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Driving Retirement in Older Adults with Dementia

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Abstract

In order to characterize the driving and mobility status of older adults with dementia, a questionnaire was mailed to 527 informants; 119 were returned. The majority of patients were diagnosed with Dementia of the Alzheimer's Type. Only 28% were actively driving at the time of survey. Informants rated 53% of current or recently retired drivers as potentially unsafe. Few informants reported using community/educational resources. Individuals with progressive dementia retire from driving for differing reasons, many subsequent to family recognition of impaired driving performance. Opportunities for education and supportive assistance exist but are underutilized.

Keywords

Alzheimer's disease; driving retirement; automobile driving

Introduction

Driving retirement is becoming a necessary reality for many older adults, particularly those with dementia. Of the 37 million older adults living in the United States in 2006, 30 million were licensed drivers, an 18% increase from 1996 (1). In the United States, the automobile is the most frequently used form of transportation by older adults, accounting for 90% of the trips outside of the home (2). Research suggests that as older adults develop physical and/or cognitive frailty, many restrict their on-road exposure or drive fewer miles per year (3). Such restriction may reduce crash risk and enhance personal safety.

As some age-associated diseases progress, driving retirement may become inevitable as men tend to outlive their driving ability by six years and women by ten years (4). Based on aging demographics and common age-related diseases, an increasing segment of the population will no longer have the ability to drive. Adverse consequences of driving retirement occur in the general older adult population. On an individual level, driving retirement can lead to decreased socialization and a reduction in out-of-home activities (5), increased depressive symptoms, decreased self-esteem (6), and an increased risk of nursing home placement (7). Responsibility

for driving often falls upon the family. As our aging driving population increases, there will likely be an increasing transportation burden to caregivers of demented patients and to society.

Dementia is increasingly recognized as a common condition in older adults with a high prevalence and incidence over 70 years of age. As many as 20% of older adults with dementia referred to dementia clinics may be actively driving (8,9). A significant number of older adults are found to have some degree of cognitive impairment when they renew their driver's license (10). In Hawaii, it was estimated that four percent of male drivers over age 75 had dementia (11). Thus, our society is faced with an increasing number of older adults who are not only currently driving with dementia, but will eventually be forced to retire from driving due to their progressive cognitive illness.

Research, to date, on dementia and driving has focused largely on determining fitness-to-drive from a medical perspective (i.e. recommendations for evaluating driving in the context of clinical health encounters). There is a paucity of information in the literature on the process of driving retirement in older adults with dementia. Family caregivers play critical roles in most aspects of dementia care, and it is reasonable to assume that many caregivers are required to address the issue of driving fitness and retirement. Little is known, however, about those factors that may trigger (or impede) concern and/or action in family relationships. This project was undertaken to fill this gap in the literature. Insights into the driving retirement process may be useful for developing strategies that health professionals can use to support patients and families in the driving retirement process.

Three objectives were considered for this study. First, the research sought to systematically quantify the presence of abnormal driving behaviors as observed by the caregiver at or near the time of driving retirement. Second, the project aimed to document the family caregiver's perspective on the decision to stop driving and to identify any perceived barriers to driving retirement. Finally, the role of educational efforts that might assist with driving retirement was explored.

Method

Participants

Participants were drawn from a consecutive, three-year series (2003-2006) of referrals to the Memory Diagnostic Center (MDC), a dementia specialty practice of the Department of Neurology, Washington University in St. Louis School of Medicine. Upon initial appointment, patients are asked to identify an informant (usually the spouse or close family member) to provide additional information on cognitive and functional change. Less than 1% of patients are unable to identify an informant. Medical records were reviewed and applicable data were extracted manually. Inclusion criteria included: (1) diagnosis of dementia from an initial or subsequent evaluation; (2) a history of past or current driving (i.e., those who never drove were excluded); and (3) an informant with a documented mailing address in the MDC database. A total of 527 patient-informant dyads met these criteria and were mailed a survey questionnaire, and 23% (N=119) patient-informant dyads returned the survey.

Survey Questionnaire

The questionnaire included several items related to driving retirement. Nineteen questions covered a range of driving issues, including the informants' observation of any abnormal driving behaviors, barriers to driving retirement, important decision-makers in the driving retirement process, and educational efforts aimed at driving retirement by clinicians in the MDC. The abnormal driving behavior categories were chosen based on those frequently cited by law enforcement officers and caregivers of drivers with dementia referred for fitness-to-

drive evaluations in the state of Missouri (12). These driving behaviors include; monitoring for traffic, maintaining speed, difficulty with turns or intersections, backing up, staying in the lane, following traffic signals or signs, parking, yielding, or difficulty with gas/brake pedals. In addition, several questions on crashes and driving status were adopted from the Driving Habits Questionnaire (13). These included questions on exposure (trips per week), questions on accidents, and driving space. A return addressed envelope with paid postage was enclosed for the return of the questionnaire and the informed consent document that requested signatures from both the informant and driver. Instructions for the questionnaire requested that the informant answer the questions regarding the driving habits of the patient. A copy of the driving questionnaire is available upon request.

Medical Diagnosis & Records Review

Patients of the MDC are referred by primary care physicians from the St. Louis metropolitan area and nine surrounding mid-western states. Referrals are made for evaluation of cognition, behavioral, and mood disorders. One of the six clinic physicians conducts the assessments and provides a diagnosis ranging from no cognitive impairment through all levels of dementia severity (see Clinical Dementia Rating description below).

A medical records review was performed to obtain more information about the patient, confirm a diagnosis, and determine if the physician addressed driving and/or made any driving-related recommendations (i.e., referral to a driving clinic or the Department of Motor Vehicles). Information in the MDC database includes the primary diagnosis given during the first clinical assessment by the MDC physician that determined the presence of dementia, the dementia severity rating, and the neuropsychological battery results administered to each patient.

Clinical Assessment

The MDC physicians conduct independent semi-structured interviews with the patient and informant. The diagnostic criteria for dementia of the Alzheimer type used in this study (impairment in memory and at least one other cognitive domain and interference with daily activities) are consistent with the Diagnostic and Statistical Manual of Mental Disorders, fourth edition (DSM-IV), definition (14) and of “probable AD” category in the National Institute of Neurological and Communicative Diseases and Stroke-Alzheimer’s Disease and Related Disorders Association criteria (15). Whenever possible, published criteria were used for other dementia disorders, including Vascular Dementia (VaD), Dementia with Lewy Bodies (DLB), and Fronto-temporal Dementia (FTD) (16-18).

Dementia Severity Rating

The Clinical Dementia Rating (CDR) (19) was used to determine the presence or absence of dementia and to stage its severity. A global CDR of 0 indicates no dementia. A CDR of 0.5 represents very mild dementia or in some cases with minimal impairment, uncertain or questionable dementia. A CDR of 1, 2, or 3 corresponds to mild, moderate, or severe dementia, respectively. Studies have shown that older adults in the mild stages of the disease (CDR=1) demented patients have difficulty passing a performance based road test (20) and a consensus statement by the Academy of Neurology concluded that patients with a CDR level of 1 should no longer drive (21). In fact, the majority of older adults do retire during the very mild or mild stages of dementia, since few older adults in studies are noted to drive at a moderate level (CDR=2) of dementia (11,22).

Statistical Analysis

All analyses were performed using Statistical Package for the Social Sciences (SPSS) (23). Descriptive statistics were used to report the demographic and clinical characteristics of the

patients and informants including age, race, sex, education, CDR, neuropsychological test results, clinical diagnoses, and questionnaire results.

Results

Sample characteristics

There were no differences between the patient characteristics (age, gender, education), average CDR or dementia severity rating, or the percentage that were diagnosed with Alzheimer's disease of those who did not return the survey (n=408) and those informant-patient dyads that did return the questionnaire (n=119). Of the 119 returned questionnaires, the mean patient age was 73.2 years (± 9.6), with a mean educational attainment of 14.0 years (± 2.8), and an average MMSE score of 21.0 (± 6.8). Most (77.5%) were Caucasian and half (48.3%) were female. The majority of patients referred to the clinic were diagnosed with Dementia of the Alzheimer's Type and had a very mild to mild rating of dementia severity. The characteristics of the sample are listed in Table 1.

Driving Behaviors

Of the 119 participants, 57% had a valid license while only 29% were active drivers. Fifty-three percent of informants rated the ability of the drivers as fair, poor, or unsafe prior to the time of driving retirement. Participants tended to stay close to their homes; only 33% drove to areas up to fifteen miles from home and only 18% drove up to a 100 mile radius of home. Of note, the majority of informants (70%) reported the presence of at least one abnormal driving behavior. Of the 34 active drivers, the average days driven per week was 4.7 (± 2.0) and 6 (18%) reported having a crash within the past year. The percentage of informants that reported impairment in specific driving behaviors with active drivers or noted near the time of driving retirement are listed in Table 2. Common driving behaviors that were documented by informants included; failure to monitor traffic, maintaining appropriate speed, difficulty with intersections or turns, and backing.

Driving retirement

For the 85 participants who retired from driving, 54% of the informants indicated worsening cognition as the reason. Family encouragement was cited as a factor 42% of the time in the decision to stop driving, which was similar to the rate (40%) that indicated there was physician involvement. Other reasons for driving retirement are noted in Table 3. The major influence on the decision for driving retirement came from the family and physician (see Table 4).

Barriers and Education

Barriers to driving retirement that were identified in responses to the questionnaire to the entire sample (N=119) included lack of insight which was noted 33% of the time, 33% stated the personality of the driver was an issue, 17% still believed the patient was safe to drive, and 14% raised concern in regards to the risk of social isolation. Only 12% stated there was family reluctance to address the issue. A lack of alternative transportation, need for an active driver, and demands on family, were less frequently cited as barriers. Less than 12% of the cases had a documented occupational therapy (OT) driving evaluation. Less than ten percent (9.4%) of the informants had read *The 36-Hour Day* (24), the important caregiver resource that extensively covers the gamut of important issues related to dementia care, and especially has specific information on driving and dementia. Only 2.4% had a documented discussion with a social worker. In over 60% of cases, no intervention or discussion was documented in the medical record.

Discussion

Driving retirement is an inevitable endpoint for persons with progressive dementia. How drivers with dementia and their families negotiate the driving retirement process is unclear, yet an important area for medical intervention and the protection of public safety. Findings from this survey-based study of a well-characterized sample of drivers with dementia provide a basis for understanding patients' and families' experiences and the ways in which future interventions may be tailored to meet specific needs.

The advanced age is consistent with the known high prevalence of this disorder in late life. Based on an average age of 75 years for the participants in this study, one might expect a predominantly female gender, but this sample was equally divided by gender. This could represent the uniqueness of the referral patterns or the small sample size. However, it is possible that the inclusion criteria (requirement for a history of driving) may have biased towards more males in the sample, since some females in this age cohort have been noted to have higher rates of driving cessation and are more likely to have never driven. The majority of participants were classified as having very mild or mild dementia (CDR 0.5 or 1), which is consistent with findings that very few older adults drive with moderate levels of dementia.

Only 28% of our sample were active drivers at the time of the initial evaluation. This percentage of active drivers that present to dementia clinics is consistent with findings in similar settings (25). By the time patients have reached a moderate to severe dementia rating in the community, very few present to a dementia clinic in the outpatient setting for an initial evaluation. However, it is interesting to note that a significant number of older adults with dementia retained their license (56.7%) despite no longer driving. We do not know why this is the case in this sample, but it is interesting to speculate on the possible reasons. Holding on to the license may indicate a situation where the individual and/or families chose to retain it for identification, had not yet formally allowed it to expire due to recent driving retirement, or perhaps were still using it on a rare occasion they may need to drive.

Few studies have systematically interviewed informants regarding the presence of abnormal driving behaviors in drivers with dementia. The elegant Hartford brochure "At the Crossroads" (26) and the AMA curriculum on the Assessment and Counseling of Older Drivers (27) have created checklists of abnormal driving behaviors. However, we are not aware that these specific tools have not been studied systematically in a physician-based clinical setting that evaluates older adults with dementia. Consistent with the observations published by studies that have used performance-based road tests (28), informants in this study often observed and documented drivers with dementia having difficulty with traffic awareness, maintaining appropriate speed, confusion with intersections, and staying in their own lane.

Thus, clinicians should consider gaining access to and interviewing informants that may have had direct observation of driving skills for the older adult with a medical impairment. Previous research suggests that family members are not reliable in determining driving safety when compared to a road test assessment (29). However, this was based on a global question of driving safety posed to caregivers. This pilot data is promising for the use of specific abnormal driving behavior checklists that could be validated and used to assist in directing fitness-to-drive evaluations or as an educational tool for driving retirement in drivers with dementia.

Of interest in this area is the evidence of on-road incident that played a decision in driving retirement in up to a quarter of our drivers. This indicates the decision to stop may have occurred abruptly for some drivers and may not have been of their personal choosing. The questionnaire did not specify what type of incident, so we are not able to report on all of the specific types of in-traffic events that were observed or came to the attention of the informants. However, there were several write-in descriptions that indicated a crash, near miss, or becoming lost

accounted for some of these incidents resulting in driving cessation for the older adult with dementia.

Since 18% of our active drivers had a crash in the past year, these types of incidents could serve as a “teaching moment” and begin a discussion on driving retirement. Family members and physicians should inquire as to these types of incidents, monitor for their occurrence, and consider utilizing their presence to direct driving recommendations or initiate discussions on driving evaluations or retirement.

Interestingly, a majority noted driving retirement was, in part, due to worsening cognition. This indicates that some drivers may have a steeper trajectory or decline that is noticed by the family and is a cause for concern. The family was noted to play a significant role as was the physician in driving retirement. This is consistent with previous reports that note these two groups are the major “stakeholders” in this process (30). This pilot study underlines that family and primary care physicians are still on the front line for decision-making in regards to medically impaired older adults and their willingness or ability to drive, especially for those drivers with dementia. Since these two groups are key stakeholders in the process, education on driving and support for caregivers and physicians in this area, may assist with these difficult decisions. Important educational information is available for families through the Hartford Insurance Company and through the Alzheimer’s Association. Physicians have access to the online version of the American Medical Associations “Assessment and Counseling of Older Adult Drivers” (27). In addition, there have been additional educational efforts specifically tailored for physicians or health professionals in the area of dementia and driving (31,32).

The DMV was rarely involved in these decisions and 15% of the drivers in this sample retired for reasons other than dementia (i.e., family and/or physician encouragement). Even more surprising was the relatively few drivers that had an evaluation by an OT or referral to a social worker. In this clinical setting, Driving Rehabilitation Specialists/OT’s and social workers may have been underutilized, but remain a valuable resource to health professionals that work in older adult settings. Further education is needed with primary care physicians and subspecialists that serve older drivers to inform them of other health professionals that may be able to assist in this area.

There appear to be several barriers to driving retirement in this sample. Clinicians should be aware that they may interfere with the decision and/or the willingness to follow recommendations for driving retirement and include; lack of insight and the personality of the driver, belief by the informant they were safe, and concerns for social isolation. Thus, there appears to a major role for education in this setting. Findings reported here suggest that 65.9% of the participants received no community resources or education as part of the driving retirement process. Anecdotally, our nursing staff in the clinic often address driving issues and provide educational information (i.e. *At the Crossroads*), but this was not consistently documented in the medical record. Mobility counseling from the early stages of disease may be the key to providing this education and combating these negative consequences (33). Physicians can be held liable if they do not warn patients and family members of safety risks while driving. Clinicians should address the driving issue in outpatient settings and document this in the medical record.

Limitations of the Study

There are several limitations to this study. A minority of the clinic population during the time period studied, completed the questionnaires (23%). Thus, the responses from these informants may not be totally accurate or reflective of the sample in our dementia clinic. However, no differences on key clinical characteristics were found in the larger sample to those that responded to the questionnaire, suggesting that the results are likely representative of a typical

patient in this specific clinical setting. This clinic resides in a tertiary referral center, is a dementia specialty clinic, and the participants were predominately white and highly educated. Thus, these findings may not be generalizable to other settings. There is always the issue of recall bias, and some of our informants were asked to recall information as far back as three years prior to the time the questionnaire was mailed. The time between driving retirement and the time the questionnaire was completed for those that were no longer active drivers was not determined. If a significant amount of time had passed since retirement, this could decrease the accuracy of recall for the informants that filled out our questionnaire.

Reluctance of informants of active drivers to identify concerns or abnormal driving behaviors for fear of intervention by the investigators may exist. Thus, it is possible that the number of abnormal driving behaviors were underreported. Finally, educational interventions are not always documented in the medical record. It is possible that staff did address driving recommendations on a more consistent manner than was identified by chart review. In addition, we were not able to review the primary care records and it is possible that further documentation on driving issues could have been present in these medical records. However, the questionnaire data appears to corroborate the chart review by noting that few drivers were referred for a driving evaluation or to the social work setting by their primary care physician or participation in a subspecialty clinic.

Conclusion

Healthcare professionals who work with older adults with dementia will likely be faced with patients who continue to drive. Efforts to document abnormal driving behaviors by informants should be explored, both as possible red flags to identify the need for a fitness-to-drive evaluation or as an educational tool to assist with driving retirement. On road incidents appear to be a critical act for some, but not all drivers with dementia. The use of such an incident as a “teaching moment” may be helpful in the education of caregivers in this process. Physicians and families are the major stakeholders in this process of driving retirement in physician-based clinics. However, these clinics should consider policies that systematically address and document education provided to older adult drivers with dementia, which may include educational materials, referral to performance-based driving clinics, social workers, or gerontological case managers. More research is needed to determine strategies to address the personality traits of the driver and those individuals who lack insight in the process of driving retirement.

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Table 1

Demographics and Characteristics of the Sample

	N=119
Age, mean (SD)	73.2(9.6)
Gender (% F)	48.3
Race (% Caucasian)	77.5
Education, mean(SD)	14.0(2.8)
MMSE, mean(SD)	21.0(6.8)
<u>CDR</u>	
0.5	53(44.2)
1.0	28(23.3)
2.0	16(13.3)
3.0	0(0)
<u>Diagnosis</u>	
DAT	52(53.1)
FTD	6(4.1)
DLB	4(6.1)

Table 2**Abnormal Driving Behaviors**

	N=119
	N (%)
Monitoring for traffic	36(30.2)
Maintaining speed	30(25.2)
Turns/Intersection	25(20.8)
Backing up	22(18.3)
Staying in lane	21(17.5)
Traffic Signs/Signals	17(14.2)
Parking	13(10.8)
Yielding	11(9.2)
Gas/Brake pedals	8(6.7)
1 or more behavior	85(70)

Informants could choose more than one response, thus totals exceed 100%

Table 3**Reasons for Driving Retirement**

	Retired Drivers (N=85)
	N (%)
Worsening cognition	46(54.1)
Family encouragement	36(42.4)
Physician encouragement	34(40.0)
On-road incident	20(23.5)
Another health condition	13(15.3)
Personal reasons	12(14.1)
Other professional encouragement	8(9.4)
Request from DMV	6(7.1)

Informants could choose more than one response, thus totals exceed 100%

Table 4

Individuals with Influence on Driving Retirement

Retired Drivers (N=85)	
	N (%)
Spouse	34(40)
Physician	31(36.5)
Patient with Dementia	27(31.8)
Adult Child	26(30.6)
DMV	8(9.4)
Other relative	5(5.9)
OT	4(4.7)
Nurse	2(2.4)
Social Worker	1(1.2)
Police	1(1.2)

Informants could choose more than one response, thus totals exceed 100%