		Chi-Square Value	Chi-Square P-Value	Lambda Value
	<100	100+			
(10) In the past six months have you referred a patient with dementia for a driving assessment?					
Yes	15 (56)	13 (65)	1.082	.582	.000
No	12 (44)	7 (35)			

The effect of a physician's years in practice upon reporting practices is offered in Table 4.14. Chi-Square and Lambda analyses were not run due to cells having fewer than five observations. Even when collapsed into <10 years in practice and 10+ years in practice, there would have been cells with fewer than five observations. Therefore it was not possible to identify significant differences in reporting practices among those who had practiced various numbers of years. While past research has not identified an effect for years of practice upon reporting practices, it is worth noting that (although there is no significance), a trend is visible in regards to the statement that "In the past six months have you referred a patient with dementia for a driving assessment?" It appears that more respond "yes" to this statement, as they accumulate more years of practice.

Table 4.14 Effect of Physician's Years in Practice Upon Reporting Practices

Years in Practice	0-5	6-10	11-15	16-20	20+
(10) In the past six months have you referred a patient with dementia for a driving assessment?					
Yes	6	3	8	6	15
No	3	1	4	2	13

* Numbers reported are total amounts of those who responded as indicated

** Statistical tests were not valid due to cells having fewer than five observations.

Intergroup differences in knowledge of policy. Table 4.15 reports the effect of a physician's specialty upon knowledge of policy. Differences in knowledge of policy between neurologists versus geriatricians were measured. Knowledge of policy was determined through

responses to questions 8a, 8b and 8c. There was no significant difference between geriatricians and neurologists in their knowledge of policy.

Table 4.15 Effect of Specialization on Knowledge of Policy

	Number (Percent)		Chi-Square Value	Chi-Square P-Value	Lambda Value
	Neurologist	Geriatrician			
(8a) It is mandatory for physicians to report drivers with dementia to the DMV in Arkansas.					
Correct	13 (48)	17 (49)	.001	.974	.000
Unsure/Incorrect	14 (52)	18 (51)			
(8b) Physicians in Arkansas have legal protection from being sued by patients that they report to the DMV.					
Correct	9 (35)	7 (20)	1.647	.199	.048
Unsure/Incorrect	17 (65)	28 (80)			
(8c) A person in Arkansas who receives a diagnosis of dementia is required to inform their auto insurance company.					
Correct	7 (26)	14 (41)	1.550	.213	.000
Unsure/Incorrect	20 (74)	20 (59)			

* These categories were condensed into one, due to few respondents answering incorrectly

Analysis of Responses to the Open Ended Question

Survey participants were asked the following question. “In the last six months, have you had a patient with dementia who refused to restrict or stop driving against your advice?” As noted earlier, 60% of respondents indicated that they had experienced a patient with dementia refusing to restrict or stop driving against their advice. Those who responded “yes” to this question were prompted to give an open ended response, detailing what the trajectory and

outcome of such a situation typically was. There were a total of 36 open ended responses provided. Following immersion in these qualitative responses, categories of predominant themes were created. Table 4.15 provides a list of overall themes and subthemes.

Table 4.15 Overall Themes and Subthemes

	Number (Percent)	Total Number (N)
Trajectory Following Patient Refusal to Discontinue Driving		
Communication with family	20 (56)	36
Removal or disabling of car	12 (60)	20
Contentious	4 (20)	20
Communication with patient	12 (60)	36
Contentious	6 (50)	12
Ongoing	4 (33)	12
Outcome Following Patient Refusal to Discontinue Driving		
DMV/authority involvement	11 (31)	36
Physician content	3 (27)	11
Physician discontent	3 (27)	11
Removal or disabling of car	7 (19)	36
Driving error or accident	5 (14)	36
Unknown	4 (11)	36
Institutionalization	3 (8)	36

Descriptions of a typical trajectory were categorized as 1) communication with family or 2) communication with the patient. Those categorized as “communication with family” were

further divided into communication that involved 1) removal or disabling of the car, or were 2) contentious. Table 4.16 provides a list of themes and subdivisions for trajectory.

Overall, twenty physicians reported involving family when a patient with dementia refused to restrict or stop driving against their advice. Of these, twelve reported that the discussion involved the removal or disabling of the patient's car. Various methods were described for families to remove or disable the patient's car. These included removal of keys, sale of the car or disengagement of the vehicle. Of the twenty physicians who reported involving family, four described communication with family as contentious. Responses that were identified as "contentious" involved instances wherein there was disagreement between the doctor and family, the family showed an unwillingness to intervene with the patient, or the patient did not heed the family's request to stop driving.

Twelve physicians reported communicating with the patient when they refused to restrict or stop driving. Responses describing trajectories that were categorized as "communication with the patient" were further divided into those that were 1) contentious and 2) ongoing. Responses that were identified as "contentious" involved instances wherein the patient continued to drive against the doctor's recommendation, disagreement ensued between the doctor and patient or the patient quit using the doctor as a physician. Six physicians reported that communication with the patient was contentious. One physician stated that "patients get upset and disagree with me or [the] diagnosis." Another described the process as "a very strong conversation with patient and family about driving and risk to both patient, passengers and public." Two respondents indicated that following the discussion, the patient did not return to see them as a physician.

Responses categorized as "ongoing" included those in which the doctors had more than a single communication with the patient regarding the issue of driving. Four respondents

described communication with the patient as ongoing. One respondent reported that they “counsel [the patient] three times then report to the DMV if they refuse to curtail driving.” Another physician stated that “often it results in a period of ongoing conversation emphasizing the importance of safe driving and how to maintain a good/similar quality of life as now.”

Table 4.16 Trajectory Following Patient Refusal to Discontinue Driving

	Number (Percent)	Total Number (N)
Communication with family	20 (56)	36
Removal or disabling of car	12 (60)	20
Contentious	4 (20)	20
Communication with patient	12 (60)	36
Contentious	6 (50)	12
Ongoing	4 (33)	12

Descriptions of a typical outcome were categorized as 1) DMV/authority involvement, 2) removal or disabling of the car, 3) driving error or accident, 4) unknown and 5) institutionalization. Those categorized as “DMV/authority involvement” were further divided into outcomes in which the physician expressed 1) content or 2) discontent at the conclusion of DMV/authority involvement. Table 4.17 provides a list of themes and subdivisions for outcomes.

While family intervention may often be successful and the preferred method of dealing with this issue, 11 of the respondents indicated the use of the DMV or other authorities in deterring a patient with dementia from driving. One respondent stated that sometimes the

“family and patient disagree with advice so I send for formal driving evaluation.” Driving authorities that physicians utilized included the DMV, state police, and adult protective services. This method was described by some respondents as being successful. For example, one physician said “I call the state DMV and send a letter regarding my concerns. In some cases a second, state driving test will occur and license be revoked.” Other respondents indicated that reporting a patient to the authorities did not always result in their preferred outcome. One said that it was “not enough that I would ‘insist’ they stop by turning them into the DMV.” Another reported that the “DMV often fails to address the problem.” A third respondent stated that “unfortunately on at least two occasions I have informed the DMV...who then ‘tested’ the patient and cleared them to resume driving (against my advice!)”

When patients refused to stop driving, physicians often reported communicating with family about removing or disabling the patient’s car. Responses did not always indicate, however, whether the family was successful in doing so. Only seven respondents implied that this communication actually led to the car being removed or disabled. One physician indicated that “when family is involved, usually the problem finally is resolved but often can take a long time even up to a year.” This statement suggests that families may struggle with the process of removing or disabling a patient’s car.

Five respondents reported outcomes that involved driving errors or accidents. One physician surveyed offered the following story:

One of my patients set out for McDonalds just a few blocks from his residence in Little Rock [Arkansas]. Around 2AM his daughter got a call from a Texas State Trooper. The patient drove to Texas and realized he was going the wrong way. He then turned around on the Interstate and had a head on collision with a van carrying a family. Somehow no one died. The patient was placed immediately into a nursing home for the rest of his life.

One physician reported that they had a patient “sneak out and ruin a transmission by driving in second gear. Ultimately the wife had to keep the keys locked up but this was a factor in him being placed in a nursing home.” Three respondents indicated that the issue of driving with dementia eventually led to long term institutionalization. Finally, four respondents indicated that they did not know what occurred following a patient’s refusal to discontinue driving.

Table 4.17 Outcome Following Patient Refusal to Discontinue Driving

	Number (Percent)	Total Number (N)
DMV/authority involvement	11 (31)	36
Physician content	3 (27)	11
Physician discontent	3 (27)	11
Removal or disabling of car	7 (19)	36
Driving error or accident	5 (14)	36
Unknown	4 (11)	36
Institutionalization	3 (8)	36

Summary of Findings

The hypothesis that geriatricians would be more likely to support mandatory reporting policy was supported. The hypothesis that those practicing in rural regions would be less likely to report patients to the DMV was also supported (although at $p \leq 10$ significance). These findings reflect suggestions and findings from past literature. It was hypothesized that those

serving more patients 65 and older and geriatricians would be more likely to report patients. While this was not the case, significant numbers of both geriatricians and those serving more patients 65 and older were found to agree with the statement, “Physicians have a responsibility to report an unsafe driver with dementia to the DMV.” This is significant in that physician opinions may not be reflective of their reporting practices. They may feel a responsibility to report, but do not actually do so.

A majority (60%) of respondents indicated that in the last six months, they had experienced a patient with dementia who refused to restrict or stop driving against their advice. Resulting communication with the patient or family following this refusal was described as often being contentious. At the point of refusal, around half of physicians reported that they involve authorities or report to the DMV. It appears that physicians often resort to a less formal intervention with the patient, having the family remove or disable the vehicle.

Chapter 5: Discussion

The number of older adults is projected to increase dramatically over the next 30 years and with this, the number of older adults who suffer from dementia will rise as well (Alzheimer's Association, 2012). Dementia affects one's ability to drive safely. Geriatricians and neurologists are regularly engaged with their patients about driving. In this study, all but one physician surveyed reported that they had discussed driving ability with both a patient and the family of a patient with dementia in the last six months. When there are safety concerns, these practitioners often refer patients for driving assessments. Of those surveyed, more than half of respondents indicated that they had referred a patient with dementia for a driving assessment in the last six months.

State policies differ in whether a physician has the ability or an obligation to make a report to the DMV when they have concerns about a patient's ability to drive safely. Some states mandate that doctors report patients with certain diagnoses for testing at the DMV. Other states do not mandate reporting, but instead offer protections from liability in the event that a doctor chooses not to make a report or decides to make a report to the DMV in good faith. In states such as Arkansas, there is no policy in place, leaving physicians with no legally viable process to report a patient of concern to the DMV.

For this dissertation research, Arkansas neurologists and geriatricians were surveyed because these professionals are often involved in the diagnosis of patients with dementia (Wilkinson et al., 2004). Physicians trained to work with patients with dementia have been shown to be the most accurate in identifying unfit drivers when compared to practitioners without specialized training (Ott et al., 2005). Optional reporting allows doctors to use their professional judgment when deciding whether to report a person with dementia to the DMV for

testing. Drivers with dementia may be reluctant to cease driving based solely on a doctor's advice, however they might be more willing to undergo a state driving exam when requested by a physician (Adler et al., 1999). This indicates the importance for doctors to have the ability to refer to the DMV for further assessment regarding driver safety.

Knowledge of Policy and Opinion Towards Policy

The purpose of this research was to answer the following research questions: (1) What knowledge do Arkansas neurologists and geriatricians have of state policy regarding reporting of at-risk drivers with dementia to the DMV; (2) What are Arkansas neurologist and geriatricians' opinions regarding various policy options for reporting of such drivers to the DMV; and (3) What are the reporting practices of Arkansas neurologists and geriatricians of drivers with dementia to the DMV?

Past research in South Carolina (where there is no reporting policy) showed high rates of uncertainty among physicians regarding the reporting process (Brooks et al., 2011). Geriatricians in states with mandatory reporting policy, however, may have a heightened awareness of the reporting process (Cable et al., 2000). This could signify that states with no reporting policy are at a disadvantage due to a lack of clarity regarding physician ability or responsibility to report patients with dementia to the DMV.

The results of this dissertation research suggest that there is a great deal of uncertainty among geriatricians and neurologists in Arkansas regarding the process of assessing and reporting drivers with dementia. Half of respondents were uncertain whether it is mandatory in the state to report drivers with dementia to the DMV. Only one quarter were aware that physicians in Arkansas do not have legal protection from being sued. A large majority of respondents feel that their legal responsibility is unclear regarding unsafe drivers. Most

physicians feel that it is their responsibility to make a medical assessment of ability to drive, however, they do not feel they have sufficient training to do so. This indicates a strong need for physician training and education surrounding state policy and medical assessment of ability to drive.

While a majority of respondents indicated that they have a responsibility to assess driver ability and report unsafe drivers to the DMV, almost half of respondents showed disfavor towards mandated reporting policy. As with previous studies (Jang et al., 2007; Marshall et al., 1999) most felt that physicians face a conflict of interest when mandated to report patients with dementia. Physicians struggle with the importance of public safety in relation to patient confidentiality. Responses also indicated that many physicians recognize the impact on an older adult's quality of life when they must stop driving. With optional reporting, physicians are provided legal protection from being sued by patients that they report. There was very strong support for this among respondents, indicating that geriatricians and neurologists in Arkansas would likely encourage the passage of optional reporting policy for the state.

Intergroup Differences in Opinion and Reporting Practices

Findings indicated that geriatricians were more likely than neurologists to feel that physicians have a responsibility to report an unsafe driver. Geriatricians were also more likely to support mandated reporting policy. Of note, however, is that geriatricians in this study also reported treating a greater number of patients with dementia than did neurologists. Results also indicated that the number of patients seen had a significant effect on whether physicians felt they had a responsibility to report unsafe drivers. Statistical analysis fell just short of identifying whether the number of patients seen affected opinion towards mandated reporting policy. It appears, however, that it may be the number of patients, rather than a difference in

specialization, that leads a physician to feel responsibility to report and support mandated reporting.

Past studies have shown a difference in opinions among doctors practicing in rural versus urban regions (Marshall et al., 2002; Snellgrove et al., 1999). Patients who live in a rural area and stop driving are not as likely to have access to public transportation as those who live in an urban region. A majority of physicians in one study expressed the view that rural residents have a greater need to drive than those residing in an urban area (Marshall & Gilbert, 2002). Results from this dissertation research did not show a significant difference between rural versus urban physicians in opinions. However, all of the rural providers strongly agreed with the statement, “Driving cessation can have a significant impact on an older adult’s quality of life.” This highlights a concern for the wellbeing of rural dwelling elders, following the loss of driving privileges. Furthermore, at $p \leq .10$, there was a significant difference between urban and rural practitioners in their reporting practices. Urban physicians were more likely to have referred a patient with dementia for a driving assessment, whereas fewer rural respondents reported making such a referral. This suggests that strong opinions among rural providers, may actually affect their reporting practices for patients with dementia. The belief that a patient’s quality of life may be affected, may make rural practitioners less likely to report them to the DMV.

When the Patient Refuses to Discontinue Driving

More than half of respondents reported that in the last six months, they had experienced a patient with dementia who refused to restrict or stop driving against their advice. At the point of refusal, however, only around half of physicians reported that they involve authorities or report to the DMV. Instead, physicians often resort to a less formal intervention with the patient, having the family remove or disable the vehicle. Responses to the open ended question in the

survey indicated that the trajectory following this situation was often lengthy and contentious. Some physicians described ongoing conversations that ensued with their patient that did not result in immediate cessation of driving. This reflects previous findings that despite expressed concern, often a significant amount of time passes before a person with dementia discontinues driving (Cotrell et al., 1999). These responses indicate that direct communication may need to take place multiple times when working with a patient on the issue of driver cessation. However, if a physician had the ability to simply report the patient for driver testing at the DMV, this conflict with the patient and family might be simplified or avoided. It is of note, however, that two physicians who reported their patient to the DMV were unhappy with the results of testing. A third physician suggested that even a report to the DMV may not lead to driver cessation.

Limitations

There were a couple of limitations to this study that should be mentioned. First, the findings are based on self-report. Physicians' actual reporting practices may vary from what they claim, especially in regards to a subject that involves behavior that could lead to liability. Additionally, the response rate for this survey was 35% of the total population of geriatricians and neurologists in the state. This may not comprise a representative sample of the opinions, knowledge, and practices of practitioners throughout the state.

Contributions to Literature

Past research findings were supported in that those practicing in rural regions were less likely to report patients to the DMV (although at $p \leq .10$ significance). An additional past study found that those serving more patients 65 and older were more likely to report patients (Jang et al., 2007). This finding, however, was drawn from a sample of family physicians throughout Canada, where reporting policies vary across provinces. This finding was not reproduced with

the sample of Arkansas neurologists and geriatricians. However, Arkansas respondents serving more patients 65 and older were found to agree with the statement, “Physicians have a responsibility to report an unsafe driver with dementia to the DMV.” This could be significant in that physician opinions may not be reflective of their reporting practices. This could indicate dissonance between the physicians’ feeling of responsibility to report, and their inability to report, due to the absence of reporting policy in Arkansas. Finally, the open ended responses from this survey offered new insight into the experiences of physicians, patients and caregivers, when a patient refuses to discontinue driving at the request of the physician.

This research offers distinctive findings in that the sample includes only neurologists and geriatricians for a single state that has no reporting policy. Past studies have identified neurologists and geriatricians as regularly being involved with the diagnosis of patients with dementia (Baloch et al., 2010; Wilkinson et al., 2004). These specialists are key stakeholders for this particular policy issue. Because the sample was state-wide, throughout Arkansas, the responses may be linked to only those practitioners who reside in a state with no reporting policy, rather than responses that are cross-regional from areas with various reporting policies.

Implications for the Future

Recommendations for Research

Physician practices, opinions and knowledge of policy have been measured through use of various questions in past surveys. Past studies have typically focused broadly (across states with differing policies) or on a particular region (without a comparison). It would be useful for future research to use a single measure to compare knowledge, opinions and practices among states with mandated policy, optional policy and no policy. Replication of this survey in states with mandatory and optional reporting policies would achieve this.

All but one physician surveyed reported that they had discussed driving ability with both a patient and the family of a patient with dementia in the last six months. More than half of respondents indicated that they had referred a patient with dementia for a driving assessment in the last six months. However, only 13 respondents indicated that they referred a patient to the DMV for testing. Most of the driving referrals were made to Occupational or Physical therapists. In future studies, it would be useful to identify the trajectories and outcomes for patients who are referred to these specialists.

Families were often instructed to remove or disable the patient's car. Future research should consider the effectiveness and impact of such an intervention. Three respondents indicated that the issue of driving eventually led to long term institutionalization for their patient. This may signify that the burden of this struggle may be more than a caregiver can handle.

Currently, there is no research to indicate the effectiveness of mandatory or optional reporting policies in reducing crash rates. There is available data for the age drivers involved in motor vehicle accidents, however, there is no state or national data available regarding crash rates with individuals suffering from cognitive impairment or dementia. These statistics would be particularly useful in learning whether there was a decline in the number of accidents, following a policy change in a single state.

Finally, research has shown that over time states with no reporting policy have moved to adopt voluntary reporting policy (Aschkenasy et al., 2006). Diffusion models of policy have suggested that states may learn from and adopt policies that exist in other states, or that states may shift to conform to nationally accepted standards (Berry & Berry, 2007). More research is needed to identify the cause and process of overarching trends towards permissive policy.

Recommendations for Practice

Based on the uncertainty expressed by practitioners in this survey regarding state policy, it is recommended that physicians be provided the education and tools to accurately assess driver risk. Use of neuropsychological testing methods can identify those patients who should go on for an on-road assessment at the DMV. Physicians would also benefit from education regarding the reporting process and state policy regarding drivers with dementia. Additionally, the DMV must have a consistent and effective system for assessment. Variation in tester administration was one of the concerns identified by the researcher who evaluated California's 3-Tier Model (Camp, 2013). In conjunction with this, for the open ended responses in this dissertation survey, three of the respondents expressed discontent with the process of driver assessment that took place at the DMV. Finally, provision of social services following loss of licensure could ameliorate concerns for decreased quality of life.

Recommendations for Policy

Research findings uncovered some division among specialists regarding the statement "physicians have a responsibility to report an unsafe driver with dementia to the DMV." This is interesting when considering whether this issue is perceived as a private or a public problem. James Anderson defines a private problem as a condition that is perceived as being one's own responsibility, whereas a public problem is viewed as requiring government action (Anderson, 1994, p. 85). Geriatricians and those serving more patients 65 and older were more likely to feel "responsibility to report an unsafe driver," which could indicate a tendency to view the topic as a public problem. Conversely, this could mean that neurologists and those serving fewer patients 65 and older may view the issue as a private problem.

Past studies have suggested that rural physicians may be less likely to report at-risk patients to driving authorities (Snellgrove et al., 2002). This dissertation research shows that

physicians practicing in rural regions were, indeed, less likely to report patients to the DMV. Unlike urban areas, rural regions lack public transportation resources such as bus routes or driving services. Due to a lack of public transportation services in rural regions, the subject of mobility for older adults, is more private in nature. It is not surprising then, that physicians practicing in rural areas are hesitant to report patients to the authorities, therefore limiting the person's mobility more so than those who reside in urban areas. Marshal et al. (1999) found that rural physicians were more likely to report patients to the DMV when restricted licensing was an option, rather than simply revoking driving privileges altogether. Offering such restrictions (such as limiting driving to daytime only) may make reporting policy more tenable to rural physicians.

Many responses to the open ended question conveyed that family was regularly involved in the process of addressing the issue of unsafe driving. In fact, communication with family was cited more often than involvement with authorities. These findings may also reflect the perspective that the problem is a private one. Rochefort and Cobb (1994) suggest that the way that stakeholders perceive a problem affects what policy solutions are considered. This division in how the problem is defined could provide insight as to why the issue has not risen to the legislative agenda.

John Kingdon (2011) emphasizes the importance of generating viable policy proposals in an effort to get an issue on the governmental agenda. These research findings indicate that while there is some division among specialists regarding mandatory reporting, optional reporting policy is widely accepted. This preference has not been previously documented, and could lead to a more direct path for this issue to reach the governmental agenda.

Over time, many states have adopted permissive reporting policies. Some states with mandated reporting policy have added physician protections from civil liability. This means that the policy is technically permissive (although titled mandated). This may not be clear to practitioners who may believe that “mandated” indicates that they must report a patient, or face legal consequences. This, however, would not be the case in a state that had added protections for physicians, to protect them from civil liability. Additionally, some reporting policies are vague in identifying the exact medical conditions that should be reported by physicians to the DMV. Legislators in Arkansas should model a policy after states which have identified specific disorders as reportable by law, without risk of liability.

Ethical dilemmas when there is no reporting policy. Out of the five ethical principles discussed (autonomy, nonmaleficence, beneficence, justice and privacy), privacy holds the most weight in states that have no established policy regarding physician report of drivers with dementia to the DMV. When doctors are not explicitly given the responsibility or permission to report through policy, then privacy laws in the healthcare setting are held as the standard for decision-making by default. If a patient refuses to follow their doctor’s advice to go to the DMV for driver testing, then the doctor has no legal ability to practice beneficence in an effort to protect public safety. The patient is allowed to retain their privacy and the ability to drive.

Patients’ family members and caregivers may be negatively affected when a doctor is unable to make a report to the DMV concerning an unsafe driver with dementia. A physician’s only option may be to encourage caregivers to report their loved one to the DMV themselves. Caregivers may be hesitant to make such a report, as it could exacerbate already complex family dynamics with a person suffering from dementia. Additionally, in some states that have no reporting policy, a report to the DMV may not be made in confidence (AMA, 2013), meaning

the patient would learn the identity of the person who reported them. This could also lead to hard feelings among family members.

The ethical principle of autonomy holds that self-determination is only due when others are not harmed. In a scenario where a doctor may not report an unfit driver to the DMV, there is also the potential for harm to occur in the form of a resulting motor vehicle accident. These dilemmas suggest that the ethical principles of nonmaleficence and autonomy are assigned less significance than the principle of privacy in states that lack reporting policy.

Ethical dilemmas and mandated reporting policy. In states that mandate doctors to report drivers to the DMV, following a diagnosis of dementia, the ethical principle of beneficence for public safety outweighs the principles of nonmaleficence, justice and privacy. The physician is expected to make a report to the DMV, regardless of whether the patient has lost the ability to drive safely. A mandatory report discounts the principle of nonmaleficence in that the patient may feel harmed due to a nonconsensual violation of their privacy. Some studies have indicated that doctors believe a conflict of interests occurs when they must report unsafe drivers to licensing authorities, and that this results in damage to the physician-patient relationship (Jang et al., 2007; Marshall & Gilbert, 1999). Also, referring a person to driver testing based upon a diagnosis, rather than a measured loss of ability may be seen as a violation of the ethical principle of justice.

The autonomy of a patient, however, may in some ways be maintained. In California, following driver testing, a person with dementia might have their license revoked or they may be directed to restrict their driving. For example, they may be told to drive only during certain times of the day or on familiar routes (California DMV, 2013). One advantage of California's mandatory reporting system is that once a person receives a diagnosis of dementia, which will

inevitably lead to deterioration of driving ability, a course of action that leads to regular testing may be put into place. With optional reporting, a patient may not continue to be seen by a doctor on a sufficiently regular basis to ensure that their driving ability has not deteriorated over time.

Optional reporting as an ethical compromise. Optional reporting allows doctors to use their best judgment before reporting a person with dementia to the DMV for testing. This allows them to choose to report (or not report) the patient to the DMV, based upon their observations in the clinical setting. This supports the ethical principle of nonmaleficence and privacy for their client more so than the mandatory reporting alternative. With optional reporting, when the beneficence of public safety is at risk, the physician is provided the means to override the principle of privacy. The patient's autonomy is still in the hands of the physician but may be extended for a longer period of time. Finally, the ethical principle of justice would be best supported, if physicians utilized an objective or standardized measure of driving ability.

From an ethical perspective, optional reporting violates the least number of ethical principles when compared to policy alternatives, and is therefore the most sound policy choice. Much can be learned, however, and applied from the system-wide programs that have been developed in states that utilize mandatory reporting policy. An ideal policy for physician reporting of drivers with dementia to the DMV would start with a research based measure of ability to drive safely. This measure of ability would take place in the physician's office. This would ensure that a patient is treated with the ethical principle of justice and that they are not referred to the DMV simply on the basis of a diagnosis but instead referred based upon a measureable loss of ability. Next, the doctor would be allowed to report at his or her discretion, so as to ensure the ability to practice beneficence for the sake of public safety. Nonmaleficence (toward the patient) and privacy could therefore be maintained for as long as safely possible.

Finally, states with optional reporting policies should include multi-faceted examinations at the DMV that offer restricted licenses which would allow for driver autonomy for as long as safely possible.

Conclusion

Neurologists and geriatricians in Arkansas are regularly faced with treating patients with dementia. Family is regularly involved in the process of discontinuation of driving, which is often contentious and ongoing. Finally, there is concern for the quality of life for dementia patients, once they cease driving – especially in rural areas. This dissertation research reveals that practitioners often feel underprepared to assess driving ability for these patients and are uncertain of policies regarding ability or responsibility to report unsafe drivers to the DMV. There is strong support among Arkansas practitioners for optional reporting and mixed support for mandated reporting policy. In conclusion, it is recommended that Arkansas legislators be notified of these findings so that they may consider adopting an optional reporting policy, allowing doctors to report patients for testing at the DMV without facing liability. Additionally, there is a need for physician education regarding state policy and assessment of patient driving ability.

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Appendix

IRB Approval of Research Compliance Protocol

March 20, 2014

MEMORANDUM

TO: Erika Gergerich
L. Jean Henry

FROM: Ro Windwalker
IRB Coordinator

RE: New Protocol Approval

IRB Protocol #: 14-03-596

Protocol Title: *Reporting Practices, Knowledge and Opinion of Policy Regarding Drivers with Dementia among Arkansas Neurologists and Geriatricians*

Review Type: EXEMPT EXPEDITED FULL IRB

Approved Project Period: Start Date: 03/20/2014 Expiration Date: 03/19/2015

Your protocol has been approved by the IRB. Protocols are approved for a maximum period of one year. If you wish to continue the project past the approved project period (see above), you must submit a request, using the form *Continuing Review for IRB Approved Projects*, prior to the expiration date. This form is available from the IRB Coordinator or on the Research Compliance website (<http://vpred.uark.edu/210.php>). As a courtesy, you will be sent a reminder two months in advance of that date. However, failure to receive a reminder does not negate your obligation to make the request in sufficient time for review and approval. Federal regulations prohibit retroactive approval of continuation. Failure to receive approval to continue the project prior to the expiration date will result in Termination of the protocol approval. The IRB Coordinator can give you guidance on submission times.

This protocol has been approved for 250 participants. If you wish to make *any* modifications in the approved protocol, including enrolling more than this number, you must seek approval *prior to* implementing those changes. All modifications should be requested in writing (email is acceptable) and must provide sufficient detail to assess the impact of the change.

If you have questions or need any assistance from the IRB, please contact me at 210 Administration Building, by phone or by email.

Documentation of Author Approval for Use of Survey

Hi Erika,

Thanks for the email and interest in my work. I am happy to share the questionnaire free of charge although ask to be cited if you use it or parts of it. That being said, I would also like to hear more about your dissertation and am available to answer any questions you might have. It is a great topic -- there has been a lot of work in the area over the years but with a lot more needed!

I have included a PDF of the questionnaire. I apologize for its not-very-clean look but couldn't find the old word file.....

Please keep me posted,
Geri

~~~~~  
Geri Adler, Ph.D.  
Associate Professor, Menninger Dept of Psychiatry  
Baylor College of Medicine  
Houston, TX  
~~~~~

Erika Gergerich

2/12/1
3

to Geri

I did receive the questionnaire and am very grateful for your willingness to share. In addition to research, I am very excited to work towards a more substantial and permissive reporting policy for Arkansas doctors. I will certainly cite and credit you in my work.

Thank you so much,

Erika Gergerich

Pre-Notification Letter

Dear Practitioner,

In the next week, you will receive a Driving and Dementia Survey in the mail. This study is being conducted by Erika Gergerich, a geriatric social worker and doctoral candidate at the University of Arkansas-Fayetteville's Public Policy Program. The purpose of this study is to assess knowledge, attitudes and reporting practices of Arkansas neurologists and geriatricians regarding drivers with dementia. These research findings will be used to help state policymakers better understand the experiences of geriatricians and neurologists who diagnose and treat drivers with dementia.

Participation in this survey is completely voluntary. However, for this survey to have meaning, it will be very important that we have a high level of participation. Thank you in advance for your cooperation. If you have any questions, please don't hesitate to contact me.

Sincerely,

Erika Gergerich, LCSW, ABD
Public Policy/University of Arkansas
School of Social Work
University of Arkansas

Cover Letter

Dear Arkansas Practitioner,

Purpose of the study:

This study is being conducted by Erika Gergerich, geriatric social worker and doctoral candidate at the University of Arkansas-Fayetteville's Public Policy Program. The purpose of this study is to assess knowledge, attitudes and reporting practices of Arkansas neurologists and geriatricians regarding drivers with dementia. These research findings will be used to help policymakers better understand the experiences of geriatricians and neurologists who diagnose and treat drivers with dementia.

Description of the study procedures and approximate duration:

I would greatly appreciate you completing the enclosed Driving and Dementia Survey and returning it in the addressed and stamped envelope provided. It should take you 5-10 minutes to complete the survey. Because the validity of the results depend on receiving a high response rate, your participation is crucial to the success of this study. The overall data collection process will take approximately six weeks. The data for this research is going to be analyzed at an individual level. If multiple physicians in your practice received this survey, it is important that each individual complete the survey separately.

Anticipated benefits/risks resulting from the study:

In 2015, I plan to publish and distribute the results of this study, based on the data provided by survey respondents. Depending on the outcomes, it could be used to guide future state level policy decisions.

Participants will not be exposed to more than minimal risk. Minimal risk is defined as risks of harm not greater, considering probability and magnitude, than those ordinarily encountered in daily life or during the performance of routine physical or psychological examinations or tests.

Description of how confidentiality will be ensured:

Each survey will have an individualized code on the top right corner of the first page so that subsequent mail outs may exclude those who have already returned the survey. A key that links each practitioner's name to their respective code will be kept on a password-locked computer, available only to the researcher. Once all data has been analyzed, the key that links practitioner names to their respective code will be permanently destroyed. Completion and return of this survey implies consent to participate.

Contact information:

Erika Gergerich
Public Policy/University of Arkansas
School of Social Work
University of Arkansas

Dr. Jean Henry
College of Education & Health Professions
University of Arkansas

This study has been reviewed and approved by the University of Arkansas' Institutional Review Board. If you have questions or concerns about your rights as a research participant, please contact Ro Windwalker, the University's IRB Coordinator, by phone or by e-mail.

Driving and Dementia Survey

Survey Code: _____

Instructions: Please indicate your answers by checking the appropriate box.

1. Do you work with older adults (50+) with dementia in your practice?

- Yes (continue to question 2)
 No

If you answered "No" to #1, it is not necessary for you to complete the remainder of this questionnaire. However, please return it so we can take your name off of the mailing list. That will help us a great deal.

Section I. About Patients with Dementia

2. In the past six months, how many patients with dementia did you see? _____
 3. Have you ever had a conversation with a patient with dementia about his or her ability to drive?

- Yes →
 No

3a. If yes, who typically initiates the conversation?

4. In general, how likely are you to ask a patient with dementia about driving?

- Very Likely
 Somewhat Likely
 Somewhat Unlikely
 Very Unlikely

II. About Families of Patients with Dementia

5. Have you ever had a conversation with the *family* of a patient with dementia about their relative's driving?

- Yes →
 No

5a. If yes, who typically initiates the conversation?

6. In general, how likely are you to ask the family of a patient with dementia about their relative's driving?

- Very Likely
 Somewhat Likely
 Somewhat Unlikely
 Very Unlikely

Section III. About your Beliefs

7. Indicate how strongly you agree or disagree with the following statements:

	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree
a. When a patient has dementia, the physician has a responsibility to make a medical assessment of their ability to drive	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Physicians have a responsibility to report an unsafe driver with dementia to the Department of Motor Vehicles	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. It should be mandatory for physicians to report drivers with dementia to the Department of Motor Vehicles	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Physicians face a conflict of interest (patient confidentiality vs. public safety) when they are mandated to report patients with dementia to the Department of Motor Vehicles.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Physicians should have legal protection from being sued by patients that they report to the Department of Motor Vehicles	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Physicians have sufficient training in assessing driving fitness in persons with dementia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Physicians' legal responsibility regarding their role with an unsafe driver is clear in Arkansas	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. Persons 65 and older should be required to take a specialized driver's test when they renew their license	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. Driving cessation can have a significant impact on an older adults' quality of life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

8. Indicate how true or false you believe each of the following statements are:

	Definitely True	Probably True	Probably False	Definitely False
a. It is mandatory for physicians to report drivers with dementia to the Department of Motor Vehicles in Arkansas	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Physicians in Arkansas have legal protection from being sued by patients that they report to the Department of Motor Vehicles	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. A person in Arkansas who receives a diagnosis of dementia is required to inform their auto insurance company	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

9. How likely are you to address driving under the following circumstances?

	Very Likely	Somewhat Likely	Somewhat Unlikely	Very Unlikely
a. Upon diagnosis of dementia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Upon an increase of dementia severity	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. If the patient becomes disoriented while driving	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. If the patient gets lost while driving	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. If the patient has a close call while driving	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. If the patient gets involved in a car accident	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

10. In the past six months have you referred a patient with dementia for a driving assessment?

- Yes
 No

- a. If yes, how many patients did you refer?

- b. To whom did you typically refer patients for a driving assessment?
- The State Department of Motor Vehicles
 Primary Care Physician
 Occupational or Physical Therapist
 Specialist in Driving
 Other: _____

11. In the last six months, have you had a patient with dementia who refused to restrict or stop driving against your advice?

- Yes
 No

- a. If yes, what is the typical trajectory and outcome of such a situation? (Use space below to write your response)

Section IV: Background Information:

12. The United States Census Bureau defines an urban area as “consisting of a densely developed territory that contains 50,000 or more people.” What type of region is your practice located in?

- Urban
 Rural

13. How many years have you been practicing in your current specialization?

- 0-5 years
 6-10 years
 11-15 years
 16-20 years
 20 + years

Thank you for taking the time to complete this survey. Please return the survey by mail, in the stamped envelope provided. You may discard the cover letter.

Reminder/Thank you Post Card

Last week a survey seeking opinions of Arkansas geriatricians and neurologists was mailed to you. If you have already completed and returned the survey, please accept our sincerest thanks.

If not, please do so today. We are especially grateful for your help because it is by listening to professionals like you that we can better meet the policy needs of our state's practitioners.

If you have not received this survey or have misplaced it, you may request a replacement by calling or emailing.