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Missing Drivers with Dementia: Antecedents and Recovery

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Abstract

OBJECTIVES—To determine the circumstance in which persons with dementia become lost while driving, how missing drivers are found, and how Silver Alert notificationsare instrumental in those discoveries.

DESIGN—A retrospective, descriptive study.

SETTING—Retrospective record review.

PARTICIPANTS—Conducted using 156 records from the Florida Silver Alert program for the time period October, 2008 through May 2010. These alerts were issued in Florida for a missing driver with dementia.

MEASUREMENTS—Information derived from the reports on characteristics of the missing driver, antecedents to missing event and discovery of a missing driver.

RESULTS and CONCLUSION—The majority of missing drivers were males, with ages ranging from 58'94, who were being cared for by a spouse. Most drivers became lost on routine, caregiver-sanctioned trips to usual locations. Only 15% were in the act of driving when found with most being found in or near a parked car and the large majority were found by law enforcement officers. Only 40% were found in the county they went missing and 10% were found in a different state. Silver Alert notifications were most effective for law enforcement; citizen alerts resulted in a few discoveries. There was a 5% mortality rate in the study population with those living alone more likely to be found dead than alive. An additional 15% were found in dangerous situations such as stopped on railroad tracks. Thirty-two percent had documented driving or dangerous errors such as, driving thewrong way or into secluded areas, or walking in or near roadways.

Keywords

dementia; driving; deaths

INTRODUCTION

Driving is a complex, highly-valued instrumental activity of daily living.[1] It is the most common form of transportation for older adults in the United States, accounting for 90% of the trips out of the home.[2] As the population ages, the number of persons with dementia (PWD) continues to rise,[3] presenting the challenge of meeting both the PWD's transportation and safety needs as well as the safety of others sharing the road. Driving may be impaired even in the mild stages of dementia and, regardless of earlier abilities, invariably worsens over time. The most common errors include incorrect turns, difficulty following a specified route, and safety errors such as leaving the driving lane. PWDs experience higher crash rates,[4] and impaired performance on road tests[5] and driving simulators.[6]

The high rates of driving difficulty and errors may be due to dementia-related deficits such as impaired reaction performance, diminished problem solving abilities, spatial disorientation, geographical memory loss, and impaired route finding. These deficits also contribute to another significant problem, that of becoming lost while driving[1,7,8] with the potential consequences of injury or death.[1,9] Despite the known risks, it is estimated that 20% of persons with dementia continue to drive.[10,11] Rowe and Bennett[3] and Hunt[4] each found that most PWD drivers who became lost while driving are found alive, but those not found within 24 hours of becoming lost have a high likelihood of dying due to exposure or other unfortunate occurrence.

There has been significant study of missing incidents when PWD are missing on foot. The antecedent circumstances are well-described and include: (1) being unable to navigate home while on a routine, independent walk in the community; (2) becoming separated from the caregiver while out in the community together; (3) being left unattended for even a short period of time; and, (4) leaving home in an agitated or angry state. Another significant characteristic of missing incidents on foot is the unpredictable nature of when a missing incident may occur.[7,8] Furthermore the response of a lost PWD is unpredictable and can make finding the individual quite difficult. For example, some PWD will seclude themselves in natural areas such as woods or ditches and remain there until found, or suffer death by exposure. A rapid response is critical however, as approximately 50% ofPWD missing on foot more than 24 hours will suffer serious injury or death.[9,12]

In contrast, there is little research examining the antecedents and associated factors specific to why or how PWD become lost while driving. In two relevant studies, the findings suggest that PWD lost while driving were conducting independent trips to a familiar location but both studies had small samples of drivers and were retrospective studies of media reports.[4,9]

In an attempt to address the problem of missing drivers with dementia, many states have alert programs, often called Silver Alert (SA), designed to broadcast alerts to law enforcement agencies and to the general public in the case of a missing senior.[13] The State of Florida enacted their SA program in October 2008 to assist in the identification and safe return of cognitively impaired drivers (http://www.floridasilveralert.com/history-of-silver-alert). The Florida program includes active, be-on-the-lookout reports to law enforcement officers. It also includes active alerts to the general public on dynamic highway signs, radio and news broadcasts presenting information about the missing car. For this study, we examined the law enforcement reports of missing drivers with a SA in Florida during the 20 months after the program began. Over this period, 168 alerts were issued, thus, on average, 2 alerts were issued per week in a state with approximately 450,000 persons with Alzheimer's disease.[14]

In the face of ever increasing numbers of PWD, the dearth of information about the lost driver, the dangers of a missing event and the increasing expenditure of community resources to locate the drivers constitute a critical public health crisis warrants further research. The purpose of this study was to examine the features (characteristics of the driver, antecedents, and discovery; role of public alerts, and outcomes) of missing driving incidents using law enforcement reports locatable as a result of the SA program. The long-termgoal of thisline of research is to better predict which PWD drivers are likely to get lost, which situations are most associated with missing events, and to develop effective strategies for safe recovery.

METHODS

This study was approved by the University of Florida Institutional Review Board and a waiver of informed consent was granted as the information used for this research was in the public domain. Data were obtained from law enforcement reports for SA issued for a 20-month period (October 2008 through May 2010). A total of 158 of the 168 reports were received. Two reports were excluded from the study because neither individual was diagnosed with nor had evidence of dementia (one had depression and committed suicide while missing, and the other had bipolar disease but no evidence of dementia). Two individuals each had two incidents of a Silver Alert; all others had a single event during this time period. Additionally, there were 4 couples that went missing, all of whom had a male driver; these cases are grouped with males for the purpose of analyses.

Data were collected <u>on</u> the demographic characteristics of the driver and the primary caregiver. All data, including race/ethnicity, were abstracted from data in the law enforcement reports. Variables were created to describe the circumstances of the how and where the PWD was located; who found the PWD; disposition (whether alive, alive but injured, or dead); the status of the car; time missing; distance traveled; the mode of recovery; and the follow-up after the event. An additional variable was created to code whether the SA notification facilitated the discovery of the missing driver. A discovery was coded as SA-facilitated when the report indicated a driver was stopped because the car matched an alert or when an individual was recognized from an alert either before or after the locator approached the individual. For instance, caseswere coded as SA-facilitated iflaw enforcement stopped an individual who was driving erratically or investigated a car stopped on the side of road, and entry of the license plate number into the state database revealed an active alert. Researchers also scored a discovery as facilitated if there was any mention of the SAassisting in the identification of the individual. Additional information was analyzed on the characteristics of the antecedents to the missing incident, coded categorically based on previous research.[7,9]

Descriptive statistics were used to describe the sample, each variable listed above, and to explore gender differences. Continuous variables were compared using unadjusted t-tests, while categorical variables were compared using Chi-square tests. For the two individuals who had more than one incident, the subject was included only once in analyses that involved person-related variables but included twice for analyses related only to the event. To handle missing data, only valid percentage is reported. Data were analyzed using IBM SPSS v19.

RESULTS

Characteristics of the Missing Drivers

The mean age of the missing drivers was 80.4±6.6years (range 58'94 years), 72.4% were males and 78.5% were Caucasian, <u>findings</u> consistent with previous reports.[9] The

characteristics of the missing drivers by gender and whether PWD was recovered due to a SA are shown in Table 1. Males were significantly more likely to be cared for by a spouse than females (p = 0.02), likely reflecting a generational-cohort effect with males being the primary driver. The mean ages of male and female drivers were not different. While the ethnic/racial mix was similar to Florida's overall mix, a larger proportion of male missing drivers were non-Caucasian (p=.04). Males tended to travel longer distances from home when found than females (116.6 vs. 64.1 miles) but this did not reach significance (p=.07).

When dichotomized by impact of a SA (see Table 1), PWD with an alert were more likely to be found by law enforcement officers than good Samaritans (p=.01), were more likely to be involved in some driving error such as speeding, wrong turns, accident (p=.03), and had prior contact with a law enforcement office during the period missing (p<.001). PWD found due to SAs also tended to travel farther distances from home (141.8 vs. 85.9 miles, p=.06).

Antecedents to the Missing Incident

Half of these drivers became lost while conducting usual, independent community activities (Table 2). These activities were endorsed by caregivers and involved driving to medical appointments, visiting family/friends, dining out and shopping. Ten PWD got lost while driving independently but in a situation that was new in some way, for instance a new stop on a usual trip or following new directions. Other caregiver-witnessed trips occurred either when the PWD drove away on an unexpected trip or leaving after becoming agitated. Importantly, 66% of these missing incidents occurred during trips in which the caregiver knew the individual was driving and had not blocked access to the keys or car.

Fewer than one-third of the cases fit the stereotypical picture in which the PWD gets unpermitted access to the keys during a lapse in caregiver supervision. These instances occurred when the caregiver was distracted elsewhere in the home, while caregiver slept or when the individual was left home alone. Four individuals (2.8%) were able to drive away without the caregiver knowing from a location other than home. Male drivers were more likely to become missing following a lapse in supervision (p=.01).

As compared to the literature regarding PWD missing without a vehicle (usually walking), there was a much larger gap between the last time the PWD was seen and the time he/she was reported missing to law enforcement (mean time 8:09 hours, median time 4:37 hours, range 0 to 131:40 hours).

Characteristics of Missing PWD Discovery

When and Where Found—Eighty-ninepercent (n = 121) of PWDs were found either the day missing or the next day (Table 3). Five percent (n = 7)were deceased by the time they were found with only one being found within 24 hours; it took longer to find those who had died (p <.001). Forty-one percent (n = 54)were found in the same county, but nearly 10% had traveled out of state by the time they were found. Distance from theplace last seenwas not different between those found alive and dead (p = 0.74). Only 20%(n=20) were still in the act of driving at the time they were located with an additional 3% stopped after being involved in an accident. The remaining 80% of drivers were stopped at time of discovery and someone identified the person as needing assistance. Of those who were stopped, about half were still sitting in a parked car and the other half had essentially become lost individuals on foot. Stopped drivers were most commonly found stopped near or in a roadway, or parked near a business or adjacent parking area. Those on foot were most commonly found near or in businesses (Table 3). Most missing PWDhad stopped safely, but 15% (n = 15)of cases werefound in an area in which harm could easily occur. This included situations in which the car was parked in an active roadway or on railroad tracks, or a PWD

was out of the car walking in or near a busy roadway/interstate. Another unsafe situationswas a PWD walking into remote, natural areas as the majority of missing PWD deaths occur in this setting.[3]

Who Found—The majority of drivers were found by law enforcement officers (Table 3). Only 24% were found by good Samaritans, a proportion that is much lower than rescuers of persons with dementia missing on foot.[9] Reasons good Samaritans intervened included: identifying a car in an unusual location (ditch, canal, trail), anindividual walking in a dangerous situation (i.e., along the highway), someoneat a gas station unable to operate the pump, or acar parked with an individual remaining inside in a residential area. Twelve PWDs (9.2%) returned home independently with 4 individuals getting assistance from family members using a cell phone.

Possible Role of Public Alerts in Finding Missing Drivers

There was evidence in the report that SAnotifications were useful in locating 23.7% (n = 31) of these drivers (Table 3). The majority of the cases were found by law enforcement as a result of pulling over a driver for irregular driving or activity patterns including erratic driving, ordriving in wrong area such as railroad tracks or natural area, For those found by law enforcement when the PWD was no longer driving, examples of why the driver might be in need of assistance included car in aninappropriate location or driver sitting on the side of a roadway. Four drivers were intercepted using information from cell phone company's tracking data of phone with the PWD.

In 6 cases, law enforcement had interacted with the missing driver but let the person continue to drive. In 3 of these cases, the car was out of fuel on the side of the road and law enforcement facilitated acquisition of additional gas. One case was pulled over for a driving error but let go with driving directions, and one case was in a minor accident but allowed to continue to drive. Finally, one driver received two separate traffic citations yet was allowed to continue to drive both times. In this case, the missing report was quite delayed so no alert was active during the time of the citations.

Only 3 drivers (2.3%) were found by good Samaritans as a result of the SA notifications. In 2 cases, good Samaritans driving on Interstate 95 in Florida recognized the missing car as it drove by. In each case, the good Samaritan called 911 and continued to follow the missing driver until law enforcement was able to intercept the car. In a third case, a citizen noticed someone lying down in the median of Interstate 75, stopped to provide help and then recognized it was an individual was the subject ofan active alert.

Outcomes of the Missing Incident

Seven individuals were found dead. The causes of death were: exposure/natural causes (3), died in a fire (2), drowning (1), and suicide by gunshot to the head (1). Four of these deaths occurred in cases in which no previous missing incident was documented. Only the variable, lived with someone or not, was related to whether the individual was found dead or alive, with those living alone more likely to be found dead (12.5%) than those found alive (2.9%; p=0.03). An additional 15 people were injured, mostly non-seriously.

Known driving or dangerous errors occurred in 32% (n = 42)of cases with some errors being severe, including head-on crashes, driving the wrong way, stopping on railroad tracks, driving into secluded natural areasand walking in a dangerous roadway. In 37 cases, a previous missing incident was reported by the caregiver. Those with an acknowledged previous incident were significantly more likely to be found in a risky situation (injured,

dead or major driving error) (46%) versus those without a documented previous missing incident (23%; p = 0.007).

Follow-up to the Missing Event

There were documented formal referrals on 21 individuals, that included: contacted the local Alzheimer's Association chapter (2), mandatory psychiatric evaluation either directly or shortly thereafter (9), referred to official agencies such as Department of Children and Families (4), and contacted Florida Department of Motor Vehicles (8). Discussions with the caregiver were documented in only 33 cases with the primary recommendations being enrolling in local law enforcement special persons' programs, instructing caregiver to terminate driving privileges, recommending tracking/locating technologies, and medical evaluations.

DISCUSSION

Consistent with studies on missing incidents on foot that use data from public records,[9,15] we found a higher proportion of missing drivers were male. In this study, two factors were more common on males: a lapse in supervision and ethnic/racial minority status. There was no evidence in this analysis to explain these findings, although possibly males are less comfortable spending days at home or have old memories of needing to be at the workplace that increases their tendency to leave the home unattended. Alternately, females may be found more quickly, not requiring the involvement of public resources and thus not appearing in this type of analyses.

The majority of events were a result of an independent trip to a usual activity gone awry. PWD drivers who lived alone were more likely to have deleterious outcomes. SA notifications were more likely to lead to discovery of lost PWD by law enforcement officials than good Samaritans. PWDs who were eventually identified by SA notifications were more likely to have experienced a driving error and have previous contact with law enforcement officers.

Further, these findings validate that PWDs who are missing by driving have very different characteristics than those missing by walking.[3] There are key differences in the following variables (driving value/walking value): median distance found away from PLS (~50 miles/ ~5 miles); most common place found (businesses and roadways/neighborhoods and walkways); and person who found (law enforcement/good Samaritans). These differences are critical when considering how to prevent an incident, and how to organize a search plan and how to use citizen alerts.

We found several key points that are critical to consider when developing a plan to enhance recovery and possibly prevent missing incidents from occurring. First, over half of PWD became lost after driving away with the caregivers' permission or knowledge as well as provision of access to the keys and car. These missing events often occurred as part of a usual trip that had been previously completed successfully. Some incidents occurred when a novel instruction was added to a routine trip, and this is likely due to the dementia deficit of inability to retain and use new information. The only option to prevent missing incidents in these cases is driving retirement. Important aspects of successful driving retirement include a partnership between the healthcare practitioner and caregiver to support the decision for driving retirement, the identification of local and state programs (i.e. Department of Motor Vehicles), and assistance in finding alternative forms of transportation in the community. An excellent guide to learn more about driving retirement, titled AMA Physician's Guide to Assessing and Counseling Older Drivers, is available at www.ama-assn.orb.

While the majority of this sample went missing during a usual activity, approximately 25% of the missing incidents occurred when the individual drove away at time the caregiver was not directly monitoring the individual (e.g., caregiver asleep or somewhere else in the home). Only these missing incidents could have been prevented by commonly recommended strategies, such as preventing access to car keys or a working vehicle. Caregivers should consider fail-safe plans for ensuring that the PWD doesn't have access to the keys such as using a locking drawer to store the keys. About 10% of the incidents occurred when the PWD was left home alone with access to a car and keys and this situation seems amenable to the above solution.

Wandering has been a term used to describe these unattended, unsanctioned exits in to the community,but thecharacteristics of missing incidents do not fit well with the currently accepted definition of wandering.[16,18] The currently accepted definition proposes that wandering is a frequent, repetitive ambulatory behavior that includes patterned activity, and that can be associated with elopements. Interestingly, however, there is no evidence in the current body of wandering research documenting that elopements occur during wandering behavior. Additionally, for unattended exits from the home, wandering behavior was not found to be an antecedent of those exits in two prospective studies.[2,7] Finally, the characteristics of wandering (repetitive, frequent, patterned activity) do not closely match the characteristics of the unattended missing incidents in this sample (singular, unpredictable, occurring during normal activities). It has been proposed that wandering and missing incidents are two different behaviors associated with dementia,[7] and this study provides further support for that distinction.

We found a number of key points that need to be considered in rapidly locating a missing driver and developing an overall government-based program to address missing drivers with dementia. First and foremost is the importance of law enforcement in finding missing drivers. Unlike those found while missing on foot,[2,9,19] missing drivers were unlikely to be found by good Samaritans or business employees. Rapid notification of law enforcement agencies in a large surrounding area is critical to finding missing drivers. These alerts must be delivered directly to law enforcement agents in the field as a 'be-on-the-lookout' alertfor an individual, rather than passive alerts that must be accessed in a database. Often SA programs provide these active alerts, such as in the state of Florida. In this data, SAs to law enforcement were important in about 20% of the recoveries. Since there were cases in which missing drivers were stopped by law enforcement but subsequently allowed to continue to drive, it will be critical to devise and test other strategies to speed the alert issuance. This may involve education to both law enforcement agencies and caregivers to request assistance as early as possible. Providing law enforcement officers with a mechanism for rapid assessment of cognitive status may assist officers in evaluating stopped drivers.[20]

Second it is critical to note the challenges that make it difficult to generate an effective citizen alert. These challenges include the large distances that lost drivers travel, the finding that over 80% were not driving at the time someone intervened,andthe facts that about half of these individuals were found outside their car. Most alerts are broadcast on highway messaging signs and television media. For alerts using these two media, there is a significant mismatch between where the alert is provided and where missing drivers are often found. For example, missing drivers were commonly found outside the car in businesses and adjacent parking areas, not areas close to either alerts provided by highway message systems or television announcements. Possibly alerts by radio media would be broadcast closer to areas that missing individuals are typically found. Since current alerts focus on a description of the car, they are not useful to citizens who may come into contact with the many lost drivers who have left their vehicle. More information on the individual may be required in the alert. Finally it will be important to study various content structures and delivery

methods of an alert to determine how best to facilitate memory of the alert and citizen awareness.

Creating effective alerts will be particularly crucial as the population of PWD increases and more alerts are needed. Extrapolated from the 450,000 PWD in Florida to a national population of 5.4 million individuals with Alzheimer's disease, this could equal 24'36 alerts per week nationwide, and 35'53 alerts including all individuals with dementia (~8 million). Importantly, this number is only for the subpopulation of those whose missing event began by driving, which accounts for less than 5% of total missing incidents in PWD.[2,7,9]

Each branch of the US Congress has proposed legislation requiring states to set-up a SA program.[21,22] The language in these acts is broad and would allow a comprehensive protocol to be developed to help all PWD, whether missing in a car or on foot. It is essential, however, that those crafting these protocols have a clear understanding of the nature of the problem including the differences between those missing by foot versus those missing while driving. The SA legislation could be strengthened by including or recommending a model policy for adoption. This model policy would need to address the strategies and techniques useful for finding each type of missing PWD, and would provide states with the critical guidance for local policies and training.

In summary, SA-type programs need separate policies and procedures for those missing by walking versus those missing while driving. These programs require a combination of participants' activities including law enforcement, citizens and agencies for follow-up activities. Critical components include: a coordinated inter-agency law enforcement response; comprehensive training for law enforcement personnel; and public awareness campaigns educating citizens about the problem of missing PWD and instructions on identifying someone who might be in need particularly when encountering an older individual on foot. Law enforcement training optimally would include understanding the nature of missing incidents in PWD; characteristics of where and how these individuals are found; and rapid techniques to evaluate cognitive functioning. Tools, such as the AD8, may be useful when law enforcement encounters an adult making unexpected driving errors.[20,23] Federal and state agencies planning for a SA program can utilize the findings of this study to inform the content of a comprehensive program.

Acknowledgments

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Table 1

Characteristic of Missing Drivers by Gender and Silver Alert Notifications

Variable	Gender of Driver			Found by Silver Alert		
	Female (n=39)	Male (n=117)	p-value	No (n=101)	Yes (n=31)	p-value
Age (years)	80.1	80.5	.28	80.3	79.8	.69
	(6.7)	(6.7)		(6.5)	(7.2)	
Race (% Caucasian)	91.7	74.3	.04	80.0	74.2	.34
Primary Caregiver(% Spouse)	35.9	64.1	.02	55.4	64.5	.38
Previously Lost (%yes)	25.6	23.9	.83	24.8	25.8	.91
Start from Home (%yes)	78.4	80.2	.24	77.6	83.9	.62
TimeLapseBetween Last Seen and Reported Missing (SD)	5:37 (4:13)	9:02 (17:26)	.27	6:44 (6:39)	12:38 (28:13)	.08
Days Missing (%<2 Days)	92.3	72.7	.13	88.2	83.9	.44
Activity Engaged "Normal" (%Yes)	68.6	45.9	.19	53.6	48.3	.69
Lapse in Supervision (%Yes)	2.8	25.7	.01	17.5	16.1	.45
Found by Law Enforcement (%Yes)	60.0	65.3	.23	56.0	87.1	.01
Driving Error (%Yes)	28.2	27.4	.91	29.9	37.9	.03
Injured (%Yes)	10.8	11.1	.87	28.7	38.7	.29
Fatality (%Yes)	2.6	5.1	.50	6.0	3.2	.81
Found in Same County (%Yes)	43.2	40.0	.35	41.8	33.3	.78
Distance Traveled (Miles)	64.1	116.6	.07	85.9	141.8	.06
	(73.5)	(153.0)		(122.1)	(163.5)	
Prior Contact With Law Enforcement (%Yes)	2.6	5.1	.68	1.0	16.1	<.001
Called Home Prior to Being Found (%Yes)	5.1	1.7	.24	4.0	0	.26

Mean (±SD)

Table 2

Antecedents to the Missing Incident

Antecedent	n	Valid Percent
Sanctioned Trips		
Independent Trip: <u>Usual</u>, Repeated Activity	74	51.4
Agitated, Caregiver-Witnessed Exit	11	7.6
Independent Trip: New Instructions	5	3.5
Independent Trip: Not Routine	5	3.5
Unsanctioned Trips		
Home Alone	14	9.7
Drove Away From Home During Supervision Lapse	11	7.6
Caregiver Asleep	9	6.3
Drove Away From Community Setting During Supervision Lapse	4	2.8
Other		
Unusual circumstances	11	7.6

Table 3

Characteristics of Missing PWD Discovery

Characteristic	N	Valid Percent
Days Missing		
Same Day	61	44.9
Next Day	60	44.1
2 Days	7	5.1
3 Days	2	1.5
4 Or More Days	3	2.2
Condition Of Driver When Found		
Alive	114	83.8
Injured	15	11.0
Dead	7	5.1
Distance From Home		
Same County	54	40.9
1 County Away	23	17.4
2 or More Counties Away	42	31.8
Different State	13	9.8
Where Found		
Roadway	33	30.0
Parking Lot/Business	31	28.2
Off Road (Woods, Railroad, Track, Ditch)	15	13.6
Home	13	11.8
Neighborhood	9	8.2
Interstate Highway	9	8.2
Relation To Car When Found		
Still Driving	20	20.0
Parked	29	29.0
Out Of Car	32	32.0
Involved In Crash	5	5.0
Condition Of Car When Found		
Undamaged	105	80.8
Damaged	7	6.2
Stuck Off Road	7	4.5
Car Not Found/Found Later	5	3.2
Out Of Gas	4	3.1
Who Found		
Law Enforcement: Silver Alert	28	21.4
Good Samaritan: Silver Alert	3	2.3
Law Enforcement: Non Silver Alert	56	42.7
Good Samaritan: Non Silver Alert	27	20.7
Returned Home By Self	12	9.2

Characteristic	N	Valid Percent
Family	5	3.8

Table 4

Number of PWDs by Driving Status and (Median Distance Traveled) at Time of Discovery

	Roadway/Interstate	Business/Parking Area	Natural area	Neighborhood
Still driving	17 (77)	0	1 (>200 miles)	1 (unknown)
In car (Parked)	11 (31)	11 (48)	7 (11)	0
Out of car	3 (106)	16 (30)	5 (20)	2 (6)
Accident	5 (147)	0	0	0