Drivers With Dementia and Outcomes of Becoming Lost While Driving

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Description
Researchers of driving and dementia have reported that drivers with early Alzheimer’s disease (AD) may continue to drive for extended periods of time, as long as their driving is evaluated or monitored. The earliest symptoms of AD are known to include loss of recent memory and the inability to recognize familiar environments. In an exploratory study, we examined 207 reports of lost drivers with dementia over 10 yr reported by newspapers and media. Seventy AD drivers were not found, 32 drivers were found dead, and 116 drivers were found alive, although of those found alive, 35 people were found injured. Miles driven and days missing were also reported in some cases, in addition to cause of death (such as drowning or exposure to weather). Becoming lost may have serious consequences. Additional research is needed in this area to more clearly understand the consequences of becoming lost while driving.

Disciplines
Occupational Therapy

Comments

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Drivers With Dementia and Outcomes of Becoming Lost While Driving

Linda A. Hunt, Alaina E. Brown, Isaac P. Gilman

Researchers of driving and dementia have reported that drivers with early Alzheimer’s disease (AD) may continue to drive for extended periods of time, as long as their driving is evaluated or monitored. The earliest symptoms of AD are known to include loss of recent memory and the inability to recognize familiar environments. In an exploratory study, we examined 207 reports of lost drivers with dementia over 10 yr reported by newspapers and media. Seventy AD drivers were not found, 32 drivers were found dead, and 116 drivers were found alive, although of those found alive, 35 people were found injured. Miles driven and days missing were also reported in some cases, in addition to cause of death (such as drowning or exposure to weather). Becoming lost may have serious consequences. Additional research is needed in this area to more clearly understand the consequences of becoming lost while driving.


Driving is a complex instrumental activity of daily living (IADL) that depends on multiple client factors. The complex cognitive functions required for driving may be impaired by dementia, the most common cognitive condition associated with aging. The broad term dementia is used to describe a complex, irreversible, and relentlessly progressive loss of cognitive function that encompasses several different diseases. Alzheimer’s disease (AD) is the most common form of dementia. AD is characterized by impairments in memory and at least one other cognitive domain. Although the cognitive profile in early AD is variable, gradually progressive memory impairment is typically observed in early stages. Additional deficits may be observed in performance intelligence, visuconstruction, attention, judgment, verbal fluency, and confrontation naming (Zec, 1993). AD affects 10% of people older than age 65 and about 50% of those older than age 85. More than 4.5 million people are thought to be affected by AD, and rates are expected to increase threefold by 2050 (Hebert, Scherr, Bienias, Bennett, & Evans, 2003).

Researchers of driving and dementia have reported that drivers who have early AD, one of the dementias that affects driving skills, may continue to drive for extended periods of time as long as their driving is evaluated or monitored by an occupational therapy driver evaluator (Hunt, Morris, Edwards, & Wilson, 1993; Hunt et al., 1997; Odenheimer, et al., 1994; Ott et al., 2008). Yet, the earliest symptoms of AD are known to include loss of recent memory and the inability to recognize familiar objects. People with AD may become disoriented in unfamiliar environments and later have difficulty finding their way in familiar environments (Uc, Rizzo, Anderson, Shi, & Dawson, 2004). Functionally, this finding means that drivers may start out driving and forget where they intended to go, do not recognize or attend to their own familiar neighborhood streets and landmarks, and consequently become lost. When
they ask for directions to return home, they may not remember information provided and consequently continue to drive, becoming more confused and lost.

For people with impaired memory, getting lost may lead to serious consequences, including injury or death. Newspapers have published the following incidents: A driver who was lost on a freeway performed a U-turn to turn around, colliding head-on with another driver; a driver who was lost at night accidentally drove the vehicle onto a boat ramp into a lake, and the body was found months later; and a driver who ran out of gas because he had driven for hours trying to find his way home got out of the car to walk and died from exposure to the weather (see Table 1). Some people believe that the news media sensationalize incidents of older driver accidents. Yet, the tragedies cited in the sample of newspaper articles we found told stories that clearly illustrate the negative effects of dementia and memory loss on driving navigation. Even when drivers requested directions from others, they became lost, most likely because they were not able to remember what was said to them.

Researchers, health care professionals, caregivers of people with AD, and people with AD may not recognize how serious memory loss and impairments in visual attention, route finding, object localization and recognition, and visuospatial skills affect driving ability (Duchek, Hunt, Ball, Buckles, & Morris, 1998; Uc et al., 2004). The focus may be on prolonging driving ability. However, Campbell, Bush, and Hale (1993) found caregivers of those with dementia reported that memory loss was the most frequent reason that patients relinquished their driving privileges, followed by other health problems, such as poor eyesight and arthritis. When caregivers report to a health care provider that a loved one with dementia has become lost while driving (Brashear et al., 2002; Holzer & Warshaw, 2000), these caregivers are usually seeking advice as to whether a driver should continue to drive. Even those who perform driving evaluations, such as occupational therapists, may ignore information concerning incidents of drivers becoming lost. Baker (2007) suggested that the decision that one is a safe driver should be based mainly on a road test. Regrettably, the professional reasoning described does not consider reports of a client getting lost, a diagnosis of dementia, a caregiver’s report, or the results of cognitive assessments (Baker, 2007). Unfortunately, during a road test people are usually provided with geographical directions and the driving conditions cannot be controlled.

We believe that the relationship between AD and becoming lost deserves exploration. In this study, we conducted the first exploratory examination of AD, driving, and the various outcomes of becoming lost through analysis of newspaper and television sources. Linda A. Hunt read several accounts of lost drivers and believed systematic collection and analysis of data from newspaper and news station reports would be an informative way of exploring this phenomenon. Although in such an exploratory study, we cannot hope to establish a causal relationship between dementia and negative outcomes for lost drivers, we believe it will present a compelling argument for the need for further investigation and a fuller understanding of the issues posed by drivers with dementia. We hope to provide awareness that mild AD may impair route navigation and that those caring for people with AD ought to consider the potential consequences of prolonging driving in this population. We believe a description of drivers with dementia may be more fully understood through data collection and analysis from various perspectives, including stories published by newspapers and reported by news stations describing the outcomes of drivers with dementia becoming lost.

Method

We conducted an extensive online search for all published or reported incidents in which an older adult diagnosed with dementia or AD became lost while driving. To ensure the most comprehensive coverage of relevant data sources, we used three search strategies: a general online search using free Web search engines, a search of missing person databases, and a search of bibliographic databases that index newspapers and other news sources. Within each search interface, we used multiple combinations of the following terms: dementia, Alzheimer, missing, lost, found, driving, drive, drove, car, and truck. We limited search results to articles or reports from the period August 1998–August 2008 and narrowed the initial results by removing any results that lacked complete information or that consisted of an older report or article about a person for whom a more recent report or article could be found (see Table 2).

Beyond these initial limits, we set general inclusion and exclusion criteria for all incidents identified in the course of searching. Incidents were included in the final data set if (1) the older adult had a confirmed diagnosis of dementia or AD, (2) the report or article stated that the adult had become lost while driving, and (3) the report or article included the date of the adult’s disappearance. Incidents were excluded from the final data set if the report or article (1) was not freely available in its entirety, (2) stated that the
<table>
<thead>
<tr>
<th>Source</th>
<th>Age of Person Missing</th>
<th>Date Missing</th>
<th>Date Found</th>
<th>No. of Days Missing</th>
<th>State Missing</th>
<th>State Found</th>
<th>Miles From Home</th>
<th>Diagnosis</th>
<th>People Dying in Situation</th>
<th>Situation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Austin American Statesman</td>
<td>76</td>
<td>11/13/04</td>
<td>12/1/04</td>
<td>18</td>
<td>AZ</td>
<td>AZ</td>
<td>25</td>
<td>Alzheimer’s disease</td>
<td>1</td>
<td>A man was found dead &lt;1 mi from his car after he and his wife got lost and ran out of gas. The man left on foot to get gas, leaving his wife in the van. The wife was found alive in their car after being stranded for 2 wk.</td>
</tr>
<tr>
<td>Boston Globe</td>
<td>78</td>
<td>2/4/01</td>
<td>2/5/01</td>
<td>1</td>
<td>OH</td>
<td>OH</td>
<td>6</td>
<td>Alzheimer’s disease</td>
<td>5</td>
<td>A man went missing from his nursing home, stole a car, and became lost while driving. He drove the wrong way on the freeway, hitting another car head on, killing himself and four passengers in the other vehicle.</td>
</tr>
<tr>
<td>Buffalo News</td>
<td>82</td>
<td>10/21/02</td>
<td>10/23/02</td>
<td>2</td>
<td>NY</td>
<td>NY</td>
<td>26</td>
<td>Alzheimer’s disease</td>
<td>1</td>
<td>After mistakenly driving into a pond on his way to the grocery store, a man died of hypothermia when he was unable to exit his vehicle.</td>
</tr>
<tr>
<td>Cleveland News Net S</td>
<td>76</td>
<td>3/13/08</td>
<td>5/7/08</td>
<td>25</td>
<td>WV</td>
<td>WV</td>
<td>44</td>
<td>Alzheimer’s disease</td>
<td>2</td>
<td>A couple was found dead near their car in a remote wooded area after getting lost while traveling to see friends. The couple was missing for &gt;2 mo.</td>
</tr>
<tr>
<td>Cumberland Times-News</td>
<td>80</td>
<td>7/7/08</td>
<td>7/8/08</td>
<td>1</td>
<td>MD</td>
<td>PA</td>
<td>30</td>
<td>Alzheimer’s disease</td>
<td>2</td>
<td>A couple got lost while driving home, becoming stranded on a remote logging road. Both exited the vehicle to find help; however, the wife died from exposure to the elements. The husband was found alive the next day next to his dead wife.</td>
</tr>
<tr>
<td>Daily Herald</td>
<td>91</td>
<td>5/10/08</td>
<td>5/13/08</td>
<td>3</td>
<td>IL</td>
<td>IL</td>
<td>50</td>
<td>Dementia</td>
<td>1</td>
<td>A woman got lost on the way to a doctor’s appointment and drove her car into a ditch. She was found dead in her car 50 mi away from her doctor’s office.</td>
</tr>
<tr>
<td>Daily News Transcript</td>
<td>84</td>
<td>4/18/03</td>
<td>4/20/03</td>
<td>2</td>
<td>MA</td>
<td>NH</td>
<td>80</td>
<td>Alzheimer’s disease</td>
<td>1</td>
<td>A man got lost while driving to pick up his wife from her bingo game, ending up in a forest. He died from exposure to the elements 1 mi from his car.</td>
</tr>
<tr>
<td>Dallas News</td>
<td>83</td>
<td>8/2/99</td>
<td>9/3/99</td>
<td>30</td>
<td>MN</td>
<td>MN</td>
<td>83</td>
<td>Dementia</td>
<td>1</td>
<td>A woman became lost in the maze of freeway exits and access roads while driving to her daughter’s home. The woman began driving erratically and was hit by another car, killing her on impact.</td>
</tr>
<tr>
<td>Deseret News</td>
<td>88</td>
<td>12/18/07</td>
<td>12/20/07</td>
<td>2</td>
<td>UT</td>
<td>UT</td>
<td>34</td>
<td>Dementia</td>
<td>3</td>
<td>A man became lost while driving to see a friend and began driving in the wrong direction on a freeway. He caused a head-on collision that killed him.</td>
</tr>
<tr>
<td>Houston KHOU</td>
<td>84</td>
<td>2/10/04</td>
<td>2/12/04</td>
<td>2</td>
<td>TX</td>
<td>TX</td>
<td>8</td>
<td>Alzheimer’s disease</td>
<td>1</td>
<td>A woman got lost on the way to a doctor’s appointment. She left her car to find help and died from exposure to the elements.</td>
</tr>
<tr>
<td>Inquirer Local News</td>
<td>73</td>
<td>8/20/99</td>
<td>10/1/99</td>
<td>42</td>
<td>OH</td>
<td>CA</td>
<td>200</td>
<td>Alzheimer’s disease</td>
<td>1</td>
<td>After getting lost and stuck in the mud, a man abandoned his car to find help. He became disoriented and was found dead beneath a tree 7 mi from a paved road.</td>
</tr>
<tr>
<td>Knoxville WBIR</td>
<td>80</td>
<td>3/20/08</td>
<td>3/24/08</td>
<td>4</td>
<td>TN</td>
<td>TN</td>
<td>45</td>
<td>Alzheimer’s disease</td>
<td>1</td>
<td>A man got lost on the way to choir practice and accidently drove his vehicle into a mine. He left his car to find help, getting lost in the mine. His body was found by mine workers several days later.</td>
</tr>
<tr>
<td>Lake Charles KPLC</td>
<td>66</td>
<td>10/12/05</td>
<td>6/7/06</td>
<td>238</td>
<td>LA</td>
<td>LA</td>
<td>8</td>
<td>Dementia</td>
<td>1</td>
<td>A man became lost on his way to the grocery store and drove into a lake. His body was found 8 mo later.</td>
</tr>
</tbody>
</table>

(Continued)
adult had only signs of or was suspected to have dementia or AD, (3) indicated signs of foul play, and (4) indicated the adult had first become lost using any mode of transportation but a car (e.g., bus, on foot).

For each incident that met the inclusion criteria, we obtained the following data about the subject of the article or report: first and last name, age, diagnosis, date missing, current status (found alive, found dead, or still missing), date found (if applicable), location (state) reported missing, location (state) where found (if applicable), approximate distance in miles between last reported location and location found, and cause of death (if applicable). Names were recorded to ensure incidents were not counted multiple times, and the source of the article or report was noted.

We placed each older adult included in the data set into one of three categories: found alive, found dead, or no further information. For adults placed in the latter category, we performed a follow-up search using the same Web search engines indicated in Table 2. The search terms for these searches were [first name], [last name], missing. If no further information could be
obtained, the adult remained in the no-further-information category.

Because this study was exploratory, we analyzed data descriptively using Excel to determine age, means, and standard deviations for the outcome groups: found alive; found dead; or uncertain outcome, which could include not found.

Results

We examined 207 reports of lost drivers with dementia over 10 yr (1998–2008). Table 3 provides demographics of and outcomes for the three groups, uncertain or not found, found alive, and found dead. Age range was 58–94 yr for all groups. Age was similar for the three groups. Most drivers in all three groups were male. Thirty-six states were represented as the initial location of the road trip. States that have a higher population of elderly people were also more represented in this study (e.g., Florida, n = 20; California, n = 22; and Texas, n = 32). For the people found alive, the range of miles was 1–1,730, with an average of 1.99 days missing (n = 116). For the people found dead, the range of miles was 4–930, with an average of 26.76 days until a body was found. Cause of death included reports of unknown, drowned after driving into a body of water, drove into a mine and could not find way out, struck a tree, unspecified motor vehicle accident, and died from exposure to elements.

Not all causes of death were reported in the newspapers. Finally, an interesting finding of this study was that people who became lost while driving and died were driving to or from familiar places such as the grocery store; the post office; a daughter’s, sister’s, or friend’s home; a doctor’s office; or choir practice (see Table 1). The average age of the passengers was for not found, 1 passenger age 77; for found alive, 7 passengers with a mean age of 88; and for found dead, 3 passengers with a mean age of 79.

Discussion

This study provides an exploratory, descriptive picture of the consequences that memory loss has for driving: becoming lost and being at risk for harm. Silverstein, Flaherty, and Salmons Tobin (2002) described the effects of AD on wandering and becoming lost. They stated that wandering requires immediate intervention because it is a life-threatening problem. We propose to further explore this phenomenon of drivers with dementia becoming lost while driving in familiar areas. We hope to design a brief standardized assessment that captures descriptors of how a caregiver would know that a driver with dementia has become lost and that helps caregivers describe the incidents, frequencies, and outcomes of becoming lost. We hypothesize that health care professionals using this assessment will readily be able to discuss this issue with
clients with dementia and their caregivers, thereby starting the process of driving cessation. In addition, it will further help in collecting empirical data on incidents of becoming lost while driving.

Holzer and Warshaw (2000) examined early AD patients retrospectively through medical records and found that 30% became lost while driving. They believed that getting lost while driving may be part of a constellation of symptoms associated with early AD. We, too, emphasize the importance of obtaining this information when evaluating older adults in the occupational therapy process. Moreover, Uç et al. (2004) found that people under the pressure of trying to find their way while driving had greater safety error, probably because of the cognitive load during driving. This greater safety error may explain why most people lost while driving were found injured or dead or were never found. In addition, Perkinson et al. (2005) reported that becoming lost was the number one behavioral indicator of unsafe driving suggested by focus group participants, which consisted of advocates for older adults and nonphysician health professionals.

We hope that this exploratory study will help change the methods of evaluating driving ability. For example, rather than having the evaluator provide geographical direction to the driver with AD, the assessment should include navigating a new route without cues. Moreover, a popular recommendation is that drivers with AD stick to their familiar routes to prolong driving. Unfortunately, few drivers with AD will remember this restriction or have the insight to believe they should adhere to such a policy of driving. Finally, when caregivers report that drivers have become lost while driving, that information needs to be weighed as heavily in the evaluation as a road test outcome.

A newsletter from the Alzheimer’s Association (1995) described one warning sign for unsafe driving that caregivers should watch for: Person is unable to locate familiar places.

Copiloting is not recommended to prolong driving because our research showed that couples became lost and died together. One report described a man with dementia who left on foot to seek help while his wife stayed in the car. The man found help and lived, but he could not remember the location of the vehicle. His wife consequently died (see Table 1).

Trends noted from the study include the following: Drivers were in the early stages of or had just been diagnosed with dementia or AD at the time of their disappearance, and many family members stated that they still thought the person was safe to be driving or were surprised by the person’s getting lost. Most people found dead had left their cars and gone walking to try to find help (most likely because they were out of gas), and many people who died also drove off the road without any indication of skid marks, indicating that they may have been unaware that they were driving on a surface that was not a road, such as a boat ramp.

This study has several limitations. First, large newspapers are unlikely to publish articles about missing older adults because there are other, bigger news stories to cover. Most case studies, therefore, came from metropolitan areas of <2 million people. Many newspapers and news stations do not maintain online archives, which limited the number of case studies that could be found. Many newspapers and news stations have also maintained Web sites only for the past few years. All of these factors may have limited the amount of data that we could collect. Therefore, this problem of becoming lost while driving may be underreported. Another significant limitation is that whether the drivers were actually diagnosed with dementia or AD by a qualified health care professional cannot be verified. We were reliant on news reports, which may or may not be correct. On a related note, dementia can also be difficult to diagnose in the early stages, which means that we may have excluded reports of lost drivers from our study because a diagnosis either had not been made or was not reported by the news source. We were also unable to verify the accuracy of any additional aspect of the news reports. Finally, we do not know how many drivers with dementia do not become lost, which would provide a valuable point of comparison.

**Conclusion**

Those who counsel both people with AD and their caregivers about driving may fail to emphasize the potential hazards. Many people with AD and their caregivers may not understand how memory loss affects driving. They may believe that it is merely forgetfulness of events
and the inconvenience of not knowing where objects are located. Usually, a health care provider will recommend a driving evaluation. If the evaluator is not knowledgeable about AD, then driving evaluations become snapshots of functional performance for only a brief period of time. See Stav, Hunt, and Arbesman (2006) for guidelines regarding the evaluation of drivers with dementia and Hunt, Carr, and Barco (2009) for a decision-making model on determining driver fitness to drive. Often, the evaluator may not take into account the caregiver report of past episodes of getting lost. Prolonging driving for those with AD may lead to tragic consequences, as documented in this study. Lucas-Blaustein, Filipp, Dungan, and Tune (1988) and Friedland et al. (1988) may have been correct when they recommended that no one with AD should drive. Future epidemiologic studies not only of crashes but also of lost drivers with AD being found injured or dead or never found may support this position. Additional research is needed in this area to more clearly understand the consequences of becoming lost while driving and why some drivers with dementia become lost and others may not.

The effects of impaired memory on the ability to drive cannot be ignored. People who get lost belong to the early AD group that some health care providers and researchers may strive to keep behind the wheel. Occupational therapists performing driver evaluations must recognize the consequences of trying to delay driving cessation for clients who have dementia and cannot be unrealistic and optimistic in their approach to prolonging driving for those with dementia. A “magic period” when it is safe for people with dementia to drive may not exist.

Occupational therapists’ role is to explain the dangers of driving and help clients and families resolve transportation options rather than prolong driving independence. Occupational therapists need to provide alternative options for transportation to people with AD and their families to help clients maintain their independence while also staying safe. Other transportation options should include escorted transportation to and from destinations to avoid the problem of becoming lost by wandering. However, there are no easy answers. Graded licensure policies that allow driving in a familiar neighborhood (Uc et al., 2004) should not be considered as a solution because, as this exploratory study has shown, clients with AD often get lost while driving to familiar locations. As a result of the early-stage symptoms of AD, drivers with AD may forget the restrictions placed on their licensure.

Finally, occupational therapists should become involved in educating law enforcement and the public on communicating with lost older drivers. People who died may have stopped and asked for directions from police officers or people in public places. The public and law enforcement need to understand that lost older adults may need physical assistance such as calling their family members or friends to meet them and provide transportation home. It is important to understand that they may not be able to follow another vehicle home. Drivers with dementia who become lost need to become passengers immediately (Hunt, 2000). It is all about avoiding tragedies.

References


