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What factors delay driving retirement by individuals with dementia? (The doctors' perspectives)

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Abstract

Introduction: An increasing number of individuals with dementia drive. Many argue that those with mild dementia are safe to do so. This study explored the attitudes, knowledge and behaviour of hospital-based doctors towards drivers with dementia. **Methods:** 20 doctors in a regional hospital in NSW were surveyed using a 20-item questionnaire. Descriptive statistics were applied to the data collected. **Results:** Half were unaware of the Austroads national guidelines; 60% incorrectly believed that they were legally obliged to report all unsafe drivers in NSW. Most felt that drivers with dementia delay driving retirement for a wide range of reasons. All participants expressed a desire for changes to current clinical practices. **Conclusion:** Drivers with dementia require guidance from their treating physicians. This study found that there is room for improvement in the attitudes, knowledge and practices of hospital-based doctors who treated drivers with dementia. Options for improved road safety and avenues for future research are discussed.

Keywords

Dementia, Doctors, Driving, Intervention, Retirement, Safety

Introduction

Background

In most OECD Member countries, older adults represent the fastest growing segment of the population, and in many, one in every four persons will be aged 65 or older by 2030 [1]. In 2030, the last of the 'Baby Boomers', individuals born between 1946 and 1965, will reach 65 years [2]. It is estimated that by 2030, 20% of the population will be 65 years or over [3]. Age is the leading risk factor for developing dementia [4] and the prevalence rate of dementia amongst those over 65 years is approximately 6.4% [5]. It would seem reasonable, therefore, to expect the number of drivers with dementia to rise [6, 7].

There is a large body of literature focusing on the complex issue of driving and dementia. However, there is a paucity of research regarding interventions which could address this increasingly important medical, social and ethical dilemma [8-10]. The aims of this study were to explore the knowledge, attitudes and behaviour of 20 doctors in a tertiary-referral hospital in regional NSW, Australia. Specifically, the objectives were to better understand factors which doctors perceived to delay driving retirement by individuals with dementia.

What is dementia?

Dementia refers to a deterioration of cognitive function which is severe enough to interfere with one's activities of daily living. As per the Diagnostic and Statistical Manual criteria, memory impairment is required to make a diagnosis of dementia and is a prominent early symptom [11]. Dementia is often accompanied by a decline in language function, ability to perform learned tasks, visuospatial skills and executive function (e.g. planning, judgement, sequencing, abstract thinking) [4]. Of the numerous conditions that can cause dementia, the most frequent include Alzheimer's disease, vascular dementia, dementia with Lewy bodies, frontotemporal dementia and alcohol-related dementia [4]. It may develop abruptly following a stroke or gradually due to Alzheimer's disease.

For many, dementia is a progressive illness. For others, it is static (i.e. the clinical features plateau). Occasionally, individuals may improve as some forms are reversible [4, 11]. The prognosis is variable and is determined by the underlying cause and the treatments applied. Increased age is a recognised risk factor for developing dementia [4, 8]. The results of pooled epidemiological data from Europe established that the prevalence of dementia rises rapidly after the age of 65 years [5]. In 2011, it was estimated that 266,574 Australians have dementia and that by 2050 this number will have risen to 942,624 [12]. At present, a large proportion of older Australians hold a class C driver licence which allows the holders to drive cars, small trucks and even vehicles that accommodate up to 12 persons [13] (Figure 1). It is anticipated that the number of older drivers on our roads will increase as the population ages [6, 7].

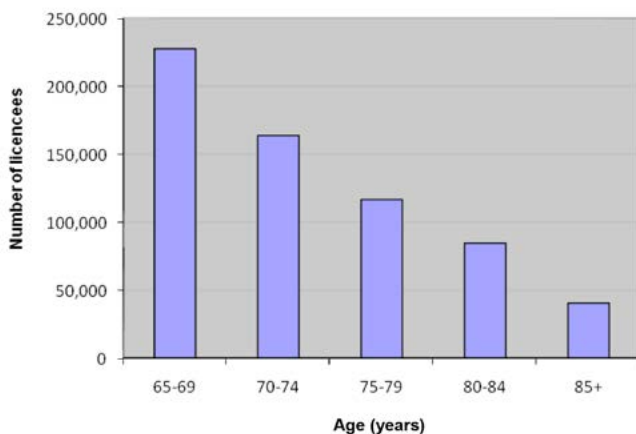


Figure 1. Numbers of class C licence holders by age group in NSW (as at December 2011) [13]

The impact of dementia on driving skills

Driving is widely acknowledged as being a complex task [14-16]. A variety of skills are necessary for safe driving including adequate memory, concentration, attention,

processing speed, planning, judgement and visuospatial skills [17]. Unfortunately, dementia frequently undermines such abilities. Given the often progressive nature of this condition, most individuals with dementia are likely to become unsafe to drive. Furthermore, many have limited insight into the potential impact the condition can have upon their driving skills [17].

There is broad consensus that those with moderate or severe dementia should not drive [6, 14]. However, what remains unclear is how best to advise individuals with very mild or mild dementia regarding the decision to drive [9, 14]. Some authors favour immediate cessation of driving by all upon diagnosis [18-20]. There is evidence, however, that a large proportion of drivers with either very mild or mild dementia can pass an on-road driving test [17, 21]. Consequently, many argue that individuals with mild dementia may be safe to drive for a limited period [6, 14, 22].

Road safety issues for drivers with dementia

Two major road safety issues are worthy of consideration with regard to drivers with dementia: (i) risk of a car crash; and (ii) risk of getting lost. Either event has the potential to jeopardise the safety of the driver, passengers or members of the community.

Several studies have shown that individuals with dementia are at greater risk of a car crash compared to age-matched controls [19-21, 23-28]; reported relative crash risks range from 2.3 [28] to 18.4 [24]. However, at least two studies have found no difference in crash rates between individuals with dementia and healthy controls [29, 30]. This discrepancy may be, in part, related to differing dementia severity amongst participants or different research designs adopted.

Although the topic of dementia and crash risk has been extensively studied [22], less is known about the issue of drivers with dementia becoming lost while driving. Individuals with Alzheimer's disease (the most common form of dementia) are at risk of wandering, becoming disorientated and getting lost [31]. This may occur in both familiar and unfamiliar environments [31]. A review of 207 media reports over a 10 year period, highlighted the potential for dire consequences when drivers with dementia become lost (e.g. not found, injury or death) [32].

Current clinical guidelines

In 2009, the Australian and New Zealand Society for Geriatric Medicine (ANZSGM) published a position statement addressing the topic of driving and dementia [6]. The ANZSGM contends that a diagnosis of dementia does not always necessitate immediate cessation of driving. For those deemed safe to drive, biannual clinical review

is recommended. In 2010, the American Academy of Neurology (AAN) conducted a systematic review of the available literature and issued a practice parameter for physicians [33]. The authors found that there does not exist a test or historical feature that can accurately establish one's risk of having a crash. Specifically, a driver's self-rating of driving ability is not a reliable indicator of increased risk of unsafe driving. The AAN proposed that individuals with mild dementia should strongly consider retirement from driving [33].

In Australia, the responsibility for issuing a licence rests with the Driver Licensing Authority (DLA) [16]. Each State and Territory has a separate DLA (e.g. Roads and Maritime Services in NSW). Mandatory reporting by health professionals of all unsafe drivers applies in South Australia and the Northern Territory [16]. In March 2012, Austroads updated its national clinical guidelines for Australian healthcare professionals [16]. This publication details the medical criteria which must be met for an individual to hold a driver licence in Australia. Individuals with dementia are deemed unfit to retain an unconditional licence (private or commercial). However, they may be eligible to hold a conditional licence once a DLA has taken into account: (i) the nature of the driving task; (ii) a medical assessment of visuospatial perception, insight, judgement, attention, reaction time and memory; and, if necessary, (iii) the results of a practical driving assessment. If a commercial licence is required, the Austroads guidelines stipulate that a medical review must be conducted by an appropriate specialist. Furthermore, Austroads insists that drivers with dementia undergo an annual review of their fitness to drive.

Methods

Participants

All participants were medical doctors recruited from a 500-bed university-affiliated teaching hospital in regional NSW, Australia. A convenience sample of 40 potential participants was emailed a standardised invitation to be involved in the study. Those who expressed an interest in participating, verbally or in writing, were provided with a Participant Information Sheet and a Consent Form. Once the predetermined quota of 20 participants was reached recruitment ceased. The study was approved by the (i) local Human Research Ethics Committee, and (ii) the hospital research governance directorate.

Design

This exploratory study employed a mixed-methods approach. More specifically, a questionnaire was created de novo so as to capture both quantitative and qualitative data. Pilot testing of the questionnaire was not undertaken.

Questionnaire

The questionnaire consisted of 20 items using a series of response options, including 16 items with 'yes' or 'no' answers. Initial questions established the clinical roles and levels of experience in caring for individuals with dementia of the participants. The knowledge base of participants was explored with questions regarding: (i) current guidelines on driving; (ii) occupational therapy driving assessments; and (iii) legal obligations of doctors to report unsafe drivers. The attitudes of participants were sought regarding: (i) safety of drivers with mild dementia; (ii) most appropriate groups to assess fitness to drive; and (iii) factors which delay driving retirement by individuals with dementia. The past behaviours of participants were established regarding: (i) advising patients to cease driving; and (ii) advising patients with dementia to cease driving. The final item was an open-ended question which enabled participants to provide comments.

Procedure

Recruitment was conducted in January 2012 over a four week period. A research assistant contacted potential participants to arrange a suitable time to complete a short questionnaire. The majority of the surveys were conducted face-to-face. The remainder were completed via telephone. It took no longer than five minutes to complete the questionnaire (using either method). All responses were recorded confidentially on sequentially numbered de-identified data sheets.

Results

A total of 20 medical doctors participated: three interns; four resident medical officers; 12 registrars; and one specialist. All respondents indicated that they had, at some time, treated an individual with dementia. Further, 85% of those sampled had previously treated someone with dementia who drives. Although all participants recollected instructing a patient to stop driving, only 65% had advised a patient with dementia to cease driving. A large majority of respondents (80%) felt that some individuals with mild dementia are safe to drive.

Half of all doctors surveyed were aware of the national Austroads 'Assessing Fitness to Drive' guidelines but only 30% knew of the Austroads guidelines for drivers with dementia. Five percent of the participants had knowledge of the ANZSGM position statement on driving and dementia, while 60% incorrectly believed that, as doctors working in NSW, they were legally obliged to notify the Driver Licensing Authority (DLA) of all unsafe drivers.

Half of the participants were aware of occupational therapy driving assessments. One in four respondents were either unsure or incorrect in their assumption that occupational therapy driving assessments are funded entirely by Medicare. Furthermore, 95% of participants were either unsure or incorrect in their estimation of the true cost of such assessments.

A question relating to the optimal time to raise the issue of driving retirement with individuals with dementia allowed respondents to select more than one answer: 80% believed the topic should be raised at the time of diagnosis and 45% felt it should be raised when a driver becomes unsafe to drive. 15% believed that the subject of driving retirement should be raised after a car crash.

As noted above, the responsibility of determining fitness to drive of individuals with dementia lies with the DLA. However, input from health professionals is often required in order to facilitate a decision. Of the doctors surveyed, more than 60% felt that a wide range of individuals should be involved in such a decision (Figure 2).

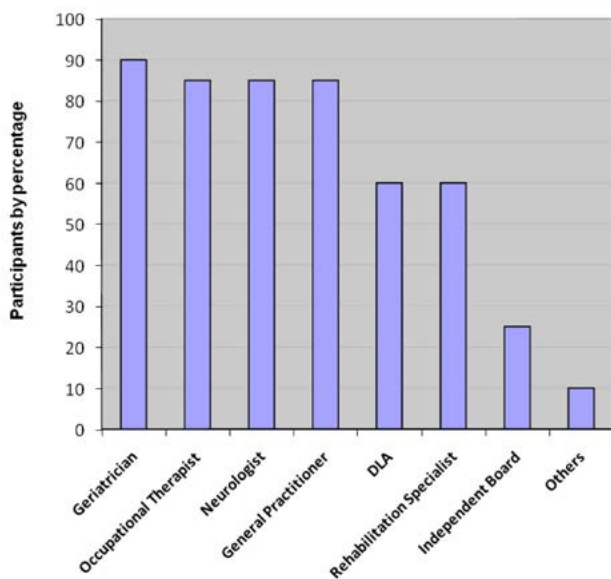


Figure 2. The individuals/groups which participants considered should be responsible for assessing fitness to drive

The participants were asked which factors they believed delayed driving retirement by individuals with dementia. Participants were directed to select one or more responses from a dozen wide-ranging options (e.g. 'denial of diagnosis by patient', 'pleasure of driving'). The majority of participants selected multiple responses (Figure 3). An open-ended item was included (termed 'others') to enable participants to document their suggestions. This item yielded only three responses: 'depression'; 'keeping appointments'; and 'lack of support'.

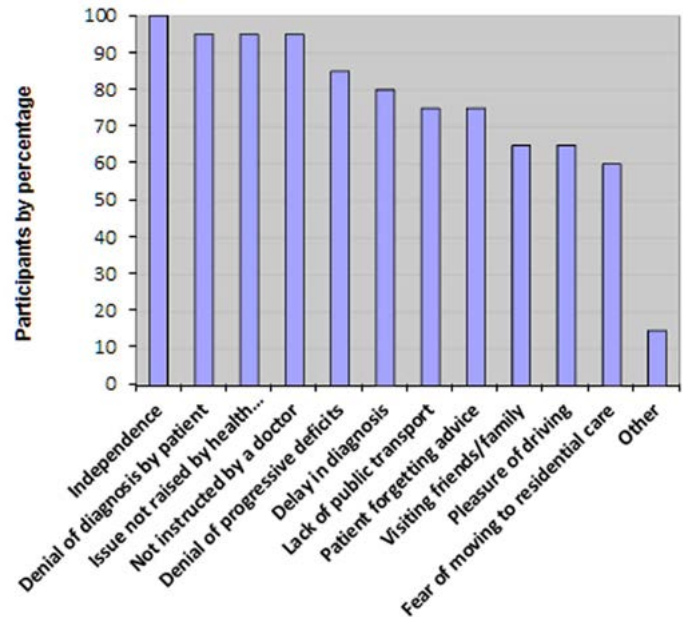


Figure 3. The factors which participants considered delayed driving retirement for individuals with dementia

The participants were also surveyed regarding their thoughts on how current practices could be improved. All participants felt that driving recommendations should be included in hospital discharge letters. Almost all (90%) participants felt it would be helpful if they were informed of the Austroads guidelines during orientation to a new hospital. Most (90%) participants felt that a client-centred booklet on 'driving and dementia' would be useful if it were made available to individuals with dementia. The final survey question enabled participants to provide comments/feedback. The single response to this question proposed that 'family should be involved in the decision making process'.

Discussion

General practitioners (GPs) in South Australia have expressed reluctance to be responsible for the assessment of fitness to drive of individuals with dementia [34]. A survey of 485 GPs revealed that 12% were unaware of their obligation, under South Australian state law, to report all unsafe drivers. This is in contrast with the findings of the current study in which 60% of respondents incorrectly believed that they are legally obliged to report all unsafe drivers in New South Wales. Most (80%) of the South Australian GPs felt that a 'multidisciplinary driving centre' would be a useful resource which mirrors the findings of the current study where the majority of doctors surveyed felt that a wide range of groups/individuals should be responsible for the assessment of fitness to drive (Figure 2).

In a US study, physicians were more likely to raise the issue of driving with their patients if they: (i) had a strong perceived role regarding driving; (ii) were older; (iii) believed it was important to address driving; and (iv) were aware of the American Medical Association's guide on older drivers [35]. They concluded that a concerted effort should be made to provide physicians with the tools to address the issue of driving and dementia. This reflects findings from the current study in which most participants felt that a number of interventions would be worth pursuing.

Another study found that 75% of Geriatricians feel that physicians are responsible for reporting patients 'who may be a danger to others' [36]. The study, involving a national survey of 467 Geriatricians in the United States, found that more than 86% would contact state authorities despite the objections of a patient. Further, 72.9% would contact authorities despite the objections of a patient's family. However, over one in four participants claimed to be unaware as to how to report an unsafe driver to the appropriate authorities.

In 2003, a survey of 220 public hospital doctors in Adelaide to determine their clinical practice, knowledge and attitudes regarding the assessment of fitness to drive found that 70% of the participants were aware of the Austroads national guidelines but their knowledge of its contents was poor [37]. Many of the respondents were uncomfortable with the responsibility of assessing fitness to drive. The conclusion was that alternative approaches to the assessment of fitness to drive should be considered. Beran [38] subsequently argued that this paper [37] should 'sound warning bells for all doctors who assess fitness to drive'. Beran's concern stemmed from the apparent apathy of hospital doctors towards the assessment of fitness to drive.

A striking finding of the current study was the lack of awareness among participants of the Austroads 'Assessing Fitness to Drive' national guidelines. Further, the majority of participants were incorrect in their belief that reporting all unsafe drivers to the DLA is mandatory in NSW. As explained earlier, mandatory reporting of unsafe drivers to the DLA only applies to health professionals (e.g. doctors, optometrists, occupational therapists) practicing in South Australia and the Northern Territory.

A lack of knowledge was apparent when participants were asked about occupational therapy driving assessments. Although such assessments are available nationally, many doctors were unaware of their existence. In addition, most respondents were inaccurate in their estimation of the true cost of such assessments. Interestingly, most participants supported the input of an occupational therapist in the decision making process. In response to a question regarding the factors which doctors consider delay driving

retirement, the majority of participants chose 10 different responses (Figure 3). This finding suggests that the decision by drivers with dementia to delay driving retirement is not based on a single factor.

Implications and recommendations for road safety

Many older drivers do not plan for driving cessation [39, 40]. Individuals with dementia often develop difficulty with planning, judgement and problem solving [4, 41]. Furthermore, it has been found that 80% of drivers with dementia continue to drive despite having a car crash [42]. This is of concern, not least because older drivers involved in a car crash are more likely to be seriously or fatally injured [43]. It would seem reasonable, therefore, that steps be taken to enhance road safety for all.

Therefore, the following measures are proposed to improve road safety:

- undergraduate curricula for medical students should include content on driving and specifically driving and dementia;
- hospital doctors should be reminded during orientation of the updated Austroads national guidelines;
- hospital doctors should be reminded during orientation of their legal obligations regarding the potential need to report unsafe drivers (mandatory in SA and NT);
- individuals with dementia who are admitted to hospital should have driving recommendations included in discharge letters;
- DLA representatives should approach hospital administrators to initiate annual sessions on DLA-led education for hospital doctors; and
- DLA representatives should approach medical schools to provide sessions to students on Australian legislative requirements for driving and specifically driving and dementia.

Strengths and limitations

To our knowledge, this is the first study to specifically examine the attitudes, knowledge and behaviour of hospital-based doctors regarding drivers with dementia. A limitation of this exploratory study is the low number of participants which precludes the use of inferential statistical analyses; thus only descriptive statistics were applied. In addition, the low sample size of this study limits the generalisability of its findings. A strength of the study is the

clear identification of a gap in knowledge of hospital-based doctors regarding the topic of driving and dementia.

Recommendations for future research

As noted earlier, 90% of doctors surveyed would find a client-centred booklet on 'driving and dementia' useful. Thus the development and evaluation of a 'decision aid' booklet designed to facilitate early retirement from driving by individuals with dementia is appropriate; this is currently being undertaken by our research group.

Conclusion

The aim of this study was to explore the subject of driving and dementia from a hospital-based doctor's perspective with the intent of facilitating improvements in road safety. The findings highlight an increasingly important road safety issue - many doctors feel trapped between the Scylla of patient autonomy and the Charybdis of reporting unsafe drivers. To navigate this strait successfully, some changes are required. It is hoped that the findings of the current study will inform clinical practice and encourage additional research focussing upon potential interventions for drivers with dementia.

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Influences on young drivers' reported driving behaviours and perceptions: a focus group study

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Abstract

Forty-four (25 females) Australian citizens aged 17-24 years, all holding a current driving licence, participated in six focus groups to discuss: personal factors – age, maturity and inexperience; and other factors (including safety campaigns) which could affect driving behaviours. Group discussions were audio taped and data analysis proceeded by grounded theory. Major themes were: intersections, parental influences, inexperience/inattention and safety campaigns. Several sub-themes associated with these

major themes were extracted from information provided by participants. Prime influencing parties on early driving experiences are outlined and potential areas for material from this study to contribute to road safety are discussed.

Keywords: Inattention; Inexperience; Parental influences; Qualitative study; Road safety campaigns