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Driving with dementia: obstacles and solutions

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Driving with dementia: obstacles and solutions

**A thesis submitted in fulfilment of the
requirements for the award of the degree of**

Doctor of Philosophy

from the

University of Wollongong

by

Dr John Carmody MB BCh FRCPI FRACP

Faculty of Science, Medicine and Health

2015

CERTIFICATION

I, John Carmody, declare that this thesis, submitted in fulfilment of the requirements for the award of Doctor of Philosophy, in the Faculty of Science, Medicine and Health, University of Wollongong, is wholly my own work unless otherwise referenced or acknowledged. The document has not been submitted for qualifications at any other academic institution.

John Carmody (Candidate)

12th March 2015

VERIFICATION

This statement verifies that the greater part of the work in the below-named manuscripts is attributed to the candidate. John Carmody contributed to study conception and design, undertook data collection and analysis, and prepared the first draft of each manuscript. He then responded to editorial suggestions of co-authors, and prepared the articles for submission to the relevant journals. Details on the contributions of co-authors can be found in Chapter 1, structure of the thesis.

Associate Professor Victoria Traynor (Principal Supervisor)

John Carmody (Candidate)

12th March 2015

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PUBLICATIONS CONSTITUTING THIS THESIS

Published Articles

Carmody, J & Traynor, V 2014, 'Driving and dementia: a modern Gordian Knot', *Journal of Neurology and Clinical Neuroscience*, vol. 1, p. 1; **(Chapter 2)**.

Carmody, J, Traynor, V & Marchetti, E 2014, 'Barriers to qualitative dementia research: the elephant in the room', *Qualitative Health Research*, doi: 1049732314554099; **(Chapter 3)**.

Carmody, J, Traynor, V & Iverson, D 2012, 'Dementia and driving: an approach for general practice', *Australian Family Physician*, vol. 41, pp. 230-233; **(Chapter 4)**.

Carmody, J, Traynor, V & Steele, A 2014, 'Dementia, decision aids and general practice', *Australian Family Physician*, in press; **(Chapter 5)**.

Carmody, J, Traynor, V, Iverson, D & Marchetti, E 2013, 'Driving, dementia and the Australian physician: *primum non nocere*', *Internal Medicine Journal*, vol. 43, pp. 625-630; **(Chapter 6)**.

Carmody, J, Granger, J, Lewis, K, Traynor, V & Iverson, D 2013, 'What factors delay driving retirement by individuals with dementia?: the doctors' perspectives', *Journal of the Australasian College of Road Safety*, vol. 24, pp. 10-16; **(Chapter 7)**.

Carmody, J, Carey, M, Traynor, V & Iverson, D 2013, 'Electronic discharge summary driving advice: current practice and future directions', *Australasian Medical Journal*, vol. 6, pp. 419-424; **(Chapter 8)**.

Carmody, J, Carey, M, Potter, J, Marchetti, E, Traynor, V & Iverson, D 2014, 'Driving and dementia: equity, obligation and insurance', *Australasian Medical Journal*, vol. 7, pp. 384-387; **(Chapter 9)**.

Carmody, J, Potter, J, Lewis, K, Bhargava, S, Traynor, V & Iverson, D 2014, 'Development and pilot testing of a decision aid for drivers with dementia', *BMC Medical Informatics and Decision Making*, vol. 14, p. 19; **(Chapter 10)**.

Article Under Review

Carmody, J, Veerhuis, N, Traynor, V & Batterham, M (submitted), 'A prospective interventional cohort study of a decision aid for drivers with dementia', *Australian and New Zealand Journal of Public Health*; **(Chapter 11)**.

OTHER PUBLICATIONS ARISING FROM THIS THESIS

Andrew, CL, Carmody, J, Lewis, K, Traynor, V & Iverson, D 2013, 'Developing a decision aid for drivers living with dementia: supporting consumers and carers in the process of making decisions about driving retirement', *Australian Occupational Therapy Journal*, vol. 60, pp. s70-71.

Butler, L 2014, *Eldernet Gazette*, viewed 22 July 2014,
http://www.eldernetgazette.co.nz/blog/_view/id_644

Carmody, J, Traynor, V & Iverson, D 2012, 'Dementia and driving: an approach for general practice (letter of reply)', *Australian Family Physician*, vol. 41, pp. 459-460.

Carmody, J, Traynor, V, Iverson, D & Andrew, C 2014, *Dementia and driving: a decision aid*, University of Wollongong, Wollongong.

Carmody, J, Traynor, V, Iverson, D & Marchetti, E 2013, 'Driving, dementia and the Australian physician: *primum non nocere* (letter of reply)', *Internal Medicine Journal*, vol. 43, pp. 1357.

DPS 2014, 'New decision aid booklet targets driving and dementia', DPS News, viewed 28 November 2014, <http://www.agedcareguide.com.au/news/2014/09/24/new-decision-aid-booklet-targets-driving-and-dementia/>

Traynor, V, Andrew, C & Carmody, J 2013, 'Navigating the road to retirement from driving', *Australian Journal of Dementia Care*, vol. 2, pp. 19-20.

Woodhead, M 2013, 'Fit-to-drive dementia guide needed: expert', *Australian Doctor*, viewed 22 July 2014, <http://www.australiandoctor.com.au/news/latest-news/fit-to-drive-dementia-guide-needed-expert>

Carmody, J & Traynor, V 2014, 'Dementia, driving retirement and decision aids (letter of reply)', *Journal of the Royal College of Physicians Edinburgh*, in press.

PRESENTATIONS ARISING FROM THIS THESIS

1. 'When can I drive again?'

Grand rounds, Wollongong hospital, May 2011.

2. 'Retirement from driving for people with dementia: a two-way street'

Three minute thesis competition, University of Wollongong, June 2011.

3. 'Driving and dementia research project: what next?'

Guest lecture series, Graduate school of medicine, University of Wollongong, September 2011.

4. 'Driving and dementia: enabling early retirement from driving'

Aged care research meeting, Bulli hospital, September 2011.

5. 'Developing a driving and dementia decisional support aid'

Driving seminar, Royal rehabilitation centre, Sydney, October 2011.

6. 'Developing a driving and dementia decision aid tool'

Aged care and rehabilitation research meeting, Sutherland hospital, November 2011.

7. 'Driving and dementia: enabling early retirement from driving'

Knowledge transfer workshop, Wesley conference centre, Sydney, February 2012.

8. 'Should your patients be driving home?'

Connecting with neuroscience conference, St George hospital, Sydney, June 2012.

9. 'Neuroscience research: a clinical perspective'

Illawarra health and medical research institute seminar, Wollongong hospital, August 2012.

10. 'Dementia and driving: a potential solution for some'

Roads and maritime services seminar, Villa d'oro function centre, August 2012.

11. 'Dementia and driving: a solution for some?'

Older driver taskforce, NSW department of transport, Sydney, October 2012.

12. 'Dementia and driving: an overview'

Local government safety meeting, City council, Shellharbour, February 2013.

13. 'Pilot study of a decision aid for drivers with dementia'

Aged care research meeting, Wollongong hospital, August 2013.

14. 'Decision aid for drivers with dementia'

Older driver safety meeting, Illawarra retirement trust, Woonona, September 2013.

15. 'Assessment of driver safety in primary care'

Clinical research meeting, Bulli medical practice, September 2013.

16. 'Can I drive home from hospital?'

Library medical staff presentation, Wollongong hospital, October 2013.

ABSTRACT

Dementia refers to a syndrome characterised by a progressive deterioration of memory and at least one other cognitive domain which interferes with daily function and independence. Epidemiological data indicate the prevalence of dementia to be 6.4% of those aged over 65. Recent estimates by the World Health Organisation claim that 35.6 million people have dementia. It is expected that this figure will double every 20 years to 115.4 million by 2050. The issue of driving is critically important for people as they age prompting calls for the development of interventions to maintain the mobility of older adults. Given the rising number of drivers with dementia on our roads, the poor uptake of public transport by older people and the negative consequences of driving cessation, there is a clear need for novel strategies to enhance both personal independence and community safety. Most medical and vehicle licensing authorities concur that individuals with moderate or severe dementia cannot drive safely. However, there remains a lack of consensus regarding the impact of mild dementia on driving ability.

The principal aims of this thesis were threefold. First, to determine the approach adopted by doctors toward drivers with dementia. This required investigation of: (i) the knowledge, attitudes and behaviour of junior doctors; (ii) the provision of driving advice in hospital discharge summaries; and (iii) Australian reporting obligations and medico-legal frameworks. Second, to create a user-friendly decision aid for drivers with dementia. International decision aid quality criteria were adopted to ensure that this decision aid would lead to: (i) reduced decisional conflict; (ii) improved knowledge levels; and (iii) enhanced decisional satisfaction. Last, to make a meaningful contribution to academic literature, public policy and future research regarding driving and dementia. This necessitated the provision of: (i) a management approach for general practitioners; (ii) an overview of existing dementia-related decision aids; (iii) an

analysis of the ethical issues faced by physicians; and (iv) a review of the barriers commonly encountered during qualitative dementia research.

This thesis by publication consists of a series of interwoven studies and reviews which address the topic of driving and dementia. Qualitative, quantitative and mixed-methods approaches were adopted, as needed, during the construction of this body of work. As with most research involving people with dementia, prospective ethical approval was secured.

Decision aids are evidence-based tools which help patients (and carers) participate in choosing among health care options. Several high-quality dementia-related decision aids already exist. This thesis incorporated the development of a novel decision aid tailored for drivers with dementia. Following a successful pilot study of 12 local participants, a prospective interventional cohort study was conducted in Australia and New Zealand among 20 participants. Following use of the decision aid, decisional conflict, knowledge and satisfaction with decision improved. Acceptability levels were high. As the first self-administered decision aid designed specifically for drivers with dementia, this booklet represents an acceptable, person-centred and low-cost intervention of relevance to an expanding portion of the community.

In summary, with the rising prevalence of dementia and an increasing reliance upon the private car, drivers with dementia require non-adversarial guidance. Of paramount importance is the need to carefully balance personal independence with community safety: *aegrescit medendo*. Amidst this context, the thesis achieved three meaningful outcomes: (i) contributed to knowledge regarding the approach of doctors toward drivers with dementia; (ii) created a decision aid which can assist people with dementia retire from driving; and (iii) informed debate, public policy and future research. Lastly, it is hoped that this body of work will counter a lingering social taboo: driving by people with mild dementia.

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LIST OF KEY ACRONYMS AND DEFINITIONS

AAN	American Academy of Neurology
ADI	Alzheimer's Disease International
AMA	Australian Medical Association
ANZSGM	Australian New Zealand Society for Geriatric Medicine
CALD	Culturally and linguistically diverse
CDR	Clinical dementia rating
DA	Decision aid
DDDA	Driving with dementia decision aid
DLA	Driver licensing authority
GP	General practitioner
IPDAS	International patient decision aids standards
MMSE	Mini mental state examination
NHMRC	National Health and Medical Research Council
NIH	National Institutes of Health
NSW	New South Wales
OECD	Organisation for Economic Cooperation and Development
SD	Standard deviation
SPSS	Statistical package for the social sciences
TIA	Transient ischaemic attack
WHO	World Health Organisation

CHAPTER 1: Introduction

Preamble

Driving is a deceptively complex task. Lipski argued that ‘until we have better evidence about what is safe, we should not allow people with dementia to drive motor vehicles’ (1997, p. 453). Over a decade later, convincing evidence about what is safe remains elusive (Martin, Marotolli & O’Neill 2009), and no clear management protocols exist for doctors caring for patients with dementia who drive. To complicate matters further, instructing a patient to retire from driving may irrevocably damage a long standing doctor-patient relationship (Odell 2005).

The principle objective of this research is to develop, pilot test and evaluate the impact of a decision aid for drivers with dementia. This booklet was generated from an established theoretical framework and moulded by expert and client feedback. Four interweaving streams of evidence provide a clear impetus for this work: (i) the prevalence of dementia is rising worldwide (OECD 2001); (ii) the number of older drivers in Australia is increasing (AA NSW 2010); (iii) individuals with dementia are increasingly dependent on cars (Eby & Molnar 2010); and (iv) decision aids have demonstrated utility in health care choices (Stacey et al. 2011).

This introductory chapter begins with a brief background of: (i) dementia; (ii) older drivers; (iii) driving and dementia; and (iv) decision aids and their theoretical underpinnings. It identifies gaps in the available literature and lists the specific aims of the research. Finally, an outline of the structure of the thesis is provided.

Background

In most Organisation for Economic Cooperation and Development (OECD) Member countries, older adults represent the fastest growing segment of the population (OECD 2001). It is estimated that by 2030, 20% of the Australian population will be 65 years or over (ABS 2008). Age is the leading risk factor for developing dementia (Ropper & Samuels 2012) and the prevalence of dementia amongst those over 65 is greater than 6% (Van der Flier & Scheltens 2005). It would seem reasonable, therefore, to expect the number of drivers with dementia to

rise (ANZSGM 2010). There is a considerable body of literature (Breen et al. 2007; Iverson et al. 2010; Martin et al. 2013) addressing the complex issue of driving and dementia. Much of this evidence is of a very high standard (e.g. systematic literature reviews (Breen et al. 2007; Iverson et al. 2010; Martin et al. 2013), critical literature reviews (Carr & Ott 2010; Odell 2005)). However, there is a paucity of research regarding interventions for this increasingly important medical, social and ethical dilemma.

Dementia

Dementia refers to a syndrome characterised by a disturbance of multiple cognitive functions. Such deficits are often accompanied by deterioration in emotional control, social behaviour, or motivation (WHO 2010). The World Health Organisation (WHO) recently established that 35.6 million people have dementia. In addition, WHO anticipates that the number of people with dementia will double every 20 years, reaching 115.4 million in 2050 (WHO 2012). The three commonest forms of dementia are Alzheimer's disease, vascular dementia and dementia with Lewy bodies (Ropper & Samuels 2009). People with dementia have a high level of medical comorbidity (Schubert et al. 2006) and a significantly reduced life expectancy (Larson et al. 2004).

The clinical features of dementia can include difficulty with learning, reasoning, spatial awareness and orientation. A large majority of patients will also experience behavioural and psychological symptoms (Burns & Iliffe 2009). Notwithstanding the wide variability in rates of decline between individuals, dementia is usually degenerative and progressive (Grand et al. 2011). Clinicians often use the mini-mental state examination to grade severity of dementia: mild 21-25; moderate 11-20; and 0-10 severe (Ropper & Samuels 2009). However, other methods do exist (Ropper & Samuels 2009). Perhaps not surprisingly, dementia often impairs executive function which impacts negatively upon decision making competency.

Older drivers

Older members of the community often rely upon a private car as their principal mode of transport (Meulenens et al. 2006). Older drivers have the lowest number of car accidents per year but have the highest risk of morbidity and mortality if involved in a crash (Meulenens et al. 2006). Many drivers aged 65 or older self-regulate their driving behaviour (Eberhard 1996). Of concern, however, is that they do not usually engage in self-planning for driving cessation (Kostyniuk & Shope 2003).

Retirement from driving can be a distressing event for older drivers (Knapp & VandeCreek 2005). It is accompanied by an increased risk of: (i) depression (Marattoli et al. 1997); (ii) difficulty accessing services (Taylor & Tripodes 2001); (iii) difficulty with social integration (Mezuk & Rebok 2008); and (iv) transfer to a nursing home (Freeman et al. 2006). Furthermore, driving cessation may be viewed as a threat to one's self-worth and independence (Snyder 2005). This is particularly true for older drivers living in rural and regional Australia with limited access to public transport.

Driving and dementia

The subject of driving and dementia raises a range of important ethical and medico-legal issues (Drazkowski & Sirven 2011; Snyder 2005). Few would disagree that there is a need to balance road safety with the transport requirements of our ageing population (Breen et al. 2007; O'Neill 2007). Yet much of the literature relating to driving and dementia focuses upon safety rather than mobility (O'Neill 2007). Achieving an appropriate balance can prove elusive as, despite the existence of evidence-based clinical guidelines (Iverson et al. 2010), many doctors simply do not discuss driving with their patients (Drickamer & Marattoli 1993; Jang et al. 2007). The need for such discussions is underscored by the fragility of older drivers and their elevated risk of injury in car crashes (Carr et al. 2010).

Decision aids

Decision making involves making choices between different courses of action or inaction; this process involves weighing up uncertain positive and negative outcomes, leading to decisional conflict (O'Connor, Jacobsen & Stacey 2002; Prunty et al. 2008). Decision aids facilitate patient involvement in decisions about their health care leading to decisions which are informed and consistent with one's values (Feldman-Stewart et al. 2007; O'Connor et al. 1998). A recent Cochrane review (Stacey et al. 2014) established that decision aids: (i) improve knowledge; (ii) reduce decisional conflict; (iii) clarify expectations of possible benefits and harms; (iv) lead to choices consistent with informed values; and (v) result in greater participation in decision making.

The Ottawa Decisional Support Framework (ODSF) (O'Connor 2006) is a theoretical framework which addresses the uncertainty or decisional conflict which may arise around health care choices. This framework consists of three components: (i) decisional needs; (ii) decisional support; and (iii) decisional quality. In line with this framework, one aim of this research is to meet the decisional needs of drivers with dementia by providing them with adequate support so as to enhance the quality of their decision making process. The ODSF has been used to develop other dementia-related decision aids (Hanson et al. 2011; Stirling et al. 2012).

Thus far, much of the transport safety literature concentrates on how best we can identify unsafe older drivers (O'Neill 2007). This study promotes a shift in thinking away from a focus on assessment of fitness to drive. Rather, it emphasises the need to facilitate planning for retirement from driving. By adopting a non-threatening approach, it is hoped that individuals with dementia will be more likely to raise this subject with their family, carer or health care professional. Further, it is anticipated that a decision aid could provide clinicians with an opportunity to offer their perspective. It is expected that the innovative adaptation of this person-centred resource will aid readers' decision making.

Aims

This research project aims to contribute to knowledge regarding the approach of doctors toward drivers with dementia, to create a decision aid which will help people with dementia retire from driving, and inform debate, public policy and future research.

The specific aims of this research are:

1. To determine the approach adopted by doctors toward drivers with dementia, including:
 - The knowledge, attitudes of behaviour of hospital-based doctors;
 - The inclusion of driving advice in electronic discharge summaries; and
 - The reporting obligations and medico-legal frameworks which apply in Australia.
2. To create a structured decision aid tailored to the needs of drivers with dementia which will:
 - Reduce decisional conflict;
 - Improve knowledge levels and decisional satisfaction; and
 - Facilitate decision making about driving retirement.
3. To inform debate, public policy and future research regarding driving and dementia by:
 - Exploring the barriers to qualitative dementia research;
 - Proposing a management approach for general practitioners;
 - Providing an analysis of the ethical issues faced by physicians; and
 - Describing existing dementia-related decision aids relevant to primary care.

Structure of the thesis

This thesis, by series of published papers, is submitted in fulfilment of the requirements of a Doctor of Philosophy. All chapters are presented as journal articles. Chapters 2 through 11 comprise ten articles: nine have been published and one has been submitted for editorial review. Although the articles are formatted according to the guidelines of each journal, the referencing has been changed to Harvard style for consistency throughout the thesis. In order to enhance coherence of this thesis by publication, a brief summary of each chapter is provided below.

Although the main thrust of each chapter is ‘signposted’ in this manner for the reader, issues are discussed in much greater depth in later chapters. Accordingly, each chapter (2-11) serves to address the specific aims of this thesis.

Chapter 2 offers a brief overview of the challenges faced by clinicians when addressing the issue of driving and dementia. This invited editorial was written by the candidate and co-authored by Associate Professor Victoria Traynor, and was published in the *Journal of Neurology and Clinical Neuroscience* in 2014.

It became clear during the course of this work that dementia research (both quantitative and qualitative) is poorly funded relative to other medical conditions. However, qualitative dementia research is hampered by additional obstacles. Chapter 3 provides a review of the literature on the barriers to qualitative dementia research. It describes the benefits of a qualitative approach and highlights the inadequacy of government funding in Australia and the United States. Potential solutions are proposed. This article was written by the candidate with co-authors Associate Professor Victoria Traynor and Professor Elena Marchetti, and was published in *Qualitative Health Research* in 2014. Subsequent to the publication of this paper, the Australian government announced a significant increase in funding of dementia-related research.

Chapter 4 provides a review of the literature on the issue of driving and dementia from a primary care perspective. Specifically, it describes the challenges faced by primary care physicians when discussing retirement from driving and proposes a multi-faceted management strategy. The article was written by the candidate with co-authors Associate Professor Victoria Traynor and Professor Don Iverson, and was published in *Australian Family Physician* in 2012.

Chapter 5 provides an overview of existing dementia-related decision aids and their relevance to general practitioners. Potential directions for future research are explored. The article was written by the candidate with co-authors Associate Professor Victoria Traynor and Ms Ana Steele, and was accepted for publication in *Australian Family Physician* in 2014.

Chapter 6 provides a review of the literature on the ethical issues which arise for Australian physicians when caring for drivers with dementia. It compares the current medico-legal framework in Australia with New Zealand, Singapore and the United States. The article was written by the candidate with co-authors Associate Professor Victoria Traynor, Professor Don Iverson and Professor Elena Marchetti, and was published in the *Internal Medicine Journal* in 2013.

Chapter 7 describes the knowledge, attitudes and behaviour of hospital-based doctors towards people with dementia who drive. This survey explores the factors which delay driving retirement from a doctor's perspective. This article was written by the candidate with co-authors Dr Jeremy Granger, Ms Kate Lewis, Associate Professor Victoria Traynor and Professor Don Iverson, and was published by the *Australasian College of Road Safety Journal* in 2013.

Chapter 8 describes the use of electronic discharge summaries by junior doctors to record driving advice for hospitalised patients. It explores the barriers to the inclusion of driving advice and offers a novel template which could be incorporated into electronic discharge summaries. The article was written by the candidate with co-authors Dr Michael Carey, Associate Professor Victoria Traynor, Professor Don Iverson and was published in the *Australasian Medical Journal* in 2013.

Chapter 9 explores several challenges experienced by people with dementia who drive. Specifically, it discusses access to public transport, mandatory reporting by health professionals and insurance company policies. The results of a telephone survey of motor vehicle insurance providers are described. The article was written by the candidate with co-authors Dr Michael Carey, Professor Jan Potter, Professor Elena Marchetti, Associate Professor Victoria Traynor and Professor Don Iverson, and was published in the *Australasian Medical Journal* in 2014.

Chapter 10 describes the development and pilot testing of a decision aid for drivers with dementia. An introduction to decision aids and their underlying theoretical framework is also provided. The article was written by the candidate with co-authors Professor Jan Potter, Ms

Kate Lewis, Dr Sanjay Bhargava, Associate Professor Victoria Traynor and Professor Don Iverson, and was published in *BMC Informatics and Medical Decision Making* in 2014.

Chapter 11 describes a prospective interventional cohort study of a decision aid for drivers with dementia. The results from this international study informed the current content and structure of the decision aid. The article was written by the candidate with co-authors Ms Nadine Veerhuis, Associate Professor Victoria Traynor and Professor Marijka Batterham, and was submitted to the *Australian and New Zealand Journal of Public Health* in 2014.

In the final chapter (Chapter 12), a concise overview of the project findings is provided. This is followed by a brief outline of the implications, limitations and strengths of this work. Recommendations for future research and a short summary are also presented.

CHAPTER 2: Dementia and driving: a modern Gordian Knot

Article published in the *Journal of Neurology and Clinical Neuroscience*

Carmody, J & Traynor, V 2014, 'Driving and dementia: a modern Gordian Knot', *Journal of Neurology and Clinical Neuroscience*, vol. 1, p. 1.

Introduction

Dementia refers to a syndrome characterised by a progressive deterioration of memory and at least one other cognitive domain (e.g. language, executive function, praxis) which interferes with one's daily function and independence. Epidemiological data indicate the prevalence of dementia to be 6.4% of those aged over 65 (Van der Flier & Scheltens 2005). Recent estimates by the World Health Organisation (WHO) claim that 35.6 million people have dementia (WHO 2012). Furthermore, the WHO (2012) anticipates that the number of people with dementia will double every 20 years, to 65.7 million in 2030 and 115.4 million in 2050. As our population is ageing, the number of older drivers on our roads is increasing. Of concern is that 30-45% of individuals with dementia continue to drive (Lloyd et al. 2001). Most medical and vehicle licensing authorities concur that individuals living with a dementia cannot drive safely (ANZSGM 2010; Iverson et al. 2010) but there is a lack of consensus about the impact of mild dementia on driving capacity (Carmody, Traynor & Iverson 2012a). Accordingly, clinicians are faced with an emerging global dilemma about how to balance the promotion of personal mobility of individuals with mild dementia with the promotion of public safety. Add to this, the inadequacy of alternative transport options for older members of the community.

International context

In most Western nations, there is requirement that clinicians report significant impediments to driving safety to a licensing authority. However, as dementia often impairs one's memory and insight, individuals with dementia, one could argue, should be exempt from such expectations. If so, who then is responsible for pursuing licence cancellation of unsafe drivers with dementia: carers; family; friends; clinicians; or government? In most Western countries, clinicians are not responsible for the cancellation of driver licences. Rather, this task is delegated to a government body (e.g. department of motor vehicles (United States), driver and vehicle licensing agency (United Kingdom), driver licensing authority (Australia)). Mandatory reporting by clinicians of unsafe drivers exists in only a minority of nations. As legislative requirements vary considerably within and among countries, it behoves clinicians to accustom themselves to local

laws and procedures (Carmody et al. 2013b). An additional salient concern of many drivers relates to motor vehicle insurance coverage. It is often suggested that impaired drivers should inform their motor vehicle insurer to ensure that their coverage remains valid. In Australia, motor vehicle insurers only require a valid driver licence and notification of a diagnosis of dementia is not necessary. Failure to do so (i.e. inform one's insurer) does not impact negatively upon an individual's cover/policy (Carmody et al. 2014b).

Assessment of driving safety

A large body of literature addresses the topic of how best to assess the safety of drivers with dementia: the American Academy of Neurology (AAN) and the Australian and New Zealand Society for Geriatric Medicine (ANZSGM) comprehensively reviewed the existing literature regarding assessment of fitness to drive of individuals with dementia (ANZSGM 2010; Iverson et al. 2010). The AAN systematic review concluded that 'there is no test result or historical feature that accurately quantifies driving risk' (Iverson et al. 2010, p. 1320). The ongoing search for a test which is both 100% sensitive and specific is admirable, yet fraught with challenges. First, on-road occupational therapy driving assessments are often regarded as the gold standard in determining fitness to drive. Yet, individuals with dementia are ill-suited to such an assessment as their condition is both progressive and often accompanied by fluctuations. Neither ANZSGM nor AAN support sole reliance upon occupational therapy assessments in determining driving safety (ANZSGM 2010; Iverson et al. 2010). Second, no off-road test, including driving simulation, can accurately recreate the complex nature of the driving task. Third, if an individual with dementia is found to have passed a test then how often must they be retested (e.g. every 6 months)? Fourth, if an individual fails a test, will they voluntarily cease driving? Finally, an undue emphasis on testing distracts drivers and clinicians from a more pertinent issue: planning for retirement from driving.

Impact of driving retirement

Driving retirement has been shown to have a negative impact upon older drivers, carers, family members and the doctor-patient relationship (Carmody et al. 2013b). Empowering older drivers with dementia to plan for driving retirement aligns with the ethical principles of autonomy, beneficence and non-maleficence (Carmody et al. 2013b). The arrangement of alternative forms of transport is crucial when considering retirement from driving. A pre-planned strategy which addresses the transition to non-driving obviates the need for clinicians to insist upon abrupt licence withdrawal when a patient becomes clearly unsafe. Adopting a sensitive approach to a potentially difficult physician-patient encounter is of paramount importance. The advent of a decision aid tailored for drivers with dementia (Carmody et al. 2014c) has the potential to serve as a helpful resource (Carmody et al. 2014a). Individuals who read this brief booklet experience reduced decisional conflict and exhibit higher knowledge scores (Carmody et al. 2014a). It would appear that non-threatening engagement trumps more paternalistic, and perhaps alienating, methods.

Conclusion

Thus far, much of the transport safety literature concentrates on how best we can identify unsafe older drivers (O'Neill 2007). Perhaps the time has come to address how we, as a society, can provide pragmatic alternative transport options for our ageing population. In contrast to Alexander's legendary approach to the Gordian Knot (Langhorne & Langhorne 1813, p. 267), the modern dilemma of driving with dementia does not require such dramatic solutions.

CHAPTER 3: Barriers to qualitative dementia research: the elephant in the room

Article published in *Qualitative Health Research*

Carmody, J, Traynor, V & Marchetti, E 2014, 'Barriers to qualitative dementia research: the elephant in the room', *Qualitative Health Research*, doi: 10.1177/1049732314554099.

Introduction

Qualitative research has, thus far, played a crucial role in improving our understanding of dementia and its impact on individuals, carers, families and the broader community (Gibson et al., 2004; Prorok et al., 2013). As our population is ageing, the impetus for improved dementia care is increasing (Burns & Iliffe, 2009; Larson et al., 2013). Qualitative research is well suited to meet this call (Beuscher & Grando, 2009; Gibson et al., 2004; Morse, 2012). Unfortunately, qualitative (and quantitative) dementia research is fraught with challenges. It is proposed that a major barrier, inadequate government funding, is the elephant in the room of dementia research. The purpose of this article is to: (i) describe the increasing need for qualitative dementia research; (ii) highlight barriers faced by researchers; and (iii) outline steps required of key stakeholders to promote dementia research. An initial description of dementia is proffered to enhance readers' understanding of the current clinical context. Priority topics for future qualitative dementia research are explored.

Background

Dementia refers to a neurocognitive disorder characterised by a disturbance of multiple higher cortical functions (e.g. memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement) (APA 2013). Cognitive deficits are often accompanied by deterioration in emotional control, social behaviour, or motivation (WHO 2010). Six and a half percent of those over the age of 65 years were found to have dementia in a large English study (Matthews et al., 2013). The World Health Organisation (WHO) recently established that 35.6 million people have dementia; 58% of whom live in low or middle-income countries. In addition, WHO anticipates that the number of people with dementia will double every 20 years, to 65.7 million in 2030 and 115.4 million in 2050 (WHO 2012).

The most common forms of dementia include Alzheimer's disease, vascular dementia, dementia with Lewy bodies, frontotemporal dementia and alcohol-related dementia (Samuels 2009). People with dementia have a high level of medical comorbidity and are often prescribed

complex medication regimens: those attending primary care have, on average, 2.4 chronic conditions and receive 5.1 medications (Schubert et al. 2006). Epilepsy, delirium, falls, oral disease, malnutrition, frailty, incontinence, sleep disorders and visual dysfunction occur more frequently in people with dementia and lead to excess disability and reduced quality of life for the affected person and their family (Kurrle et al. 2012). A large prospective observational study of community-dwelling older Americans with dementia established that the median survival from initial diagnosis was 4.2 years for men and 5.7 years for women (Larson et al. 2004).

A diagnosis of dementia is based on the history provided by an individual, a collateral history taken from an informant and a physical examination. A formal neuropsychological assessment can provide valuable additional information (APA 2013). The clinical features of dementia vary but can include difficulty with: (i) learning and memory; (ii) handling complex tasks; (iii) reasoning; (iv) spatial ability and orientation; and (v) language (US HHS 1996). Up to 90% of people with dementia will experience behavioural and psychological symptoms ranging from agitation and pacing to wandering and getting lost (Burns & Iliffe 2009). Depending on the form of dementia, there is wide variability in rates of decline between individuals and in the rapidity with which the condition develops. Of concern is that dementia is usually degenerative and progressive (Grand et al. 2011).

Pearls: the need for dementia-related research

Alzheimer's Disease International (ADI), in its 2010 World Alzheimer Report, predicted a near doubling in global societal costs incurred by dementia from \$604 billion in 2010 to \$1,117 billion by 2030 (Wimo & Prince 2010). More recently, ADI called on governments and research funders worldwide to rearrange existing priorities and provide a tenfold increase in current levels of research funding in line with other conditions, such as cancer (Prince et al. 2013). Of the research areas identified by ADI as important, several are well suited to a qualitative approach: (i) the values and preferences of people with dementia and their carers; (ii) the impact of long-term care delivery on quality of life and service satisfaction; (iii) how best to implement

person-centred care in community care and residential home settings; and (iv) the impact of care delivery on professional care workers (e.g. mood, burnout and retention).

In 2010, the Australian Government commissioned a review of existing dementia research (Seeher et al. 2010). The authors, charged with the task of identifying gaps in the available literature, determined that there remained a large number of unanswered questions relating to dementia which are worthy of research. Specifically, they highlighted the need for a greater understanding of the experiences and needs of people with dementia and their carers. Furthermore, they argued that research using qualitative as well as quantitative methods is required (Seeher et al. 2010). Three years later in the United Kingdom, these findings were echoed by the James Lind Alliance priorities for dementia research review (Alzheimer's Society 2013).

Notwithstanding the clear necessity for additional research, the Australian National Health and Medical Research Council (NHMRC), which allocates more than \$720 million of research funding annually, only awarded \$25.5 million for dementia research in the 2012-2013 financial year. This figure is small when compared to other NHMRC funding recipients: \$158.4 million for cancer research; \$97.9 million for cardiovascular disease research; \$60.3 million for mental health research; and \$56.8 million for diabetes research (NHMRC 2013).

In the United States (US), the prevalence of dementia among persons aged 70 and older is 14.7% (Hurd et al. 2013). Hurd et al. (2013) estimated that the annual US monetary cost of dementia is between \$157 and \$215 billion. The authors concluded that dementia represents a substantial financial burden on society, similar to that of heart disease and cancer. Despite such compelling findings, the National Institutes of Health (NIH), which allocate over \$30 billion of research funding annually, only awarded \$0.65 billion for dementia research in 2013. This figure represents a small fraction of the NIH funding awarded to other recipients: \$5.27 billion for cancer research; \$2.17 billion for mental health research; \$1.96 billion for cardiovascular disease research; and \$1.01 billion for diabetes research (NIH 2013a).

It would appear then that funding for dementia research lags far behind that allocated to other important medical conditions. Most funding is channeled into quantitative rather than qualitative research projects (NHMRC 2013; NIH 2013b; Padgett & Henwood 2009). Although qualitative research projects are often small in scale, some can be resource-intensive and expensive to conduct (Padgett & Henwood 2009). In the absence of adequate financial support, qualitative researchers defer or abandon valuable projects. This is an unfortunate dilemma as, in contrast to a quantitative approach, qualitative research has the potential to capture the meaningful experiences and life values of people with dementia and their carers (Beuscher & Grando 2009; Gibson et al. 2004; Morse 2012; Prorok et al. 2013).

Qualitative health research serves as an important tool in our understanding of health care (Morse 2012). This form of inquiry is well suited for ‘why’, ‘how’ and ‘what’ questions about human behaviour, motives, views and barriers (Neergaard et al. 2009, p. 2). Accordingly, with its mainly inductive approach qualitative research is ideal for problem identification, hypothesis generation, theory formation and concept development (Neergaard et al. 2009). A large international body of qualitative dementia-related literature with several strands now exists (Beard 2012; Dalby et al. 2012; Dewing 2007; Evans & Lee 2014; McDonnell & Ryan 2013; Prorok et al. 2013). The existing body of high-quality qualitative dementia research, incorporating varied methodologies (e.g. grounded theory, meta-ethnography, immersion crystallisation, participatory approach, phenomenology), strengthens the argument in favour of this mode of inquiry.

To date, qualitative researchers have already addressed a series of important issues including: (i) individuals’ perception of their illness; (ii) exploration of carers’ experiences; and (iii) impact of dementia on friends and family (Prorok et al. 2013); among others. However, several gaps in our knowledge remain (e.g. optimal psychosocial interventions for carers, achieving social integration, evaluation of training and education in dementia care) (Moniz-Cook et al. 2011). Careful prioritisation of the gaps which warrant further qualitative research is needed (Prorok et al. 2013).

Pith: barriers and the elephant in the room

An indirect measure of qualitative research is publication in peer-review medical journals. Shuval et al. (2011) conducted a retrospective review of the publishing patterns of 67 general internal medicine journals (e.g. British Medical Journal, Lancet, New England Journal of Medicine). The authors established that the proportion of qualitative studies published in medical journals, although low, rose over a ten year period from 1.2% (1998) to 4.1% (2007). They argued that the overt dominance of quantitative research in medical journals may obstruct our (i) learning how to improve health care services/delivery, and (ii) understanding of the impact of interventions as experienced by patients/health care providers (Shuval et al. 2011). What, then, are the barriers to successful qualitative research?

Beuscher and Grando (2009) described three key obstacles to qualitative dementia research: (i) determining capacity to provide informed consent; (ii) engaging in effective communication; and (iii) ensuring credibility of data. However, additional hurdles do exist. First, unpredictable ethical challenges can arise in the conduct of qualitative research with people with dementia (Heggestad et al. 2012). For example, interviewees may divulge sensitive or inappropriate personal or financial details to researchers in the course of an interview. Furthermore, researchers may become aware of inappropriate carer/partner behaviour which warrants notification of a treating physician or the police. Accordingly, ethics review boards may be reticent to grant approval of dementia research. An in depth appraisal of the ethics relating to qualitative dementia research is beyond the scope of this article and is available elsewhere (Beuscher & Grando 2009; Carmody et al. 2013b; Dewing 2007; Heggestad et al. 2012; Hellström et al. 2007).

Second, recruitment of participants for dementia research can prove challenging in culturally and linguistically diverse (CALD) populations (Shanley et al. 2013) for a number of complex reasons, such as: past abuse of CALD groups in research; social stigma associated with dementia; cost of participation; lack of access to research; language barriers; and a belief that memory loss is a normal part of ageing (Chao et al. 2011; Hinton 2000). Third, a structured

review of 434 original research articles published over a two year period in an international geriatric medicine journal found that 29% of researchers explicitly exclude individuals with cognitive impairment from participation (Taylor et al. 2012). Moreover, this often occurs without explanation or mention of exclusion as a limitation (Taylor et al. 2012). Last, a major impediment to the conduct of qualitative dementia research is the clear inadequacy of government funding. Sadly, the dearth of dementia research funding represents an elephant in the room as it is rarely mentioned, and instead, usually neglected or ignored as a topic of discussion by the media and in contemporary medical literature (Kmietowicz 2012).

An array of theoretical explanations are required to address the wide range of barriers that arise in qualitative dementia research: (i) ageism; (ii) apathy; (iii) cultural context; (iv) denial; (v) lack of political impetus; (vi) nihilism; (vii) social stigma; and (viii) taboo. Unfortunately, people with dementia have been largely excluded from research in the past (Dewing 2002; McKeown et al. 2010). Furthermore, until the 1990s researchers tended to overlook their perspectives (Hubbard et al. 2003; McKeown et al. 2010). An overly medical model has dominated past research endeavours (Downs 1997; McKeown et al. 2010; Shuval et al. 2011). Thus, a person with dementia was viewed as a disease entity, unable to contribute directly to an understanding of their condition (Cottrell & Schultz 1993; McKeown et al. 2010). This approach hampered a holistic understanding of the needs of individuals with dementia and their carers.

Regardless of the barriers (or their theoretical underpinnings) faced by qualitative dementia researchers, people with dementia and their carers are keen to avail of excellent health care. Members of the community have a reasonable expectation of health care researchers, clinicians and policy makers: a passionate and clear focus upon person-centred care. Qualitative researchers are well placed to address the key components of person-centred care: (i) respect for individuals' needs and preferences; (ii) emotional support; (iii) physical comfort; (iv) information, communication and education; (v) continuity and transition; (vi) co-ordination of care; (vii) involvement of family and friends; and (viii) access to care (Luxford et al. 2011). In

order to achieve or maintain high-quality person-centred care, qualitative dementia researchers will require support to address a series of hurdles.

Provocation: a call for change

The conduct of qualitative dementia research is beset with barriers. Overcoming such obstacles is increasingly important as our population ages and the prevalence of dementia rises (Larson et al. 2013). Changes to policy and practice are required of four key stakeholders to facilitate meaningful qualitative dementia research: (i) health professionals; (ii) researchers; (iii) media; and (iv) government. Acknowledgement of insufficient funding as the elephant in the room is an important first step on the path to improved research output and better patient care. *Sine qua non* is the careful prioritisation of relevant topics worthy of qualitative research.

Health professionals play a crucial role in the development of qualitative research. At times, physicians (and, perhaps, other clinicians) require reminding that a quantitative approach is not always the most important or relevant methodology when dealing with people (Malterud 2001). Malterud (2001) and Shuval et al. (2011) propose that quantitative and qualitative forms of inquiry should be viewed by physicians as complementary. Harrington et al. (2009) suggest that the traditional view of clinical research (led by physicians relying heavily on statisticians) is no longer viable or appropriate. They argue that conducting clinical research without dedicated training and experience in the field is unacceptable. Although leading academic research hospitals offer clinical research training programs to their employees (Harrington et al. 2009), a large proportion of hospitals do not. The introduction of a formalised research training module for interested health professionals in hospitals has the potential to result in an improved understanding of and appreciation for qualitative research methods.

Researchers are largely responsible for the direction and design of their studies. Important gaps exist within the dementia literature which would be well suited to qualitative studies (Prorok et al. 2013; Seeher et al. 2010). It would appear that researchers should consider three pressing issues. First, in view of the numerous challenges which accompany dementia research,

researchers would be wise to adopt pragmatic study designs. The application of overly restrictive exclusion criteria (e.g. poor English language skills, living in residential care, cognitive impairment) should be avoided as it limits the relevance (e.g. credibility, dependability) of one's findings.

Second, experienced qualitative researchers are in a position to promote the use of alternative forms of consent. Bartlett (2012) provides a detailed account of adopting a form of process consent in her qualitative study of people with dementia. Process consent, as originally described by Dewing (2002), involves asking participants for verbal consent at each stage of data collection and reminding them that they may withdraw at any stage. This method is appropriate for people with limited capacity for informed consent who, on observation, can communicate and express their wishes (Dewing 2007). Unfortunately, a consensus does not yet exist regarding the application of concepts such as assent and dissent in dementia research or which procedures researchers should use in practice (Black et al. 2010). This has the potential drawback of delaying or preventing research to understand and manage important issues relevant to dementia care (e.g. agitation) (Black et al. 2010).

Third, a key ingredient in attracting funding is a researcher's ability to craft compelling research questions which address major gaps in the literature (see below). A careful focus upon pertinent deficiencies in the literature can lead to macro-level solutions (e.g. enhancement of qualitative research training, interdisciplinary research groups, lobbying of funding agencies, and media engagement).

The media can serve a wide range of positive roles with regard to dementia (e.g. awareness, education, research funding, and study recruitment). National consumer organisations (e.g. Alzheimer's Australia, Alzheimer's Foundation of America, and Alzheimer's Society) rely heavily on media to reach members and the broader community. This valuable relationship results in greater awareness, reduces social stigma, informs debate and encourages fundraising. Thus, the conduct of dementia research (i.e. qualitative and quantitative) is expedited. Advocacy efforts that portray the need for increased research funding with videos and stories of

individuals with dementia are a helpful strategy often adopted by national consumer bodies. Positive portrayals of people with dementia in magazines (Kessler & Schwender 2012) are an example of the constructive approach adopted by some journalists. However, negative portrayals of individuals with dementia also exist.

A comprehensive United Kingdom report on dementia, commissioned by the Alzheimer's Society, criticised the media for their tendency to portray dementia in its most severe form thereby perpetuating negative perceptions of the condition (Williamson 2008). Furthermore, contributors to the report argued that there was inadequate coverage of dementia in the media and that this had contributed to ignorance, fear, misunderstanding and consequently social stigma (Williamson 2008). Of concern, is that the media often focus on new cures for dementia and unfairly raise people's expectations and hopes (Williamson 2008). In an attempt to curtail sensational journalism, dementia consumer groups now offer online guides to media regarding appropriate language and content for reports (Alzheimer's Australia 2013a; Alzheimer's Foundation of America 2013). Such measures may successfully counteract the influence of ageism and social stigma which, all too frequently, accompany dementia.

Adequate government funding of dementia research is long overdue (Alzheimer's Australia 2013b; Kmietowicz 2012). Leading researchers, national consumer organisations and prominent community members are prevailing on governments to recognise the far-reaching impact of dementia and the clear need for additional research funding (Prince et al. 2013). Specific clinical and research priorities relating to dementia have been identified by both clinicians and researchers (Alzheimer's Society 2013; Burns & Iliffe 2009; Moniz-Cook et al. 2011; Prince et al. 2013; Seeher et al. 2010). These include: (i) raising awareness of dementia; (ii) highlighting the need for early diagnosis and investigation; (iii) improving the care for people with dementia in general hospitals and institutional settings; (iv) focusing on the benefits of non-drug interventions; and (v) increasing dementia research funding.

Prioritisation of gaps in the literature is a crucial prerequisite when planning qualitative dementia research. Cogent reviews of major deficiencies and directions for future dementia

research are available. Notable among these reviews are: (i) the James Lind Alliance dementia priority setting partnership (Alzheimer's Society 2013); (ii) the INTERDEM manifesto (Moniz-Cook et al. 2011); and (iii) the Australian dementia research mapping project (Seeher et al. 2010). Many of these priority areas could be addressed/evaluated using qualitative methods. However, it behoves our public representatives in government to acknowledge these calls and act appropriately. Meeting the therapeutic challenge of dementia (using quantitative research methods) is of paramount importance since the rising prevalence of dementia poses serious challenges for health care systems (Yates 2013). Enhanced government funding and support of qualitative research will be required to realise these goals.

Conclusion

Dementia is becoming increasingly prevalent as our population is ageing (Larson et al. 2013). Accordingly, the social and economic impact of dementia is expected to soar, unless a novel therapy is discovered that can prevent or treat this condition (Yates 2013). Globally, dementia is a major cause of disability in later life: it contributes 11.2% of all years lived with disability. This is in contrast to stroke (9.5%), musculoskeletal disease (8.9%), heart disease (5%), and cancer (2.4%) (Burns & Iliffe 2009).

Current attempts to engage in qualitative dementia research are hampered by numerous obstacles. Inadequate funding, the elephant in the room, hinders progress and condemns many worthwhile qualitative studies to failure. In spite of a pressing need to promote dementia research, many qualitative researchers persevere and conduct their studies with meagre government funding. Although funding agencies claim to support worthwhile and feasible projects (Carey & Swanson 2003), qualitative dementia researchers are often relegated to sifting through the flotsam and jetsam of government funding. Promising government policy developments are now emerging in several countries (Benson 2013; Hurd et al. 2013; Kmietowicz 2012) (e.g. modification of existing research funding models, strengthening of national dementia strategies). However, it remains to be seen if such developments result in much-needed qualitative dementia research.

CHAPTER 4: Dementia and driving: an approach for general practice

Article published in *Australian Family Physician*

Carmody, J, Traynor, V & Iverson, D 2012, 'Dementia and driving: an approach for general practice', *Australian Family Physician*, vol. 41, pp. 230-233.

Case study

Olive, a 75 year old widow, has been attending your practice for over a decade. Three years ago, she was diagnosed with Alzheimer's disease but has remained relatively independent since. She lives with her daughter, Julie, and drives a car. Olive is compliant with her anticholinesterase medication. However, Julie reports further deterioration in her mother's memory with recent episodes of wandering. Upon questioning, you establish that Olive has been getting lost whilst driving. Furthermore, she has recently had a minor car crash and two near-misses. During your consultation with Olive, she becomes defensive, denies a history of accidents and states confidently that she is a safe driver. In your office, her mini-mental state examination (MMSE) score is 20/30. The remainder of her examination is unremarkable. A reasonable course of management would include: (i) holding a frank, yet sensitive, discussion with Olive and her family members regarding the risks posed to her and to others in view of her dementia; (ii) highlighting alternative transport options e.g. taxi subsidies, public transport; (iii) explaining the necessity of driving retirement and that measures should be taken to remove her access to automobiles; (iv) documenting your discussion; and (v) considering formal notification of the DLA (driver licensing authority) as per local legislative requirements.

Introduction

Driving is a deceptively complex task (Drazkowski & Sirven 2011). In 1997, Lipski argued that 'until we have better evidence about what is safe, we should not allow people with dementia to drive motor vehicles' (Lipski 1997, p. 453). Over a decade later, convincing evidence about what is safe remains elusive (Martin, Marottoli & O'Neill 2009). Moreover, no clear management protocols exist for Australian general practitioners (GPs) caring for patients with dementia who drive. To complicate matters further, instructing a patient to retire from driving may irrevocably damage a long-standing doctor-patient relationship (Odell 2005). Snellgrove & Hecker (2002) established that an overwhelming majority of GPs do not wish to be responsible for the assessment of fitness to drive in people with dementia.

What is dementia?

Dementia refers to a syndrome characterised by a progressive deterioration of memory and at least one other cognitive domain (e.g. language, executive function, praxis) which interferes with one's daily function and independence (APA 1994). There are numerous conditions which result in dementia. The commonest causes are Alzheimer's disease (60% of cases), vascular dementia (5-20% of cases), Lewy body disease and frontotemporal dementia (Thal, Grundman & Klauber 1988). Other less common causes include alcoholism, Parkinson's disease, Huntington's disease, progressive supranuclear palsy and normal pressure hydrocephalus.

Scope of this issue in Australia

Meta-analysis of epidemiological data has established that the prevalence of dementia in people over the age of 65 is 6.4% (Van der Flier & Scheltens 2005). However, the incidence of new cases rises exponentially after one reaches 65 years of age. It is estimated that the number of people in Australia with dementia has reached 257,000 and will rise to 591,000 by 2030 (Access Economics 2009). Given the ever increasing number of older drivers (AA NSW 2010), there is a pressing need for research addressing how best to enable early retirement from driving.

What is the impact of dementia on driving skills?

Two major issues of relevance to drivers with dementia are: (i) the progressive nature of the condition; and (ii) the potential for loss of insight. There is evidence that driving skills deteriorate with increasing dementia severity (Dubinsky, Stein & Lyons 2000). More specifically, dementia frequently leads to impaired visuospatial skills, attention, memory and judgement (Johansson & Lundberg 1997). Driving is a complex task which requires such functions. Visuospatial skills are necessary to ensure accurate depth perception, lane alignment and overtaking. Attention and judgement are important factors when negotiating roundabouts or intersections. Memory deficits can contribute to getting lost and may result in errors whilst driving (Johansson & Lundberg 1997). The patterns of neurological deficit that occur in dementia vary depending upon the subtype.

What are the risks?

Older drivers have relatively few crashes (AA NSW 2010; Williams & Carsten 1989). However, when the number of accidents per distance travelled is calculated, the crash risk of drivers over the age of 75 is similar to that of 16-24 year old drivers (O'Neill 1992; Williams & Carsten 1989). It is not surprising that drivers with dementia have a significantly higher risk of car accidents compared to aged-matched cognitively normal drivers (Lipski 1997). Two studies which compared the crash risk of individuals with dementia to cognitively normal controls determined an odds ratio ranging from 7.9 to 10.7 (Friedland et al. 1988; Zuin et al. 2002). Unfortunately, for a variety of reasons, many individuals with dementia do continue to drive after diagnosis (Carr, Jackson & Alquire 1990; Odenheimer 1993). Several researchers have found that many retire from driving only after they have had one or more crashes (Friedland et al. 1988; Kapust & Weintraub 1992; Kazniak, Keyl & Albert 1991). In addition, one study demonstrated that 80% of those who were involved in a crash continued to drive afterward, with almost 40% having at least one more crash (Cooper et al. 1993).

Driving and mild dementia

Dobbs argues that although a diagnosis of early dementia should alert a doctor to the fact that a patient may not be competent to drive, it is not sufficient reason to enforce driving retirement in all cases (Dobbs 1997). There is evidence to support such a claim; for example, Ott and Daiello (2010) found that pooled data from two longitudinal studies (Duchek et al. 2003; Ott et al. 2008) involving 134 drivers with dementia established that 69% of drivers with mild dementia and 88% of drivers with very mild dementia and could pass on-road driving assessments.

National and international guidelines

A systematic review of the available literature by the American Academy of Neurology identified several characteristics as indicative of patients with dementia who are at increased risk of unsafe driving (Iverson et al. 2010). These included the CDR (clinical dementia rating) score, a carer's rating of a patient's driving ability as marginal or unsafe, a history of reported traffic offences, a history of crashes, reduced driving mileage, self-reported situational avoidance, MMSE (mini-mental state examination) scores of ≤ 24 , and aggressive or impulsive personality characteristics. Interestingly, the review also determined that an individual's self-rating of driving ability was not a reliable indicator of accident risk. The review established that there is insufficient evidence to support or refute the benefit of either neuropsychological testing or interventional strategies for drivers with dementia. Unfortunately, as there is neither a test nor a historical feature that accurately quantifies driving risk, clinicians can only make 'qualitative estimates of driving risk' (Iverson et al. 2010, p. 1320). Iverson et al. (2010) concluded that patients with mild dementia are at a substantially higher risk for unsafe driving and thus should strongly consider discontinuing driving.

In 2009, the Australian and New Zealand Society for Geriatric Medicine released a position statement which specifically addressed the topic of driving and dementia (ANZSGM 2010). Some of the key features of this position statement are listed in Figure 1.

Selection of key features of the ANZSGM position statement
<ul style="list-style-type: none"> • Some people with mild dementia may drive safely • It is not reasonable to suspend one's licence based solely on a diagnosis of mild dementia • A driving co-pilot is not a recognised safe practice for reducing safety risk in dementia • An occupational therapy on-road driving test is accepted as a gold standard assessment • Neuropsychological results generally do not sufficiently or consistently correlate with on-road driving performance • Regular review (at least 6 monthly) of safe driving capacity is required in patients who retain a driving licence in early dementia

Figure 1. Selection of key features of the ANZSGM position statement

Striking a balance

The process of retirement from driving may be either voluntary or involuntary. Enabling voluntary early retirement from driving could potentially reduce crash-related morbidity and mortality. It is widely recognised that ‘autonomy for the elderly is an extremely important goal both socially and economically’ (Ott & Daiello 2010, p. 81). Unfortunately, the transition to non-driving has been linked to increased rates of depression (Ragland, Satariano & MacLeod 2005) and placement in residential care (Freeman et al. 2009). This highlights an important, yet unresolved, issue: how should society, licensing authorities and the medical profession manage the issue of retirement from driving in a judicious manner?

What are the legislative requirements for Australian GPs and their patients?

As per the Austroads guidelines, an individual must not drive if ‘there is significant impairment of memory, visuospatial skills, insight or judgement or if there are problematic hallucinations or delusions’ (Austroads 2003). Furthermore, all drivers in Australia with a condition which may impact upon his/her ability to drive are legally obliged to inform the DLA. Most adults, however, are unaware of this obligation (National Transport Commission 2006).

Both South Australia and the Northern Territory have mandatory reporting legislation in place which applies to health professionals. Discretionary reporting applies to GPs in the remaining states and territories (Figure 2). The Australian Medical Association (2008) and Somerville, Black and Dunne (2010) argue that mandatory reporting, by doctors, of all unfit drivers is inappropriate for a variety of reasons (e.g. it encourages concealment of symptoms).

Legislative requirements for Australian GPs		
State / Territory	Mandatory reporting	Indemnity from legal action
ACT	No	Yes
Northern Territory	Yes	No
NSW	No	Yes
Queensland	No	Yes
South Australia	Yes	Yes
Tasmania	No	Yes
Victoria	No	Yes
Western Australia	No	Yes

Figure 2. Legislative requirements for Australian GPs

A suggested management strategy for GPs

- Raise the issue of driving with all patients with cognitive impairment
- Avoid an over-reliance on MMSE scores (Iverson et al. 2010; Snellgrove & Hecker 2002)
- Acknowledge that some spouses are unreliable judges of driving skills. They may be afraid to raise their concerns with you in view of the potential consequences.
- Aim to provide an early diagnosis of dementia (if possible) as this enables individuals and their families to plan for the transition to not driving (AA NSW 2010; Workman, Dickson & Green 2010)

- Remind your patient of his/her obligation to report his/her diagnosis to the DLA
- Direct your patient and his/her family members to reliable sources of additional information e.g. Alzheimer's Australia (see *Resources*)
- Discuss alternative forms of transport e.g. public transport, family members
- Consider discussing the potential impact an accident would have upon others
- Inform patients that should an accident occur they may face civil or criminal prosecution
- Explain that one's car or life insurance policies may be void if one drives when deemed medically unfit to do so
- Document your discussions
- Reassess dementia severity and fitness to drive every 6 months for those patients with mild dementia who are deemed safe to continue driving (ANZSGM 2010; Draskowski & Sirven 2011; Snellgrove & Hecker 2002)
- Consider an occupational therapist driver assessment referral (limited by availability and cost) which can be repeated (see *Resources*)
- If unsure as to how to proceed then refer to a Geriatrician or Neurologist

Conclusion

The complex and serious issue of driving and dementia warrants a direct, yet sensitive approach by clinicians. For many patients, licence cancellation may be indicated without on-road assessment (Fox & Bashford 1997) and accepted without complaint. However, on occasion, individuals and/or their spouses may be reluctant to fall in line with a GP's well-founded recommendations. Optimal patient management is hampered by the lack of explicit national DLA guidelines or review mechanism which health professionals can access (Snellgrove & Hecker 2002). It would seem that, for now, GPs remain dependent upon the art and science of medicine in order to achieve a satisfactory outcome for patients and the wider community.

Resources

- Alzheimer's Australia: www.alzheimers.org.au
 - Austroads: <http://www.austroads.com.au/>
 - National Dementia Hotline: 1800 100 500
 - <http://www.alzheimers.org.au/national-dementia-helpline.aspx>
 - Occupational Therapy Australia: <http://www.otaus.com.au/>
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CHAPTER 5: Dementia, decision aids and general practice

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Carmody, J, Traynor, V & Steele A, 'Dementia, decision aids and general practice', *Australian Family Physician*.

Introduction

Up to 50% of people aged 85 years and above have dementia, with Alzheimer's disease, vascular dementia, Lewy body dementia and frontotemporal dementia representing the most frequent forms (Declercq et al. 2013). It is projected that, by 2050, over one million Australians will have dementia (Access Economics 2009). Accordingly, each general practitioner (GP) in Australia will see, on average, three new cases per year (Pond 2012). Despite a significant knowledge gap regarding the epidemiology of dementia in Australia, it is known that Indigenous Australians have a much higher prevalence of the condition (Li et al. 2014).

As aged care services become increasingly stretched, the management of patients with dementia and their attendant complex care needs will inevitably fall to GPs (Pond 2012). Fortunately, GPs are well placed to provide practical and emotional support to assist patients and their carers to come to terms with living with dementia (Iliffe et al. 2009). However, a recent review of dementia management in primary care called for (i) a greater focus upon person-centred and customised care for patients and their carers, and (ii) an evaluation of relevant interventions or alternative models of service delivery (Robinson et al. 2010).

It is widely recognised that patient-centred care forms the basis of general practice. This approach refers to an understanding of the whole person, an appreciation of their illness experience and a mutual agreement on problems, goals and roles (Stewart 2003; Barry & Edgman-Levitan 2012). The purpose of this paper is to highlight how dementia-related decision aids can facilitate the sharing of decisions within the primary care setting.

What are decision aids?

Identifying and making a decision about health care options can prove challenging for some individuals (Stacey et al. 2014). Decision aids (in the form of pamphlets, booklets, videos, or web-based tools) provide structured information on the options and outcomes relevant to an individual's health. They offer evidence-based guidance on reaching an informed choice consistent with one's values and preferences (Elwyn et al. 2006). Rather than replace the role of

clinicians, decision aids are designed to act as adjuncts to the doctor-patient interaction. Specifically, decision aids can be used when (i) there is more than one reasonable option, (ii) no option has a clear advantage in terms of health outcomes, or (iii) each option has benefits and harms that a patient may value differently (Stacey et al. 2014). Given the global proliferation of decision aids, guidelines informing the development of high quality decision aids were established by the International Patient Decision Aids Standards (IPDAS) collaboration (Elwyn et al. 2006). A recent Cochrane review established that decision aids improve people's knowledge regarding options, reduce decisional conflict, stimulate people to take a more active role in decision making, and facilitate risk assessment (Stacey et al. 2014).

Driving retirement

There exists a pressing need to assist people with dementia in their decision making regarding retirement from driving: (i) the number of drivers with dementia on our roads is rising (AA NSW 2010; Eby & Molnar 2010); (ii) alternative forms of transport are lacking (AA NSW 2010); and (iii) individuals with dementia are increasingly dependent on cars (AA NSW 2010). Unfortunately, instructing a patient to retire from driving may irrevocably damage a long-standing doctor-patient relationship (Odell 2005). To mitigate this risk, a novel decision aid tailored for drivers with dementia has recently been released (see *Resources*) (Carmody et al. 2014c). This easy to read booklet provides an overview of important safety issues and highlights alternative forms of transport for drivers in Australia or New Zealand. A detailed description of the complex issue of driving and dementia is beyond the scope of this article but comprehensive reviews are available elsewhere (Breen et al. 2007; Carmody, Traynor & Iverson 2012a; Carmody et al. 2013b).

Respite service choices

Respite care, a crucial component of carer support, assists people with dementia to remain living at home for as long as possible (Alzheimer's Australia 2009). Early use of respite care enables people with dementia and their carers to continue to engage socially with others: an important

step in combating the social isolation and stigma which often accompany a diagnosis of dementia (Alzheimer's Australia 2009). Respite services, either at home, in a day-care centre or in a residential care facility, can temporarily reduce a carer's physical and emotional workload (Stirling et al. 2012). Yet, only 32% of individuals with dementia approved for residential respite care avail of this resource within 12 months of approval (AIHW 2010). With this discrepancy in mind, researchers at the University of Tasmania have developed a decision aid (the Gold book) which explains the respite options available to patients and their carers (Stirling et al. 2012). A recent randomised trial confirmed the benefit of this relatively simple intervention (Stirling et al. 2012). Specifically, most carers found this decision aid to be useful as it provided them with decisional support (Stirling et al. 2012). Furthermore, the trial demonstrated that use of the Gold book led to improved carer knowledge levels and reduced decisional conflict (Stirling et al. 2012).

Use of anti-psychotic medicines

Dementia is usually characterised by prominent cognitive deficits. However, non-cognitive symptoms are common and can dominate the clinical presentation (Declercq et al. 2013). Behavioural and psychiatric symptoms such as agitation, hallucinations, depression, delusions, and wandering have been observed in over 60% of people with dementia (Declercq et al. 2013). Perhaps not surprisingly, antipsychotic agents are often used to treat such symptoms: risperidone is the only antipsychotic approved for this indication in Australia (NPS 2013). Long-term use of such agents for behavioural and psychiatric symptoms, however, warrants regular clinical review and consideration of withdrawal (RANZCP 2009). In this context, their effectiveness is limited and vigilance is required regarding potential adverse outcomes, including higher mortality with long-term use (Declercq et al. 2013). The Royal Australian and New Zealand College of Psychiatrists has emphasised the importance of informed consent when patients with dementia are offered antipsychotic agents (RANZCP 2009). More recently, a decision aid addressing the use of antipsychotic agents by people with dementia has become available on-line to assist patients, carers and clinicians (NHS 2009). This clinically relevant

decision aid, structured as a pamphlet, provides helpful visual representations of the risks associated with antipsychotic use (e.g. cerebrovascular morbidity, mortality).

Feeding options in advanced dementia

For people with dementia, dysphagia can lead to malnutrition, dehydration, weight loss, functional decline, fear of eating and drinking and decreased quality of life (Alagiakrishnan, Bhanji & Kurian 2013). The prevalence of dysphagia in people over the age of 65 who reside in long-term care facilities ranges from 40% to 50% but is probably higher in those with dementia (Alagiakrishnan, Bhanji & Kurian 2013; Hanson et al. 2011). A recent systematic review, examining the issue of dysphagia amongst people with dementia, highlighted the dearth of evidence regarding the usefulness of diagnostic tests, effect of postural changes, modification of fluid and diet consistency, behavioural management and use of medications in this population (Alagiakrishnan, Bhanji & Kurian 2013). Furthermore, the placement of percutaneous endoscopic gastrostomy tubes does not lead to improved (i) rates of aspiration pneumonia, (ii) quality of life or (iii) mortality (Alagiakrishnan, Bhanji & Kurian 2013). At times, carers and families attribute unrealistic benefits to tube feeding: consent discussions often focus unduly on procedural risks rather than potential outcomes and alternative approaches (Hanson et al. 2011). To address this clinical conundrum, a carer-centred decision aid has been developed which contains helpful information about feeding options for people with dementia (Hanson et al. 2011). Carers are informed of the advantages and disadvantages of feeding tubes versus assisted oral feeding. This decision aid also explores the issue of end-of-life feeding for comfort and affirms the role of carers in the decision-making process.

Other dementia-related decision aids

Several other dementia-related decision aids have been developed (see *Resources*) which address a broad range of topics including: (i) long-term care options; (ii) anticholinesterase use; (iii) carer decision regarding placement; and (iv) goals of care for high-level care residents. Given the proliferation of decision aids over the past decade, the Ottawa Hospital Research

Institute has assumed the Sisyphean task of maintaining an up-to-date, publicly accessible, inventory of currently available decision aids (see *Resources*).

Incorporation into primary care

In a study of 181 rural GPs in the United States, 63% felt that lack of time was the greatest barrier to their engaging in shared decision making (King et al. 2012). Thus, decision aids which can be used independently at home (i.e. without assistance) may reduce consultation times in primary care, improve knowledge levels, and enhance patient satisfaction. All four decision aids described earlier can be used in such a manner. It would suffice, for many people with dementia (or their carers), to be provided with a pertinent decision aid by a practice nurse which can then be taken home to read. Ideally, such an approach would negate the need for lengthy office-based consultations. Further evaluation of the impact of dementia-related decision aids upon primary care services/systems is an important issue worthy of future research.

Challenges in dementia-related decision aid development

The development of high quality, clinically meaningful decision aids relies upon both qualitative and quantitative research methods. To date, relatively few decision aids have been developed specifically for individuals with dementia. Unfortunately, dementia-related research is often hampered by a range of obstacles (Carmody, Traynor & Marchetti 2014). First, human research ethics committee approval of dementia-related projects is a critical, yet time consuming, step in the research process. Second, securing informed consent from participants with dementia or their guardians is, at times, a challenging hurdle. Last, inadequate funding opportunities often preclude the conduct of promising dementia-related research projects (Carmody, Traynor & Marchetti 2014).

Conclusion

Although discussion about patient-centred care is of paramount importance, there remains a need to convert rhetoric into reality by routinely engaging patients in decision making (Barry & Edgman-Levitan 2012). Clinicians (including GPs) can facilitate shared decision making by providing patients (or carers) with decision aids which raise awareness and improve understanding of treatment options and possible outcomes. Decision aids, as per the IPDAS collaboration guidelines, are useful evidence-based tools designed to help patients/carers participate in choosing among health care options (Elwyn et al. 2006).

Given that, in the past, people with dementia were frequently excluded from clinical research, it is refreshing to observe the rising number of decision aids tailored specifically for people with dementia. It is hoped that future decision aid research will address the specific needs of: (i) people with early-onset dementia; (ii) culturally and linguistically diverse (CALD) groups (Li et al. 2014); and (iii) individuals seeking guidance on advanced care planning, guardianship and power-of-attorney. By addressing the varied and complex needs of people with dementia and their carers, decision aids have the potential to serve as powerful tools in the provision of person-centred care.

Resources

- Alzheimer's Australia: www.alzheimers.org.au
 - National Dementia Hotline: 1800 100 500
 - Ottawa Hospital Research Institute: <https://decisionaid.ohri.ca/>
 - Driving decision aid:
<http://smah.uow.edu.au/nursing/adhere/drivingdementia/index.html>
 - Feeding options decision aid: https://decisionaid.ohri.ca/docs/das/Feeding_Options.pdf
 - Respite care decision aid: Stirling C. The Gold Book for carers: guiding options for life with dementia. Hobart: University of Tasmania, 2009.
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CHAPTER 6: Driving, dementia and Australian physicians: *primum non nocere*?

Article published in *Internal Medicine Journal*

Carmody, J, Traynor, V, Iverson, D & Marchetti, E 2013, 'Driving, dementia and the Australian physician: primum non nocere', *Internal Medicine Journal*, vol. 43, pp. 625-630.

Introduction

The prevalence of dementia is increasing globally, and in Australia, the number of individuals with dementia is predicted to expand four-fold, from 266,574 in 2011 to almost one million in 2050 (Access Economics 2011). More than one million Australians aged over 70 years are current licence holders (Austroads 2005). For a variety of reasons, physicians will be increasingly requested to assess the driving fitness of people with dementia as: (i) our population is ageing; (ii) life expectancy is increasing; and (iii) a greater proportion of older women are driving (Knapp & Van de Creek 2005). Thus, there is a clear need for stakeholders (Figure 3) to discuss the topic of driving and dementia whilst simultaneously appreciating the inextricably-linked ethical issues.

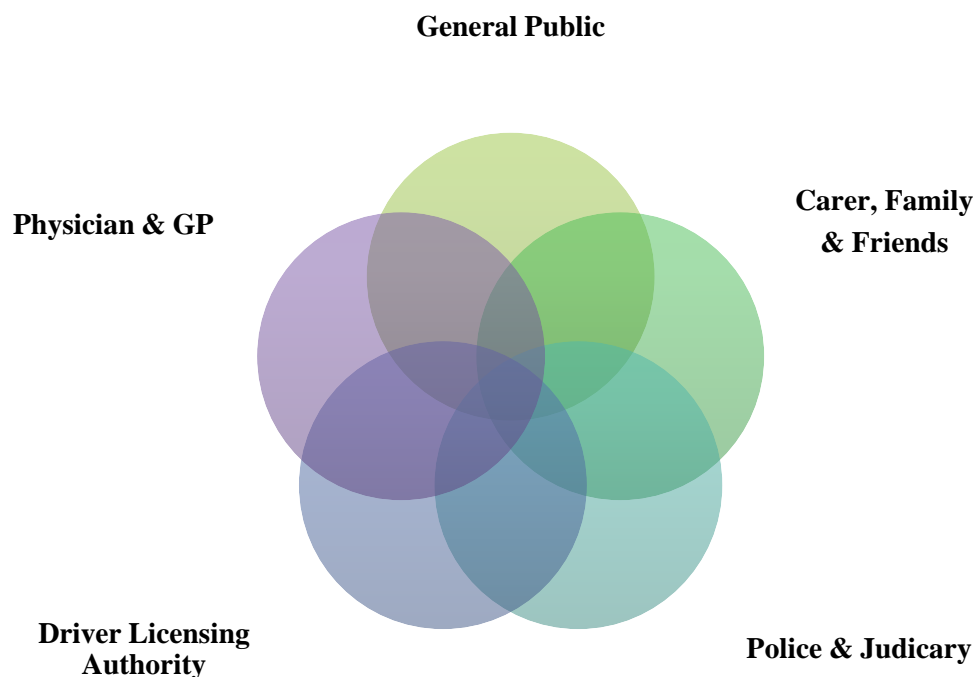


Figure 3. Relevant stakeholders for drivers with dementia

Older members of our community increasingly rely upon a private car for their transport needs (AA NSW 2010; Meuleners et al. 2006). Public transport use by older Australian adults is low (ABS 2012). In their study of car dependency in urban Australia, Buys et al. (2012) highlight several key determinants of transport usage: convenience; affordability; availability; and health/mobility. The authors argue that the comparative ease, comfort and privacy afforded by private car use are major barriers to public transport use (Buys et al. 2012).

Although older drivers have the lowest number of car accidents per year, they have the highest risk of morbidity and mortality if involved in a crash (Meuleners et al. 2006). Many drivers aged 65 years or older self-regulate their driving behaviour: they tend to avoid driving at night and often limit their driving to familiar surroundings, good weather and non-peak hours (Eberhard 1996). Notwithstanding such self-imposed restrictions, there is evidence that older drivers do not engage in self-planning for driving cessation (Kostyniuk & Shope 2003). Of concern is that individuals who are unaware of their declining capabilities may not take corrective action, thus placing them at higher risk of crashes.

Dementia is most commonly caused by Alzheimer's disease, vascular dementia, Lewy body disease or frontotemporal dementia (Thal, Grundman & Klauber 1988). Perhaps not surprisingly, the natural history of dementia is variable. Yet, many people with early dementia are capable of driving safely (ANZSGM 2010; Breen et al. 2007; Carr & Ott 2010). Thus, attempts to apply a uniform approach to all drivers with dementia could prove overly restrictive. It is widely accepted that patients with dementia develop difficulty with planning, judgement and problem solving (Johansson & Lundberg 1997; Ropper & Samuels 2009). In addition, there is evidence that a large majority of drivers with dementia continue to drive despite having had a car accident (Cooper et al. 1993). Despite such findings, it remains unclear as to when a person with dementia becomes unsafe to drive (AA NSW 2010; Brown & Ott 2004; Eby & Molnar 2010). Most authorities concur that individuals with moderate or severe dementia should not drive (ANZSGM 2010; Brown & Ott 2004; Carr & Ott 2010; Iverson et al. 2010). However,

such a consensus does not exist with regard to drivers with mild dementia (Brown & Ott 2004; Carr & Ott 2010).

Consequences of driving cessation

Retirement from driving can be a distressing event for older drivers (Knapp & Van de Creek 2005). It is associated with an increased risk of: (i) depression (Marottoli et al. 1997); (ii) difficulty accessing services (Taylor & Tripodes 2001); (iii) difficulty with social integration (Mezuk & Rebok 2008); and (iv) transfer to a nursing home (Freeman et al. 2006). Driving cessation may be viewed by some as a threat to one's self-worth and independence (Snyder 2005). Furthermore, individuals no longer capable of safely driving a motor vehicle may be viewed negatively by others and stigmatised.

Regardless of driving status, carers (e.g. spouse, family member, friend, paid-carer) of people with dementia are at risk of social isolation, psychological morbidity, depression and financial disadvantage (Logiudice 2002). Of concern is that the carers of drivers with dementia may not raise the issue of impaired driving skills with health care professionals because: (i) driving cessation may result in a carer becoming housebound (Berger & Rosner 2000); (ii) a carer may wish to avoid being seen as responsible for a physician's instruction to stop driving; and (iii) a carer may be cognitively impaired and oblivious to unsafe driving behaviours. Thus, sole reliance upon a carer's account of driving skills/safety is probably unwise (Iverson et al. 2010).

Interestingly, driving cessation may alter family dynamics. A form of role reversal can develop whereby an adult child assumes the role of driver for their parent with dementia (Berger & Rosner 2000). People with dementia may become dependent upon their children for their transport needs. Acknowledgement of a loved one's increasing reliance upon others is an uneasy process for some as it can highlight the progressive erosion of an individual's independence by their illness (Berger & Rosner 2000).

Instructing an individual to stop driving may have a detrimental effect upon a doctor-patient relationship (e.g. loss of trust, poor compliance, failure to attend for review). Occasionally,

patients can become upset, irritated or angry during a consultation (Carr & Ott 2010). Difficult physician-patient encounters, such as these, can lead to dissatisfaction for patients, physicians and family members (Breen & Greenberg 2010). As a result, individuals in real need of ongoing care may choose to sever ties with the medical community. Moreover, should older Australians perceive an overly strict approach by physicians towards drivers, it is conceivable that this could deter them from seeking medical review (Berger & Rosner 2000).

Somerville, Black & Dunne (2010) argued that much of the responsibility for assessing fitness to drive in Australia has been shifted from driver licensing authorities to doctors. This leads to a conflict of interest for clinicians and can jeopardise doctor-patient relationships. Furthermore, the ethical principles of justice and beneficence can be subverted: (i) doctors may feel coerced into certifying unsafe drivers (Somerville, Black & Dunne 2010); (ii) patients may visit several doctors until certified; and (iii) patients may not disclose symptoms to physicians so as to ensure certification is provided. Although Somerville, Black & Dunne (2010) focused upon seizures/epilepsy specifically, many of the points raised are applicable to other conditions (e.g. dementia, syncope, severe peripheral neuropathy, narcolepsy).

Current guidelines

In 2005, Beran proposed that, with regard to driving safety, dementia ‘is a growing and serious consideration’ (p. 367). He argued that the Austroads national guidelines (2003) should allocate the theme of dementia a more in depth appraisal. The updated Austroads guidelines, which came into effect in March 2012, stipulate that individuals with dementia are precluded from holding an unconditional licence (Austroads 2012). However, a driver licensing authority may award a conditional private licence following consideration of the: (i) nature of the driving task; (ii) information provided by the treating doctor; and (iii) results of a practical driver assessment if required. Austroads suggests that the treating doctor provide information regarding the level of impairment and the likely impact on driving ability of any of the following: visuospatial

perception; insight; judgement; attention; reaction time; and memory. Furthermore, annual medical review is recommended.

In 2010, the Australian and New Zealand Society for Geriatric Medicine (ANZSGM) released a position paper addressing driving and dementia. ANZSGM proposes that some people with mild dementia may drive safely for a limited time but require medical review, at least, every six months. Although physicians should remain cognisant of the negative consequences of licence cancellation, public interests must remain paramount. Consequently, should a physician harbour reasonable doubts about an individual's road safety then a breach of clinical confidentiality is legitimate. Following a systematic review of the relevant literature, the American Academy of Neurology published a practice parameter on the evaluation and management of driving risk in dementia (Iverson et al. 2010). The authors established that there is no test result or historical feature that accurately quantifies driving risk. In addition, there was insufficient evidence to support or refute a benefit of interventional strategies (e.g. modified licence, driver training). This report echoed the ANZSGM call for six-monthly review.

In 2008, the Australian Medical Association (AMA) issued a position statement on the role of medical practitioners in determining fitness to drive. A sample of several key points is provided in tabular form (Table 1). Although the AMA acknowledges that independent transport is highly valued by Australians, it highlights that the possession of a licence to drive is a privilege, not a right. It is the role of the State to decide whether an individual can hold a licence. If treating doctors are expected to serve as decision-makers, an unacceptable ethical conflict arises whereby the doctor-patient relationship is threatened. This is particularly important in relation to commercial vehicle drivers (e.g. taxi, bus, truck).

Table 1. Selection of points from the AMA Position Statement 2008

The role of the medical practitioner in determining fitness to drive	
<hr/>	
1.	Identify drivers impaired by their medical conditions
2.	Determine the degree of impairment (when possible)
3.	Advise a patient that he/she is unsafe to drive
4.	Subject to patient consent, inform a licensing authority on request
5.	Mandatory reporting is not acceptable
6.	Doctors should be protected in law whether they report an unsafe driver or not
7.	Some patients may lack insight or withhold information in order to obtain a licence

Local and international legislative perspectives

Australian physician reporting requirements are not uniform in all states and territories (Table 2) (Austroads 2012; Carr et al. 2010; NZTA 2009; SMA 2011). Health professionals (e.g. occupational therapists, optometrists, physicians, physiotherapists) in South Australia and the Northern Territory are obliged to report all unsafe drivers to their local driver licensing authority. Such legislative requirements do not apply elsewhere in Australia where reporting of unsafe drivers is entirely at the discretion of individual health professionals. Of concern is that many physicians and patients are unaware of local regulations (Kelly, Warke & Steele 1999).

The juxtaposition of discordant legislation within a nation is not unique to Australia. Snyder (2005) highlighted an ethical (and legislative) dichotomy that exists in the United States: physicians who report a driver with dementia in New York can face legal action for actions such as breach of patient confidentiality while physicians who fail to report a driver with dementia in California can face criminal misconduct charges. Curiously, physicians in California and Oregon are obliged to report all drivers with dementia (Drazkowski & Sirven 2010).

Table 2. International comparison of private vehicle driver assessment regulatory frameworks

	Australia	New Zealand	United States	Singapore
Mandatory reporting by doctors of unsafe drivers	Yes (NT & SA) No (all other states and territories)	Yes (if a physician suspects that an individual 'is likely to drive against medical advice')	Yes (varied forms of mandatory reporting exist in eight states: California; Delaware; Georgia; Maine; Nevada; New Jersey; Oregon; Pennsylvania)	No
Option for modified licence (e.g. not to drive at night)	Yes	Yes	Yes (some states)	No
Indemnity/protection for doctors against civil liability upon reporting unsafe driver	No (NT) Yes (all other states & territories)	Yes	Yes (30 states only)	No
Age-dependent medical review for all drivers	No (NT & VIC) Yes (SA from age 70; ACT, NSW, QLD, TAS from age 75; WA from age 80)	Yes (age 75, 80 and biennial thereafter)	No (most states)	Yes (age 65 and triennial thereafter)
Age-dependent on-road driving assessment for all drivers	Yes (NSW†, SA & WA from age 85) No (all other states and territories)	No	No (most states)	No

ACT, Australian Capital Territory; NSW, New South Wales; NT, Northern Territory; QLD, Queensland; SA, South Australia; TAS, Tasmania; VIC, Victoria; WA, Western Australia. †NSW drivers aged 85 years do not have to undergo an on-road assessment and may opt instead for a modified licence.

Potential solutions

In the absence of explicit national or international guidelines, how can Australian physicians balance patient need, public safety and the doctor-patient relationship in a judicious manner?

Measures worthy of consideration include:

- Increased awareness by physicians of the updated Austroads national guidelines (2012) and of local legislative requirements (Table 2);
 - Open, direct and early discussion of a diagnosis of dementia with patients and their families should be considered. This would allow management strategies to be put in place promptly and enable patients and their families to plan for the future (Carr & Ott 2010; Logiudice 2002);
 - The current Austroads guidelines (2012) should be amended to fall in line with both the ANZSGM position statement (2010) and the AAN practice parameter (Iverson et al. 2010): all drivers with dementia should undergo medical review every 6 months (Carmody, Traynor & Iverson 2012a; Hoggarth et al. 2011);
 - A variable state and territory approach to older driver assessment and reporting requirements is not ideal and warrants review. A consistent national standard is needed.
 - Mandatory reporting requirements should be abolished in all states and territories and indemnity from civil liability should be afforded to health professionals nationally (including the Northern Territory) (AMA 2008);
 - Beran & Devereux proposed that Australian driver licences should display a ‘bold and unequivocal notice’ advising drivers of their responsibility to report any medical conditions that may affect their capacity to drive safely (2007, p. 338);
 - Federal government funding of occupational therapy on-road driver assessments would remove an important barrier to assessment; and
-

- Future research efforts could be directed towards solving the unmet mobility and transport needs of older Australians.

Novel approach

A promising avenue for future research may lie in the application of novel decision-making techniques to the driving and dementia dilemma. A recent survey of hospital-based doctors established that 90% would find a client-centred booklet about driving and dementia useful (Carmody et al. 2013a). Our research group has field-tested a patient-centred booklet tailored for drivers with dementia (Carmody et al. 2014a). This decision aid provides a simple outline of the benefits and risks of driving for people with dementia. It encourages and facilitates clarification of values, promotes planning for early retirement from driving and directs the reader to speak with their doctor. This resource has been developed in line with the International Patient Decision Aids Standards (IPDAS) collaboration guidelines (Elwyn et al. 2006) and will be modified to suit Australian drivers. The final content and presentation will be moulded by client feedback.

Conclusion

Driving retirement can have a negative impact upon older drivers, carers, family members and doctor-patient relationships. Empowering older drivers with dementia to plan for driving retirement aligns with the ethical principles of autonomy, beneficence and non-maleficence. Early planning for retirement can facilitate the arrangement of alternative forms of transport. Such an approach could negate the need for clinicians to insist upon abrupt cessation of driving when a patient becomes clearly unsafe. Adopting a sensitive approach to a potentially difficult physician-patient encounter is also helpful (Breen & Greenberg 2010).

Although driving and dementia may represent a Gordian Knot for some physicians, viable solutions do exist (see above). For now, the ethical principle of *primum non nocere* (above all, do no harm) could serve as a useful guide for day-to-day practice. Although not appropriate for all clinical scenarios, this Latin aphorism attributed to the famous English physician, Thomas

Sydenham (1624-1689), is a useful reminder of the need to avoid inflicting harm. However, this principal does not only apply to physicians: unsafe drivers should also be expected to do no harm to themselves or other members of society. While some drivers may lack the necessary insight to meet such expectations, there exists an opportunity to engage in advanced care planning with individuals with early dementia to ease their transition to driving retirement.

Perhaps the time has come to focus upon enhancing older drivers' transport options rather than curtailing them (Carmody, Traynor & Iverson 2012b; Eberhard 2008; O'Neill 2007). To this end, it is hoped that future research, policy and practice will centre upon the crucial mobility and transport needs of our senior citizens.

Resources

<http://www.fightdementia.org.au/>

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CHAPTER 7: What factors delay driving retirement by individuals with dementia? The doctors' perspectives.

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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 (OECD 2001). In 2030, the last of the Baby Boomers, individuals born between 1946 and 1965, will reach 65 years (ABS 2003). Age is the leading risk factor for developing dementia (Ropper & Samuels 2009) and the prevalence rate of dementia amongst those over 65 years is approximately 6.4% (Van der Flier & Scheltens 2005). It would seem reasonable, therefore, to expect the number of drivers with dementia to rise (AA NSW 2010; ANZSGM 2010).

There is 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 (Brown & Ott 2004; Carmody, Traynor & Iverson 2012a; Carmody, Traynor & Iverson 2012b). 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 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 (APA 2000). 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) (Ropper & Samuels 2009). 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 (Ropper & Samuels 2009). 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 (APA 2000; Ropper & Samuels 2009). 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 (Brown & Ott 2004; Ropper & Samuels 2009). The results of pooled epidemiological data from Europe established that the prevalence of dementia rises rapidly after the age of 65 years (Van der Flier & Scheltens 2005). In 2011, it was estimated that 266,574 Australians have dementia and that by 2050 this number will have risen to 942,624 (Deloitte Access Economics 2011). 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 (RMS 2011) (Figure 4). It is anticipated that the number of older drivers on our roads will increase as the population ages (AA NSW 2010; ANZSGM 2010).

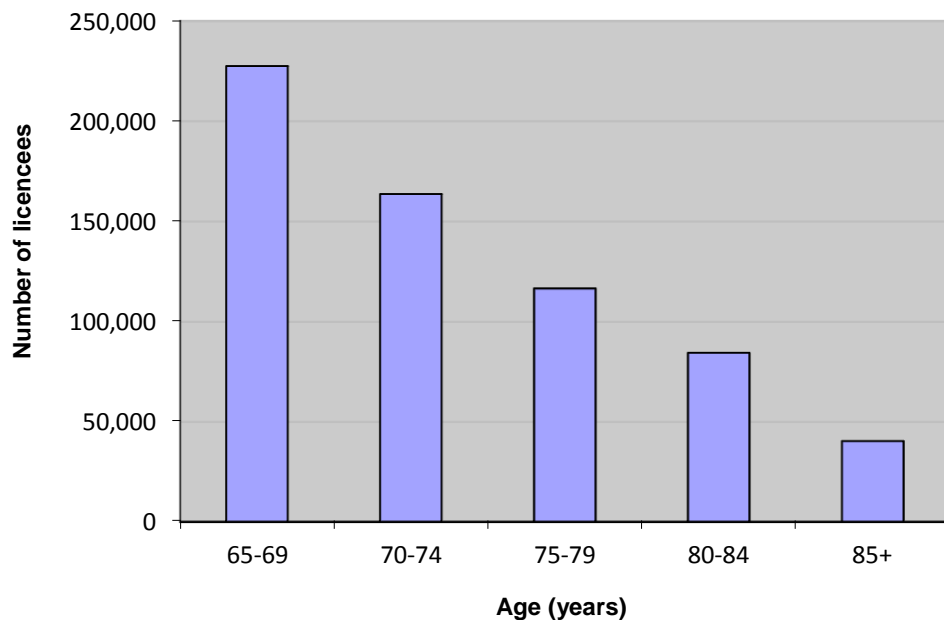


Figure 4. Number of class C licence holders by age group in NSW (as at December 2011)

The impact of dementia on driving skills

Driving is widely acknowledged as being a complex task (Austroads 2012; Drazkowski & Sirven 2011; Ott & Daiello 2010). A variety of skills are necessary for safe driving including adequate memory, concentration, attention, processing speed, planning, judgement and visuospatial skills (Ott et al. 2008). 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 (Ott et al. 2008).

There is broad consensus that those with moderate or severe dementia should not drive (ANZSGM 2010; Ott & Daiello 2010). However, what remains unclear is how best to advise individuals with very mild or mild dementia regarding the decision to drive (Carmody, Traynor & Iverson 2012a; Ott & Daiello 2010). Some authors favour immediate cessation of driving by all upon diagnosis (Friedland et al. 1988; Lipski 1997; Lucas-Blaustein et al. 1988). There is evidence, however, that a large proportion of drivers with either very mild or mild dementia can pass an on-road driving test (Duchek et al. 2003; Ott et al. 2008). Consequently, many argue that individuals with mild dementia may be safe to drive for a limited period (ANZSGM 2010; Breen et al. 2007; Ott & Daiello 2010).

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 (Cooper et al. 1993; Drachman & Swearer 1993; Dubinsky et al. 1992; Duchek et al. 2003; Fitten et al. 1995; Friedland et al. 1988; Lucas-Blaustein et al. 1988; Tuokko et al. 1995; Zuin et al. 2002); reported relative crash risks range from 2.3 (Drachman & Swearer 1993) to 18.4 (Dubinsky et al. 1992). However, at least two studies have

found no difference in crash rates between individuals with dementia and healthy controls (Carr et al. 2000; Trobe et al. 1996). 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 (Breen et al. 2007), 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 (Uc et al. 2004). This may occur in both familiar and unfamiliar environments (Uc et al. 2004). 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) (Hunt et al. 2010).

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 (ANZSGM 2009). 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 (Iverson et al. 2010). 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 (Iverson et al. 2010).

In Australia, the responsibility for issuing a licence rests with the Driver Licensing Authority (DLA) (Austroads 2012). 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 (Austroads 2012). In March 2012, Austroads updated its national clinical guidelines for Australian health care professionals

(Austroads 2012). 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 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 5).

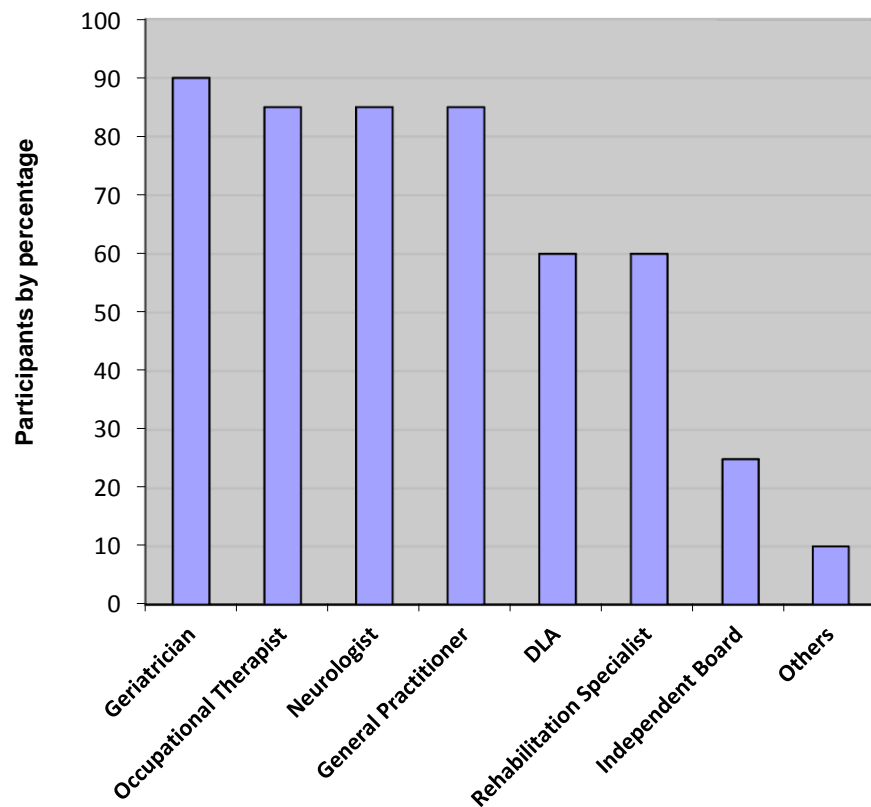


Figure 5. The groups participants considered should be responsible for assessing fitness to drive

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 6). 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’.

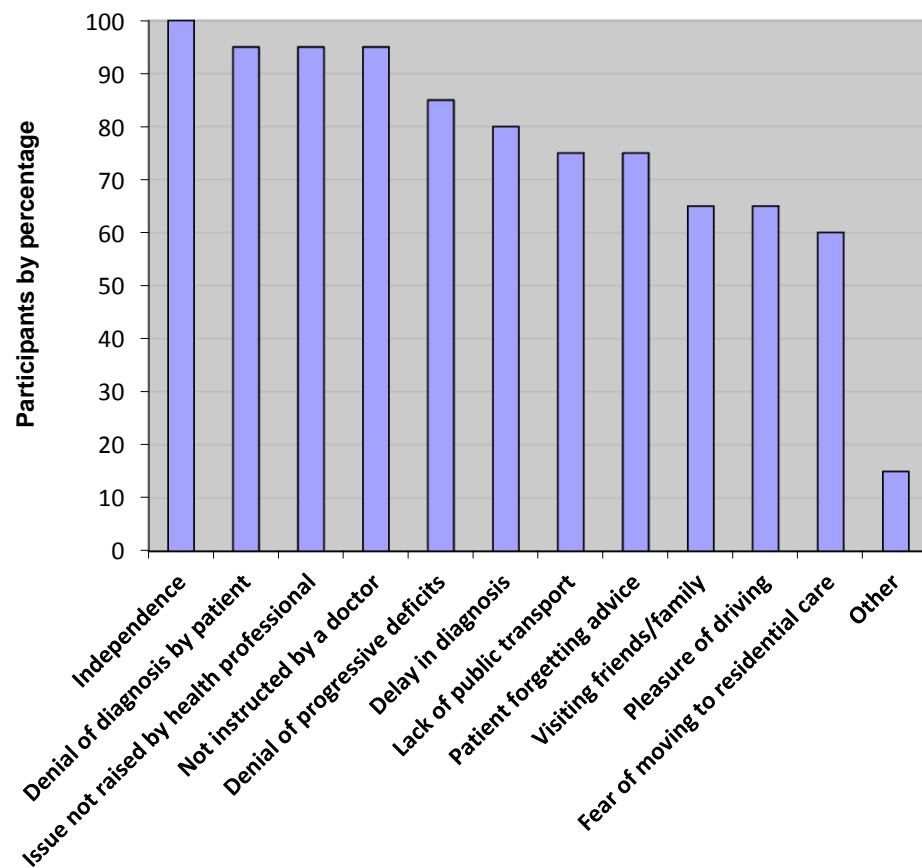


Figure 6. The factors which participants considered delayed driving retirement for individuals with dementia

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 (Snellgrove & Hecker 2002). 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 5).

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 (Adler & Rottunda 2011). 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 (Cable et al. 2000). 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 (Shanahan, Sladek & Philips 2007). 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 (2008, p. 149) subsequently argued that this paper (Shanahan, Sladek & Philips 2007) 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) practising 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 6). 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 (Charlton et al. 2006; Kostyniuk & Shope 2003). Individuals with dementia often develop difficulty with planning, judgement and problem solving (Johansson & Lundberg 1997; Ropper & Samuels 2009). Furthermore, it has been found that 80% of drivers with dementia continue to drive despite having a car crash (Cooper et al. 1993). This is of concern, not least because older drivers involved in a car crash

are more likely to be seriously or fatally injured (Catchpole 2007). 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.

CHAPTER 8: Electronic discharge summary driving advice: current practice and future directions

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Introduction

Contemporary hospital medical practice is increasingly reliant upon technological advances. The advent of electronic medical record systems has facilitated widespread use of electronic discharge summaries. Consequently, many hospitals no longer rely on handwritten discharge summaries. Instead, many patients and/or general practitioners are provided with a printed electronic discharge summary. The advantages of this approach may include: (i) improved legibility (O’Leary et al. 2009); (ii) safer transition to primary care; (iii) greater general practitioner satisfaction (O’Leary et al. 2009); and (iv) expedited data retrieval should a patient be readmitted. The primary aim of this paper is to present the results of an exploratory study of the documentation of driving advice in electronic discharge summaries. A secondary aim is to propose a measure that may help close an important gap in hospital discharge processes: the frequent omission of driving advice from discharge summaries.

A wide range of health problems impact upon one’s ability to drive safely (AMA 2010; Marshall 2008); for example, there is evidence that stroke survivors have a slight to moderate increase in crash risk (Marshall 2008). Of concern is that drivers are often unaware of their legal obligation to inform driver licensing authorities of relevant changes to their health (e.g. stroke, seizure, dementia) (Austroads 2012; Carmody et al. 2013b; NTC 2006).

The Austroads national guidelines stipulate a non-driving period of two weeks after a transient ischaemic attack (TIA), a minimum of four weeks after stroke, and one month to two years after a seizure (Austroads 2012). Patients expect clinicians to advise them of applicable driving restrictions (Rowe & Owen 2001) during the course of a hospital admission. Yet, there is evidence that a large proportion of patients are not counselled regarding driving safety (Fisk, Owsley & Pulley 1997; Goodyear & Roseveare 2003; Gupta, Mehra & Gupta 2010; Kelly, Warke & Steele 1999; MacMahon, O’Neill & Kenny 1996; Orr & Elworthy 2008; Shareef et al. 2009). A review of driving studies found several clinician-related factors were responsible for inadequate counselling: apathy; lack of knowledge; poor verbal communication skills; and incomplete discharge summaries (Frampton 2003; Goodyear & Roseveare 2003; Gupta, Mehra

& Gupta 2010; Kelly, Warke & Steele 1999; Ormerod & Heafield 2000; Orr & Elworthy 2008; Shareef et al. 2009).

In a position paper addressing discharge planning, the Australian and New Zealand Society for Geriatric Medicine described the transfer of information between hospitals and general practitioners as an important aspect of patient care (Lim et al. 2009). Unfortunately, communication and information transfer at hospital discharge is often deficient (Johnstone, Bagnall & Chan 2003; Kripalani et al. 2007). Standardised electronic discharge summaries may improve the transfer of relevant information to general practitioners (Kripalani et al. 2007). There is evidence that electronic discharge summaries improve the quality and timeliness of discharge summaries and enhance communication between inpatient and outpatient health care services (O’Leary et al. 2009).

Individuals who have sustained an acute stroke or TIA require advice regarding the resumption of driving. Thus, a busy tertiary hospital stroke unit was deemed an appropriate service to sample. The present study is, to our knowledge, the first to assess the inclusion of driving advice in Australian discharge summaries.

Methods

Design

This quantitative study involved a retrospective audit of driving advice provided by junior hospital doctors as noted in inpatient electronic discharge summaries.

Setting

This study was undertaken in the stroke unit of a 500-bed university-affiliated teaching hospital in regional New South Wales, Australia. The hospital serves a large catchment area with a population of 275,983 people, 28% of whom are older than 55 years (ABS 2011a). Annually there are a total of 540 inpatient admissions to the stroke unit.

Sample

The sample comprised electronic discharge summaries created by junior hospital doctors during one month, August 2012, for patients who were discharged from the stroke unit.

Data collection

In September 2012, all data was retrieved from an electronic medical records database. Electronic discharge summaries were examined using a datasheet developed by two of the authors (JC and MC). The datasheet consisted of nine items: age; gender; diagnosis; inpatient complications; relevant co-morbidities; deficit at time of discharge; driving advice; length of stay; and discharge destination. Data were recorded in a confidential and de-identified manner. Descriptive statistics were applied in view of the sample size.

Ethics committee approval

This study was approved by the local human research ethics committee (HE 12/327) and hospital research governance directorate.

Results

A total of 41 electronic discharge summaries were created during the month selected (i.e. 100% of stroke unit electronic discharge summaries). As three of the patients died during hospitalisation, a total of 38 electronic discharge summaries were used for analysis.

Demographic profile of patients

The initial sample ($n = 41$) consisted of electronic discharge summaries for 20 males and 21 females with an age range of 25 to 97 years (mean 72.1 years). At the point of discharge, a final diagnosis of stroke was recorded for 20 patients, TIA for nine patients, and seizure for four patients ($n = 29$). Three patients received a combined diagnosis (e.g. stroke and seizure). Other diagnoses included undetermined ($n = 3$), migraine ($n = 2$), cerebral hypoperfusion, meningioma, peripheral vertigo, Bell's palsy, hypertensive crisis, delirium and viral encephalitis.

Patient length-of-stay ranged from 0.9 to 63.8 days (mean 10.5 days, median 6.6 days); 19 individuals had clinically returned to normal by the time of discharge. However, a further 19 had residual neurological deficit when discharged. Discharge destination was identified as home ($n = 24$), rehabilitation unit ($n = 11$), died ($n = 3$), other hospital ($n = 2$), or unknown ($n = 1$).

All summaries were assessed to establish the existence of co-morbidities relevant to driving safety: dementia ($n = 1$) and epilepsy ($n = 3$) were identified in four patients. In addition, each electronic discharge summary was screened to identify inpatient complications relevant to driving safety (e.g. myocardial infarction, ventricular tachycardia). This yielded four events in three patients: major surgery; seizure; TIA; and pulmonary embolism.

Driving advice provided

Driving advice was recorded in only eight (21.1%) electronic discharge summaries. No driving advice was found in the remaining 30 summaries (78.9%). Patients who experienced major complications and patients discharged to rehabilitation did not have driving advice recorded in their electronic discharge summaries.

Twenty-five patients were discharged from the hospital with a diagnosis of stroke or TIA; seven (28%) had driving advice recorded in their discharge summary. One patient with viral encephalitis was provided with written driving advice. Patient discharge diagnosis by driving advice is displayed in Figure 7. One-third of patients discharged home ($n = 8$) had driving advice recorded in their discharge summaries. Driving advice by discharge destination is displayed in Figure 8.

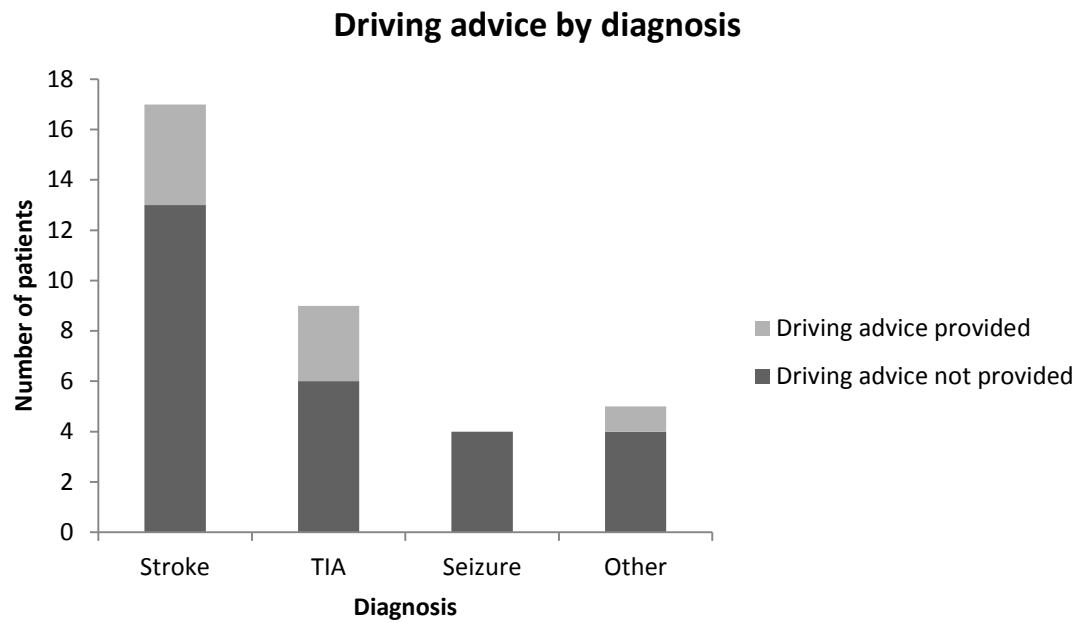


Figure 7. Driving advice by diagnosis as recorded in 38 electronic discharge summaries

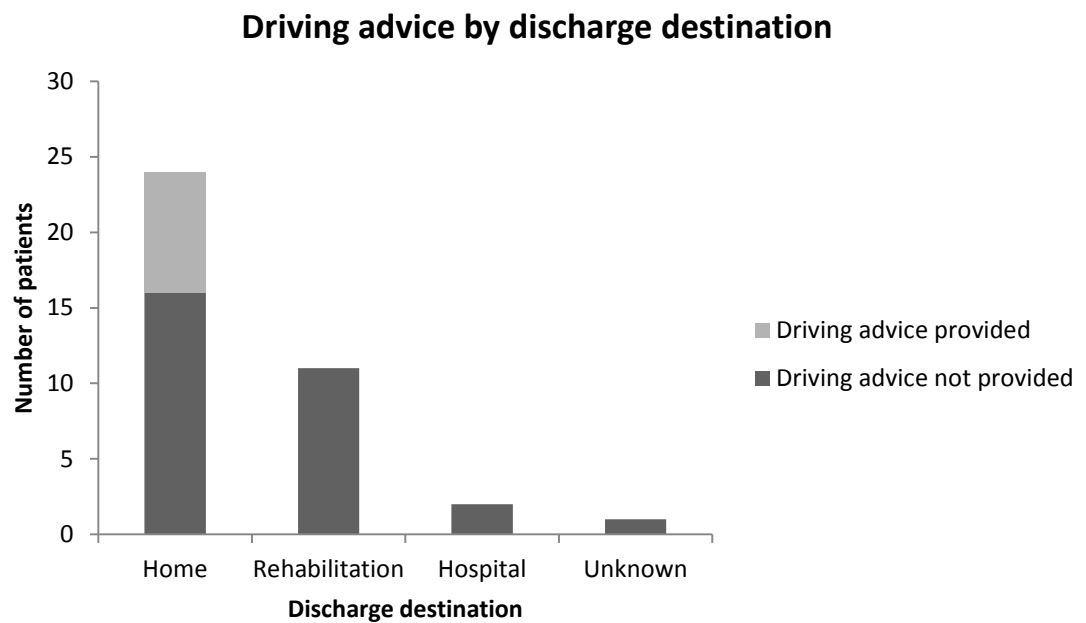


Figure 8. Driving advice by discharge destination as recorded in 38 discharge summaries

Discussion

The key finding of this study is that driving advice is frequently omitted from in-patient hospital electronic discharge summaries for individuals who have sustained a stroke or TIA. Specifically, 72% (18/25) of patients with a diagnosis of stroke or TIA did not receive written advice regarding driving restrictions. Of concern is that none of the four individuals who presented with seizure had driving advice recorded in their discharge summaries. An unexpected finding was that patients who developed major complications during hospitalisation, or were discharged to a rehabilitation service, were not provided with written driving advice. These findings highlight an important discrepancy between national driving guidelines (Austroads 2012) and local clinical practice.

Fisk, Owsley & Pulley (1997) reported that 48% of active pre-stroke drivers did not receive driving advice from any source after their stroke. A retrospective review of the medical records of patients who had sustained a TIA or stroke, were deficit-free and discharged directly home found that driving advice was not recorded ($n = 30$) (Goodyear & Roseveare 2003). A review of the medical records of 118 Scottish patients admitted with psychosis established that only 5.1% ($n = 6$) of discharge summaries contained driving advice (Orr & Elworthy 2008). The authors suggested that the introduction of a standardised discharge summary with relevant prompts would ensure patients receive appropriate driving advice. Shareef et al. (2009) proposed that patients discharged from an emergency department with a diagnosis of seizure, syncope or altered level of consciousness should receive written driving advice. The authors recommended that a checkbox be added to electronic discharge summaries to encourage the inclusion of appropriate written advice.

Poor documentation of driving status and/or driving advice in discharge summaries may be multi-factorial in origin. First, junior hospital doctors often write numerous discharge summaries daily whilst simultaneously requesting consults, answering pages, and writing orders. Second, senior clinicians may not raise the issue of driving safety during ward rounds. Third, electronic discharge summaries may not incorporate a driving advice prompt. Thus, it

would appear that there is no agreed approach for busy, multi-tasking, junior doctors regarding the inclusion of driving advice in discharge summaries. Greysen et al. (2012) argued that targeted interventions are needed to improve existing discharge care practices in teaching hospitals.

A strength of the present study is the sampling of a patient group in need of explicit driving advice. An additional strength relates to the use of a pragmatic retrospective design. A prospective study could introduce observer bias if an investigator were a member of the unit under study (Hróbjartsson et al. 2012). A limitation of the current study was the inability to determine pre-admission driving status or prior discussions with doctors regarding driving restrictions. However, given that 63.5% of NSW residents aged 65 and over hold a class C licence (ABS 2011b; RMS 2012), one would anticipate that approximately 26 of the 41 study participants were licence holders. This limitation could have been overcome by contacting patients post-discharge, but ethical approval was not sought to do so. Given the exploratory nature of this study, a small sample size was drawn from a single centre. In spite of this limitation, it is hoped that the findings will prompt discussion amongst clinicians thereby facilitating review of existing discharge practices in other hospitals and possibly the conduct of larger studies examining this issue.

The electronic discharge summaries selected for analysis in this study were completed by post-graduate year two (PGY-2) doctors; in reality, most hospital discharge summaries are compiled by PGY-1 or PGY-2 doctors. Although this task affords junior doctors valuable experience, a crucial component of ongoing medical care is allocated to the least experienced member of often large, multi-disciplinary clinical teams (Johnstone, Bagnall & Chan 2003). Perhaps not surprisingly, the use of template-based discharge summaries has been shown to be more satisfactory than narrative summaries (Johnstone, Bagnall & Chan 2003; Orr & Elworthy 2008). In view of the findings of the present study and a review of the available literature, the authors propose that a simple driving advice checkbox template (Figure 9) be included in all electronic discharge summaries.

Driving Advice	
Fit to drive	<input type="checkbox"/>
Not fit to drive	<input type="checkbox"/>
Other (see text)	<input type="checkbox"/>
May resume driving in	<input type="checkbox"/> weeks/months

Figure 9. Proposed electronic discharge summary driving advice check-box template

Conclusion

Stroke survivors are frequently keen to resume driving (Marshall et al. 2007). However, in this study, we have shown that driving advice is omitted from the majority of electronic discharge summaries. This has important medical, ethical, and societal implications (Rowe & Owen 2001). Moreover, it highlights a striking gap in current clinical practice. The simple measure we have proposed, if adopted widely, could reduce the risk of unfit patients resuming driving (Marshall 2008), improve continuity of care, and enhance communication between health care providers. Future research could evaluate the impact of such a template upon: (i) patients; (ii) general practitioners; and (iii) hospital staff (e.g. doctors, nurses, occupational therapists).

What this study adds

- A large proportion of individuals over the age of 65 hold a class C licence.
- Current documentation of driving advice in discharge summaries is poor.
- A discharge summary driving advice checkbox may serve as a useful *aide-mémoire* for both junior and senior doctors.

CHAPTER 9: Driving and dementia: equity, obligation and insurance

Article published in the *Australasian Medical Journal*

Carmody, J, Carey, M, Potter, J, Marchetti, E, Traynor, V & Iverson, D 2014, 'Driving and dementia: equity, obligation and insurance', *Australasian Medical Journal*, vol. 7, pp. 384-387.

Introduction

Driving is a complex task, yet some people with dementia are capable of driving safely (AA NSW 2010; ANZSGM 2010; Austroads 2012; Breen et al. 2007; Fox & Bashford 1997). As driving a vehicle is a privilege and not a right (AMA 2008; Lipski 1997; Wilson & Pinner 2013), clinicians are often called upon to provide guidance regarding their patients' ability to drive safely (Breen et al. 2007; Carmody et al. 2013b; Carmody, Traynor & Iverson 2012a). The Australian Bureau of Statistics has predicted that by 2056, one in four Australians will be aged over 65 (ABS 2008). Older members of our community are increasingly dependent upon the private car as their preferred, and in some cases only viable, mode of transport (AA NSW 2010; Wilson & Pinner 2013). Given that the prevalence of dementia rises with age, we can expect an increased number of drivers with dementia on our roads (AA NSW 2010). As outlined in the National Health and Medical Research Council 2013-15 Strategic Plan, Australian Health Ministers have designated dementia and injury prevention as National Health Priority Areas (NHMRC 2012). Thus, there now exists both an impetus and an opportunity to address the issue of driving and dementia on a national level. The purpose of this editorial is to consider (i) the social impact of a loss of licence, (ii) driver and health professional obligations to report conditions that can adversely affect driving, and (iii) the response of motor vehicle insurers to the issue of driving with dementia.

Equity: city versus country

Almost two decades ago, PS Lipski (1997) touched upon the social isolation endured by rural drivers with dementia when they lose their licence. A century earlier, Henry Lawson (1890) expressed concern in the *Albany Observer* that 'the voices of the country people are scarcely ever heard on momentous questions'. Given that maintaining mobility and independence are key concerns of older citizens (ANZSGM 2010; Buys et al. 2012; Huber 2010), retirement from driving can represent a life-changing event, and particularly so for people living in rural and regional Australia (Ibrahim, Bandopadhyay & Ley 2013).

Sadly, the topic of retirement from driving is often shrouded in taboo (Buys et al. 2012). The consequent lack of planning of driving retirement places older drivers at risk of social isolation. Add to this the findings of a recent Queensland study, which reported that the key determinants of transport use by older people are: (i) convenience; (ii) affordability; (iii) availability; and (iv) health (Buys et al. 2012). Therefore, those who live in non-urban areas must endure a form of geographical inequity; i.e. inadequate access to public transport. This emerging dilemma prompted Fox and Bashford (1997) to call for improved planning and the provision of safe, convenient and affordable transport options for older non-drivers. More recently, Ibrahim et al. (2013) have used both print and visual media to highlight the challenges faced by clinicians when assessing geographically isolated drivers with dementia for fitness to drive.

Obligation to report

All drivers in Australia are required to report to the driver licensing authority (DLA) any illness or health condition that may affect their ability to drive safely (e.g. dementia, epilepsy). Accordingly, drivers who fail to notify the DLA may be liable at common law if they knowingly continue to drive with a condition that can adversely affect their driving (Austroads 2012). The Austroads Assessing Fitness to Drive guidelines (2012) were recently updated and warn drivers that there may be long-term financial, insurance and legal consequences if they do not report relevant impairments to the DLA. However, many drivers (46% in one study (AA NSW 2010)) are unaware of their obligation to report. Dementia is often accompanied by a range of cognitive deficits (e.g. loss of insight, judgement, planning) which may impede reporting.

Perhaps not surprisingly, there have been calls by clinicians for driver licences to clearly display a reminder of the necessity to report pertinent medical conditions to the DLA (AA NSW 2010; Beran & Devereux 2007; Carmody et al. 2013b). Only health professionals practising in South Australia and the Northern Territory are obliged to report unsafe drivers to the DLA (Austroads 2012). Furthermore, clinicians in South Australia are required to inform individuals of their intent to notify the DLA (Motor vehicles act 1959). In all but one state (Queensland) and one

territory (Northern Territory), statute provides both civil and criminal indemnity for health professionals who report drivers they believe to be unsafe. In Queensland, although clinicians are exempt from civil and administrative liability, no explicit exemption from criminal liability exists. Health professionals in the Northern Territory are not afforded indemnity from civil or criminal liability. Six years ago, the Australian Medical Association (AMA) (2008) proposed that (i) mandatory reporting is unacceptable, and (ii) doctors should be protected in law regardless of whether they report an unsafe driver. Unfortunately, the requisite state-based legislative amendments have not yet ensued.

Thus, many health professionals remain unsure as to whether they are obliged to notify their local DLA of unsafe drivers (Carmody et al. 2013a; Carmody et al. 2013b). This is reflected by a lack of driving advice in hospital discharge summaries (Carmody et al. 2013d; Gupta, Mehra & Gupta 2010; MacMahon, O'Neill & Kenny 1996; Rowe & Owen 2001). Given that people aged 65 and over account for 39% of all Australian hospital separations (AIHW 2013), there exists a valuable but missed opportunity to provide and record driving advice. Sole reliance upon the acute hospital sector for this purpose is, however, unwise for several reasons: (i) unsafe drivers without need for admission are missed; (ii) falling lengths of stay preclude meaningful safety assessments; and (iii) acutely unwell patients are likely to perform poorly if tested whilst hospitalised.

Insurance implications

There is a dearth of research addressing the issue of dementia and motor vehicle insurance. A literature search of MEDLINE from 2004 to 2014 using the key words driving, dementia and insurance failed to yield any relevant papers. Moreover, little is known of the approach motor vehicle insurers adopt towards drivers with dementia. A study of three insurance providers by Alzheimer's Australia NSW (2010) concluded that insurance company guidelines are neither clear nor consistent for drivers with dementia. In order to explore this issue further, we contacted eight Australian motor vehicle insurance company claims managers. All stated that a pre-existing diagnosis of dementia does not preclude application for motor vehicle insurance

(personal correspondence). Furthermore, if applicants hold a valid driver licence then a diagnosis of dementia does not impact negatively upon one's access to different forms of insurance cover (e.g. comprehensive, third party). This approach is in line with the Insurance Council of Australia Code of Practice (i.e. insurers will only ask for and take into account relevant information when assessing applications) and mirrors the stance adopted by the Association of British Insurers (Breen et al. 2007). Of concern, however, is that drivers with dementia may erroneously assume that the mere possession of motor vehicle insurance equates to indefinite fitness to drive.

Conclusion

Current projections are that almost one million Australians will have dementia by 2050. Hence, there is a pressing societal need to meet the transport needs of older citizens, and specifically individuals with dementia. Inadequate or inaccessible public transport for rural and regional communities remains an important barrier to retirement from driving. While the Federal Government recognises the need to cater for the changing needs of the older population, the State Government approach remains inconsistent. The time has come to cross the Rubicon (i.e. pass a point of no return) by (i) improving access to alternative forms of transport, and (ii) harmonising State legislative frameworks in line with the AMA position statement (2008).

Health professionals (including general practitioners) are well placed to remind individuals that the Austroads guidelines (2012) stipulate that a diagnosis of dementia precludes their holding an unconditional licence. Furthermore, if an individual continues to drive (despite their doctor's advice) and does not notify the DLA, they are not fulfilling their legal obligations. Should the driver become involved in a motor vehicle accident under these circumstances and it is determined that dementia was a contributing factor, s/he may be subject to prosecution.

Individuals with dementia are often reluctant to raise the issue of driving with their general practitioner and *vice versa* (Carmody, Traynor & Iverson 2012a). It is conceivable that drivers are similarly reticent to notify motor vehicle insurers of a diagnosis of dementia. It would

appear that Australian motor vehicle insurers do not decline or restrict coverage for clients with dementia. In addition, it seems that many insurers simply require applicants to possess a valid driver's licence. We propose that increased community and clinician awareness of Australian insurer expectations may facilitate otherwise difficult discussions or decisions about driving, dementia and insurance.

Assessing fitness to drive by clinicians is fraught with hazards (Carmody et al. 2013b; Carmody, Traynor & Iverson 2012a). No single office-based assessment tool can be used to determine driving safety (Iverson et al. 2010). Accordingly, some patients opt for an occupational therapist on-road driving assessment. Unfortunately, such assessments are: (i) costly (approximately \$500-\$700); (ii) not easily accessible for individuals living in regional or remote areas; and (iii) not well suited to assess progressive neurological disorders (e.g. dementia, motor neurone disease) as repeated testing is required (e.g. every six months). In contrast, stable medical conditions (e.g. past stroke, amputation or polio) are well suited to occupational therapist on-road driving assessment: a helpful option for clinicians, particularly if they are unsure as to how to proceed. Although failure at an on-road assessment may have a negative impact upon a doctor-patient relationship, the long-term benefits to an individual, their family and the broader community are of much greater importance.

There is a clear need to improve the existing assessment and reporting pathways *vis a vis* fitness to drive. In addition to strategies suggested elsewhere (Carmody et al. 2013a; Carmody, Traynor & Iverson 2012a), perhaps driving advice should now be routinely incorporated in Australian hospital discharge summaries? This would lessen the considerable burden of assessment of fitness to drive largely (and perhaps unfairly) borne by general practitioners.

CHAPTER 10: Development and pilot testing of a decision aid for drivers with dementia

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Background

The rising global prevalence of dementia represents an increasingly important medical, societal and economic issue. Alzheimer's Disease International (ADI) and the World Health Organisation (WHO) have identified dementia as a public health priority (2012). Worldwide, there are more than 35.6 million people living with dementia (WHO 2012). By 2050 this figure is projected to rise to 115 million and the ADI and WHO have called for a more dementia friendly society (WHO 2012). To achieve this goal there needs to be improved planning and provision for individuals living with dementia (Lancet Neurology 2012; WHO 2012).

Dementia is a condition characterised by impairment of memory and at least one other cognitive domain (e.g. executive function, language, praxis) which interfere with daily function and independence (APA 2013). The incidence and prevalence of dementia increase with age (Blass & Rabins 2008). Although Alzheimer's disease is the most frequent cause of dementia, other neurological disorders can be responsible (e.g. vascular dementia, Lewy Body dementia, frontotemporal dementia). For many patients, symptoms begin insidiously and may pass unnoticed for some time (Blass & Rabins 2008). As the condition progresses, the ability to drive safely is eventually lost (Breen et al. 2007). Yet, many individuals continue to drive after receiving a diagnosis of dementia (Carr, Shead & Storandt 2005; Herrmann et al. 2006).

As our population is ageing, the number of older drivers is increasing (Department for transport 2011; Eby & Molnar 2010; Martin, Marottoli & O'Neill 2009). Twenty years ago, 14% of all licence holders in the United States were aged 65 years or more (FHA 1993); today it is 16.3% (FHA 2011). In the United Kingdom, 18.8% of the driving population is over 65 years (Department for transport 2011). This dependence by older individuals upon private cars is multifactorial (Buys et al. 2012; Edwards et al. 2010): (i) access to a car provides a sense of control, self-worth and independence (Drazkowski & Sirven 2011; Snyder 2005); (ii) use of a car can enhance social interactions (Musselwhite & Haddad 2010); (iii) alternative forms of transport are often lacking (Kostyniuk & Shope 2003); and (iv) older drivers seldom plan for retirement from driving (Kostyniuk & Shope 2003). Furthermore, driving retirement is

negatively associated with depression (Marottoli et al. 1997), difficulty accessing services (Taylor & Tripodes 2001) and nursing home placement (Freeman et al. 2006).

The subject of driving and dementia raises a range of important ethical and medico-legal issues (Berger & Rosner 2000; Brown & Ott 2004; Carmody et al. 2013b; Drazkowski & Sirven 2011; Snyder 2005). In essence, there is a need to balance road safety with the transport requirements of our ageing population (Breen et al. 2007; Carmody, Traynor & Iverson 2012a; Carmody, Traynor & Iverson 2012b; O'Neill 2007; O'Neill 2010). Unfortunately, much of the literature relating to driving and dementia focuses upon safety rather than mobility (O'Neill 2007). Achieving the correct balance can prove elusive as, despite the existence of evidence-based clinical guidelines (Carr et al. 2010; Iverson et al. 2010), many physicians simply do not raise the topic of driving retirement with individuals living with a dementia (Carmody et al. 2013a; Drickamer & Marottoli 1993; Jang et al. 2007). The need for such discussions is underscored by the fragility of older drivers and their elevated risk of injury in car crashes (Carr et al. 2010).

The majority of older drivers do not have dementia. However, given that increasing age is the leading risk factor for developing dementia (Ropper & Samuels 2009), it is reasonable to expect more and more drivers with dementia on our roads. Thus, there is a pressing need to assist people with dementia in their decision making regarding retirement from driving. The overall purpose of this research project is to establish how a self-administered decision aid (DA) can assist drivers with dementia make decisions about driving retirement. The primary outcome measure was decisional conflict. The secondary outcome measures were knowledge, decision, satisfaction with the decision, booklet use and booklet acceptability.

Use of such a DA promotes a shift in focus away from assessment of fitness to drive. Rather, it emphasises the need to facilitate planning for driving retirement. Such preparation for driving retirement has been likened to a Ulysses contract (Howe 2000; O'Neill 2010) (Ulysses asked his crew to tie him to the ship's mast on the condition that they ignored his pleas to be released when seduced by the song of the sirens (O'Neill 2010)). It is anticipated that, by adopting a

collaborative approach, individuals living with a dementia will be more likely to raise the subject of driving retirement with their family, carer or health care professional.

Theoretical considerations

Decision making refers to the process of making choices between different courses of action or inaction; this process involves weighing up uncertain positive and negative outcomes, leading to decisional conflict (O'Connor, Jacobsen & Stacey 2002; Prunty et al. 2008). DAs facilitate patient involvement in decisions about their health care leading to decisions which are informed and consistent with one's values (Feldman-Stewart et al. 2007; O'Connor et al. 1998). A recent Cochrane review (Stacey et al. 2014) established that DAs: (i) improve knowledge; (ii) reduce decisional conflict; (iii) clarify expectations of possible benefits and harms; (iv) lead to choices consistent with informed values; and (v) result in greater participation in decision making. Furthermore, DAs appear to have a positive effect on communication with health professionals despite a variable effect on actual choices (Stacey et al. 2014). Given that patients' health care needs and preferences vary, it is appropriate to tailor communication strategies accordingly (Bensing, Rimondini & Visser 2013).

The Ottawa Decisional Support Framework (ODSF) (O'Connor 2006) is a theoretical framework which is used to address the uncertainty or decisional conflict which may arise around health care choices. This framework consists of three components: (i) decisional needs; (ii) decisional support; and (iii) decisional quality. In line with this framework, the authors aimed to meet the decisional needs of drivers with dementia by providing them with adequate support so as to enhance the quality of their decision making process. The ODSF has been used to develop other dementia-related DAs: (i) respite service choices by carers of people with dementia (Stirling et al. 2012); and (ii) feeding options in end-stage dementia (Hanson et al. 2011).

Methods

DDDA development

The structure of this driving with dementia decision aid (DDDA) was informed by a wide range of resources: (i) the ODSF (O'Connor 2006); (ii) the Ottawa Personal Decision Guide (O'Connor & Stacey 2012); (iii) the Australian National Health and Medical Research Council guide 'How to prepare and present information for consumers of health services' (NHMRC 1999); and (iv) the International Patient Decision Aids Standards (IPDAS) collaboration guidelines (Elwyn et al. 2006).

The content of the DDDA was derived from a three-step approach. Firstly, relevant literature addressing driving and dementia was reviewed (Carmody et al. 2013a; Carmody et al. 2013b; Carmody, Traynor & Iverson 2012a;). The attitudes of drivers aged over 55 towards existing driving and dementia resources were also sought. This served to clarify important deficiencies which apply to currently available resources for individuals planning to retire from driving (Andrew, Traynor & Iverson 2011). Secondly, a development panel was formed which consisted of two clinicians and two senior academics. A draft DDDA was created and refined by the development panel using an iterative process. Thirdly, an expert review panel provided feedback on the draft DDDA. The panel comprised nine members from Australia ($n = 7$), Canada ($n = 1$), and the United Kingdom ($n = 1$), three of whom had experience in the development of DAs. Responses were sought around five categories: (i) layout; (ii) reading ease; (ii) length; (iv) accuracy; and (v) relevance. The findings were used to modify the draft DDDA.

DDDA presentation

The DDDA booklet (Appendix F) opens with a brief introduction which is followed by a guide on how to use the DA. Readers then progress through four key steps: (i) clarification of decision and values; (ii) decisional needs and support; (iii) considering the options; and (iv) advising others of one's decision. Information about the impact of dementia upon driving skills is

included, and contact details for the Australian National Dementia Hotline are provided. To enhance reader engagement, detailed content (e.g. author affiliations, disclaimers, funding, references, scheduled updates) is provided at the end of the booklet.

In line with the recommendations of health communication experts (Butow et al. 1998; Hibbard & Peters 2003; NHMRC 1999), a range of strategies were used to enhance reader understanding of the content of the DDDA. Information was presented clearly (e.g. large font size, A4 sized pages) and concisely (e.g. 12 pages long, short sentences). A Flesch reading ease of 84.1 and a Flesch-Kincaid grade level of 3.8 were achieved suggesting that most 4th grade students would be capable of reading the booklet. The pilot version of the DDDA fulfills 40 of 47 IPDAS collaboration quality criteria and is registered on-line with the Ottawa Hospital Research Institute decision aid library inventory (Elwyn et al. 2006; OHRI 2014). The seven unmet quality criteria relate to the effectiveness of a DA and will be addressed in a randomised controlled trial.

Pilot study

This pilot study involved a pre and post study design. Recruitment was undertaken over eight months in 2012. Ethical approval was provided by the regional Human Research and Ethics Committee and the local health district Research Governance Office. Potential participants were approached at two sites in regional New South Wales, Australia: (i) a university-affiliated tertiary hospital Aged Care dementia clinic; and (ii) a community-based Primary Care center. Inclusion criteria consisted of: (i) a history of dementia (self-reported or clinically confirmed) regardless of duration or severity; (ii) current driver; (iii) ability to read English; and (iv) ability to provide written consent to participate. Individuals who no longer drive were excluded. A convenience sampling technique was used to recruit participants; thus, individuals living with a dementia who were patients within these services were approached about possible participation. Potential participants were asked by their treating clinician if they were interested in learning more about a study on driving and dementia.

Procedures

Individuals who expressed interest in becoming involved in this study were provided with a participant information sheet and a consent form. Signed consent forms were returned via reply-paid envelope. A research assistant telephoned each participant to complete a pre-booklet survey. The pilot version DDDA (Appendix F) was then mailed to participants. One week later, a post-booklet survey was conducted thus affording participants adequate time to reflect upon the contents of the booklet.

Measures

Participant demographics, knowledge, decision (about driving retirement) and decisional conflict were recorded during the pre-booklet survey. Except for the demographic details, the post-booklet survey assessed the same measures in addition to booklet use, booklet acceptability, and satisfaction with decision. In addition, open-ended questions were included at the end of the post-booklet survey to assess the acceptability of the DA by participants.

The primary outcome measure, decisional conflict, was measured with a low-literacy decisional conflict scale (O'Connor 2014a) previously used in other DA studies (Smith et al. 2010). This scale measures personal perceptions of (i) uncertainty in choosing options, and (ii) modifiable factors contributing to uncertainty (O'Connor 2006). The secondary outcome measures (knowledge, decision, satisfaction with decision, booklet use and booklet acceptability) were assessed using existing tools. Dementia knowledge was measured using a 10-item survey based on the Ottawa knowledge questionnaire template (O'Connor 2014b). The content of the dementia knowledge quiz was informed by reviewing the available literature relating to dementia and driving. Participants' decision regarding driving was recorded as: (i) stop driving now; (ii) drive less; (iii) stop driving later; (iv) unsure; or (v) other. Satisfaction with decision was measured using a validated satisfaction with decision scale (Holmes-Rovner et al. 1996). Booklet use was reviewed by establishing the length of time required to read the booklet, and whether assistance was required by the participant to use it. Booklet acceptability was measured

using an eight-item survey adapted from the Ottawa acceptability tool (O'Connor & Cranney 2014): this component of the post-booklet survey was used to seek feedback from participants on how the booklet could be improved. Descriptive statistical analysis was performed using SPSS version 21 (IBM, Chicago, USA).

Results

Twelve participants completed the pre and post-booklet surveys: nine males and three females (Table 3). The mean age was 75.4 (range 66–88, SD 6.7). The living arrangements of participants included living at home with a spouse/partner ($n = 9$), living alone ($n = 1$) and living in a nursing home ($n = 2$). The highest level of education among participants was: primary school ($n = 3$); high school ($n = 3$); certificate/diploma ($n = 4$); undergraduate degree ($n = 1$); and post-graduate degree ($n = 1$). All participants were either unemployed or retired. The mean duration of driving experience was 54.4 years (range 40–69, SD 7.9). One participant was instructed by a doctor to stop driving two weeks prior to entering the study but was, up until that time, still driving and doing so daily. The remaining participants ($n = 11$) were active drivers: two to six times per week ($n = 3$); once a day ($n = 4$); and more than once a day ($n = 4$). A mean booklet reading time of 30 minutes was reported (range 5–60, SD 20.7). All but two participants ($n = 10$) read the booklet without assistance.

Table 3. Demographic characteristics of study participants

Variable	Participants
Age (mean)	75.4 years
Gender	9 males / 3 females
Living arrangements	
With spouse/partner at home	9 (75%)
With other family at home	-
Alone at home	1 (8.3%)
Hostel	-
Nursing home	2 (16.6%)
Other	-
Highest level of education	
Primary school	3 (25%)
High school	3 (25%)
Certificate/diploma	4 (33.3%)
Undergraduate degree	1 (8.3%)
Postgraduate degree	1 (8.3%)
Employment status	
Employed	-
Unemployed / retired	12 (100%)
Volunteer worker	-
Length of driving experience (mean)	54.4 years
Driving frequency	
Less than once a week	-
Once a week	-
Two to six times per week	3 (25%)
Once a day	4 (33.3%)
More than once a day	4 (33.3%)

The mean knowledge score was 5.3 pre-booklet (SD 2.4); this rose to 5.8 post-booklet (SD 2.6) (maximum possible score = 10). When asked which driving option was preferred, participants chose: stop driving now ($n = 10$ pre-booklet, $n = 7$ post-booklet); drive less ($n = 0$ pre-booklet, $n = 1$ post-booklet); stop driving later ($n = 1$ pre-booklet, $n = 1$ post-booklet); and unsure ($n = 1$ pre-booklet, $n = 3$ post-booklet). The low-literacy decisional conflict scale results range from zero to 100 (a high score indicates high decisional conflict) (O'Connor 2014a). A mean score of 22.5 was recorded pre-booklet (range 0–60, SD 17.1); this fell to 7.5 post-booklet (range 0–30,

SD 9.7). Post-booklet satisfaction with decisions about driving retirement was high (mean 4.68/5, range 4.16-5, SD 0.3).

All participants found the length and information content of the DDDA to be ‘just right’ (Table 4). A large majority described the booklet as balanced (83.3%) with information presented in a ‘good’ or ‘excellent’ manner (91.6%). Most participants (91.6%) felt that the DDDA helped them decide about driving and all would recommend the booklet to others. Qualitative feedback regarding the booklet was favourable (Table 5).

Table 4. Decision aid acceptability

Variable	Participants
Information presentation	
Poor	-
Fair	1 (8.3%)
Good	3 (25%)
Excellent	8 (66.6%)
Booklet length	
Too long	-
Too short	-
Just right	12 (100%)
Was there enough information to decide about driving?	
Too much information	-
Too little information	-
Just right	12 (100%)
Was the booklet balanced?	
Slanted against driving	1 (8.3%)
Slanted in favor of driving	1 (8.3%)
Balanced	10 (83.3%)
Was the booklet useful in helping decide about driving?	
Yes	11 (91.6%)
No	1 (8.3%)
Would you recommend the booklet to others?	
Yes	12 (100%)
No	-

Table 5. Qualitative feedback from participants and family

Question	Responses
Was the booklet useful in helping decide about driving?	<ul style="list-style-type: none"> • Found it very useful. • Did not feel it was relevant for me. • Interesting – made him [husband] think about the issue. Had not really considered it before. • Very helpful. Used it to have a roundtable discussion with grown children and husband.
What did you like about the booklet?	<ul style="list-style-type: none"> • Reasonably fair and easy to read. • Well set out, clearly organised, easy to understand. • The checklists were helpful. • A lot of good information. It included things that people need to know. Enjoyed filling check boxes. • Very easy to navigate. The options in the checklists are very comprehensive. All steps are very clear. • The booklet brought home some things that we had already been thinking about, and helped to put them into practice. It has made us change the way we do things. It is brief, to the point. • The content is very relevant to others, not just dementia. Good to use as a tool to start conversation with others.
How do you think we could improve the booklet?	<ul style="list-style-type: none"> • No, it covers everything well. • Have more people review it. • Be more specific when referring to doctor – do you mean general practitioner?

Discussion

The purpose of this research was to establish if a self-administered DA can assist drivers with dementia make decisions about driving retirement. This pilot study provided an opportunity for individuals with dementia, who are often excluded from medical research, to express their views about the decision to retire from driving (Taylor et al. 2012). Overly restrictive study protocols often preclude the recruitment of older participants (Zulman et al. 2011), and particularly people

with cognitive impairment or multiple co-morbidities. Thus, individuals with dementia can be denied access to new interventions or therapies. This study helped to redress this imbalance through the development and preliminary evaluation of a DA for drivers with dementia.

Most participants completed the booklet without assistance, requiring an average reading time of 30 minutes. A concerted effort was made during the development phase to ensure the study booklet was clear, concise and sensitive to the needs (e.g. cognitive requirements) of individuals with dementia. As reported in the development of a low literacy DA elsewhere (Elwyn et al. 2009), simple strategies were employed to improve the readability of the DDDA and reduce the cognitive effort required (Hibbard & Peters 2003) by using: (i) large font size; (ii) active voice; (iii) short sentences; and (iv) simple diagrams. Consequently, a low Flesch-Kincaid reading grade level of 3.8 was achieved.

The IPDAS collaboration criteria (Elwyn et al. 2006) serve as a validated measure of DA quality, as well as a useful guide in the development of new DAs. The DDDA rated highly in two of three quality domains: (i) content 20/20; (ii) development process 20/20; and (iii) effectiveness 0/7. The final version of the DDDA booklet will be forwarded to the IPDAS instrument assessment team in Cardiff, United Kingdom (Elwyn et al. 2009) for an objective assessment against IPDAS quality criteria. This will serve two important functions: (i) confirm that the DDDA has undergone comprehensive and rigorous development; and (ii) provide assurance that it satisfies internationally agreed standards of quality.

It is widely acknowledged that the recruitment of individuals with dementia is fraught with challenges (Iliffe et al. 2011; Wilcock et al. 2007). Accordingly, a limitation of this pilot study is its low sample size. An additional limitation is the absence of delayed follow-up data (e.g. six month follow-up survey). Notwithstanding these limitations, encouraging improvements in participant knowledge and decisional conflict were observed following use of the DDDA. In addition, booklet acceptability was high and qualitative feedback from participants was favourable. In view of these preliminary findings, a randomised controlled trial has been initiated to better understand the clinical impact of the DDDA (ACTRN 12613000174785). A

potential limitation of this pilot study is the nature of the literature review which informed the development of the DDDA. A systematic review was not undertaken: (i) to avoid undue replication of existing reviews; (ii) as a low yield of additional relevant studies was anticipated; (iii) as it was unlikely to alter the DDDA development; and (iv) as it was unlikely to alter the methods, results or outcomes of this pilot study.

Conclusion

Discussion with individuals with dementia about driving retirement often represents a challenging clinical encounter for health professionals (Carmody et al. 2013a; Carmody et al. 2013b; Carmody, Traynor & Iverson 2012a). A Pyrrhic victory may ensue whereby individuals with dementia are instructed to cease driving yet they neither heed their clinician's advice nor return for medical review. Thus, there exists a clear need to facilitate conversations related to early retirement from driving. Ideally, such discussions would occur shortly after a diagnosis is reached. This pilot study demonstrates how a multi-faceted approach (i.e. development panel, review panel and field testing) resulted in the creation of a feasible and acceptable DA for individuals with dementia. This DDDA provides a simple and balanced outline of the benefits and risks of driving. It facilitates clarification of values, promotes planning for retirement from driving and encourages the reader to speak with their doctor. The DA resource was developed in line with the IPDAS collaboration guidelines (Elwyn et al. 2006) and pilot tested by drivers with dementia. However, further research is required to evaluate the impact of this DA in the target group. Accordingly, a randomised controlled trial of drivers with dementia is currently underway.

There is a need for a comprehensive and inclusive approach to older drivers with cognitive impairment (Carmody et al. 2013a; Carmody, Traynor & Iverson 2012a; Carr & Ott 2010; Jang et al. 2007). This study describes an intervention which contributes towards the achievement of an important goal: enhancing patients' quality of life while simultaneously maintaining personal and public safety (Carr & Ott 2010). It is intended that, ultimately, the DDDA will be made freely available to patients, carers and clinicians by providing copies to (i) local, state and

national health care authorities, (ii) national road safety organisations, and (iii) relevant consumer support groups. The booklet is designed to facilitate discussion about a frequently neglected issue: driving retirement by individuals with dementia. Although the focus of this study was on drivers with dementia, the methods used should guide future DA development (e.g. driving and epilepsy, driving and sleep apnoea, dementia and management of finances).

CHAPTER 11: A prospective interventional cohort study of a decision aid for drivers with dementia

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Carmody, J, Veerhuis, N, Traynor, V & Batterham, M (submitted), ‘A prospective interventional cohort study of a decision aid for drivers with dementia’, *Australian and New Zealand Journal of Public Health*.

Introduction

Increasing age is the principal risk factor for the development of dementia (Larson 2008). Although there is evidence that the incidence of dementia is falling, improvement in life expectancy will inevitably result in a net increase in the number of older people with dementia (Larson 2013). The issue of driving is critically important for people as they age (Ross et al. 2009) prompting calls for the development of interventions to maintain the mobility of older adults (Ross et al. 2009). Given the rising number of drivers with dementia on our roads, the poor uptake of public transport by older people and the negative consequences of driving cessation (Martin et al. 2009), there is a clear need for novel strategies to enhance both personal independence and community safety (Yates 2014).

Determination of fitness to drive by physicians is fraught with hazards (Breen et al. 2007). First, there is no test or historical feature that can accurately quantify driving risk (Iverson et al. 2010). Accordingly, the American Academy of Neurology asserts that physicians can only make qualitative estimates of driving risk (Iverson et al. 2010). Second, the legal requirements to assess cognitively impaired drivers vary among states (and countries) and are subject to interpretation (Adler 2011; Carmody et al. 2013b). Physicians who report a driver with dementia in New York can face legal action for breach of patient confidentiality. Yet, physicians who fail to report a driver with dementia in California may face criminal misconduct charges (Snyder 2005). Third, physicians have different perceptions regarding their role in driving discussions and thus do not behave uniformly when faced with this issue (Adler 2011). A reluctance to address fitness to drive often stems from valid concerns (Jang et al. 2007). Although instruction to cease driving by a physician leads to fewer crashes (Redelmeier et al. 2012), insistence upon abrupt driving cessation can (i) reduce quality of life, (ii) jeopardise the doctor-patient relationship, and (iii) burden family members (Jang et al. 2007). Last, the age-old tenets of *primum non nocere* (Carmody et al. 2013b) and *cura personalis* do impact upon the decision making process of physicians in their attempt to balance patient need and societal expectations in a just manner (Yates 2014).

Identifying and making a decision about one's health can be difficult for patients. Decision aids are person-centered tools used when each option has benefits and harms that patients may value differently (Stacey et al. 2014). Specifically, decision aids are pamphlets, booklets, videos or web-based tools which help patients consider their options and encourage participation with health professionals in making a decision (Stacey et al. 2014). Designed to present balanced, evidence-based information, they provide patients and families with structured information about a clinical choice and promote shared decision-making (Elwyn et al. 2006; Hanson et al. 2011). A recent systematic review confirmed that decision aids (i) improve people's knowledge regarding options, (ii) reduce decisional conflict, (iii) encourage active participation in decision making, and (iv) enhance the accuracy of risk perception (Stacey et al. 2014).

The present study involved testing the impact of a decision aid upon drivers with dementia. Notwithstanding the barriers posed by dementia-related research (Carmody, Traynor & Marchetti 2014), the authors sought to build upon a successful pilot study (Carmody et al. 2014a) and other existing decision aids designed for people with dementia and their carers (Hanson et al. 2011; Mitchell et al. 2001; NHS 2013; Stirling et al., 2012). Although a range of reasonable interventions for drivers with dementia have been posited to date (Adler 2007; Breen et al. 2007; Classen et al. 2014; Yates 2014), a recent systematic review (Martin et al. 2012) highlighted the absence of randomised evidence regarding interventions which can (i) help safe drivers to remain mobile or (ii) reduce crashes. In this study, a user-friendly intervention (i.e. decision aid) was adopted, in keeping with Barry & Edgman-Levitan's assertion (2012) that shared decision making represents the pinnacle of patient-centred care. Of particular relevance to clinical practice is the potential to promote early retirement from driving by people with dementia in a non-adversarial manner, thus preserving valuable doctor-patient relationships.

Methods

Initially, this study was designed and conducted as a multicenter, open label, randomised controlled trial. A baseline telephone survey was conducted at the outset. This was followed by two more telephone surveys at one week and three months. Recruitment was undertaken widely throughout Australia and New Zealand. However, in view of a low participation rate at six months, the study design was altered to a prospective interventional cohort study. This approach ensured that half of all participants entered the intervention group.

Study participants

Drivers with dementia in Australia and New Zealand were recruited over a 15 month period from April 2013. Inclusion criteria consisted of: (i) a history of dementia (self-reported or clinically confirmed) regardless of duration or severity; (ii) current driver; and (iii) ability to read and speak English. Individuals who no longer drive were excluded. Age and sub-type of dementia had no bearing on recruitment.

Intervention

A driving with dementia decision aid (DDDA) served as the intervention in this study. The development and pilot testing of this tool have been described elsewhere (Carmody et al. 2014a). No significant changes were made to the layout or content of the booklet given the positive feedback received from participants in the pilot study. The content of the DDDA was informed by a targeted literature review, a local development panel and a multidisciplinary international review panel. The structure of the decision aid was guided by the Ottawa Decisional Support Framework (OHRI 2014), Australian National Health and Medical Research Council guide 'How to prepare and present information for consumers of health services' (NHMRC 1999), and the International Patient Decision Aids Standards collaboration guidelines (Elywn et al. 2006).

Initially, participants were randomly assigned to receive the DDDA or standard care. Upon receipt of written consent, a research assistant mailed the booklet to individuals within the

intervention group. Latterly, in view of low recruitment, all remaining participants were allocated a DDDA. Consequently, half of all participants were allocated to the intervention group ($n = 10$), and the remaining participants formed a control group which received standard care ($n = 10$).

Outcome measures

Participants underwent a total of three telephone surveys: (i) at entry into the study; (ii) at one week (post-allocation); and (iii) at three months. All surveys were conducted by an experienced research assistant.

The primary outcome measure was decisional conflict. Decisional conflict refers to personal uncertainty about which course of action to take when choice among competing options involves risk, regret, or challenge to personal life values (LeBlanc et al. 2009). It can be influenced by several factors (e.g. inadequate knowledge, unclear values, inadequate support, or the perception that an ineffective decision has been made). In this study, it was measured with a low-literacy decisional conflict scale (OHRI 2014) as used in other DA studies (Smith et al. 2010). This scale measures personal perceptions of uncertainty in choosing options and modifiable factors contributing to uncertainty.

The secondary outcome measures were knowledge, decision, satisfaction with decision, booklet use and booklet acceptability. These were assessed with existing tools. Dementia knowledge was measured using a 10-item survey based on the Ottawa knowledge questionnaire template (OHRI 2014). The content of this dementia knowledge test was derived from relevant literature. Participants' decision regarding driving was recorded as: (i) no change; (ii) stop driving now; (iii) drive less; (iv) stop driving later; or (v) other (e.g. unsure). Satisfaction with decision was measured with a widely used satisfaction with decision scale (Holmes-Rovner et al. 1996). Booklet use was assessed by establishing the length of time required to read the booklet, and whether assistance was required by the participant to use it. Booklet acceptability was measured using an eight-item survey adapted from the Ottawa acceptability tool (OHRI 2014): this

component of the second survey was used to seek feedback from participants on how the booklet could be improved. In addition, open-ended questions were included at the end of the second and third surveys to assess the acceptability of the DDDA.

Additional measurements at baseline

During the first telephone survey, in addition to the measures described above, demographic information was recorded (e.g. age, gender, level of education, living arrangements, frequency of driving, employment status, access to public transport).

Sample size

Originally, the sample size was calculated to detect the minimal clinically important differences between the decision aid group and the usual care group for the primary outcome. An effect size of 0.5 was considered clinically significant and has been reported in other randomised controlled trials of decision aids (O'Connor et al. 1998). With a sample size of 63 (in each group), the study would have an 80% power at a .05 significance level to detect an effect size of 0.5 for decisional conflict. Despite a lower than anticipated number of participants, recruitment was ceased at month 15 due to time and budgetary constraints. Thus, a total of 20 participants were recruited; half of whom comprised the intervention group.

Statistical analysis

Descriptive statistical analysis was performed using SPSS version 22 (IBM, Armonk NY, USA). Linear mixed models were used to compare the changes in responses between groups over time. There were no significant group effects; the main effect for time and the interaction are reported. Exact tests were used to compare the proportions between groups with regard to their preferred decision.

Ethical considerations

The human research ethics committee of the University of Wollongong and Illawarra Shoalhaven Local Health District approved the study (HE12/016). Informed consent was

secured in writing from all participants. A guardian provided written consent for individuals incapable of doing so because of cognitive impairment. The study was prospectively registered with the Australian New Zealand clinical trials registry (registration number 12613000174785).

Results

Twenty drivers with dementia aged 49 to 85 (mean 72, SD 8.3) participated, four of whom were female. Most participants resided in Australia ($n = 17$) but three were from New Zealand. All lived at home. The vast majority (90%) reported driving more than once a week; 10% more than once a day. Access to public transport was described as poor or very poor by 15%. The past driving experience of drivers was recorded as 32 to 67 years (mean 54.5, SD 8.4). With regard to education levels, most had obtained a certificate/diploma or above (75%). Almost all were retired (90%) and, interestingly, many were engaged in volunteer work (25%).

Half of the participants were allocated a booklet ($n = 10$). This group (i.e. the intervention group) reported a mean reading time of 26 minutes. Two people (20%) required assistance to read it. Many (80%) felt that the presentation of information was either good or excellent. Booklet length was deemed 'just right' by a large majority (90%). Most found the decision aid (i) to be balanced (80%), (ii) contained enough information to decide about driving (70%), and (iii) helped them decide about driving (70%). All would recommend the booklet to others. With regard to qualitative feedback, comments included 'straight forward', 'easy to read and use', 'helps you to discuss with your partner about driving', 'good insight into driving', 'gets you thinking', and 'persuaded me to look for additional support and seek help'.

At baseline, the mean decisional conflict score was 25.8/100 (SD 21.9). In the intervention group, this dropped to 11 (SD 13.7) within one week, and remained low at three months (mean 16.4, SD 21). In contrast, decisional conflict scores were higher in the control group at one week (mean 17.5, SD 12.3) and at three months (mean 19, SD 15.2). There was a trend for an overall time effect ($p = .052$), with the decrease between the baseline and week one assessments being of borderline significance ($p = .05$). However, the overall change between baseline and

three months ($p = .705$) or one week and three months ($p = .10$) were not significant. There was no significant difference between groups over time ($p = .0639$) (Figure 10). When the groups were pooled the change in time was significant ($p = .049$), again with the difference between baseline and one week ($p = .048$) being the only significant difference in the post hoc analysis. The difference from baseline to three months ($p = .543$) or one week to three months were not significant ($p = 1.0$).

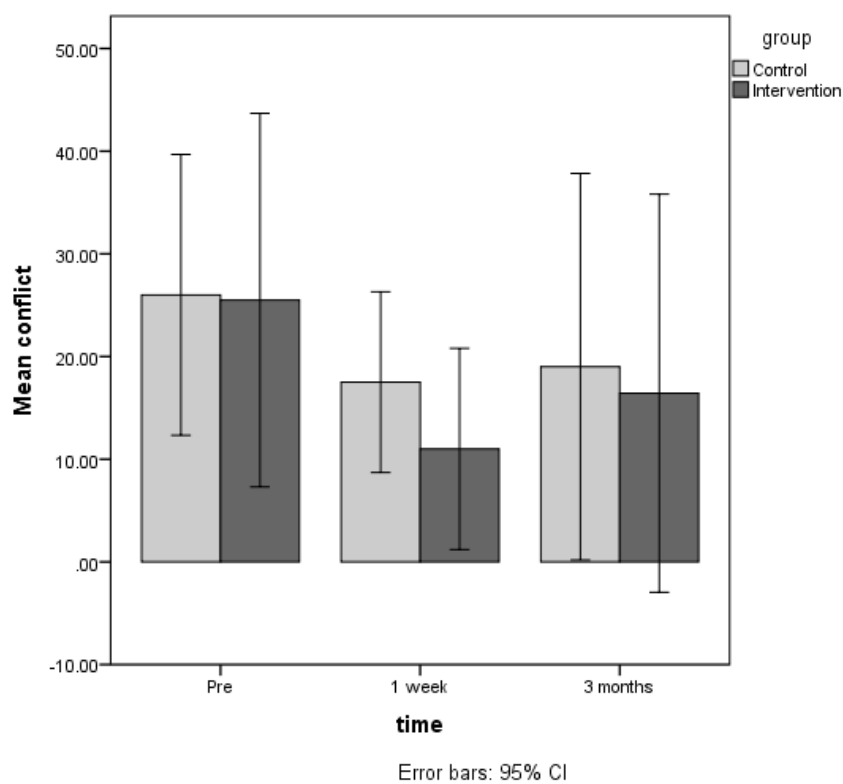


Figure 10. Mean decisional conflict scores in both study groups over time

At the outset, the mean knowledge score was 6.25/10 (SD 2.2). Among those who received a booklet, the mean knowledge score rose to 7.5 (SD 2.2) one week later. At three months, their score was marginally higher at 7.7 (SD 1.8). Knowledge scores in the control group were lower at one week (mean 5.4, SD 2.1) and three months (mean 6.6, SD 1.3). There was no statistically significant overall time effect ($p = .502$) or difference between groups over time ($p = .167$) (Figure 11).

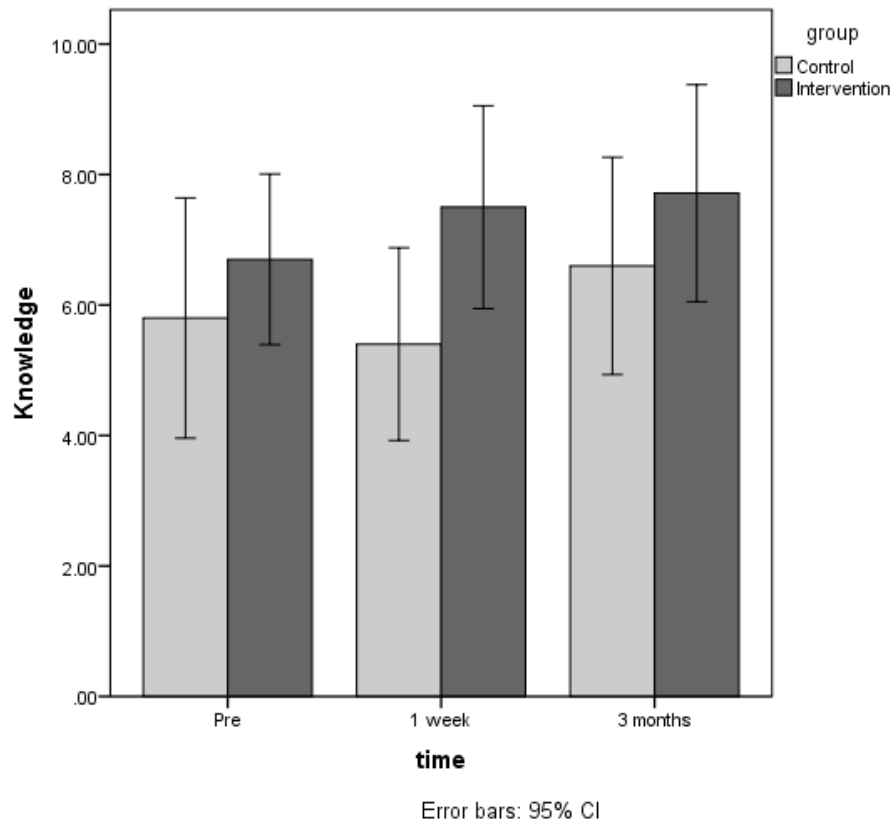


Figure 11. Mean knowledge scores in both study groups over time

Originally, in terms of their preferred decision, 75% of participants ($n = 15$) selected ‘no change’, 15% chose to ‘stop driving later’ and 10% were ‘unsure’. One week after receiving the decision aid, 30% selected ‘no change’, 50% opted to ‘drive less’ and 20% preferred to ‘stop driving later’. At three months, 29% of the intervention group selected ‘no change’, 29% to ‘drive less’, 14% to ‘stop driving later’ and 29% wished to consider ‘other options’. However, in the control group at week one, 60% selected ‘no change’ and 40% planned to ‘stop driving later’. At three months, 80% opted for ‘no change’ and 20% remained ‘unsure’. The differences between the groups were not statistically significant at baseline ($p = 1.0$). At one week the proportion that indicated they would drive less was statistically higher in the intervention versus the control group ($p = .045$). At three months there were no differences in proportions between groups ($p = .470$).

The mean satisfaction with decision score at baseline was 4.4/6 (SD .5). This rose slightly to 4.6 (SD .4) at one week, and 4.5 (SD .3) at three months. In the control group, satisfaction with decision scores were lower at one week (mean 4.3, SD .4) and three months (mean 4.4, SD 0.5). There was no overall time effect ($p = .915$), or difference between groups over time ($p = .62$).

Discussion

The provision of counseling regarding risks of driving was recently selected as one of ten key dementia management quality measures by the multi-agency Physician Consortium for Performance Improvement (Odenheimer et al. 2013). In response, the present study confirmed that a self-administered decision aid, designed specifically for drivers with dementia, was acceptable, easy to use, reduced decisional conflict, improved knowledge levels and enhanced decisional satisfaction. Qualitative feedback was positive and all participants allocated the booklet would recommend it to others. Most participants described the decision aid as balanced and well presented. Furthermore, the majority found that it contained enough information and assisted them in reaching a decision regarding driving. These results are in keeping with the promising findings of an earlier pilot study (Carmody et al. 2014a) and a recent Cochrane review which affirmed the benefits of decision aids in clinical practice (Stacey et al. 2014).

Dissemination

To date, only a draft version of the DDDA was available on-line (Carmody et al. 2014a). Upon completion of data collection in the present study, the decision aid was made publically accessible free-of-charge to patients, carers and clinicians (Carmody et al. 2014c). In addition, it is now listed in the Ottawa Hospital Research Institute (OHRI 2014) decision aid inventory. Australian driver licensing authorities have expressed interest in displaying the DDDA at their registration offices nationally. At present, the authors are collaborating with academic colleagues in North Carolina with a view to modifying the DDDA for release in the United States in 2015.

Strengths

Older adults and people with dementia are often under-represented in modern medical research. A review of 109 randomised controlled trials published in five leading medical journals found that more than 20% excluded participants aged 70 and older (Zulman et al. 2011). Taylor et al. (2012) in their systematic review of published research papers, found a pattern of frequent, often unexplained, and usually unacknowledged exclusion of people with cognitive impairment from geriatric research. Given the clear need for improved driving retirement planning among drivers with dementia, the authors of the present study ensured that the DDDA was trialed among the population of interest (i.e. regardless of age or dementia severity). This approach greatly enhances the external validity of the study.

Limitations

Originally, a much larger sample size was anticipated. Several measures were undertaken to enhance recruitment during the course of this study: (i) 15 month recruitment period; (ii) 350 study flyers mailed to health professionals; (iii) group email to all members of the Australian and New Zealand Society for Geriatric Medicine; (iv) 69 press releases forwarded to local and national media agencies; (v) 11 presentations to relevant community/carers groups; (vi) nine radio interviews; and (vii) national advertisement in the Alzheimer's Australia consumer newsletter. Notwithstanding such promotion, it is likely that multiple factors hampered recruitment. First, many participants probably found the study entry materials too difficult to understand. Although the DDDA was purposefully designed to be easy to read (Flesch reading ease 84.1, Flesh-Kincaid grade level 3.8), the ethics approval process stipulated that participants read two complex documents prior to enrollment; the consent form and participant information form readability levels were poor with Flesh-Kincaid grade levels of 12.5 and 9 respectively. Second, potential participants may have erroneously assumed that enrollment in the study would lead to licence cancellation (AA NSW 2010). Last, individuals who could not read and write fluently in English were excluded as the booklet is, currently, only available in English. Versions of the DDDA in other languages are now planned.

Conclusion

The present study confirmed several benefits of a decision aid tailored specifically for drivers with dementia. This novel person-centered tool is acceptable and easy to use, reduces decisional conflict and improves knowledge levels. Perhaps future dementia-related decision aid research could focus on the specific needs of: (i) people with early-onset dementia; (ii) culturally and linguistically diverse groups; and (iii) individuals seeking guidance on advanced care planning, guardianship and power-of-attorney. However, the development of such interventions will require dementia-related research to be given greater primacy by clinicians, academics and funding bodies.

CHAPTER 12: Concluding remarks

Preamble

The research in this thesis by publication has extended current knowledge regarding dementia and driving. A pre-determined concise set of aims were realised during the course of this work. First, the approach adopted by doctors towards drivers with dementia was explored. This involved establishing the knowledge, attitudes and behaviour of hospital-based doctors. As suspected, a lack of inclusion of driving advice in electronic discharge summaries was confirmed. More broadly, Australian health professional reporting obligations and medico-legal frameworks *vis a vis* fitness to drive were explored. Second, a structured decision aid designed for drivers with dementia was developed, tested and successfully disseminated. This low-cost intervention was shown to reduce decisional conflict, improve knowledge levels, enhance decisional satisfaction and facilitate decision making about driving retirement. Third, this research informed debate, public policy and future research regarding driving and dementia. This was achieved by publishing (i) a review of the barriers to qualitative dementia research, (ii) a pragmatic management approach for general practitioners, (iii) an overview of dementia-related decision aid use in primary care, and (iv) an in depth analysis of relevant ethical issues faced by Australian physicians.

In this concluding chapter, a succinct overview of the project findings is presented. This is followed by a brief outline of the implications, limitations and strengths of this work. Some recommendations for future research are then suggested. Finally, a short summary encapsulating the core features of this thesis is provided.

Overview of findings

Health professionals are faced with an emerging global dilemma: how should they balance personal mobility with public safety? Given that legislative requirements vary considerably within and between countries, it behoves clinicians to accustom themselves to local laws and procedures. A brief synopsis of the subject of driving and dementia was provided in Chapter 2.

Specifically, the following areas were addressed: (i) the international context; (ii) the assessment of driving safety; and (iii) the impact of driving retirement. It was proposed that a pre-planned strategy addressing the transition to non-driving would obviate the need for clinicians to insist upon abrupt licence withdrawal when a patient becomes clearly unsafe.

Recent extensive reviews of the dementia literature highlight a clear need for additional qualitative research to address the experiences of people with dementia and their carers. To date, the vast majority of published dementia research is quantitative in nature and attracts the bulk of government funding. Yet, qualitative dementia research is poorly resourced and less frequently published. In chapter 3, the contrast of qualitative dementia-related research with the more recognised quantitative approach was explored. It was proposed that inadequate funding represents the elephant in the room of dementia research. This chapter described and emphasised the need for qualitative dementia research, highlighted existing barriers, and outlined potential solutions. Examples of obstacles were provided and theoretical underpinnings were described. The recently announced increase in funding of dementia-related research by the Australian government is welcome news. However, several other barriers to qualitative dementia-related research remain.

As our population ages, general practitioners are increasingly faced with the clinical dilemma of determining fitness to drive. Unfortunately, the clinical management of drivers with dementia is fraught with hazards. There is a considerable body of literature addressing driving and dementia. Much of this evidence is of a very high standard (e.g. systematic literature reviews (Breen et al. 2007; Iverson et al. 2010; Martin et al. 2013)). However, there is a paucity of research regarding interventions for this increasingly important medical, social and ethical issue. Thus, an overview of the complex subject of driving and dementia, as it relates to primary care, was prepared (Chapter 4). The purpose of this chapter was to assist general practitioners in their care of drivers with dementia. Accordingly, an evidence-based management strategy was proposed.

As a result of the complex care needs which accompany dementia, general practitioners are often called upon to address a range of challenging clinical issues. Chapter 5 offered an introduction on the use of decision aids by general practitioners when caring for patients with dementia. Decision aids are evidence-based tools which can help people participate in choosing among health care options. In contrast to advanced care plans, individual medical decision aids only address a single topic of clinical relevance. Several existing high-quality dementia-related decision aids, of relevance to primary care, were described. In addition, obstacles which can arise during the development of dementia-related decision aids were explored. For the purposes of this chapter, the selected decision aids were chosen following a critical review of the pertinent literature. The evidence supporting each decision aid is referenced for the reader and can be measured against the IPDAS collaboration criteria (Appendix G).

Older Australians are heavily reliant on automobiles as their sole form of transport. As the prevalence of dementia rises, it is anticipated that the number of drivers with dementia will increase over time. Much of the literature relating to driving and dementia focuses on safety rather than mobility. The purpose of Chapter 6 was to highlight several topical ethical issues which pertain to Australian drivers with dementia. It was recommended that future research, policy and practice should centre on the crucial mobility and transport needs of our senior citizens. At present, there is no evidence that advance care plans either incorporate driving retirement or are successful in doing so.

Drivers with dementia require guidance from their treating physicians. Chapter 7 explored the knowledge, attitudes and behaviour of hospital-based doctors towards drivers with dementia. This exploratory study recruited a convenience sample of twenty doctors in a regional hospital in NSW were surveyed. A pragmatic approach was adopted given the limited resources available to the researchers. Relevant high-quality evidence (including systematic and critical literature reviews) informed the design of this study. Half of the participants 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 expressed a desire for changes to current clinical practice. This study also found that there is room for improvement in the knowledge, attitudes and practices of junior doctors who treat drivers with dementia. Improved road safety measures and potential avenues for future research were discussed. Existing driving guidelines (from Australia and the United States), based on systematic literature reviews, were also presented.

Many older drivers are unaware of their obligation to inform authorities of conditions which may impact upon their driving safety. Chapter 8 sought to establish the adequacy of driving advice in electronic discharge summaries from an Australian stroke unit. One month of inpatient electronic discharge summaries were reviewed. Of 41 participants, the mean age was 72. Only eight discharge summaries included driving advice. Thus, the documentation of driving advice in electronic discharge summaries was poor. This may have important public health, ethical and medico-legal implications. The manner in which older individuals are managed in an acute public hospital setting is relevant to older drivers with dementia. The findings of this, albeit small, study lead one to suspect that poor documentation of driving advice is widespread. However, further research is required to confirm this suspicion. Chapter 8 also proposes a novel (and, as yet, untested) driving advice template which has the potential to improve documentation in discharge summaries.

As outlined in the National Health and Medical Research Council 2013-15 Strategic Plan, Australian health ministers have designated dementia and injury prevention as national health priority areas. Accordingly, there now exists both an impetus and an opportunity to address the issue of driving and dementia on a national level. The purpose of chapter 9 was to consider: (i) the social impact of a loss of licence; (ii) driver and health professional obligations to report conditions that can adversely affect driving; and (iii) the response of motor vehicle insurers to the issue of driving with dementia. The findings of a telephone survey of motor vehicle insurance companies were also presented.

Chapter 10 described the pilot study of a self-administered decision aid among local drivers with dementia. The primary outcome measure was decisional conflict. Knowledge, decision,

satisfaction with decision, booklet use and acceptability were the secondary outcome measures. A mixed methods approach was adopted. Drivers with dementia were recruited from an Aged Care clinic and a Primary Care centre in NSW, Australia. Telephone surveys were conducted before and after participants read the booklet. To aid brevity, the detailed psychometric properties of each component of the surveys were omitted. Aside from the knowledge survey, only widely-used established surveys were incorporated into this study (e.g. decisional conflict, satisfaction with decision). Twelve participants were recruited (mean age 75). Decisional conflict improved following use of the decision aid. Most participants felt that the decision aid: (i) was balanced; (ii) presented information well; and (iii) helped them decide about driving. In addition, mean knowledge scores improved after booklet use. Thus, the decision aid showed promise as a useful tool for drivers with dementia.

In order to test the impact of this decision aid on individuals with dementia who drive, a prospective interventional cohort study was conducted in Australia and New Zealand among twenty drivers with dementia (Chapter 11). The successfully piloted decision aid booklet described in chapter 10 served as the intervention. Identical outcome measures (e.g. knowledge; a measure of particular relevance to individuals with dementia who drive) were applied. Over a three month period, participants underwent three telephone surveys. Following use of the decision aid, decisional conflict, knowledge and satisfaction with decision improved. Acceptability levels were high. As the first self-administered decision aid designed specifically for drivers with dementia, this booklet represents an acceptable, person-centred, low-cost intervention of relevance to an expanding portion of the community.

Implications

The implications of each chapter are outlined individually above. Unfortunately, given the nature of a thesis by publication, some repetition is inevitable. Thus, in order to enhance coherence for the reader, several overarching implications of this research are provided below.

To date, individuals with dementia have not had access to a person-centred approach towards driving retirement. This research spearheaded the creation of a user-friendly self-administered decision aid tailored for drivers with dementia in Australia and New Zealand. Efforts are now underway to make this tool available in the United States. By confronting the taboo which accompanies the issue of driving cessation, this research has helped restore the balance between personal independence and community safety.

Clinical practice varies within and among countries in the assessment of fitness to drive. A streamlined, easily accessible and fair management pathway for people with dementia does not exist. This research identified several pressing obstacles faced by clinicians. In response, an evidence-based approach, which incorporated use of a novel decision aid, was devised and then disseminated to general practitioners.

Thus far, much of the transport literature has focussed unduly upon safety rather than maintenance of independence. This research, as presented in multiple academic publications, highlighted the importance of access to alternative forms of public transport by older drivers. From an academic perspective, the promotion of a balanced approach towards issues of such great social import (e.g. dementia and driving) can effect major change in how clinicians, academics and policy makers plan for the future.

Public policy regarding the assessment of fitness to drive by older drivers is fraught with controversy. Mandatory age-based driving assessments exist in some jurisdictions for older drivers but, interestingly, not for younger drivers. During the course of this work, numerous presentations, informal discussions, media interviews and over a dozen journal publications culminated in a heightened awareness of driving and dementia. It is hoped that this research will lead to improved public policy which can meet the needs of a vulnerable group within society (i.e. older drivers with dementia). Enhanced access to public transport, rather than stricter licensing processes, is sorely needed.

Limitations

An earnest attempt was made to highlight and address the limitations of this research in several preceding chapters (i.e. 7, 8, 10 and 11). It is hoped that current and future researchers will benefit through the publication of not only the findings but also the attendant limitations of this work. Although this thesis makes a significant contribution to the existing literature, the limitations have an important bearing upon the external validity of its findings.

A major limitation of this research was the inability to complete an adequately powered quantitative study (chapter 11) which could detect statistically significant findings. Although sufficient funding, staffing, advertising and administrative support were in place for a successful multinational randomised controlled trial, participant recruitment was disappointingly low. Consequently, the use of inferential statistical analysis was either very limited or precluded. The relegation to descriptive statistics weakened the impact of the study and, perhaps more worryingly, may deter researchers from undertaking similarly important dementia-related projects in the future.

Several minor limitations emerged at the outset of both decision aid studies (chapters 10 and 11). First, only participants fluent in English and capable of providing informed consent in writing were recruited. Second, both the participant information sheets and consent forms were more difficult to comprehend than the intervention under study (i.e. the decision aid). Third, it became clear, through informal feedback from clinicians and members of the community, that some potential participants assumed (erroneously) that entry into either study would result in licence cancellation. Fourth, reliance upon the accuracy of participant survey responses raises the possibility of response bias. Fifth, the Hawthorne effect may have modified the behaviour of both groups in chapter 11. As participants were aware of their involvement in a study, they may have altered their driving patterns accordingly. Similarly, social desirability bias may have impacted upon participant responses. Last, dementia severity was not determined during either decision aid study as all participants were active drivers who were capable of (i) providing informed written consent, and (ii) successfully completing each of the telephone surveys.

Thesis by publication is an increasingly popular option for doctoral students in general and for part-time candidates in particular. Each manuscript undergoes a vigorous peer-review process which undoubtedly enhances the quality of the final product. Further, students quickly learn of the importance of meticulous research methodology, careful analysis and thoughtful discussion. However, the thesis by publication approach has several important attendant limitations which are worthy of note. First, as a thesis usually addresses a specific topic, each published manuscript/chapter contains a similar introduction. Consequently, as is the case in this thesis, a degree of repetition is inevitable and, perhaps, unavoidable. Second, if most chapters in a thesis are successfully published, it is highly likely that a distinct and different subtopic is addressed in each paper. As a result, the coherence of the final thesis is potentially threatened. However, as is the case in this research, this challenge can be overcome by (i) carefully crafting linked overarching aims at the outset of one's candidature, and (ii) providing clear introduction and conclusion chapters for the reader. Last, the contribution of each author to a co-authored publication is not always apparent. Thus, a doctoral candidate must ensure that he/she is the primary author of every chapter, including all published co-authored papers. This can be successfully accomplished, as is the case in this thesis, with careful supervisory oversight.

Strengths

Despite such limitations this thesis also has a number of strengths. It addresses an interesting topic; driving and dementia. Against the background of an ageing population, increasingly dependent on the private car, there existed a clear rationale for conducting this research. From the outset, a pre-determined, well-defined focus was strictly adhered to. This work was supported by (i) strong theoretical underpinnings through several critical and comprehensive literature reviews, and (ii) robust research methodologies (qualitative, quantitative and mixed). The aims and hypotheses were carefully constructed. At each stage, data collection, analysis and critical appraisal were of a high standard.

This research is original and it makes a serious contribution to existing knowledge, literature and debate. Nine of ten chapters, two letters of reply and a decision aid booklet have already

been published in refereed journals. Framed as a thesis by publication, it is hoped that the chapters flow well and are interesting to read. The conclusions offered in each chapter clearly meet the research goals. Care was taken to acknowledge and then reflect upon limitations as they arose. Accordingly, it is anticipated that clinicians, researchers and policy makers will reference this work. Dissemination of the decision aid is already underway in Australia and New Zealand. Following collaboration with academic peers overseas, modification of the decision aid for use in the United States is planned.

As a whole, a major strength of this thesis is the manner in which it was completed. First, the candidate undertook a part-time 'PhD integrated' program of study which incorporated eight units of coursework study during the first two years of candidature. Perhaps counter-intuitively, this approach expedited grant writing, ethics applications and manuscript preparation. Second, adopting a thesis by publication structure as a part-time PhD student establishes a clear and manageable timeline. Accordingly, this framework resulted in the timely completion of meaningful research within four years. Last, as is the case in this thesis, invaluable peer-review is received throughout one's candidature and serves to greatly enhance the quality of one's research training and output.

Recommendations for future research

The findings of this research have spurred several new questions worthy of further scrutiny. Most of the preceding chapters include specific recommendations for future research (chapters 2, 3, 5, 6, 7, 8, 10 and 11). While this thesis has created a decision aid for drivers with dementia which has been directly translated into practice, it also has wider applicability. It is anticipated that the dissemination strategy will be examined in future studies. Further research is needed to test the efficacy of decision aids (i) in other dementia-related areas (e.g. CALD groups, early-onset dementia), and (ii) for other medical conditions which impact upon driving safety (e.g. diabetes mellitus, epilepsy, obstructive sleep apnoea, Parkinson's disease). Of particular interest would be whether use of the decision aid alters driving frequency? Perhaps both subjective and objective measures of car use following exposure to the decision aid could be assessed?

Summary

With the rising prevalence of dementia in our community and an increasing dependency upon the private car, drivers with dementia require non-adversarial guidance. Of paramount importance is the need to carefully balance personal independence with community safety: *aegrescit medendo*. Amidst this context, this body of work achieved three meaningful outcomes: (i) contributed to knowledge regarding the approach of doctors toward drivers with dementia; (ii) created a novel decision aid which will help people with dementia retire from driving; and (iii) informed debate, public policy and future research. It is hoped that this research will also help to counter a lingering social taboo: driving by people with mild dementia.

REFERENCES

- Access Economics 2009, *Keeping dementia front of mind: incidence and prevalence 2009-2050*,
Access Economics Pty Limited, viewed 22 July 2014,
http://www.fightdementia.org.au/common/files/NAT/20090800_Nat_AE_FullKeepDemFrontMind.pdf
- Access-Economics 2011, *Dementia across Australia: 2011-2050*, Alzheimer's Australia, Canberra.
- Adler, G 2007, 'Intervention approaches to driving and dementia', *Health and Social Work*, vol. 32, pp. 75-79.
- Adler, G & Rottunda, SJ 2011, 'The driver with dementia: a survey of physician attitudes, knowledge, and practice', *American Journal of Alzheimer Disease and Other Dementias*, vol. 26, pp. 58-64.
- Alagiakrishnan, K, Bhanji, RA & Kurian, M 2013, 'Evaluation and management of oropharyngeal dysphagia in different types of dementia: a systematic review', *Archives of Gerontology and Geriatrics*, vol. 56, pp. 1-9.
- Alzheimer's Australia 2009. *Discussion paper 17: respite care for people living with dementia*, Alzheimer's Australia, viewed 13 June 2014,
http://www.fightdementia.org.au/common/files/NAT/20090500_Nat_NP_17RespCarePplLivDem.pdf
- Alzheimer's Australia 2013a, *Media: reporting on dementia*, viewed 4 July 2014,
<http://www.fightdementia.org.au/media.aspx>
- Alzheimer's Australia 2013b, *G8 Summit: increasing dementia research funding to find a cure*, viewed 4 July 2014, <http://www.fightdementia.org.au/g8-summit-increasing-dementia-research-funding-to-find-a-cure-.aspx>
-

Alzheimer's Australia NSW (AA NSW) 2010. *Driving and dementia in NSW: a discussion paper*, AA NSW, Sydney, viewed 13 June 2014,

http://www.fightdementia.org.au/common/files/NSW/2010NSWDriving_andDementiaNSWDiscussionPaper.pdf

Alzheimer's Foundation of America 2013, *Media centre*, viewed 4 July 2014,

<http://www.alzfdn.org/MediaCenter/current.html>

Alzheimer's Society 2013, *Outcomes of the James Lind Alliance dementia priority setting partnership*, viewed 4 July 2014,

http://alzheimers.org.uk/site/scripts/documents_info.php?documentID=1804

American Medical Association (AMA) 2010, *Physician's guide to assessing and counseling older drivers*, 2nd edn, AMA, Chicago.

American Psychiatric Association (APA) 1994, *Diagnostic and statistical manual*, 4th edn, APA press, Washington DC.

American Psychiatric Association (APA) 2000, *Diagnostic and statistical manual of mental disorders*, 4th edn, text revised, APA press, Washington DC.

American Psychiatric Association (APA) 2013, *Diagnostic and statistical manual of mental disorders*, 5th edn, American Psychiatric Publishing, Arlington, VA.

Andrew, C, Traynor, V & Iverson, D 2011, *Dementia and retirement from driving: people with dementia and their carers critique available tools*, viewed 27 January 2014,
<http://ro.uow.edu.au/cgi/viewcontent.cgi?article=2222&context=hbspapers>.

Assessing fitness to drive 2006, *Interim review report*, National Transport Commission, Melbourne, viewed 22 July 2014,

<http://www.ntc.gov.au/filemedia/Reports/AFTDInterimReviewReportJul06.pdf>

Australian and New Zealand Society for Geriatric Medicine (ANZSGM) 2010, 'Position statement number 11: driving and dementia', *Australasian Journal on Ageing*, vol. 29, pp. 137-141.

Australian Bureau of Statistics (ABS) 2003, *Baby boomers and the 2001 census*, ABS, Canberra, viewed 13 June 2014, <http://www.abs.gov.au>.

Australian Bureau of Statistics (ABS) 2008, *Population projections, Australia 2006 to 2101*, ABS, Canberra, viewed 13 June 2014, <http://www.abs.gov.au/Ausstats/abs@.nsf/mf/3222.0>.

Australian Bureau of Statistics (ABS) 2011a, *Census data 2011*, viewed 12 May 2014, <http://www.censusdata.abs.gov.au>

Australian Bureau of Statistics (ABS) 2011b, *Population by age and sex 2011*, viewed 12 May 2014, <http://www.abs.gov.au/AUSSTATS/abs@.nsf/webpages/statistics?opendocument>

Australian Bureau of Statistics (ABS) 2012, *Environmental issues: transport and motor vehicle usage*, ABS, Canberra.

Australian Institute of Health and Welfare (AIHW) 2010, *Bulletin 78: dementia and the take-up of residential respite care*, AIHW, Canberra, viewed 13 June 2014, <http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=6442452967>

Australian Institute of Health and Welfare (AIHW) 2013, *Australian hospital statistics 2011-12*, AIHW, Canberra, viewed 13 June 2014, <http://www.aihw.gov.au/publication-detail/?id=60129543133>.

Australian Medical Association (AMA) 2008, *The role of the medical practitioner in determining fitness to drive motor vehicles*, AMA, Canberra, viewed 22 July 2014, <http://www.ama.com.au/node/3021>

- Austroads 2003, *Assessing fitness to drive for commercial and private vehicle drivers: Guidelines and standards for health professionals in Australia*, 3rd edn, Austroads, Sydney, viewed 2 March 2014, <http://www.austroads.com.au/aftd/index.html>
- Austroads 2005, *Road Facts 2005: an overview of the Australian and New Zealand road systems*, Austroads, Sydney.
- Austroads 2012, *Assessing fitness to drive for commercial and private vehicle drivers: medical standards for licensing and clinical management guidelines*, 4th edn, Austroads, Sydney.
- Barry, MJ & Edgman-Levitan, S 2012, 'Shared decision making: the pinnacle of patient-centered care', *New England Journal of Medicine*, vol. 366, pp. 780-781.
- Bartlett, R 2012, 'Modifying the diary interview method to research the lives of people with dementia', *Qualitative Health Research*, vol. 22, pp. 1717-1726.
- Beard, RL 2012, 'Art therapies and dementia care: a systematic review', *Dementia*, vol. 11, pp. 633-656.
- Bensing, J, Rimondini, M & Visser, A 2013, 'What patients want', *Patient Education and Counseling*, vol. 90, pp. 287-290.
- Benson, S 2013, 'Abbott vows to cut futile research', *The Daily Telegraph*, viewed 4 March 2014, <http://www.dailytelegraph.com.au/news/nsw/abbott-vows-to-cut-futile-research/story-fni0cx12-1226710934260>
- Beran, RG 2005, 'Analysis and overview of the guidelines for assessing fitness to drive for commercial and private vehicle drivers', *Internal Medicine Journal*, vol. 35, pp. 364-368.
- Beran, RG 2008, 'Comment on medical aspects of fitness to drive. What do public hospital doctors know and think?', *Internal Medicine Journal*, vol. 38, p. 149.
- Beran, RG & Devereux, JA 2007, 'Road not taken: lessons to be learned from Queen v. Gillett', *Internal Medicine Journal*, vol. 37, pp. 336-339.
-

- Berger, JT & Rosner, F 2000, 'Ethical challenges posed by dementia and driving', *Journal of Clinical Ethics*, vol. 11, pp. 304-308.
- Beuscher, L & Grando, VT 2009, 'Challenges in conducting qualitative research with individuals with dementia', *Research in Gerontological Nursing*, vol. 2, pp. 6-11.
- Black, BS, Rabins, PV, Sugarman, J & Karlawish, JH 2010, 'Seeking assent and respecting dissent in dementia research', *American Journal of Geriatric Psychiatry*, vol. 18, pp. 77-85.
- Blass, DM & Rabins, PV 2008, 'Dementia: in the clinic', *Annals of Internal Medicine*, vol. 148, pp. 1-16.
- Breen, DA, Breen, DP, Moore, JW, Breen, PA & O'Neill, D 2007 'Driving and dementia', *British Medical Journal*, vol. 334, pp. 1365-1369.
- Breen, KJ & Greenberg, PB 2010, 'Difficult physician-patient encounters', *Internal Medicine Journal*, vol. 40, pp. 682-688.
- Brown, LB & Ott, BR 2004, 'Driving and dementia: a review of the literature', *Journal of Geriatric Psychiatry and Neurology*, vol. 17, pp. 232-240.
- Burns, A & Iliffe, S 2009, 'Dementia', *British Medical Journal*, vol. 338, pp. 405-409.
- Butow, P, Brindle, E, McConnell, D, Boakes, R & Tattersall, M 1998, 'Information booklets about cancer: factors influencing patient satisfaction and utilization', *Patient Education and Counseling*, vol. 33, pp. 129-141.
- Buys, L, Snow, S, van Megen, K & Miller, E 2012, 'Transportation behaviours of older adults: an investigation into car dependency in urban Australia', *Australasian Journal on Ageing*, vol. 31, pp. 181-186.
- Cable, G, Reisner, M, Gerges, S & Thirumavalavan, V 2000, 'Knowledge, attitudes, and practices of geriatricians regarding patients with dementia who are potentially dangerous
-

- automobile drivers: a national survey', *Journal of the American Geriatric Society*, vol. 48, pp. 14-17.
- Carey, MA & Swanson, J 2003, 'Funding for qualitative research', *Qualitative Health Research*, vol. 13, pp. 852-856.
- Carmody, J, Carey, M, Potter, J, Marchetti, E, Traynor, V & Iverson, D 2014b, 'Driving and dementia: equity, obligation and insurance', *Australasian Medical Journal*, vol. 7, pp. 384-387.
- Carmody, J, Carey, M, Traynor, V & Iverson, D 2013d, 'Electronic discharge summary driving advice: current practice and future directions', *Australasian Medical Journal*, vol. 6, pp. 419-424.
- Carmody, J, Granger, J, Lewis, K, Traynor, V & Iverson, D 2013a, 'What factors delay driving retirement by individuals with dementia?: the doctors' perspectives', *Journal of the Australasian College of Road Safety*, vol. 24, pp. 10-16.
- Carmody, J, Potter, J, Lewis, K, Bhargava, S, Traynor, V & Iverson, D 2014a, 'Development and pilot testing of a decision aid for drivers with dementia', *BMC Medical Informatics and Decision Making*, 14:19.
- Carmody, J & Traynor, V 2014, 'Driving and dementia: a modern Gordian Knot', *Journal of Neurology and Clinical Neuroscience*, vol. 1, p. 1.
- Carmody, J, Traynor, V & Iverson, D 2012a, 'Dementia and driving: an approach for general practice', *Australian Family Physician*, vol. 41, pp. 230-233.
- Carmody, J, Traynor, V & Iverson, D 2012b, 'Dementia and driving: an approach for general practice (letter of reply)', *Australian Family Physician*, vol. 41, pp. 459-460.
- Carmody, J, Traynor, V, Iverson, D & Andrew, C 2014c, *Dementia and driving: a decision aid*, University of Wollongong, Wollongong, viewed 13 June 2014, <http://smah.uow.edu.au/nursing/adhere/drivingdementia/index.html>
-

- Carmody, J, Traynor, V, Iverson, D & Marchetti, E 2013b, 'Driving, dementia and the Australian physician: primum non nocere', *Internal Medicine Journal*, vol. 43, pp. 625-630.
- Carmody, J, Traynor, V, Iverson, D & Marchetti, E 2013c, 'Driving, dementia and the Australian physician: primum non nocere (letter of reply)', *Internal Medicine Journal*, vol. 43, pp. 1357.
- Carmody, J, Traynor, V & Marchetti, E 2014, 'Barriers to qualitative dementia research: the elephant in the room', *Qualitative Health Research*, doi: 1049732314554099.
- Carmody, J, Traynor, V & Steele, A 2014, 'Dementia, decision aids and general practice', *Australian Family Physician*, in press.
- Carr, DB, Ducheck, J & Morris, JC 2000, 'Characteristics of motor vehicle crashes of drivers with dementia of the Alzheimer type', *Journal of the American Geriatric Society*, vol. 48, pp. 18-22.
- Carr, DB, Jackson, T & Alquire, P 1990, 'Characteristics of an elderly driving population referred to a geriatric assessment center', *Journal of the American Geriatric Society*, vol. 38, pp. 1145-1150.
- Carr, DB & Ott, BR 2010, 'The older adult driver with cognitive impairment: "It's a very frustrating life"', *Journal of the American Medical Association*, vol. 303, pp. 1632-1641.
- Carr, DB, Schwartzberg, JG, Manning, L & Sempek, J 2010, *Physician's guide to assessing and counseling older drivers*, 2nd edn, National Highway Traffic Safety Administration, Washington, DC, viewed 27 January 2014, <http://www.ama-assn.org/resources/doc/public-health/older-drivers-guide.pdf>
- Carr, DB, Shead, V & Storandt, M 2005, 'Driving cessation in older adults with dementia of the Alzheimer's type', *Gerontologist*, vol. 45, pp. 824-827.
-

- Catchpole, J 2007, 'Why do older drivers have a high rate of involvement in casualty crashes per distance driven?', *Journal of the Australian College of Road Safety*, vol. 18, pp. 33-41.
- Chao, SZ, Lai, NB, Tse, MM, Ho, RJ, Kong, JP, Matthews, BR, Miller, BL & Rosen, HJ 2011, 'Recruitment of Chinese American elders into dementia research: the UCSF ADRC experience', *The Gerontologist*, vol. 51, pp. s125-133.
- Charlton, J, Oxley, J, Scully, J, Koppel, S, Congiu, M, Muir, C & Fildes, B 2006, *Self-regulatory driving practices of older drivers in the Australian Capital Territory and New South Wales*, Monash University Crash Research Centre, Melbourne.
- Classen, S, Monahan, M, Auten, B & Yarney, A. 2014, 'Evidence-based review of interventions for medically at-risk older drivers', *American Journal of Occupational Therapy*, vol. 68, pp. e107-114.
- Cooper, PJ, Tallman, K, Tuokko, H & Beattie, BL 1993, 'Vehicle crash involvement and cognitive deficit in older drivers', *Journal of Safety Research*, vol. 24, pp. 9-17.
- Covinsky, KE & Yaffe, K 2004, 'Dementia, prognosis and the needs of patients and caregivers', *Annals of Internal Medicine*, vol. 140, pp. 573-574.
- Creswell, JW & Plano Clark, VL 2007, *Designing and conducting mixed methods research*, Sage publications, Thousand Oaks, CA.
- Dalby, P, Sperlinger, DJ & Boddington, S 2012, 'The lived experience of spirituality and dementia in older people living with mild to moderate dementia', *Dementia: International Journal of Social Research and Practice*, vol. 11, pp. 75-94.
- Declercq, T, Petrovic, M, Azermi, M, Vander Stichele, R, De Sutter, AI, van Driel, ML & Christiaens T 2013, 'Withdrawal versus continuation of chronic antipsychotic drugs for behavioural and psychological symptoms in older people with dementia', *Cochrane Database of Systematic Reviews*, vol. 3, no. CD007726.
-

Deloitte Access Economics 2011, *Dementia across Australia: 2011-2050*, viewed 13 June 2014, <http://www.fightdementia.org.au/research-publications/access-economics-reports.aspx>.

Department for transport 2011, *National travel survey*, viewed 27 January 2014, <https://www.gov.uk/government/publications/national-travel-survey-2011>

Dewing, J 2002, 'From ritual to relationship: a person centred approach to consent in qualitative research with older people who have a dementia', *Dementia: The International Journal of Social Research and Practice*, vol. 1, pp. 156-171.

Dewing, J 2007, 'Participatory research: a method for process consent for people who have dementia', *Dementia: International Journal of Social Research and Practice*, vol. 6, pp. 11-25.

Dobbs, AR 1997, 'Evaluating the driving competence of dementia patients', *Alzheimer Disease and Associated Disorders*, vol. 11, pp. 8-12.

Downs, M 1997, 'The emergence of the person in dementia research', *Ageing and Society*, vol. 17, pp. 597-607.

Drachman, DA & Swearer, JM 1993, 'Driving and Alzheimer's disease: the risk of crashes', *Neurology*, vol. 43, pp. 2448-2456.

Drazkowski, JF & Sirven, JI 2011, 'Driving and neurologic disorders', *Neurology*, vol. 76, pp. s44-49.

Drickamer, MA & Marottoli, RA 1993, 'Physician responsibility in driver assessment', *American Journal of Medical Science*, vol. 306, pp. 277-281.

Dubinsky, RM, Stein, AC & Lyons, K 2000, 'Practice parameter: risk of driving and Alzheimer's disease (an evidence-based review)', *Neurology*, vol. 54, pp. 2205-2211.

Dubinsky, RM, Williamson, A, Gray, CS & Glatt, SL 1992, 'Driving in Alzheimer's disease', *Journal of the American Geriatric Society*, vol. 40, pp. 1112-1116.

- Duchek, JM, Carr, DB, Hunt, L, Roe, CM, Xiong, C, Shah, K & Morris, JC 2003, 'Longitudinal driving performance in early-stage dementia of the Alzheimer type', *Journal of the American Geriatric Society*, vol. 51, pp. 1342-1347.
- Eberhard, J 2008, 'Older drivers' "high per-mile crash involvement: the implications for licensing authorities"', *Traffic Injury Prevention*, vol. 9, pp. 284-290.
- Eberhard, JW 1996, 'Safe mobility for senior citizens', *IATSS Research*, vol. 20, pp. 29-37.
- Eby, DW & Molnar, LJ 2010, 'Driving fitness and cognitive impairment: issues for physicians', *Journal of the American Medical Association*, vol. 303, pp. 1642-1643.
- Edwards, JD, Bart, E, O'Connor, ML & Cissell, G 2010, 'Ten years down the road: predictors of driving cessation', *Gerontologist*, vol. 50, pp. 393-399.
- Elwyn, G, O'Connor, AM, Bennett, C, Newcombe, RG, Politi, M, Durand, MA, Drake, E, Joseph-Williams, N, Khangura, S, Saarimaki, A, Sivell, S, Stiel, M, Bernstein, SJ, Col, N, Coulter, A, Eden, K, Härter, M, Rovner, MH, Moumjid, N, Stacey, D, Thomson, R, Whelan, T, van der Weijden, T & Edwards, A 2009, 'Assessing the quality of decision support technologies using the International Patient Decision Aid Standards instrument (IPDASi)', *Plos One*, vol. 4, p. e4705.
- Elwyn, G, O'Connor, A, Stacey, D, Volk, R, Edwards, A, Coulter, A, Thomson, R, Barratt, A, Barry, M, Bernstein, S, Butow, P, Clarke, A, Entwistle, V, Feldman-Stewart, D, Holmes-Rovner, M, Llewellyn-Thomas, H, Moumjid, N, Mulley, A, Ruland, C, Sepucha, K, Sykes, A & Whelan, T 2006, 'Developing a quality criteria framework for patient decision aids: online international Delphi consensus process', *British Medical Journal*, vol. 333, pp. 417-422.
- Evans, D & Lee, E 2014, 'Impact of dementia on marriage: a qualitative systematic review', *Dementia: International Journal of Social Research and Practice*, vol. 13, pp. 330-349.
-

Federal Highway Administration (FHA), US Department of Transport 1993, *Distribution of licensed drivers 1993*, viewed 27 January 2014,

<http://www.fhwa.dot.gov/ohim/hs93/Sec3.pdf>

Federal Highway Administration (FHA), US Department of Transport 2011, *Distribution of licensed drivers 2011*, viewed 8 August 2014,

<http://www.fhwa.dot.gov/policyinformation/statistics/2011/>

Feldman-Stewart, D, Brennenstuhl, S, McIssac, K, Austoker, J, Charvet, A, Hewitson, P, Sepucha, KR & Whelan, T 2007, 'A systematic review of information in decision aids', *Health Expectations*, vol. 10, pp. 46-61.

Fisk, GD, Owsley, C & Pulley, LV 1997, 'Driving after stroke: driving exposure, advice, and evaluations', *Archives of Physical Medicine and Rehabilitation*, vol. 78, pp. 1338-1345.

Fitten, LJ, Perryman, KM, Wilkinson, CJ, Little, RJ, Burns, MW, Pachana, N, Mervis, JR, Malmgren, R, Siembieda, DW & Ganzell, S 1995, 'Alzheimer and vascular dementias and driving: a prospective road and laboratory study', *Journal of the American Medical Association*, vol. 273, pp. 1360-1365.

Fox, GK & Bashford, GM 1997, 'Driving and dementia: balancing personal independence and public safety', *Medical Journal of Australia*, vol. 167, pp. 406-407.

Frampton, A 2003, 'Who can drive home from the emergency department? A questionnaire based study of emergency physicians' knowledge of DVLA guidelines', *Emergency Medicine Journal*, vol. 20, pp. 526-530.

Freeman, EE, Gange, SJ, Munoz, B & West, SK 2009, 'Driving status and risk of entry into long-term care in older adults', *American Journal of Public Health*, vol. 96, pp. 1254-1259.

Friedland, RP, Koss, E, Kumar, A, Gaine, S, Metzler, D, Haxby, JV & Moore, A 1988, 'Motor vehicle crashes in dementia of the Alzheimer type', *Annals of Neurology*, vol. 24, pp. 782-786.

- Gibson, G, Timlin, A, Curran, S & Wattis, J 2004, 'The scope for qualitative methods in research and clinical trials in dementia', *Age and Ageing*, vol. 33, pp. 422-426.
- Goodyear, K & Roseveare, C 2003, 'Driving restrictions after stroke: doctors' awareness of DVLA guidelines and advice given to patients', *Clinical Medicine*, vol. 3, pp. 86-87.
- Grand, JHG, Caspar, S & MacDonald, SWS 2011, 'Clinical features and multidisciplinary approaches to dementia care', *Journal of Multidisciplinary Healthcare*, vol. 4, pp. 125-147.
- Greysen, SR, Schiliro, D, Horwitz, LI, Curry, L & Bradley, EH 2012, "'Out of sight, out of mind': house staff perceptions of quality-limiting factors in discharge care at teaching hospitals", *Journal of Hospital Medicine*, vol. 7, pp. 376-381.
- Gupta, DR, Mehra, A & Gupta, D 2010, 'Discharge: have you advised on driving?' *Quality and Safety in Health Care*, vol. 19, p. 80.
- Hanson, LC, Carey, TS, Caprio, AJ, Lee, TJ, Ersek, M, Garrett, J, Jackman, A, Gilliam, R, Wessell, K & Mitchell, SL 2011, 'Improving decision-making for feeding options in advanced dementia: a randomized, controlled trial', *Journal of the American Geriatric Society*, vol. 59, pp. 2009-2016.
- Harrington, RA, Califf, RM, Hodgson, PK, Peterson, ED, Roe, MT & Mark, DB 2009, 'Careers for clinician investigators', *Circulation*, vol. 119, pp. 2945-2950.
- Heggestad, AKT, Nortvedt, P & Slettebø, Å 2012, 'The importance of moral sensitivity when including persons with dementia in qualitative research', *Nursing Ethics*, vol. 20, pp. 30-40.
- Hellström, I, Nolan, M, Nordenfelt, L & Lundh, U 2007, 'Ethical and methodological issues in interviewing persons with dementia', *Nursing Ethics*, vol. 14, pp. 608-619.
-

- Herrmann, N, Rapoport, MJ, Sambrook, R, Hebert, R, McCracken, P & Robillard, A 2006, 'Predictors of driving cessation in mild to moderate dementia', *Canadian Medical Association Journal*, vol. 175, pp. 591-595.
- Hibbard, JH & Peters, E 2003, 'Supporting informed consumer health care decisions: data presentation approaches that facilitate the use of information in choice', *Annual Review of Public Health*, vol. 24, pp. 413-433.
- Hinton, L, Guo, Z, Hillygus, J & Levkoff, S 2000, 'Working with culture: a qualitative analysis of barriers to the recruitment of Chinese-American family caregivers for dementia research', *Journal of Cross-Cultural Gerontology*, vol. 15, pp. 119-137.
- Hoggarth, P, Innes, C, Dalrymple-Alford, J, Croucher, M, Severinsen, J, Gray, J, Oxley, J, Brook, B, Abernethy, P & Jones, R 2011, 'Assessment of older drivers in New Zealand: the current system, research and recommendations', *Australasian Journal of Ageing*, vol. 30, pp. 148-155.
- Holmes-Rovner, M, Kroll, J, Schmitt, N, Rovner, DR, Breer, ML, Rothert, ML, Padonu, G & Talarczyk, G 1996, 'Patient satisfaction with health care decisions: the satisfaction with decision scale', *Medical Decision Making*, vol. 16, pp. 58-64.
- Howe, EG 2000, 'Improving treatments for patients who are elderly and have dementia', *Journal of Clinical Ethics*, vol. 11, pp. 291-303.
- Gróbjartsson, A, Thomsen, AS, Emanuelsson, F, Tendal, B, Hilden, J, Boutron, I, Ravaut, P & Brorson, S 2012, 'Observer bias in randomised clinical trials with binary outcomes: systematic review of trials with both blinded and non-blinded outcome assessors', *British Medical Journal*, vol. 344, pp. e1119-1130.
- Hubbard, G, Downs, M & Tester, S 2003, 'Including older people with dementia in research: challenges and strategies', *Ageing and Mental Health*, vol. 7, pp. 351-362.
-

- Huber, P 2010, 'Older drivers: of which colour is the traffic light?', *European Journal of Geriatric Medicine*, vol. 1, pp. 91-92.
- Hunt, LA, Brown, AE & Gilman, IP 2010, 'Drivers with dementia and outcomes of becoming lost while driving', *American Journal of Occupational Therapy*, vol. 64, pp. 225-232.
- Hurd, MD, Martorell, P, Delavande, A, Mullen, KJ & Langa, KM 2013, 'Monetary costs of dementia in the United States', *New England Journal of Medicine*, vol. 368, pp. 1326-1334.
- Ibrahim, J, Bandopadhyay, P & Ley, J 2013, 'Comparing the use of traditional versus new media technologies in order to promote awareness amongst medical practitioners about the complex issues surrounding whether people with dementia should give up their driving', *Australian Journal on Ageing*, vol. 32, p. 37, viewed 13 June 2014, <http://www.youtube.com/watch?v=4F9z8mPhcTw>.
- Iliffe, S, Curry, L, Kharicha, K, Rait, G, Wilcock, J, Lowery, D, Tapuria, A, Kalra, D & Ritchie, C 2011, 'Developing a dementia research registry: a descriptive case study from North Thames DeNDRoN and the EVIDEM programme', *BMC Medical Research Methodology*, vol. 11, p. 9.
- Iliffe, S, Robinson, L, Brayne, C, Goodman, C, Rait, G, Manthorpe, J & Ashley, P 2009, 'Primary care and dementia: 1. diagnosis, screening and disclosure', *International Journal of Geriatric Psychiatry*, vol. 24, pp. 895-901.
- Iverson, DJ, Gronseth, GS, Reger, MA, Classen, S, Dubinsky, RM & Rizzo, M 2010, 'Practice parameter update: evaluation and management of driving risk in dementia. Report of the Quality Standards Subcommittee of the American Academy of Neurology', *Neurology*, vol. 74, pp. 1316-1324.
- Jang, RW, Man-Son-Hing, M, Molnar, FJ, Hogan, DB, Marshall, SC, Auger, J, Graham, ID, Korner-Bitensky, N, Tomlinson, G, Kowgier, ME & Naglie, G 2007, 'Family physicians'
-

- attitudes and practices regarding assessments of medical fitness to drive in older persons', *Journal of General Internal Medicine*, vol. 22, pp. 531-543.
- Johansson, K & Lundberg, C 1997, 'The 1994 international consensus conference on dementia and driving: a brief report', *Alzheimer Disease and Associated Disorders*, vol. 11, pp. s62-69.
- Johnstone, K, Bagnall, F & Chan, DKY 2003, 'Discharge summaries in aged care: improving communication between an aged care unit and general practitioners', *Australasian Journal on Ageing*, vol. 22, pp. 213-214.
- Kapust, LR & Weintraub, S 1992, 'To drive or not to drive: preliminary results from the road testing of patients with dementia', *Journal of Geriatric Psychiatry and Neurology*, vol. 5, pp. 210-216.
- Kazniak, AW, Keyl, PM & Albert, MS 1991, 'Dementia and the older driver', *Human Factors*, vol. 33, pp. 527-537.
- Kelly, R, Warke, T & Steele, I 1999, 'Medical restrictions to driving: the awareness of patients and doctors', *Postgraduate Medical Journal*, vol. 75, pp. 537-539.
- Kessler, EM & Schwender, C 2012, 'Giving dementia a face? The portrayal of older people with dementia in German weekly news magazines between the years 2000 and 2009', *The Journals of Gerontology: Series B Psychological Sciences and Social Sciences*, vol. 67, pp. 261-270.
- King, VJ, Davis, MM, Gorman, PN, Rugge, JB & Fagnan, LJ 2012, 'Perceptions of shared decision making and decision aids among rural primary care clinicians', *Medical Decision Making*, vol. 32, pp. 636-644.
- Kmietowicz, Z 2012, 'Cameron launches challenge to end 'national crisis' of poor dementia care', *British Medical Journal*, vol. 344, p. e2347.
-

- Knapp, S & Van de Creek, L 2005, 'Ethical and patient management issues with older, impaired drivers', *Professional Psychology: Research and Practice*, vol. 36, pp. 197-202.
- Kostyniuk, LP & Shope, JT 2003, 'Driving and alternatives: older drivers in Michigan', *Journal of Safety Research*, vol. 34, pp. 407-414.
- Kripalani, S, LeFevre, F, Phillips, CO, Williams, MV, Basaviah, P & Baker, DW 2007, 'Deficits in communication and information transfer between hospital-based and primary care physicians: implications for patient safety and continuity of care', *Journal of the American Medical Association*, vol. 297, pp. 831-841.
- Kurle, S, Brodaty, H & Hogarth, R 2012, *Physical comorbidities of dementia*, Cambridge University Press, Cambridge.
- Lancet Neurology 2012, 'Public health planning for dementia must start now', *Lancet Neurology*, vol. 11, p. 477.
- Langhorne, J & Langhorne, W 1813, *Plutarch's lives*, 2nd edn, vol. 4, Baldwin, London.
- Larson, EB & Langa, KM 2008, 'The rising tide of dementia worldwide', *Lancet*, vol. 372, pp. 430-432.
- Larson, EB, Shadlen, MF, Wang, L, McCormick, WC, Bowen, JD, Teri, L & Kukull, WA 2004, 'Survival after initial diagnosis of Alzheimer disease', *Annals of Internal Medicine*, vol. 140, pp. 501-509.
- Larson, EB, Yaffe, K & Langa, KM 2013, 'New insights into the dementia epidemic', *New England Journal of Medicine*, vol. 369, pp. 2275-2277.
- Lawson, H 1890, 'The mistakes of other colonies', *Albany Observer*.
- LeBlanc, A, Kenny, DA, O'Connor, AM & Légaré, F 2009, 'Decisional conflict in patients and their physicians: a dyadic approach to shared decision making', *Medical Decision Making*, vol. 29, pp. 61-68.
-

- Li, SQ, Guthridge, SL, Eswara Aratchige, P, Lowe, MP, Wang, Z, Zhao, Y & Krause, V 2014, 'Dementia prevalence and incidence among the Indigenous and non-Indigenous populations of the Northern Territory', *Medical Journal of Australia*, vol. 200, pp. 465-469.
- Lim, WK, Chong, C, Caplan, G & Gray, L 2009, 'Australian and New Zealand Society for Geriatric Medicine position statement no. 15: discharge planning', *Australasian Journal on Ageing*, vol. 28, pp. 158-164.
- Lipski, PS 1997, 'Driving and dementia: a cause for concern', *Medical Journal of Australia*, vol. 167, pp. 453-454.
- Lloyd, S, Cormack, C, Blais, K, Messeri, G, McCallum, MA, Spicer, K & Morgan, S 2001, 'Driving and dementia: a review of the literature', *Canadian Journal of Occupational Therapy*, vol. 68, pp. 149-155.
- Logiudice, D 2002, 'Dementia: an update to refresh your memory', *Internal Medicine Journal*, vol. 32, pp. 535-540.
- Lucas-Blaustein, MJ, Filipp, L, Dungan, C & Tune, L 1988, 'Driving in patients with dementia', *Journal of the American Geriatric Society*, vol. 36, pp. 1087-1091.
- Luxford, K, Safran, D.G & Delbanco, T 2011, 'Promoting patient-centered care: a qualitative study of facilitators and barriers in healthcare organizations with a reputation for improving the patient experience', *International Journal for Quality in Health Care*, vol. 23, pp. 510-515.
- MacMahon, M, O'Neill, D & Kenny, RA 1996, 'Syncope: driving advice is frequently overlooked', *Postgraduate Medical Journal*, vol. 72, pp. 561-563.
- Malterud, K 2001, 'Qualitative research: standards, challenges, and guidelines', *Lancet*, vol. 358, pp. 438-488.
-

- Marottoli, RA, Mendes de Leon, CF, Glass TA, Williams CS, Cooney LM Jr, Berkman LF, Tinetti ME 1997, 'Driving cessation and increased depressive symptoms: prospective evidence from the New Haven EPESE', *Journal of the American Geriatric Society*, vol. 45, pp. 202-206.
- Marshall, SC 2008, 'The role of reduced fitness to drive due to medical impairments in explaining crashes involving older drivers', *Traffic Injury Prevention*, vol. 9, pp. 291-298.
- Marshall, SC, Molnar, F, Man-Son-Hing, M, Blair, R, Brosseau, L, Finestone, HM, Lamothe, C, Korner-Bitensky, N & Wilson, KG 2007, 'Predictors of driving ability following stroke: a systematic review', *Topics in Stroke Rehabilitation*, vol. 14, pp. 98-114.
- Martin, AJ, Marottoli, R & O'Neill, D 2009, 'Driving assessment for maintaining mobility and safety in drivers with dementia', *Cochrane Database Systematic Review*, vol. 1, no. CD006222.
- Matthews, FE, Arthur, A, Barnes, LE, Bond, J, Jagger, C, Robinson, L & Brayne, C 2013, 'A two-decade comparison of prevalence of dementia in individuals aged 65 years and older from three geographical areas of England: results of the cognitive function and ageing study I and II', *Lancet*, vol. 382, pp. 1405-1412.
- McDonnell, E & Ryan, A 2013, 'Male caregiving in dementia: a review and commentary', *Dementia: International Journal of Social Research and Practice*, vol. 12, pp. 238-250.
- McKeown, J, Clarke, A, Ingleton, C & Repper, J 2010, 'Actively involving people with dementia in qualitative research', *Journal of Clinical Nursing*, vol. 19, pp. 1935-1943.
- Meuleners, LB, Harding, A, Lee, AH & Legge, M 2006, 'Fragility and crash over-representation among older drivers in Western Australia', *Accident Analysis and Prevention*, vol. 38, pp. 1006-1010.
- Mezuk, B & Rebok, GW 2008, 'Social integration and social support among older adults following driving cessation', *Journals of Gerontology Series B Psychological Sciences and Social Science*, vol. 63, pp. s298-303.
-

- Mitchell, SL, Tetroe, J & O'Connor, AM 2001, 'A decision aid for long-term tube feeding in cognitively impaired older persons', *Journal of the American Geriatric Society*, vol. 49, pp. 313-316.
- Moniz-Cook, E, Vernooij-Dassen, M, Woods, B, Orrell, M & Interdem Network 2011, 'Psychosocial interventions in dementia care research: the INTERDEM manifesto', *Aging and Mental Health*, vol. 15, pp. 283-290.
- Morse, JM 2012, *Qualitative health research: creating a new discipline*, Left Coast Press, Walnut Creek, California.
- Motor Vehicles Act 1959, s148.
- Musselwhite, C & Haddad, H 2010, 'Mobility, accessibility and quality of later life', *Quality in Ageing and Older Adults*, vol. 11, pp. 25-37.
- National Health and Medical Research Council (NHMRC) 1999, *How to prepare and present evidence-based information for consumers of health services: a literature review*, NHMRC, Canberra, viewed 27 January 2014, <http://www.nhmrc.gov.au/guidelines/publications/cp72>
- National Health and Medical Research Council (NHMRC) 2012, *NHMRC strategic plan 2013-2015*, NHMRC, Canberra, viewed 22 July 2014, http://www.nhmrc.gov.au/files_nhmrc/publications/attachments/nh160_nhmrc_strat_plan_201315.pdf
- National Health and Medical Research Council (NHMRC) 2013, *Research funding statistics and data*, viewed 22 July 2014, <http://www.nhmrc.gov.au/grants/research-funding-statistics-and-data/national-health-priority-areas-nhpas>
- National Health Service (NHS) 2009, *Patient decision aid: antipsychotic drugs in dementia*, viewed 22 July 2014, http://www.npc.nhs.uk/therapeutics/cns/dementia/resources/pda_dementia_antipsychotics.pdf
-

- National Institutes of Health (NIH) 2013a, *Estimates of funding for various research, condition, and disease categories*, viewed 22 July, http://report.nih.gov/categorical_spending.aspx
- National Institutes of Health (NIH) 2013b, *Research portfolio online reporting tools*, viewed 22 July 2014, <http://projectreporter.nih.gov/reporter.cfm>
- National prescribing service (NPS) 2013, *Antipsychotic overuse in Australia: is there a problem?*, viewed 22 July, <http://www.nps.org.au/publications/health-professional/health-news-evidence/2013/antipsychotic-dementia>
- National Transport Commission (NTC) 2006, *Assessing fitness to drive: interim review report*, NTC, Melbourne, viewed 12 May 2014, <http://www.ntc.gov.au/filemedia/Reports/AFTDInterimReviewReportJul06.pdf>
- Neergaard, MA, Olesen, F, Andersen, RS & Sondergaard, J 2009, 'Qualitative description - the poor cousin of health research?', *BMC Medical Research Methodology*, vol. 9, p. 52.
- New Zealand Transport Agency (NZTA) 2009, *Medical aspects of fitness to drive: a guide for medical practitioners*, NZTA, Palmerston North, viewed 8 August 2014, <http://www.nzta.govt.nz/resources/medical-aspects/>
- O'Connor, AM 2006, *Ottawa decision support framework to address decisional conflict*, viewed 27 January 2014, <https://decisionaid.ohri.ca/docs/develop/ODSF.pdf>
- O'Connor, AM 2014a, *Low literacy decisional conflict scale*, viewed 27 January 2014, https://decisionaid.ohri.ca/eval_dcs.html
- O'Connor, AM 2014b, *Ottawa knowledge questionnaire*, viewed 27 January 2014, http://decisionaid.ohri.ca/eval_know.html
- O'Connor, AM & Cranney, A 2014, *Ottawa acceptability questionnaire*, viewed 27 January 2014, http://decisionaid.ohri.ca/eval_accept.html
-

- O'Connor, AM, Jacobsen, M & Stacey, D 2002, 'An evidence-based approach to managing women's decisional conflict', *Journal of Obstetrics Gynaecology and Neonatal Nursing*, vol. 31, pp. 570-581.
- O'Connor, AM & Stacey, D 2012, *Ottawa personal decision guide*, viewed 27 January 2014, <http://decisionaid.ohri.ca/docs/das/OPDG.pdf>
- O'Connor, AM, Tugwell, P, Wells, GA, Elmslie, T, Jolly, E, Hollingworth, G, McPherson, R, Bunn, H, Graham, I & Drake, E 1998, 'A decision aid for women considering hormone replacement therapy after menopause: decision support framework and evaluation', *Patient Education and Counseling*, vol. 33, pp. 267-279.
- O'Neill, D 1992, 'The doctor's dilemma: the ageing driver and dementia', *International Journal of Geriatric Psychiatry*, vol. 7, pp. 297-301.
- O'Neill, D 2007, 'Driving and dementia', *Canadian Medical Association Journal*, vol. 176, p. 351.
- O'Neill, D 2010, 'Deciding on driving cessation and transport planning in older drivers with dementia', *European Geriatric Medicine*, vol. 1, pp. 22-25.
- Odell, M 2005, 'Assessing fitness to drive: part 2', *Australian Family Physician*, vol. 34, pp. 475-477.
- Odenheimer, G, Borson, S, Sanders, AE, Swain-Eng, RJ, Kyomen, HH, Tierney, S, Gitlin, LN, Forciea, MA, Absher, J, Shega, J, & Johnson, J 2013, 'Quality improvement in neurology: dementia management quality measures', *Journal of the American Geriatric Society*, vol. 62, pp. 558-561.
- Odenheimer, G 1993, 'Dementia and the older driver', *Clinical Geriatric Medicine*, vol. 9, pp. 349-364.
- O'Leary, KJ, Liebovitz, DM, Feinglass, J, Liss, DT, Evans, DB, Kulkarni, N, Landler, MP & Baker, DW 2009, 'Creating a better discharge summary: improvement in quality and
-

timeliness using an electronic discharge summary', *Journal of Hospital Medicine*, vol. 4, pp. 219-225.

Organisation for Economic Cooperation and Development (OECD) 2001, *Ageing and transport: mobility and safety issues*, OECD, Paris.

Ormerod, S & Heafield, MT 2000, 'Medical restrictions to driving: awareness of patients and doctors', *Postgraduate Medical Journal*, vol. 76, p. 524.

Orr, EM & Elworthy, TSE 2008, 'Audit of advice on driving following hospitalisation for an acute psychotic episode', *Psychiatric Bulletin*, vol. 32, pp. 106-107.

Ott, BR & Daiello, LA 2010, 'How does dementia affect driving in older patients?', *Aging Health*, vol. 6, pp. 77-85.

Ott, BR, Heindel, WC, Papandonatos, GD, Festa, EK, Davis, JD, Daiello, LA & Morris, JC 2008, 'A longitudinal study of drivers with Alzheimer disease', *Neurology*, vol. 70, pp. 1171-1178.

Ottawa Hospital Research Institute (OHRI), viewed 27 January 2014,

<https://decisionaid.ohri.ca/>

Padgett, DK & Henwood, BF 2009, 'Obtaining large-scale funding for empowerment-oriented qualitative research: a report from personal experience', *Qualitative Health Research*, vol. 19, pp. 868-874.

Pond, D 2012, 'Dementia: an update on management', *Australian Family Physician*, vol. 41, pp. 936-939.

Prince, M, Prina, M & Guerchet, M 2013, *World Alzheimer report: an analysis of long-term care for dementia*, Alzheimer's Disease International, London.

Prorok, JC, Horgan, S & Seitz, DP 2013, 'Health care experiences of people with dementia and their caregivers: a meta-ethnographic analysis of qualitative studies', *Canadian Medical Association Journal*, vol. 185, pp. e669-680.

- Prunty, MC, Sharpe, L, Butow, P & Fulcher, G 2008, 'The motherhood choice: a decision aid for women with multiple sclerosis', *Patient Education and Counseling*, vol. 71, pp. 108-115.
- Ragland, DR, Satariano, WA & MacLeod KE 2005, 'Driving cessation and increased depressive symptoms', *Journal of Gerontology Series A*, vol. 60, pp. 399-403.
- Redelmeier, DA, Yarnell, CJ, Thiruchelvam, D & Tibshirani, RJ 2012, 'Physicians' warnings for unfit drivers and the risk of trauma from road crashes', *New England Journal of Medicine*, vol. 367, pp. 1228-1236.
- Roads and Maritime Services (RMS) 2011, *Licence class by licence type by licence holder's age group as at 31 December 2011*, table 2.1.6, viewed 13 June 2014, <http://www.rta.nsw.gov.au/cgi-bin/index.cgi?fuseaction=statstables.show&cat=Licensing>.
- Roads and Maritime Services (RMS) 2012, *Driver licensing statistics 2012*, viewed 12 May 2014, <http://www.rta.nsw.gov.au/cgi-bin/index.cgi?fuseaction=statstables.show&cat=Licensing>
- Robinson, L, Iliffe, S, Brayne, C, Goodman, C, Rait, G, Manthorpe, J, Ashley, P & Moniz-Cook, E 2010, 'Primary care and dementia: 2. Long-term care at home: psychosocial interventions, information provision, carer support and case management', *International Journal of Geriatric Psychiatry*, vol. 25, pp. 657-664.
- Ropper, AH & Samuels, MA 2009, Dementia and the amnesic (Korsakoff) syndrome with comments on the neurology of intelligence and memory, in Ropper AH, Samuels MA (eds.), *Adams and Victor's principles of neurology*, 9th edn, McGraw-Hill, New York, viewed 8 August 2014, <http://www.accessmedicine.com/content.aspx?aID=3633470>
- Ross, LA, Anstey, KJ, Kiely, KM Windsor, TD, Byles, JE, Luszcz, MA & Mitchell, P 2009, 'Older drivers in Australia: trends in driving status and cognitive and visual impairment', *Journal of the American Geriatric Society*, vol. 57, pp. 1868-1873.
-

Rowe, R & Owen A 2001, 'Advice given to psychiatric inpatients concerning driving', *Psychiatric Bulletin*, vol. 25, pp. 400-401.

Royal Australian and New Zealand College of Psychiatrists (RANZCP) 2009, *Practice guideline 10: antipsychotic medications as a treatment of behavioural and psychological symptoms in dementia*, viewed 8 August 2014,
http://www.ranzcp.org/Files/Resources/College_Statements/Practice_Guidelines/pg10-pdf.aspx

Schubert, CC, Boustani, M, Callahan, CM, Perkins, AJ, Carney, CP, Fox, C, Unverzagt, F, Hui, S & Hendrie, HC 2006, 'Comorbidity profile of dementia patients in primary care: are they sicker?', *Journal of the American Geriatric Society*, vol. 54, pp. 104-109.

Seeher, K, Withall, A & Brodaty, H 2010, *The dementia research mapping project - the 2010 update: report for the department of health and ageing*, Australian government, Canberra, viewed 4 December 2014,
<http://www.dementiaresearch.com.au/images/dcrc/pdf/drm.pdf>

Shanahan, EM, Sladek, RM & Phillips, P 2007, 'Medical aspects of fitness to drive. What do public hospital doctors know and think?', *Internal Medicine Journal*, vol. 37, pp. 372-376.

Shanley, C, Leone, D, Santalucia, Y, Adams, J, Ferrerosa-Rojas, JE, Kourouche, F, Gava, S & Wu, Y 2013, 'Qualitative research on dementia in ethnically diverse communities: fieldwork challenges and opportunities', *American Journal of Alzheimer's Disease and Other Dementias*, vol. 28, pp. 278-283.

Shareef, YS, McKinnon, JH, Gauthier, SM, Noe, KH, Sirven, JI & Drazkowski, JF 2009, 'Counseling for driving restrictions in epilepsy and other causes of temporary impairment of consciousness: how are we doing?', *Epilepsy Behaviour*, vol. 14, pp. 550-552.

- Shuval, K, Harker, K, Roudsari, B, Groce, NE, Mills, B, Siddiqi, Z & Shachak, A 2011, 'Is qualitative research second class science? A quantitative longitudinal examination of qualitative research in medical journals', *PloS One*, vol. 6, p. e16937.
- Singapore Medical Association (SMA) 2011, *Medical guidelines on fitness to drive*, 2nd edn, SMA, Singapore, viewed 8 August 2014, <http://www.sma.org.sg/UploadedImg/files/15327%20SMA.pdf>
- Smith, SK, Trevena, L, Simpson, JM, Barratt, A, Nutbeam, D & McCaffery, KJ 2010, 'A decision aid to support informed choices about bowel cancer screening among adults with low education: randomized controlled trial', *British Medical Journal*, vol. 341, p. c5370.
- Snellgrove, CA & Hecker, JR 2002, 'Driving and dementia: general practitioner attitudes, knowledge and self-reported clinical practices in South Australia', *Australasian Journal on Ageing*, vol. 21, pp. 210-212.
- Snyder, CH 2005, 'Dementia and driving: autonomy versus safety', *Journal of the American Academy of Nurse Practitioners*, vol. 17, pp. 393-402.
- Somerville, ER, Black, AB & Dunne, JW 2010, 'Driving to distraction: certification of fitness to drive with epilepsy', *Medical Journal of Australia*, vol. 192, pp. 342-344.
- Stacey, D, Légaré, F, Col, NF, Bennett, CL, Barry, MJ, Eden, KB, Holmes-Rovner, M, Llewellyn-Thomas, H, Lyddiatt, A, Thomson, R, Trevena, L & Wu JHC 2014, 'Decision aids for people facing health treatment or screening decisions', *Cochrane Database of Systematic Reviews*, Issue 1, no. CD001431.
- Stewart, M 2003, *Patient-centered medicine: transforming the clinical method*, Radcliffe Medical, Abingdon.
- Stirling, C, Leggett, S, Lloyd, B, Scott, J, Blizzard, L, Quinn, S & Robinson, A 2012, 'Decision aids for respite service choices by carers of people with dementia: development and pilot RCT', *BMC Medical Informatics and Decision Making*, vol. 12, pp. 21.
-

- Taylor, BD & Tripodes, S 2001, 'The effects of driving cessation on the elderly with dementia and their caregivers', *Accident Analysis and Prevention*, vol. 33, pp. 519-528.
- Taylor, JS, DeMers, SM, Vig, EK & Borson, S 2012, 'The disappearing subject: exclusion of people with cognitive impairment and dementia from geriatrics research', *Journal of the American Geriatric Society*, vol. 60, pp. 413-419.
- Thal, LJ, Grundman, M & Klauber, MR 1988, 'Dementia: characteristics of a referral population and factors associated with progression', *Neurology*, vol. 38, pp. 1083-1090.
- Trobe, JD, Waller, PF, Cook-Flannagan, CA, Teshima, SM & Bieliauskas, LA 1996, 'Crashes and violations among drivers with Alzheimer disease', *Archives of Neurology*, vol. 53, pp. 411-416.
- Tuokko, H, Tallman, K, Beattie, BL, Cooper, P & Weir, J 1995, 'An examination of driving records in a dementia clinic', *Journals of Gerontology Series B*, vol. 50, pp. s173-181.
- Uc, EY, Rizzo, M, Anderson, SW, Shi, Q & Dawson, JD 2004, 'Driver route-following and safety errors in early Alzheimer disease', *Neurology*, vol. 63, pp. 832-837.
- United States Department of Health and Human Services (US HHS) 1996, 'Clinical practice guidelines, number 19: recognition and initial assessment of Alzheimer's disease and related dementias', AHCPR publication, no. 97-0702.
- Van der Flier, WM & Scheltens, P 2005, 'Epidemiology and risk factors of dementia', *Journal of Neurology, Neurosurgery and Psychiatry*, vol. 76, pp. s2-7.
- Wilcock, J, Bryans, M, Turner, S, O'Carroll, R, Keady, J, Levin, E & Iliffe, S 2007, 'Methodological problems in dementia research in primary care: a case study of a randomized controlled trial', *Primary Health Care Research and Development*, vol. 8, pp. 12-21.
- Williams, AF & Carsten, O 1989, 'Driver age and crash involvement', *American Journal of Public Health*, vol. 79, pp. 326-327.
-

- Williamson, T 2008, *Dementia: out of the shadows*, Alzheimer's Society, London, viewed 4 July 2014, http://alzheimers.org.uk/site/scripts/download_info.php?fileID=454
- Wilson, S & Pinner, G 2013, 'Driving and dementia: a clinician's guide', *Advances in Psychiatric Treatment*, vol. 19, pp. 89-96.
- Wimo, A & Prince, M 2010, *World Alzheimer Report: the global economic impact of dementia*, Alzheimer's Disease International, London.
- Workman, B, Dickson, F & Green, S 2010, 'Early dementia: optimal management in general practice', *Australian Family Physician*, vol. 39, pp. 722-726.
- World Health Organisation (WHO) 2010, *International statistical classification of diseases and related health problems 10th revision*, viewed 22 July 2014, <http://www.who.int/classifications/icd/icdonlineversions/en/>
- World Health Organisation (WHO) 2012, *Dementia fact sheet no. 362*, viewed 22 July 2014, <http://www.who.int/mediacentre/factsheets/fs362/en/>
- World Health Organisation (WHO) 2012, *Dementia: a public health priority*, viewed 27 January 2014, http://www.who.int/mental_health/publications/dementia_report_2012/en/
- Yates, D 2010, 'The challenge of dementia therapy', *Nature Reviews Neurology*, vol. 6, p. 57.
- Yates, M & Ibrahim, JE 2014, 'Responsible management of motor vehicle drivers with dementia', *Journal of the Royal College of Physicians Edinburgh*, vol. 44, pp. 4-7.
- Zuin, D, Ortiz, H, Boromei, D & Lopez, OL 2002, 'Motor vehicle crashes and abnormal driving behaviours in patients with dementia in Mendoza, Argentina', *European Journal of Neurology*, vol. 9, pp. 29-34.
- Zulman, DM, Sussman, JB, Chen, X, Cigolle, CT, Blaum, CS & Hayward, RA 2011, 'Examining the evidence: a systematic review of the inclusion and analysis of older adults in randomized controlled trials', *Journal of General Internal Medicine*, vol. 26, pp. 783-790.
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Appendix A

Ethics materials and surveys reported in Chapter 7

University of Wollongong



APPROVAL – ISLHD AUTHORISATION

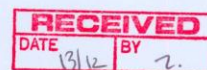
In reply please quote HE11/484

Further Enquiries Ph: 4221 3386

SF:CJ

9 December 2011

Dr John Carmody
Neurology Department
Level 4, Block C
Wollongong Hospital
Crown Street
WOLLONGONG NSW 2500



Dear Dr Carmody

I am pleased to advise that the Human Research Ethics application referred to below has been **approved**.

Ethics Number:	HE11/484
AuRED Number:	LNR/11/WGONG/164
Project Title:	What factors delay driving retirement by individuals with dementia?: a physician's perspective.
Name of Researchers:	Dr John Carmody, Professor Richard Fleming, Mr Jeremy Granger
Documents Reviewed/Approved:	1. Application Form 2. Participant Information Sheet 3. Consent Form 4. Interview Questions
Approval Date:	8 December 2011
Expiry Date:	7 December 2012

The University of Wollongong/ISLHD Health and Medical HREC is constituted and functions in accordance with the NHMRC *National Statement on Ethical Conduct in Human Research*. The HREC has reviewed the research proposal for compliance with the *National Statement* and approval of this project is conditional upon your continuing compliance with this document.

A condition of approval by the HREC is the submission of a progress report annually and a final report on completion of your project. The progress report template is available at <http://www.uow.edu.au/research/rso/ethics/UOW009385.html>. This report must be completed, signed by the appropriate Head of School and returned to the Research Services Office prior to the expiry date.

2

As evidence of continuing compliance, the Human Research Ethics Committee also requires that researchers immediately report:

- proposed changes to the protocol including changes to investigators involved
- serious or unexpected adverse effects on participants
- unforeseen events that might affect continued ethical acceptability of the project.

Please note that approvals are granted for a twelve month period. Further extension will be considered on receipt of a progress report prior to expiry date.

Before you can proceed with the project you must first have authorisation from the ISLHD. A copy of this advice has been forwarded to them.

Please note that Governance approval is required for research within NSW Ministry of Health. If you have not yet done so, you will need to complete a Site Specific Application for each site and lodge it with the appropriate Research Governance Unit for each site.

If you have any queries regarding the HREC review process, please contact the Ethics Unit on phone 4221 3386 or email rso-ethics@uow.edu.au.

Yours sincerely

Associate Professor Sarah Ferber
Chair, UOW & ISLHD Health and Medical
Human Research Ethics Committee

cc: Governance Officer, Research Directorate, ISLHD



Health
Illawarra Shoalhaven
Local Health District

Research Directorate
Telephone: 02 4253 4800
Facsimile: 02 4253 4803

TRIM NO: D11/77662
Ref: HE11/484
APPROVAL

Dr John Carmody
Staff Specialist Neurologist
Neurology Department
Level 4, Block C
Wollongong Hospital

Dear Dr Carmody

HREC project number: HE11/484

Project title: What factors delay driving retirement by individuals with dementia?: a physician's perspective

Thank you for submitting a Site-Specific Assessment Form for Low and Negligible Risk Research application for authorisation of the above project. I am pleased to inform you that authorisation has been granted for this study to take place at the following site:

- Neurology Department – Wollongong Hospital

The following conditions apply to this research project. These are additional to those conditions imposed by the Human Research Ethics Committee that granted ethical approval:

1. Proposed amendments to the research protocol or conduct of the research which may affect the ethical acceptability of the project, and which are submitted to the lead HREC for review, are copied to the research governance officer;
2. Proposed amendments to the research protocol or conduct of the research which may affect the ongoing site acceptability of the project, are to be submitted to the research governance officer.

Yours faithfully

KRISTY PIERCE
Research Governance Officer

22 December 2011

Research Directorate
Level 8, Block C, Wollongong Hospital
(LMB 8808, SCMC NSW 2521)

University of Wollongong



Health
Illawarra Shoalhaven
Local Health District

INTERVIEW QUESTIONS FOR DEMENTIA AND DRIVING RETIREMENT STUDY

QUESTIONS: (circle appropriate responses) (may circle >1 option if wished)

1. What is your current clinical role?
 - Intern / Resident / Registrar / Consultant
2. As a doctor, have you ever been involved in the care of a person with dementia?
 - Yes / No
3. As a doctor, have you been involved in the care of a person with dementia who drives?
 - Yes / No
4. Are you aware of the Austroads guidelines 'Assessing Fitness to Drive 2003'?
 - Yes / No
5. Are you aware of the Austroads guidelines regarding individuals with dementia?
 - Yes / No
6. Are you aware of the Australia and New Zealand Society of Geriatric Medicine (ANZSGM) driving and dementia position statement (2009)?
 - Yes / No
7. Have you ever instructed a patient to stop driving?
 - Yes / No
8. Have you ever instructed a person with dementia to stop driving?
 - Yes / No
9. Are you aware of occupational therapist driving assessments?
 - Yes / No
10. How much do you think occupational therapist driving assessments cost?
 - _____ / Don't know
11. Do you think occupational therapist driving assessments are covered by Medicare?
 - Yes / No
12. Are doctors in NSW legally obliged to inform the RTA of all unsafe drivers?
 - Yes / No
13. In your opinion, are some people with mild dementia safe to drive?
 - Yes / No

14. In your opinion, which of the following groups should be responsible for assessing the fitness to drive of people with dementia?

- | | Y | N |
|-------------------------------------|--------------------------|--------------------------|
| • Roads and Traffic Authority (RTA) | <input type="checkbox"/> | <input type="checkbox"/> |
| • Independent review board | <input type="checkbox"/> | <input type="checkbox"/> |
| • General practitioners | <input type="checkbox"/> | <input type="checkbox"/> |
| • Geriatricians | <input type="checkbox"/> | <input type="checkbox"/> |
| • Neurologists | <input type="checkbox"/> | <input type="checkbox"/> |
| • Rehabilitation specialists | <input type="checkbox"/> | <input type="checkbox"/> |
| • Occupational therapists | <input type="checkbox"/> | <input type="checkbox"/> |
| • Other(s) _____ | <input type="checkbox"/> | <input type="checkbox"/> |

15. In your opinion, which of these factors delay retirement from driving by people with dementia?

- | | Y | N |
|---|--------------------------|--------------------------|
| • Delay in diagnosis of dementia | <input type="checkbox"/> | <input type="checkbox"/> |
| • Denial of diagnosis by patient | <input type="checkbox"/> | <input type="checkbox"/> |
| • Denial of progressive neurological deficits by patient | <input type="checkbox"/> | <input type="checkbox"/> |
| • Pleasure of driving | <input type="checkbox"/> | <input type="checkbox"/> |
| • Independence | <input type="checkbox"/> | <input type="checkbox"/> |
| • Visiting friends / family | <input type="checkbox"/> | <input type="checkbox"/> |
| • Issue of driving not raised by health professionals | <input type="checkbox"/> | <input type="checkbox"/> |
| • Patient not instructed by a doctor to stop driving | <input type="checkbox"/> | <input type="checkbox"/> |
| • Patient forgetting advice to retire from driving | <input type="checkbox"/> | <input type="checkbox"/> |
| • Fear of need to move to residential care upon driving cessation | <input type="checkbox"/> | <input type="checkbox"/> |
| • Lack of public transport options (e.g. taxi subsidies) | <input type="checkbox"/> | <input type="checkbox"/> |
| • Other(s) _____ | | |

16. Do you think driving recommendations should be included in patient discharge letters? Yes / No _____

17. Do you think it would be helpful if JMOs were made aware of the Austroads 'Assessing Fitness to Drive' guidelines at orientation? Yes / No _____

18. When do you think the issue of driving should be raised with someone who has been diagnosed with dementia?

- at time of initial diagnosis ☐
- when they become unsafe to drive ☐
- if they have an accident ☐
- other _____ ☐

19. Would you find it useful if a patient-centred booklet on 'driving and dementia' were available to give to people with dementia?

20. Are there any other comments you wish to make?

- _____

Appendix B

Ethics materials and surveys reported in Chapter 8



APPROVAL - ISLHD AUTHORISATION

In reply please quote: HE12/327

Further Enquiries Phone: 4221 3386

16 August 2012

Dr John Carmody
Neurology
The Wollongong Hospital
Level 4, Block C, Crown Street
WOLLONGONG NSW 2500

Dear Dr Carmody

I am pleased to advise that the Human Research Ethics application referred to below has been **approved. Before you can proceed with the project you must first have authorisation from the AHS. A copy of this advice has been forwarded to the ISLHD.**

Ethics Number:	HE12/327
AuRED Number:	LNR/12/WGONG/90
Project Title:	Discharge letters and driving advice: a retrospective study
Name of Researchers:	Dr John Carmody, Mr Michael Carey
Sites Approved:	Wollongong Hospital
Documents Approved/Reviewed:	LNR submission code: AU/6/9CE013
Approval Date:	16 August 2012
Expiry Date:	15 August 2013

The University of Wollongong/ISLHD Health and Medical HREC is constituted and functions in accordance with the NHMRC National Statement on Ethical Conduct in Human Research. The HREC has reviewed the research proposal for compliance with the National Statement and approval of this project is conditional upon your continuing compliance with this document.

A condition of approval by the HREC is the submission of a progress report annually and a final report on completion of your project. The progress report template is available at <http://www.uow.edu.au/research/rso/ethics/UOW009385.html>. This report must be completed, signed by the appropriate Head of School and returned to the Research Services Office prior to the expiry date.

As evidence of continuing compliance, the Human Research Ethics Committee also requires that researchers immediately report:

Ethics Unit, Research Services Office
University of Wollongong NSW 2522 Australia
Telephone (02) 4221 3386 Facsimile (02) 4221 4338
Email: rso-ethics@uow.edu.au Web: www.uow.edu.au



Health
Illawarra Shoalhaven
Local Health District

Research Directorate
Telephone: 02 4253 4800
Facsimile: 02 4253 4803

TRIM NO: D12/54109
Ref: HE12/327
APPROVAL

Dr John Carmody
Staff Specialist Neurologist
Neurology Department
Level 4 – Block C
Wollongong Hospital



Dear Dr Carmody

HREC project number: HE12/327
Project title: Discharge letters and driving advice: a retrospective study

Thank you for submitting a Site-Specific Assessment Form for Low and Negligible Risk Research application for authorisation of the above project. I am pleased to inform you that authorisation has been granted for this study to take place at the following site:

- Neurology Department – Wollongong Hospital

The following conditions apply to this research project. These are additional to those conditions imposed by the Human Research Ethics Committee that granted ethical approval:

1. Proposed amendments to the research protocol or conduct of the research which may affect the ethical acceptability of the project, and which are submitted to the lead HREC for review, are copied to the research governance officer;
2. Proposed amendments to the research protocol or conduct of the research which may affect the ongoing site acceptability of the project, are to be submitted to the research governance officer.

Yours faithfully

KRISTY PIERCE
Research Governance Officer

30 August 2012

Research Directorate
Level 8, Block C, Wollongong Hospital
(LMB 8808, SCMC NSW 2521)

Summary of data to be collected

1. **Age**
 - To be recorded in years
2. **Gender**
 - Male or female
3. **Discharge Diagnosis** (includes presenting complaint) - one or more of the following to be selected in a tick box format:
 - Stroke
 - TIA
 - Seizure
 - Non-organic
 - Other (if so, diagnosis to be recorded as free text)
4. **Inpatient Events** - to be selected in a tick box format from the following:
 - Stroke
 - TIA
 - Seizure
 - Non-organic
 - DVT
 - PE
 - Acute coronary syndrome / MI
 - Arrhythmia (record as free text e.g. VT, afib, VF, pauses)
 - Pacemaker insertion
 - Surgery (record as free text e.g. Carotid endarterectomy)
5. **Background history** - to be selected in a tick box format from the following:
 - Dementia
 - Cognitive impairment
 - Epilepsy
6. **Deficit at time of discharge**
 - Yes or no
7. **Advice regarding driving documented in discharge letter**
 - Yes or no
 - If yes advice noted to be recorded as free text
8. **Length of stay**
 - in days
9. **Discharge destination**
 - Home or other in a tick box format
 - If other, destination to be recorded in written format

Appendix C

Ethics materials and surveys reported in Chapter 9



AMENDMENT APPROVAL - ISLHD

In reply please quote: HE13/020

Further Enquiries Phone: 4221 3386

17 July 2013

Dr John Carmody
 Department of Neurology
 Level 4, Block C
 Neurology Department
 Wollongong Hospital
 LMB 8808
 South Coast Mail Centre NSW 2521
john.carmody@sesiahs.health.nsw.gov.au

Dear Dr Carmody

I am pleased to advise that amendments received on 11 June 2013 to the following Human Research Ethics application have been **approved**.

Ethics Number:	HE13/020
AuRED Number:	LNR/13/WGONG/4
Project Title:	Driving and dementia: insurance implications and legislative requirements
Name of Researchers:	Dr John Carmody, Mr Michael Carey
Amendment Approval Date:	11 July 2013
Amendments Approved:	<ol style="list-style-type: none"> 1. Permission to conduct survey via telephone. 2. Revised Letter of Invitation. 3. Telephone Script
Expiry Date:	25 February 2014

Please remember that in addition to reporting proposed changes to your research protocol, the HREC requires that researchers immediately report:

- serious or unexpected adverse effects on participants
- unforeseen events that might affect continued ethical acceptability of the project.

The University of Wollongong/Illawarra Shoalhaven Local Health District Health and Medical HREC is constituted and functions in accordance with the NHMRC *National Statement on Ethical Conduct in Human Research*.

A condition of approval by the HREC is the submission of a progress report annually and a final report on completion of your project. The progress report template is available at <http://www.uow.edu.au/research/rso/ethics/UOW009385.html>. This report must be completed, signed by the appropriate Head of School and returned to the Research Services Office prior to the expiry date.

If you have any queries regarding the HREC review process, please contact the Ethics Unit on phone 4221 3386 or email rso-ethics@uow.edu.au.

A copy of this advice has been forwarded to the ISLHD for their records.

Yours sincerely _____

Professor Jim Greenstein
Chair, UOW & ISLHD Health and Medical
Human Research Ethics Committee

cc: Governance Officer, Research Directorate, ISLHD

Survey – Motor vehicle insurance implications of a diagnosis of dementia

Instructions

Please select your company's responses below and elaborate in free text after '*comment*' if wished.

1. Are motor vehicle insurance customers obliged to report pre-existing medical conditions?

Yes ☐ No ☐ Other ☐

Comment:

2. If a motor vehicle insurance customer does not disclose a pre-existing diagnosis of dementia, is their policy void?

Yes ☐ No ☐ Other ☐

Comment:

3. Does your company require medical reviews for new or existing motor vehicle insurance customer? If yes, when?

Yes ☐ No ☐ When? _____

Comment:

4. At what age does your company require medical reviews and how often are they required?

Age? _____ Frequency? _____ (e.g. yearly, every 5 years)

Comment:

5. Is your company prepared to provide motor vehicle insurance to individuals with dementia?

Yes ☐ No ☐ Other ☐

Comment:

Email: john.carmody@sesiahs.health.nsw.gov.au

Fax: 02 42534436

1 | Page

6. What level of dementia severity is your company prepared to provide motor vehicle insurance to individuals with dementia?

Mild ☐ Moderate ☐ Severe ☐ All ☐

Comment:

7. If a driver has a diagnosis of dementia and is deemed safe to drive by a physician will your company continue to provide motor vehicle insurance?

Yes ☐ No ☐ Other ☐

Comment:

8. If a driver has a diagnosis of dementia and is deemed safe to drive by a physician does your company request regular medical reviews?

Yes ☐ No ☐ Other ☐

Comment:

9. If a driver has a diagnosis of dementia and is deemed safe to drive by a physician is the cost of their premium affected?

Yes ☐ No ☐ Other ☐

Comment:

10. If your company provides multiple types of motor vehicle insurance (e.g. compulsory, comprehensive or 3rd party property) do your policies or premiums relating to individuals with dementia vary?

Yes ☐ No ☐ Other ☐

Comment:

This completes the survey. For the purposes of data standardisation we request you record your job/position here: _____. Thank you very much for taking the time to contribute to our goal of ensuring patients with a diagnosis of dementia get the best possible advice in regards to motor vehicle insurance. Please return by email, fax or mail.

Dr John Carmody MRCPI FRACP

Email: john.carmody@sesiahs.health.nsw.gov.au

Fax: 02 42534436

2 | Page

Appendix D

Ethics materials and surveys reported in Chapter 10

**APPROVAL****In reply please quote HE12/016**

Further Enquiries Ph: 4221 3386

SF:MOT

2 April 2012

Dr John Carmody
Neurology Department
Level 4, Block C
Wollongong Hospital



Dear Dr Carmody,

Thank you for your response to the HREC letter regarding the ethics application below. I am pleased to advise that the application has been **approved**.

Ethics Number: HE12/016
 Au RED Number: HREC/12/WGONG/19
 Project Title: Development of a novel Decision Aid for drivers with dementia: Consumer views
 Researchers: Dr John Carmody, A/Professor Victoria Traynor, Professor Don Iverson, Dr Kate Lewis, Dr Jan Potter
 Sites/CIs approved:

Site	Principal Investigator for site
Bulli Hospital	Dr John Carmody
Wollongong Hospital	Dr John Carmody

Documents Reviewed/Approved: Initial Application
 Participant Information Sheet v.3 dated 27.3.2012
 Consent Form v.3 dated 27.3.2012
 Explanatory information letter dated 21.3.2012
 Dementia and Driving: A Decision Aid
 Pre-Booklet Survey (Appendix 4) v.2 dated 21.3.2012
 Pre-Booklet Survey (Appendix 5) v.2 dated 21.3.2012

Approval Date: 29 March 2012

Expiry Date: 28 March 2013

The University of Wollongong/ISLHD Health and Medical HREC is constituted and functions in accordance with the NHMRC *National Statement on Ethical Conduct in Human Research*. The HREC has reviewed the research proposal for compliance with the *National Statement* and approval of this project is conditional upon your continuing compliance with this document.

A condition of approval by the HREC is the submission of a progress report annually and a final report on completion of your project. The progress report template is available at <http://www.uow.edu.au/research/rso/ethics/UOW009385.html>. This report must be completed, signed by the appropriate Head of School and returned to the Research Services Office prior to the expiry date.

As evidence of continuing compliance, the Human Research Ethics Committee also requires that researchers immediately report:

- proposed changes to the protocol including changes to investigators involved
- serious or unexpected adverse effects on participants
- unforeseen events that might affect continued ethical acceptability of the project.

Please note that approvals are granted for a twelve month period. Further extension will be considered on receipt of a progress report prior to expiry date.

Before you can proceed with the project you must first have authorisation from the ISLHD. A copy of this advice has been forwarded to them.

Please note that Governance approval is required for research within NSW Ministry of Health. If you have not yet done so, you will need to complete a Site Specific Application for each site and lodge it with the appropriate Research Governance Unit for each site.

If you have any queries regarding the HREC review process, please contact the Ethics Unit on phone 4221 3386 or email rso-ethics@uow.edu.au.

Yours sincerely,

**Associate Professor Sarah Ferber
Chair, UOW & ISLHD Health and Medical
Human Research Ethics Committee**

cc: Governance Officer, Research Directorate, ISLHD
cc: Assoc. Professor Victoria Traynor; Professor Don Iverson



Health
Illawarra Shoalhaven
Local Health District

Research Directorate
Telephone: 02 4253 4800
Facsimile: 02 4253 4803

TRIM NO: D12/21672
Ref: HE12/016
APPROVAL

Dr John Carmody
Neurology Department
Level 4 – Block C
Wollongong Hospital

Dear Dr Carmody

HREC project number: HE12/016
Project title: Development of a novel Decision aid for drivers with dementia: Consumer views

Thank you for submitting a Site-Specific Assessment application for authorisation of the above project. I am pleased to inform you that authorisation has been granted for this study to take place at the following sites:

- Aged Care, Lawson House – Wollongong Hospital
- Aged Care – Bulli Hospital

The following conditions apply to this research project. These are additional to those conditions imposed by the Human Research Ethics Committee that granted ethical approval:

1. Proposed amendments to the research protocol or conduct of the research which may affect the ethical acceptability of the project, and which are submitted to the lead HREC for review, are copied to the research governance officer;
2. Proposed amendments to the research protocol or conduct of the research which may affect the ongoing site acceptability of the project, are to be submitted to the research governance officer.

Yours faithfully

KRISTY PIERCE
Research Governance Officer

24 April 2012

Research Directorate
Level 5, Block C, Wollongong Hospital
(LMB 8608, SCMC NSW 2521)

‘Dementia and Driving: A decision aid’

Pilot Study 2012

Pre-intervention Telephone Survey

DEMOGRAPHICS

1. Age? _____
2. Gender? _____
3. Living arrangements
 - With spouse/partner at home ☐
 - With other family at home ☐
 - Alone at home ☐
 - Hostel ☐
 - Nursing home ☐
 - Other _____
4. Highest level of schooling?
 - Primary school ☐
 - High school ☐
 - Certificate/diploma ☐
 - Undergraduate degree ☐
 - Postgraduate degree ☐
5. Employment status?
 - Employed ☐
 - Unemployed/Retired ☐
 - Volunteer worker ☐
6. Do you drive?
 - Yes / No _____
 - If yes, then for how long? _____
 - If no, then when did you stop? _____
7. How often do you drive now?
 - Less than once a week ☐
 - Once a week ☐
 - 2-6 times per week ☐
 - Once a day ☐
 - More than once a day ☐

KNOWLEDGE (adapted from Ottawa Knowledge Questionnaire template, O'Connor 1999)

1. About 1% of people over the age of 65 have dementia
 - True / False / Unsure _____
2. Alzheimer's disease is a common form of dementia
 - True / False / Unsure _____
3. Dementia can interfere with one's judgement and ability to plan
 - True / False / Unsure _____
4. Driving is a simple task
 - True / False / Unsure _____
5. Dementia can affect a person's driving skills
 - True / False / Unsure _____
6. Drivers with dementia do not get lost when driving
 - True / False / Unsure _____
7. Drivers with dementia have the same risk of car accident as others of equal age
 - True / False / Unsure _____
8. The driving skills of older drivers worsen over time
 - True / False / Unsure _____
9. Drivers with dementia do not need regular medical review
 - True / False / Unsure _____
10. The National Dementia Hotline is only available to doctors
 - True / False / Unsure _____

Final score = _____/10

DECISION

Which driving option do you prefer?

- Stop driving now ☐
- Drive less ☐
- Stop driving later ☐
- Unsure ☐
- Other _____

DECISIONAL CONFLICT SCORE (low literacy version, O'Connor 1993)

Considering the option you prefer, please answer the following questions*:

- | | |
|---|--------------------------|
| 1. Do you know which options are available to you? | Yes / Unsure / No |
| 2. Do you know the benefits of each option? | Yes / Unsure / No |
| 3. Do you know the risks of each option? | Yes / Unsure / No |
| 4. Are you clear about which benefits matter most to you? | Yes / Unsure / No |
| 5. Are you clear about which risks matter most to you? | Yes / Unsure / No |
| 6. Do you have enough support from others to make a choice? | Yes / Unsure / No |
| 7. Are you choosing without pressure from others? | Yes / Unsure / No |
| 8. Do you have enough advice to make a choice? | Yes / Unsure / No |
| 9. Are you clear about the best choice for you? | Yes / Unsure / No |
| 10. Do you feel sure about what to choose? | Yes / Unsure / No |

*Scoring:

Yes = 0 points. Unsure = 2 points. No = 4 points.

Final score = total x 2.5

(Range 0-100)

‘Dementia and Driving: A decision aid’

Pilot Study 2012

Post-intervention Telephone Survey

BOOKLET USE

How long did it take you to complete the booklet?

- _____ mins

Did you need someone's help to use it?

- Yes / No _____

KNOWLEDGE (adapted from Ottawa Knowledge Questionnaire template, O'Connor 1999)

1. About 1% of people over the age of 65 have dementia
 - True / False / Unsure _____
2. Alzheimer's disease is a common form of dementia
 - True / False / Unsure _____
3. Dementia can interfere with one's judgement and ability to plan
 - True / False / Unsure _____
4. Driving is a simple task
 - True / False / Unsure _____
5. Dementia can affect a person's driving skills
 - True / False / Unsure _____
6. Drivers with dementia do not get lost when driving
 - True / False / Unsure _____
7. Drivers with dementia have the same risk of car accident as others of equal age
 - True / False / Unsure _____
8. The driving skills of older drivers worsen over time
 - True / False / Unsure _____
9. Drivers with dementia do not need regular medical review
 - True / False / Unsure _____
10. The National Dementia Hotline is only available to doctors
 - True / False / Unsure _____

Final score = _____/10

ACCEPTABILITY (adapted from the Ottawa Acceptability tool, O'Connor 1996)

We would like to know what you think about the booklet you have read.

1. How do you rate the way information was presented?
 - Poor ☐
 - Fair ☐
 - Good ☐
 - Excellent ☐
2. Regarding the length of the booklet - was it:
 - Too long ☐
 - Too short ☐
 - Just right ☐
3. Was there enough information to decide about driving?
 - Too much information ☐
 - Too little information ☐
 - Just right ☐
4. Do you feel the booklet was balanced? Was it:
 - Slanted against you driving ☐
 - Slanted in favour of you driving ☐
 - Balanced ☐
5. Did you find the booklet useful in helping you decide about driving?
 - Yes / No _____
 - Comments _____
6. What did you like about the booklet?
 - _____
7. How do you think we could improve the booklet?
 - _____
8. Would you recommend the booklet to others?
 - Yes / No _____

DECISION

Which driving option do you prefer?

- Stop driving now ☐
- Drive less ☐
- Stop driving later ☐
- Unsure ☐
- Other _____

DECISIONAL CONFLICT SCORE (low literacy version, O'Connor 1993)

Considering the option you prefer, please answer the following questions:

- | | |
|---|--------------------------|
| 1. Do you know which options are available to you? | Yes / Unsure / No |
| 2. Do you know the benefits of each option? | Yes / Unsure / No |
| 3. Do you know the risks of each option? | Yes / Unsure / No |
| 4. Are you clear about which benefits matter most to you? | Yes / Unsure / No |
| 5. Are you clear about which risks matter most to you? | Yes / Unsure / No |
| 6. Do you have enough support from others to make a choice? | Yes / Unsure / No |
| 7. Are you choosing without pressure from others? | Yes / Unsure / No |
| 8. Do you have enough advice to make a choice? | Yes / Unsure / No |
| 9. Are you clear about the best choice for you? | Yes / Unsure / No |
| 10. Do you feel sure about what to choose? | Yes / Unsure / No |

Scoring:

Yes = 0 points. Unsure = 2 points. No = 4 points.

Final score = total x 2.5

(Range 0-100)

SATISFACTION WITH DECISION (SWD Scale, Holmes-Rovner 1996)

Please use one of the following answers only:

- Strongly disagree [1 point]
- Disagree [2 points]
- Neither agree nor disagree [3 points]
- Agree [4 points]
- Strongly agree [5 points]

1. I am satisfied that I am adequately informed about the issues important to my decision

- Answer _____

2. The decision I made was the best decision possible for me personally

- Answer _____

3. I am satisfied that my decision was consistent with my personal values

- Answer _____

4. I expect to successfully carry out the decision I made

- Answer _____

5. I am satisfied that this was my decision to make

- Answer _____

6. I am satisfied with my decision

- Answer _____

Final score = total _____ ÷ 6

Appendix E

Ethics materials, advertising fliers and trial registration reported in Chapter 11

**AMENDMENT APPROVAL - ISLHD****In reply please quote: HE12/016**

Further Enquiries Phone: 4221 3386

18 December 2012

Dr John Carmody
 Neurology Department
 Level 4, Block C
 Wollongong Hospital
 Crown Street
 WOLLONGONG NSW 2500

Dear Dr Carmody,

I am pleased to advise that your amendment request to the following Human Research Ethics application have been approved.

Ethics Number:	HE12/016
AuRED Number:	HREC/12/WGONG/19
Project Title:	Development of a novel Decision Aid for drivers with dementia: Consumer views
Researchers:	Dr John Carmody, A/Professor Victoria Traynor, Professor Don Iverson, Dr Kate Lewis, Dr Jan Potter
Amendments:	Additional 140 participants recruited via Alzheimer's Australia NSW through advertising in State Newsletter
Amendment Approval Date:	18 December 2012
Expiry Date:	28 March 2013

Please remember that in addition to reporting proposed changes to your research protocol the HREC requires that researchers immediately report:

- serious or unexpected adverse effects on participants
- unforeseen events that might affect continued ethical acceptability of the project.

The University of Wollongong/ ISLHD Health and Medical HREC is constituted and functions in accordance with the NHMRC National Statement on Ethical Conduct in Human Research.

A condition of approval by the HREC is the submission of a progress report annually and a final report on completion of your project. The progress report template is available at <http://www.uow.edu.au/research/rso/ethics/UOW009385.html>. This report must be completed, signed by the appropriate Head of School and returned to the Research Services Office prior to the expiry date.

Ethics Unit, Research Services Office
 University of Wollongong NSW 2522 Australia
 Telephone (02) 4221 3386 Facsimile (02) 4221 4338
 Email: rso-ethics@uow.edu.au Web: www.uow.edu.au

**AMENDMENT APPROVAL - ISLHD**

In reply please quote: HE12/016

Further Enquiries Phone: 4221 3386

1 May 2013

Dr John Carmody
 Neurology Department
 Level 4, Block C
 Wollongong Hospital
 Crown Street
 WOLLONGONG NSW 2500

Dear Dr Carmody,

I am pleased to advise that amendments dated 24 April 2013 to the following Human Research Ethics application have been **approved**.

Ethics Number: HE12/016
 AuRED Number: HREC/12/WGONG/19
 Project Title: Development of a novel Decision Aid for drivers with dementia:
 Consumer views
 Name of Researcher/s: Dr John Carmody, A/Professor Victoria Traynor, Professor Don
 Iverson, Dr Kate Lewis, Dr Jan Potter

Sites/CIs reviewed:

Site	Principal Investigator for site
Bulli Hospital	Dr John Carmody
Wollongong Hospital	Dr John Carmody

Amendment Approval Date: 30 April 2013
 Amendments Approved: Dissemination of advertisement to additional clinicians:
 (i) General Practitioners in Illawarra region
 (ii) Members of Australian & New Zealand Society for Geriatric medicine
 (iii) Community-based dementia nurses in NSW
 Expiry Date: 28 March 2013

Please remember that in addition to reporting proposed changes to your research protocol, the HREC requires that researchers immediately report:

- serious or unexpected adverse effects on participants
- unforeseen events that might affect continued ethical acceptability of the project.

The University of Wollongong/Illawarra Shoalhaven Local Health District Health and Medical HREC is constituted and functions in accordance with the NHMRC *National Statement on Ethical Conduct in Human Research*.

A condition of approval by the HREC is the submission of a progress report annually and a final report on completion of your project. The progress report template is available at <http://www.uow.edu.au/research/rso/ethics/UOW009385.html>. This report must be completed, signed by the appropriate Head of School and returned to the Research Services Office prior to the expiry date.

If you have any queries regarding the HREC review process, please contact the Ethics Unit on phone 4221 3386 or email rso-ethics@uow.edu.au.

A copy of this advice has been forwarded to the ISLHD for their records.

Yours sincerely,

**Associate Professor Sarah Ferber
Chair, UOW & ISLHD Health and Medical
Human Research Ethics Committee**

cc: Governance Officer, Research Directorate, ISLHD

cc: Assoc. Professor Victoria Traynor; Professor Don Iverson



AMENDMENT APPROVAL

In reply please quote: HE12/016

Further Enquiries Phone: 4221 3386

4 September 2013

Dr John Carmody
Neurology Department
Level 4, Block C
Wollongong Hospital
Crown Street
WOLLONGONG NSW 2500

Dear Dr Carmody,

I am pleased to advise that your amendment request to the following Human Research Ethics application have been approved.

Ethics Number:	HE12/016
AuRED Number:	HREC/12/WGONG/19
Project Title:	Development of a novel Decision Aid for drivers with dementia: Consumer views
Researchers:	Dr John Carmody, A/Professor Victoria Traynor, Professor Don Iverson, Dr Kate Lewis, Dr Jan Potter
Amendments:	Additional recruitment of participants from Alzheimer's Australia and Alzheimer's New Zealand
Amendment Approval Date:	3 September 2013
Expiry Date:	28 March 2014

Please remember that in addition to reporting proposed changes to your research protocol the HREC requires that researchers immediately report:

- serious or unexpected adverse effects on participants
- unforeseen events that might affect continued ethical acceptability of the project.

The University of Wollongong/ ISLHD Health and Medical HREC is constituted and functions in accordance with the NHMRC National Statement on Ethical Conduct in Human Research.

A condition of approval by the HREC is the submission of a progress report annually and a final report on completion of your project. The progress report template is available at <http://www.uow.edu.au/research/rso/ethics/UOW009385.html>. This report must be completed, signed by the appropriate Head of School and returned to the Research Services Office prior to the expiry date.

A copy of this advice has been forwarded to the ISLHD for their records.

If you have any queries regarding the HREC review process, please contact the Ethics Unit on phone 4221 3386 or email rso-ethics@uow.edu.au.

Ethics Unit, Research Services Office
University of Wollongong NSW 2522 Australia
Telephone (02) 4221 3386 Facsimile (02) 4221 4338
Email: rso-ethics@uow.edu.au Web: www.uow.edu.au

Yours sincerely

Professor Jim Greenstein
Chair, UOW & ISLHD Health and Medical
Human Research Ethics Committee

cc: Assoc. Professor Victoria Traynor; Professor Don Iverson
Governance Officer, Research Directorate, ISLHD

Ethics Unit, Research Services Office
University of Wollongong NSW 2522 Australia
Telephone (02) 4221 3386 Facsimile (02) 4221 4338
Email: rso-ethics@uow.edu.au Web: www.uow.edu.au

Dear John Carmody,

Re: Development of a novel decision aid for drivers with dementia and its effect on decisional conflict

Thank you for submitting the above trial for inclusion in the Australian New Zealand Clinical Trials Registry (ANZCTR).

Your trial has now been successfully registered and allocated the ACTRN:
ACTRN12613000174785

Web address of your trial: <http://www.ANZCTR.org.au/ACTRN12613000174785.aspx>

Date submitted: 8/02/2013 11:42:51 AM

Date registered: 12/02/2013 3:28:01 PM

Registered by: John Carmody

If you have already obtained Ethics approval for your trial, could you please send the ANZCTR a copy of at least one Ethics Committee approval letter? A copy of the letter can be sent to info@actr.org.au (by email) OR (61 2) 9565 1863, attention to ANZCTR (by fax).

Please be reminded that the quality and accuracy of the trial information submitted for registration is the responsibility of the trial's Primary Sponsor or their representative (the Registrant).

The ANZCTR allows you to update trial data, but please note that the original data lodged at the time of trial registration and the tracked history of any changes made will remain publicly available.

The ANZCTR is recognised as an ICMJE acceptable registry (<http://www.icmje.org/faq.pdf>) and a Primary Registry in the WHO registry network (<http://www.who.int/ictrp/network/primary/en/index.html>).

If you have any enquiries please send a message to info@actr.org.au or telephone +61 2 9562 5333.

Kind regards,
ANZCTR Staff
T: +61 2 9562 5333
F: +61 2 9565 1863
E: info@actr.org.au
W: www.ANZCTR.org.au

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DEMENTIA AND DRIVING RESEARCH



AlzNSW is participating in a dementia and driving project with the University of Wollongong and the Illawarra Shoalhaven Local Health District.

If you have dementia and drive a car, researchers at the University of Wollongong would like to invite you to participate in a telephone survey.

All participants will be mailed a free information booklet on driving and dementia. The aim of the study is to seek your feedback on this booklet.

If you would like to learn more about joining this study please contact Dr John Carmody MRCPI FRACP, Staff Specialist Neurologist, Wollongong Hospital.

E: john.carmody@sesiahs.health.nsw.gov.au

T: (02) 4253 4430 or 0427 468 544

Post: Neurology Department,
Level 4, Block C,
Wollongong Hospital,
Wollongong NSW 2500

14 IN TOUCH AUTUMN 2013

DEMENTIA & DRIVING: A DECISION AID

If you have dementia and drive a car, researchers at the University of Wollongong would like to invite you to participate in a telephone survey.

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University of Wollongong



Health
Illawarra Shoalhaven
Local Health District



WHEN SHOULD I STOP DRIVING? DEMENTIA AND DRIVING: A DECISION AID

If you have dementia and drive a car, researchers at the University of Wollongong would like to invite you to participate in a telephone survey. All participants will be mailed a free information booklet on driving and dementia. The aim of the study is to seek your feedback on this booklet.

For more information about joining this study please contact:

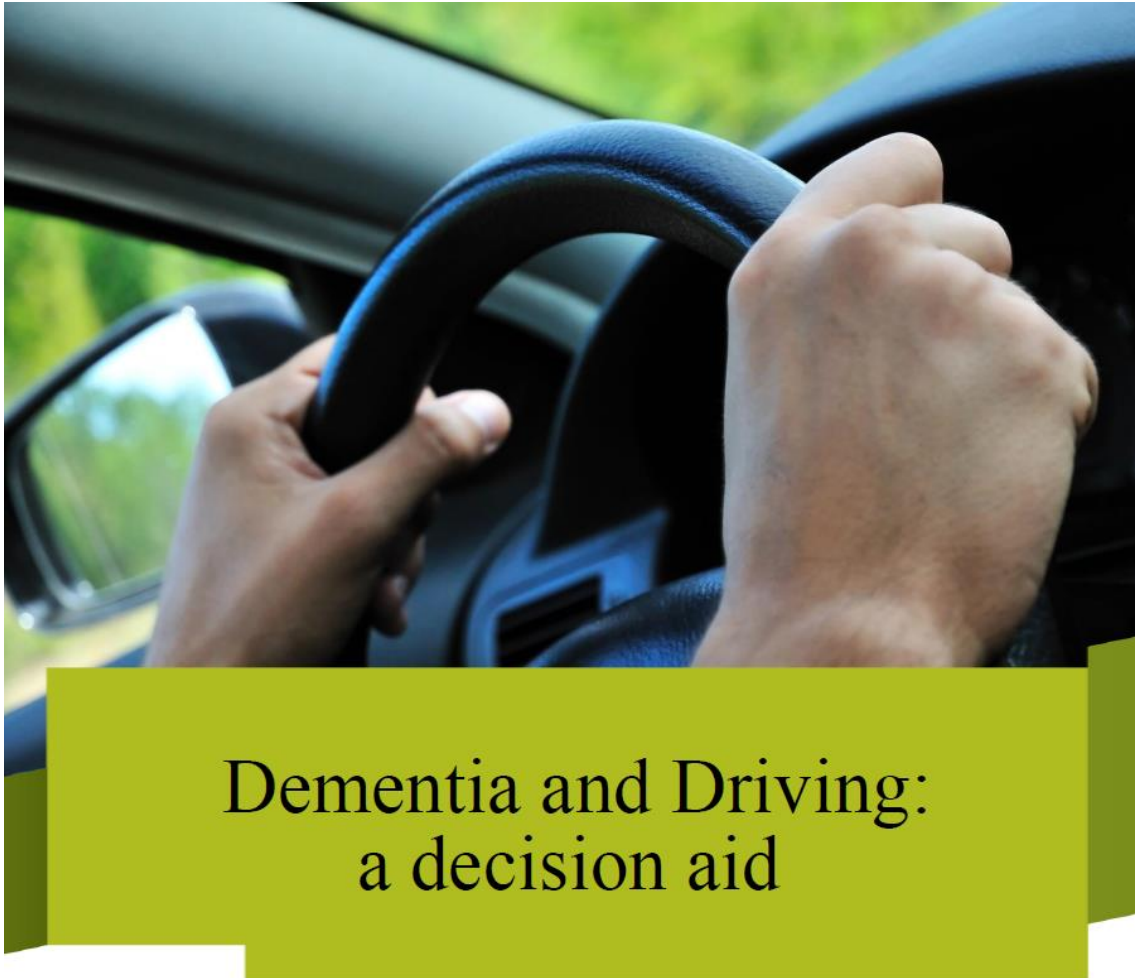
Dr John Carmody MRCPI FRACP
Staff Specialist Neurologist, Wollongong Hospital
Email: john.carmody@sesiahs.health.nsw.gov.au

Telephone: (02) 4253 4430	or	0427 468 544	(Australian residents)
Telephone: 0061 2 4253 4430	or	0061 4 2746 8544	(New Zealand residents)



Appendix F

Driving with dementia decision aid reported in Chapters 10 and 11



Dementia and Driving: a decision aid

Dr John Carmody FRACP

A/Prof Victoria Traynor PhD

Prof Don Iverson PhD

Ms Catherine Andrew MSc

**UNIVERSITY OF
WOLLONGONG**



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INTRODUCTION

A diagnosis of dementia can come as quite a shock. It is accompanied by a variety of changes to one's lifestyle and needs. This booklet may be used by any driver who has dementia.

Most older adults have driven safely and remained accident-free for many years. Unfortunately, dementia can silently disrupt driving skills. At times, family members notice unsafe driving behaviour before you do. For a variety of reasons, the issue of driving safety is often not raised by doctors, nurses, family or friends.

The aim of this booklet is to assist you in deciding when to stop driving after receiving a diagnosis of dementia. It is hoped that early planning for retirement from driving will avoid the need to stop suddenly in the future.

INSTRUCTIONS

- Please read this booklet from beginning to end
- You will be guided through 4 steps
- Use a pencil to answer questions
- Tick these green boxes if you agree
- Please write your answers on the dotted lines _ _ _ _ _
- You may reuse this booklet as often as you wish

STEP 1: TO HELP CLARIFY YOUR DECISION

What is dementia?

Usually, dementia is a condition which gradually disrupts one's memory, speech, concentration, judgement and ability to plan. The most common forms of dementia are Alzheimer's disease, vascular dementia, Lewy body disease and Frontotemporal dementia. About 6% of people over the age of 65 are affected. Dementia is associated with many other conditions and medication use. Some forms of dementia increase your risk of seizures and strokes.

Can dementia affect your driving skills?

Yes. Eventually, most people with dementia become unsafe to drive.

Driving is a complex task. In order to drive safely, you rely upon a variety of skills such as judgement, memory, attention and the ability to assess your surroundings. Unfortunately, people with dementia often lose these important skills. For many, this happens without you realising it. Over time, your risk of becoming lost or having a car accident rises significantly.

What are your options?

- Continue driving with no change
- Stop driving now
- Drive less
- Stop driving later

STEP 1: TO HELP CLARIFY YOUR DECISION

How far along are you with making a decision about driving?

- ☐ I have not yet thought about my options
- ☐ I am thinking about my options
- ☐ I have almost made my decision
- ☐ I have already made my decision

How will you cope without your car?

People with dementia wish to drive for a number of reasons: the pleasure of driving; independence; shopping; work; visiting family or friends; going to appointments; and travelling. Many are afraid to discuss driving safety for fear of losing their licence.

Fortunately, many helpful alternative forms of transport exist:

- Family or friends
- Public transport (e.g. bus, train, ferry)
- Taxi (subsidies are available for some)
- Relocating to more central location (e.g. moving to live closer to a town centre)

Many people underestimate how much money they could save by retiring from driving. One no longer needs to pay for annual registration, car insurance, maintenance checks, repairs and ever increasing fuel costs.

STEP 1: TO HELP CLARIFY YOUR DECISION

Have you noticed any warning signs of unsafe driving?

Driving errors are a sign that your driving skills may no longer be adequate. Have you experienced any of the following warning signs while driving?

- ☐ Find changing lanes difficult to do
- ☐ Find roundabouts difficult to use
- ☐ Drive very slowly
- ☐ Confuse left and right
- ☐ Become lost on short trips
- ☐ Drive on the wrong side of the road
- ☐ Notice damage to my car that I cannot explain
- ☐ Have car accidents

How often do you experience any of these warning signs?

- ☐ Never
- ☐ Rarely
- ☐ Sometimes
- ☐ Often

STEP 2: WHAT DO YOU NEED TO MAKE YOUR DECISION?**Support**

- Do I have enough help or advice from others to make a choice? Yes ☐ No ☐
- Am I being forced by others to make a choice? Yes ☐ No ☐

Knowledge

- Do I know my options? Yes ☐ No ☐
- Do I know the benefits and risks of each option? Yes ☐ No ☐

Values

- Am I clear about which benefits and risks matter most to me? Yes ☐ No ☐

Certainty

- Do I feel sure about the best choice for me? Yes ☐ No ☐

STEP 3: WEIGHING YOUR OPTIONS

Support

- Who else is involved with my decisions about driving? _____
- What option do they prefer? _____

Options = No change / Stop driving now / Drive less / Stop driving later

- Is this person pressuring me? ☐ Yes ☐ No
- Can this person help me? ☐ Yes ☐ No
- What do I prefer? ☐ I prefer to decide for myself
☐ I prefer to let someone else decide
☐ I prefer to share the decision with others

Knowledge

Most experts would agree that drivers with dementia are at a higher risk of getting lost or having a car accident. Some researchers have found the risk of accident to be 2.5 to 10 times higher than other people of the same age. This is a difficult topic to research and your exact risk is uncertain.

What are the benefits of driving?

- Independence
- Pleasure of driving
- Visiting family & friends
- Going to appointments
- Travel

What are the risks of driving?

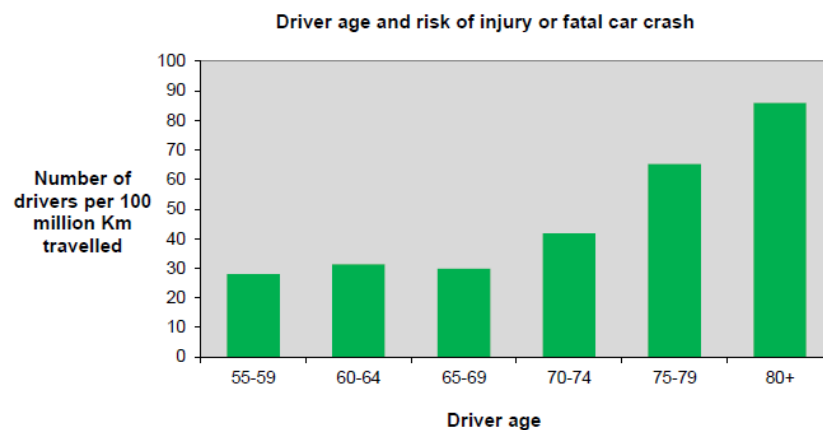
- Becoming lost
- Car accident
- Personal injury
- Injury to others
- Death

STEP 3: WEIGHING YOUR OPTIONS

Knowledge

Does your risk change over time?

Yes, it does. Your driving skills will worsen over time. Also, your risk of serious injury or death following a car crash rises as you get older. This bar chart shows the number of healthy drivers who are injured or killed in car crashes according to age. However, drivers with dementia are estimated to be at an even higher risk (up to 10 times greater).



What are the guidelines in Australia?

The Australian and New Zealand Society of Geriatric Medicine says:

- Some people with mild dementia may be safe to continue driving for a limited period of time

The Austroads national guidelines state that:

- People with dementia may be eligible to hold a conditional driver licence
- Medical review of ability to drive is necessary every 12 months

STEP 3: WEIGHING YOUR OPTIONS

Values

What is the most important reason for you to continue driving?

- ☐ Independence
- ☐ Pleasure of driving
- ☐ Visiting family
- ☐ Visiting friends
- ☐ Going to appointments
- ☐ Travelling to new places
- ☐ Shopping
- ☐ Poor access to public transport
- ☐ Other -----

What is the most important reason for you to stop driving?

- ☐ Risk of getting lost
- ☐ Risk of a car crash
- ☐ Risk of injury to me
- ☐ Risk of injury to others
- ☐ Crash leading to death
- ☐ Worried family
- ☐ Worried friends
- ☐ Other -----

Of all the items on this page – which is the single most important item for you?

- -----

STEP 4: WHAT NEXT?

Support

If you feel you do not have enough support to make a decision then you can seek additional support from others. Who do you prefer to speak to? You can use this later to remind you.

- My doctor (general practitioner or specialist)
- My family
- My friends
- National Dementia Hotline 1800 100 500
- Alzheimer's Australia counsellor 1800 100 500

Knowledge

If you do not have enough information to make a decision then you can ask for more facts from others. Where would you prefer to go to?

- My doctor (general practitioner or specialist)
- My local library
- National Dementia Hotline 1800 100 500
- Alzheimer's Australia website www.fightdementia.org.au
- Austroads website www.austroads.com.au

STEP 4: WHAT NEXT?

Values

Here are a few tips on how to clarify the values that mean the most to you. You may choose as many of these options as you wish:

- Talk to others who have made the decision
- Discuss with others what matters most to me
- Consider joining a local support group
 - details available from the National Dementia Hotline [1800 100 500](tel:1800100500)

Questions

What questions need answering to help you decide? You may wish to show these to other people such as your doctor. Discussing this booklet with family and friends is often helpful.

1. _____
2. _____
3. _____

STEP 4: WHAT NEXT?

Through this booklet you have now considered

- How dementia affects driving skills
- Your options regarding driving
- What you have noticed about your own driving
- What supports you have
- The reasons for and against driving
- Where to go for more information or support

Decision

Having read this booklet, have you reached a decision about driving? What have you decided?

- ☐ I will continue driving with no change
- ☐ I will stop driving now
- ☐ I will drive less
- ☐ I will stop driving later
- ☐ I am unsure

The Next Step

Please arrange an appointment to meet with your doctor to discuss this further. You may find it helpful to bring this booklet with you. Please reuse this booklet as often as you wish.

REFERENCES

- Alzheimers Australia 2005, *About you driving: information for people with dementia*. www.fightdementia.org.au/common/files/NAT/20050700_Nat_HS_8.4Driving.pdf
- American Psychiatric Association Diagnostic and Statistical Manual 1994, 4th ed. Washington DC: APA Press.
- Australian and New Zealand Society for Geriatric Medicine 2009, *Position statement number 11: Driving and dementia*. www.anzsgm.org/posstate.asp
- Austroads. *Assessing fitness to drive for commercial and private vehicle drivers: medical standard for licensing and clinical management guidelines*. 4th ed. Sydney: Austroads; 2012.
- Breen, DA, Breen, DP, Moore, JW, Breen, PA and O'Neill, D 2007, 'Driving and dementia', *British Medical Journal*, vol. 334, pp. 1365-1369.
- Carr, DB, Duchek, J and Morris, JC 2000, 'Characteristics of motor vehicle crashes of drivers with dementia of the Alzheimer's type', *Journal of the American Geriatric Society*, vol. 48, pp. 18-22.
- Dubinsky, RM, Stein, AC and Lyons, K 2005, 'Practice parameter: risk of driving and Alzheimer's disease (an evidence-based review)', *Neurology*, vol. 54, pp. 2205-2211.
- Man-Son-Hing, M, Marshall, SC, Molnar, FJ and Wilson, KG 2007, 'Systematic review of driving risk and the efficacy of compensatory strategies in persons with dementia', *Journal of the American Geriatric Society*, vol. 55, pp. 878-884, 2007.
- Martin, AJ, Marottoli, R and O'Neill, D 2009, 'Driving assessment for maintaining mobility and safety in drivers with dementia', *Cochrane Database of Systematic Reviews*, issue 1.
- Ministry of Transport 2011, *New Zealand household travel survey 2006-2010. Risk on the road: drivers and their passengers V2.0*, Wellington, New Zealand. www.transport.govt.nz/research/Documents/Risk-2011-Drivers-and-passengers.pdf
- Thal, LJ, Grundman, M and Klauber, MR 1988, 'Dementia: characteristics of a referral population and factors associated with progression', *Neurology*, vol. 38, pp. 1083-1090.
- Uc, EY, Rizzo, M, Anderson, SW, Shi, Q and Dawson, JD 2004, 'Driver route following and safety errors in early Alzheimer disease', *Neurology*, vol. 63, pp. 832-837.
- Van der Flier, WM and Scheltens, P 2005, 'Epidemiology and risk factors of dementia', *Journal of Neurology, Neurosurgery and Psychiatry*, vol. 76, pp. 2-7.
- Zuin, D, Ortiz, H, Boromei, D and Lopez, OL 2002, 'Motor vehicle crashes and abnormal driving behaviours in patients with dementia in Mendoza, Argentina', *European Journal of Neurology*, vol. 9, pp. 29-34.

MISCELLANEOUS

CONFLICT OF INTEREST

Financial support was provided by the (i) Wollongong Hospital, and (ii) NSW Roads and Maritime Services (RMS). Neither the authors nor their affiliated organisations stand to gain financially from the use of this booklet.

ADAPTED FROM

The Ottawa Personal Decision Guide © 2006, O'Connor, Jacobsen & Stacey. Ottawa Hospital Research Institute (OHRI), Ottawa, Canada.

DISCLAIMER

The aim of this booklet is not to replace the advice of your doctor or health professional. All efforts were taken to ensure the content of this booklet was accurate at the time of publication. This version (number 2, 2013) will be updated in 2 years (2015).

ACKNOWLEDGEMENTS

The authors wish to acknowledge the work of Prof Annette O' Connor and Prof Dawn Stacey (The Patient Decision Aids Research Group, OHRI, Canada). We wish to thank the reviewers of this booklet: A/Prof Guy Bashford; Dr Vida Bliokas; Prof Andrew Bonney; Ms Jenny Davies; Prof Glyn Elwyn's Decision Laboratory (Cardiff University, Wales); Ms Robyn Faine (Alzheimer's Australia NSW); Ms Kate Lewis; Prof Elena Marchetti; Prof Jan Potter; Mr Robert Reynolds (RMS, NSW); Mr Anton Saarimaki (OHRI, Canada); and Dr Christine Stirling. We would also to thank the patients, carers and family members who contributed to the creation of this decision aid. Without their kind assistance, this work would not have been possible. Lastly, the invaluable support of Mr Robert Reynolds, Roads and Maritime Services, Wollongong, NSW is gratefully acknowledged.

Dementia and Driving: a decision aid

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Appendix G

International Patient Decision Aid Standards (IPDAS) collaboration criteria



International Patient Decision Aid Standards Collaboration

Criteria Checklist

This checklist was published in the following article:

Elwyn G, O'Connor A, Stacey D, Volk R, Edwards A, Coulter A, Thomson R, Barratt A, Barry M, Bernstein S, Butow P, Clarke A, Entwistle V, Feldman-Stewart D, Holmes-Rovner M, Llewellyn-Thomas H, Moumjid N, Mulley A, Ruland C, Sepucha K, Sykes A, Whelan T. Developing a quality criteria framework for patient decision aids: online international Delphi consensus process. *BMJ* 2006;333:417. [<http://www.bmj.com/cgi/content/full/333/7565/417>]

I. Content

Provide **information** about options in sufficient detail for decision making?

	Yes	No
Does the patient decision aid describe the health condition?		
Does the patient decision aid list the options?		
Does the patient decision aid list the options of doing nothing?		
Does the patient decision aid describe the natural course without options?		
Does the patient decision aid describe procedures?		
Does the patient decision aid describe positive features [benefits]?		
Does the patient decision aid describe negative features of options [harms / side effects / disadvantages]?		
Does the patient decision aid include chances of positive / negative outcomes?		
Does the patient decision aid describe what test is designed to measure?		
Does the patient decision aid include chances of true positive, true negative, false positive, false negative test results?		
Does the patient decision aid describe possible next steps based on test result?		
Does the patient decision aid include chances the disease is found with / without screening?		
Does the patient decision aid describe detection / treatment that would never have caused problems if one was not screened?		

Present **probabilities** of outcomes in an unbiased and understandable way?

	Yes	No
Does the patient decision aid use event rates specifying the population and time period?		
Does the patient decision aid compare outcome probabilities using the same denominator?		
Does the patient decision aid compare outcome probabilities using the time period?		
Does the patient decision aid compare outcome probabilities using the scale?		
Does the patient decision aid describe uncertainty around probabilities [words, numbers, diagrams]?		
Does the patient decision aid allow the patient to select a way of viewing probabilities based on their own situation [e.g. age]?		
Does the patient decision aid place probabilities in context of other events?		
Does the patient decision aid use both positive and negative frames [e.g. showing both survival and death rates]?		

Include methods for **clarifying and expressing patients' values**?

	Yes	No
Does the patient decision aid describe the procedures and outcomes to help patients imagine what it is like to experience their physical, emotional and social effects?		
Does the patient decision aid ask patients to consider which positive and negative features matter most?		
Does the patient decision aid suggest ways for patients to share what matters most with others?		

Include **structured guidance** in deliberation and communication?

	Yes	No
Does the patient decision aid...		
Does the patient decision aid provide steps to make a decision?		
Does the patient decision aid suggest ways to talk about the decision with a health professional?		
Does the patient decision aid include tools [worksheet, question list] to discuss options with others		

II. Development Process

Present information in a **balanced manner**?

	Yes	No
Is the patient decision aid able to compare positive / negative features of options?		
Does the patient decision aid show negative / positive features with equal detail [fonts, order, display if statistics]?		

Have a **systematic development process**?

	Yes	No
Does the patient decision aid include developers' credentials / qualifications?		
Does the patient decision aid find out what users [patients, practitioners] need to discuss options?		
Does the patient decision aid have a peer review by patient / professional experts not involved in development and field testing?		
Has the patient decision aid been field tested with users patients facing the decision?		
Has the patient decision aid been field tested with practitioners presenting options?		
The field tests with users [patients, practitioners] show the patient decision aid is acceptable?		
The field tests with users [patients, practitioners] show the patient decision aid is balanced for undecided patients?		
The field tests with users [patients, practitioners] show the patient decision aid is understood by those with limited reading skills?		

Use up to date **scientific evidence** that is cited in a reference section or technical document?

	Yes	No
Does the patient decision aid provide references to evidence used?		
Does the patient decision aid report steps to find, appraise, summarise evidence?		
Does the patient decision aid report date of last update?		
Does the patient decision aid report how often patient decision aid is updated?		
Does the patient decision aid describe quality of scientific evidence [including lack of evidence]?		
Does the patient decision aid use evidence from studies of patients similar to those of target audience?		

Disclose **conflicts of interest**?

	Yes	No
Does the patient decision aid report source of funding to develop and distribute the patient decision aid?		
Does the patient decision aid report whether authors or their affiliations stand to gain or lose by choices patients make after using the patient decision aid?		

Use **plain language**?

	Yes	No
Is the patient decision aid written at a level that can be understood by the majority of patients in the target group?		
Is the patient decision aid written at a grade 9 or equivalent level or less according to readability score [SMOG or FRY]?		
Does the patient decision aid provide ways to help patients understand information other than reading [audio, video, in-person discussion]?		

Meet additional criteria if the patient decision aid is **internet based**?

	Yes	No
Does the patient decision aid provide a step-by step way to move through the web pages?		
Does the patient decision aid allow patients to search for key words?		
Does the patient decision aid provide feedback on personal health information that is entered into the patient decision aid?		
Does the patient decision aid provide security for personal health information entered into the decision aid?		
Does the patient decision aid make it easy for patients to return to the decision aid after linking to other web pages?		
Does the patient decision aid permit printing as a single document?		

Meet additional criteria if **stories** are used in the patient decision aid?

	Yes	No
Does the patient decision aid use stories that represent a range of positive and negative experiences?		
Does the patient decision aid report if there was a financial or other reason why patients decided to share their story?		
Does the patient decision aid state in an accessible document that the patient gave informed consent to use their stories?		

III. **Effectiveness:** Does the patient decision aid ensure decision making is informed and values based?

Decision process leading to **decision quality**...

	Yes	No
The patient decision aid helps patients to recognise a decision needs to be made?		
The patient decision aid helps patients to know options and their features?		
The patient decision aid helps patients to understand that values affect decision?		
The patient decision aid helps patients to be clear about option features that matter most?		
The patient decision aid helps patients to discuss values with their practitioner?		
The patient decision aid helps patients to become involved in preferred ways?		

A pdf version of this checklist is available for download on <http://www.decisionlaboratory.com>

Note: Based on this IPDAS checklist, a new instrument has been developed to assess the quality of decision support interventions – IPDASi. For details see: <http://www.ipdasi.org/> or contact: IPDAS@Cardiff.ac.uk