Addendum O

Driving and Dementia:
Report on the November 24, 1997 Conference Sponsored by the Committee of Aging of the Michigan State Medical Society

Introduction

As the population of Michigan ages, we can expect both the absolute and relative number of elderly drivers to increase. In addition, since the prevalence of Alzheimer disease and other dementias increases with age, we can expect the number of older drivers with dementia to grow as well. Concern about this issue will bring clinicians and policy makers together to address the conflict between the public's safety and the individual's loss of identity and independence when he or she is no longer allowed to drive because of the cognitive or behavioral consequences of a progressive dementing illness.

Because of its sensitivity, physicians are often reluctant to broach the subject of driving with their older patients, especially those who may be medically and physically sound and only mildly impaired cognitively. Likewise, family members have similar difficulties trying to decide when and how to intervene. In addition, Michigan physicians face a possible violation of the confidentiality of the doctor-patient relationship if they notify the Secretary of State about a potentially impaired driver.

In an effort to address driving and dementia in a systematic way, the Michigan State Medical Society (MSMS) through its Committee on Aging convened a one day conference of clinicians, sociologists, representatives from interested governmental agencies and non-governmental organizations, and experts on driving and dementia. The goals of the November 24, 1997 conference were:

to propose primary care approaches to the evaluation and management of the older driver with cognitive decline to review current reporting methods for potentially impaired drivers and to estimate resources needed by the Secretary of State to evaluate increasing numbers of older drivers at risk for dementia

to propose methods to enhance communication between physicians and the Secretary of State to anticipate legal and legislative consequences and activities related to driving and dementia to propose support services for those who must give up driving.

The purpose of this report is to provide Michigan physicians with the findings of the conference along with an annotated bibliography*. There is still no definitive answer with regard to precisely when a person with mild dementia should stop

driving, but physicians who care for older Michiganians should be involved in the process from both clinical and policy perspectives. We anticipate that this report will raise awareness among Michigan's physicians and stimulate dialogue among physicians and others concerned about the driver with dementia.

Methods

Following literature review, discussion with MSMS members and other physicians, and meetings with representatives from the Secretary of State, AARP, the Alzheimer Association, Office of Services to the Aging, Michigan Nurses Association, Michigan Department of Transportation, and others, the Committee on Aging hosted a one day conference to address the issues related to driving and dementia.

Participants met initially in a plenary session to review clinical aspects of dementia and to discuss the goals of the day's activities. Following the plenary session, five work groups deliberated independently to address each of the following goals:

(1) propose primary care approaches to the evaluation and management of the older driver with cognitive decline

(2) review current reporting methods for potentially impaired drivers and estimate resources needed by the Secretary of State to evaluate the increasing number of older drivers at risk for dementia

(3) propose methods to enhance communication between physicians and the Secretary of State

(4) anticipate legal and legislative consequences and activities related to driving and dementia

(5) propose support services for those who must give up driving.

Appendix 1* lists the participants in the conference and the agency or organization each represents.

At the end of the day, participants again gathered in a plenary session, and the chair of each work group summarized the group's activities and presented preliminary recommendations. During the following months, work group chairs submitted more detailed recommendations which were collated and edited by the conference co-chairs.

Summary of Opening Plenary Session

The opening plenary session consisted of two parts. First, the charge given to the Committee on Aging by the MSMS House of Delegates regarding driving and dementia was discussed with conference participants. Included were a summary of background material evaluated by the Committee on Aging and the Committee's proposed action plan and timetable. Second, an overview of Alzheimer disease and related dementias was presented since a number of the conference participants were not clinicians.

Background and action plan

Table 1* depicts the number of licensed drivers in Michigan in 1997 by age range as well as the number estimated to have dementia based upon national prevalence data and the number who are cognitively impaired at the time of renewal. These estimates suggest that close to 90,000 people who had a license to drive in Michigan in 1997 had sufficient dementia to effect driving, a number expected to double in the next 30 years if demographic projections are correct.

Physicians report regularly to the MSMS Committee on Aging that they are not confident about the appropriate actions to take when trying to evaluate and manage the patient who presents with early signs of dementia and who also continues to drive. Their anecdotal concerns seem valid intuitively, and if projections of the number of older drivers at risk for dementia are accurate, the burden of evaluating these patients will be considerable. Furthermore, the development of consistent guidelines for such evaluations is crucial. To address this expressed need of the membership, the MSMS through its House of Delegates directed the Committee on Aging to make recommendations regarding driving and dementia. The Committee on Aging chose a conference format as its approach to generating the recommendations with the specific goals as previously outlined. However, some physicians and some organizations cautioned against this approach arguing that there are inadequate data regarding dementia and driving, that we lack appropriately validated and reliable tools to do assessments, and that drivers with dementia do not pose a significant public health threat. In addition, some experts are concerned that linking driving and dementia may discourage early evaluation. The latter concern may be a valid one based on anecdotal reports from California where physician reporting of dementia is mandatory. After careful consideration, the Committee on Aging decided to proceed despite these concerns because the numbers are compelling and because both physicians and families need guidance in attempting to deal with driving and dementia.

Update on Alzheimer disease and related dementias

According to the Agency for Health Care Policy and Research (AHCPR) Clinical Practice Guideline on the Recognition and Initial Assessment of Alzheimer Disease and Related Dementias, “dementia is a syndrome of progressive decline

that relentlessly erodes intellectual abilities, causing cognitive and functional deterioration, which leads to impairment of social and occupational functioning. After onset, many patients live a decade or more with advancing debility. Alzheimer disease represents one cause for the dementia syndrome. In this country, the other major cause is vascular dementia, previously called multi-infarct dementia.

The dementia syndromes affect up to four million people in the U.S. with direct and indirect costs to society in the $90 billion range annually. Early stages of dementia may be difficult to diagnose and at times may be hard to distinguish from depression or from medical conditions such as hypothyroidism or vitamin B12 deficiency. While there are symptomatic treatments for some of the cognitive and behavioral consequences of dementia, especially Alzheimer disease (AD), no treatment is available to halt or reverse the course of the disease. The cholinesterase inhibitors are FDA approved drugs for AD and have been demonstrated to stabilize cognitive decline temporarily.

Safe operation of a motor vehicle requires multiple skills, a number of which can be adversely impacted in the setting of progressive cognitive decline. For example, short term memory, way finding, visuospatial processing, and executive functioning for complex tasks as well as judgement and insight can be impaired in early dementia even though the individual may seem to perform well in casual social settings. In such circumstances, only a systematic evaluation can identify deficits, clarify the extent of such deficits and their consequences, and determine appropriate interventions.

Summary of Work Group Activities

Office Evaluation

The work group considering office evaluation identified a number of problems and issues faced by health care providers regarding driving and dementia, the most important of which are lack of training in recognition and diagnosis of dementia at the primary care level and lack of consensus about the appropriate tests to use to evaluate a person’s ability to drive safely when early dementia is present. Additional concerns voiced by the clinicians in the work group are similar to those previously submitted to the Committee on Aging by MSMS members:

confusion about the legality of reporting the driver with dementia and concerns about breaching confidentiality, lack of knowledge about the mechanism of reporting when the decision is made to do so (which forms to use, whom to contact, etc.), concern that the Secretary of State will determine that driving is an "all or none" situation when some patients could drive with certain restrictions (e.g., limited radius with a co-pilot present), reluctance for the physician to become the "bad guy", concern that the person with dementia may be the only

driver in the family, and concern about reimbursement for the labor-intensive assessments and discussion regarding driving and dementia.

The AHCPR has suggested six symptoms, which should trigger an evaluation for the presence of dementia, especially in a person who has a family history of dementia (Table 2*). While the frequency of dementia syndromes increases with advancing age, only family history and Down syndrome have been identified as definite risk factors for Alzheimer disease. Other proposed risk factors with insufficient evidence include previous head trauma, a family history of Down syndrome, thyroid disease, hearing loss, and the age of the patient's mother at the time of conception (the older the patient's mother at the time of conception, the greater the risk).

An additional trigger for an evaluation for the presence of dementia in an older driver includes a concern by a family member, friend, or member of the community or a referral from the Secretary of State. In fact, the AHCPR considers possible difficulty with driving as a symptom that may indicate dementia (handling complex tasks, Table 2*).

Once the need for an evaluation is triggered, participants in the office evaluation work group recommend a self-administered or family-completed questionnaire such as the Functional Activities Questionnaire (FAQ) (Appendix 2*). A score of 9 or higher on the FAQ is the established cut point and should be followed by a focused history including relevant medical, family, social, cultural, and medication information (including alcohol use) as well as details regarding the cognitive or behavioral symptoms potentially affecting the patient’s ability to drive. Multiple sources of patient information may be necessary in order to obtain details of the focused history. Family members are important historians when evaluating patients with early dementia. Suggested questions to ask the patient about his or her driving are listed in Table 3*.

Focused physical examination should follow collection of historical data. The neurological component of the focused physical examination is particularly important to exclude a localizing or lateralizing process and to exclude delirium. Additional key elements include supine and standing blood pressure and pulse, assessment of vision and hearing, evaluation for evidence of heart failure, respiratory insufficiency, and problems with mobility and balance.

As assessment of the mental status is the pivotal component of the initial office evaluation and should be quantitative, valid, and reliable. The Mini-Mental State Examination (MMSE) fits these criteria and has population-based norms by age and educational level (Appendix 3*). However, no single mental status test is clearly superior, and any of a number of tests is acceptable, including the Mental Status Questionnaire, the Short Portable Mental Status Questionnaire, the Blessed Information-Memory-Concentration Test, Abbreviated Mental Test, and

the Blessed Orientation-Memory-Concentration Test. Factors such as visual impairment, sensory impairment, and physical disability may affect the choice of the screening mental status test.

Following the completion of the FAQ (or equivalent), a focused history and physical examination, and a mental status assessment, the physician determines the need for further evaluation to clarify the diagnosis, including a consideration of depression or delirium, and to determine the cognitive and behavioral consequences if dementia is confirmed. While these additional evaluations are in process, the patient should be advised not to drive and encouraged to consider a road test by the Secretary of State prior to resumption of driving if mild dementia is confirmed. The Alzheimer Association suggests that the physician should write out and sign a prescription that prohibits driving while the patient is being evaluated so that the family can present it to the patient if he/she forgets about the physician's advice.

Current relationship with Secretary of State and potential resource needs

Section 257.320 of the Michigan Vehicle Code permits the Secretary of State to conduct an assessment review of a person when the Secretary of State has reason to believe that the person is incompetent to drive a motor vehicle or is afflicted with a mental or physical infirmity or disability rendering it unsafe for that person to drive a motor vehicle. The Secretary of State's Driver Assessment Support Unit (DASU) accepts for review all requests, including letters as well as requests submitted on form OC-88 (Appendix 4*) from private citizens, law enforcement officers, doctors, court personnel, and branch office employees.

When reviewing requests for reassessment, the DASU determines whether there is a connection between the concerns identified and the person's ability to drive safely. The DASU then considers the person's current driving status (e.g., the person may not have a valid license), the most recent contact the driver has had with the Secretary of State, and the driving record, including convictions or crash involvement. A driver will not be considered for re-examination on the basis of age alone.

After the initial review, if the DASU has reasonable concern, the driver will be requested to submit a medical statement or attend an assessment review. If the DASU determines that the condition could or may affect driving, medical information is requested from the physician. This medical information may clarify the concerns and no further testing by DASU will be necessary. If the DASU determines that the condition would or does affect driving, additional medical information is requested simultaneously with the scheduling or driver re-examination.

There are currently 34 analysts working in the DASU and based in branch offices who do the 60 minute reassessments which include a review of the medical statement, vision testing, a written test on the rules of the road, and a road test in the driver's own vehicle. The workload varies seasonally with a marked increase in referrals each spring when older drivers who vacation in the south return to Michigan.

Staff members from the Secretary of State believe that physicians underutilize the current system of driver referral because of liability concerns. It is clear, however, that the number of staff members in the DASU in Lansing and the number of analysts statewide would need to be increased substantially if all drivers with evidence of mild dementia require re-examination.

Proposed relationship with Secretary of State and potential legal issues

The intensity of the conflict between a Michigan physician's obligation to preserve the confidentiality of the doctor-patient relationship and the obligation to the public to report conditions which may impair an individual's driving ability is expected to increase. There is no requirement at present to report, and case law favors the maintenance of confidentiality unless a specific third party (not the public in general) is in jeopardy. This "duty to warn" takes legal precedence over patient confidentiality but only if a specific third party is in "imminent danger", rarely the case in driving and dementia.

The current relationship between the physician and the Secretary of State is primarily through the OC-88* form, but as previously noted, this method of communication has limitations.

The work group makes the following recommendations:

1. Develop and disseminate a practice guideline to physicians regarding driving and dementia, including the determination of the level of dementia which definitely precludes driving (moderate to severe dementia).

2. Encourage physician reporting of drivers with moderate to severe dementia to the Secretary of State and work for legislative action that will provide immunity from liability for such "good faith" reporting.

3. Require more frequent in-person evaluation of drivers at risk for dementia, which includes not only vision screening but also a screening test for cognitive decline. Those who do not pass the cognitive screen should be referred to a physician for evaluation (specifically to identify and address treatable conditions such as depression, polypharmacy, inadequately managed medical problems, etc.) and then undergo on-road testing if indicated.

4. Educate physicians and the public regarding the medical, ethical, regulatory, and legal issues involving driving and dementia.

Support Services

Despite observations that multiple complex and inter-related psychosocial problems may emerge when an older person with dementia gives up driving voluntarily or has driving privileges suspended or revoked, there is a paucity of literature addressing these issues. For example, what is the impact of this loss on physical decline, socialization, and overall well being and quality of life? How does the person with dementia and his or her family cope with and compensate for the loss since driving not only contributes to a person's (and perhaps his or her spouse's) independence but in some instances helps define who the person is?

Public transportation as well as transportation provided by service organizations and volunteer groups vary from community to community, have clear urban-rural differences, are frequently poorly coordinated, and are beginning to encounter problems obtaining sufficient liability coverage. In addition, accessing public transportation may require more cognitive skills than the person with dementia possesses, including the ability to read schedules, to tell time, to way find, and to count money. Furthermore, marketing of transportation provided by service organizations and volunteer groups may not reach those with dementia who are unable to comprehend advertisements in newsletters and newspapers or on radio or television. Finally, the goal of the existing transportation system is to allow people to access medical care and to do basic shopping (food, personal items, and clothes) rather than to provide them with opportunities for socialization and entertainment.

The work group makes the following recommendations:

1. Educate physicians regarding the increased risk of a more rapid than expected decline in physical and cognitive function, mood, and socialization after a person with dementia loses his or her driving privilege. The Michigan State Medical Society should encourage such activity in both undergraduate and graduate medical education programs in the state.

2. Educate the public regarding the issues of driving and dementia. One strategy is to develop mobility planning similar to current estate or pre-retirement planning. Organizations such as the AARP and the Alzheimer Association may be approached to coordinate initiatives in public education and mobility planning.

3. Develop a centralized site for coordinating transportation services within each community so that the older adult has a single number to call for any

transportation need (medical, errands, or socialization). The local Area Agency on Aging may be a possible resource for the coordinating activity.

4. Create a transportation counselor position at local Secretary of State offices who would provide general information for the person with mild dementia who must stop driving and would refer the person and/or family to a local transportation coordination center.

5. Host a statewide conference on driving and dementia to develop additional strategies to enhance transportation services for older adults in general and persons with dementia in particular. These strategies should include outcome measures and methods to assess cost effectiveness.

6. Encourage interdisciplinary research assessing the impact of driving cessation on affect, social activity patterns, and functional status.

Conclusion

The issue of diving and dementia is a complex one in which somewhat crude biomedical evaluations and recommendations regarding mild dementia or possible early dementia may have profound psychosocial consequences for a patient and his or her family. While there is agreement that a well established diagnosis of moderate to severe dementia precludes safe driving, how we deal with mild dementia and “possible early dementia” is problematic.

The MSMS Committee on Aging recommends that physicians maintain a high index of suspicion for dementia when their older patients exhibit the symptoms listed in Table 2* and that they work with the patient and family to limit driving while more thorough screening and evaluation activities are conducted. At the same time, physicians must be highly sensitive to the enormous loss this represents for many such patients.

In addition, physicians must work with senior advocacy groups, legislators, and the Secretary of State to develop methods to identify drivers who are impaired because of dementia and to suspend their driving privileges. At the same time, we must assure that older drivers who are not impaired are not unduly inconvenienced by whatever methods are employed and that age alone is not a criterion for additional testing or re-examination.

* For a complete report on Driving and Dementia, please contact Jennifer Finney, Coordinator at MSMS Headquarters via e-mail at jfinney@msms.org or at (517) 336-5735.