Dementia and retirement from driving: people with dementia and their carers critique available tools

Catherine Andrew
*University of Wollongong, cla391@uowmail.edu.au*

Victoria Traynor
*University of Wollongong, vtraynor@uow.edu.au*

Donald Iverson
*University of Wollongong, iverson@uow.edu.au*

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Abstract
Introduction: Discuss current thinking about the role of practitioners in supporting a person with dementia to consider retirement from driving. Highlight findings from a research project involving drivers over 55 and people with dementia about what support they consider helpful in considering retirement from driving.

Keywords
people, their, carers, driving, critique, dementia, available, tools, retirement

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Driving and Dementia: 
A qualitative study evaluating consumer driving assessment tools

Catherine Andrew,
School of Nursing, Midwifery and Indigenous Health
Associate Professor Victoria Traynor,
School of Nursing, Midwifery and Indigenous Health
and
Pro Vice-Chancellor (Health) Professor Don Iverson,
Vice Chancellor’s Unit
University of Wollongong

**Introduction**

- Discuss current thinking about the role of practitioners in supporting a person with dementia to consider retirement from driving
- Highlight findings from a research project involving drivers over 55 and people with dementia about what support they consider helpful in considering retirement from driving

**Background**

- Driving is a complex task that can be compromised by dementia
- Diagnosis on its own is not sufficient evidence to recommend driving retirement
- Practitioners and policy makers consider on-road assessments an accurate predictor of driving capabilities for people with dementia
- Consumers who are asked to complete on-road assessment can be reluctant to accept findings
- Most effective ways to support people with dementia considering retirement from driving are not yet known

**Research Aims and Objectives**

- The aim of this study was to:
  - Discover what drivers over-55 valued in a dementia decisional support tool for driving
- Specific objective was to:
  - Evaluate consumer driver assessment tools for over-55s
Qualitative Study

- Sample
  - Current drivers over 55 years identifying as having (i) a dementia and (ii) no cognitive impairment
- 2 x interviews (group and one-to-one)
  1. What drivers want in a driving decisional support tool for dementia
- Evaluation of consumer driving assessment tools
- Recruitment strategies
  - Newsletter items
  - Newspaper articles
  - Clinical contacts
- Data analysis (using n-vivo to manage data)
  1. Thematic analysis
  2. Content analysis

Results 1: Profile of participants

- Drivers over 55 years (n=15)
  - drivers with a dementia (n=2)
  - drivers with no cognitive impairment (n=13)
- 20 interviews
- Geographical location
  - NSW (n=13)
  - ACT (n=1)
  - Tasmania (n=1)

Results 2: Driving patterns of participants

- 100% held a driver license (n=15)
- 93% drove every day (n=14)
- 50% of the drivers with a dementia (n=1)
- 100% drove for grocery shopping (n=15)
- 47% drove in cities (n=7)
- 77% drove for holidays (n=12)

Results 3: Evaluation of 5 consumer driving assessment tools

- ‘About You: Information for People with Dementia: Driving Help Sheet’
- ‘At the Crossroads’
- ‘Driving Decisions Workbook’
- ‘Driving Safely while Ageing Gracefully’
- ‘Over 55 Rating Scale’

Five Elements of Tools Important to Consumers

i. Availability of tools
ii. Sensitivity to the complexity of the decision-making process
iii. Relevancy for dementia of generic over-55 tools
iv. Interactive functions in tools
v. Format of the tools

(i) Availability of tools

- 1 x tool had previously been seen by the participants

  “That [tool] was pretty good … I even asked the nurse, ‘How come we haven’t been given this at any of the carers’ groups?’ … You know, some … [are] trying to bloody still drive.”
  (About You) (Group G, Interview 2, p. 4)

  “I guess what I’m saying is how do we get it into their hands? Like with this excellent [tool] how do you say to your friend, ‘Look, there’s a thing, … I’ll print it out for you, maybe you should do it and see how you far.’
  (Driving Decisions Workbook) (Group G, Interview 2, p 3)
(ii) Sensitivity to the complexity of the decision-making process

“Anyone that’s fair dinkum and honest … it’s compelling … I’ve got a few problems that I would like to clarify”. … “I’m in the 75 to 85 range, there’d be something in there that they would have to say, ‘I’d better pay more attention to this.’ … It’s a warning document.”

(At the Crossroads) (Group I, Interview 2, p. 6)

“I like … the way things were pointed out to me like the loss of driving around dusk and dawn, the loss of sight, I should say, ‘Difficult times maybe to avoid driving.’ … and distances. Things I probably wouldn’t have thought about … because I take it for granted … and I don’t have to worry about it. But when they talk about things like lack of concentration, you know, ‘Does your mind wander off?’” “And I took that on board.”

(Over 55 Workbook) (Group B, Interview 2, p. 1)

(iii) Relevancy for dementia of generic over-55 tools

• 2 x tools dementia specific

(At the Crossroads) (Group I, Interview 2, p. 8)

“• 1 x tool explicitly addressed issues related to cognition

(Driving Decisions Workbook)

“Oh yeah, it’d become a bible. You could call it, it is a bible. It’s very comprehensive.”

(Driving Decisions Workbook) (Group I, Interview 2, p. 5)

“The tool would be the best, … for someone that’s perhaps older, perhaps a bit of confusion this would have to be better because you’re not confronting them with a lot of words and the information really that comes out of it would be arriving at the same conclusion.”

(Driving Decisions Workbook) (Group A, Interview 2, p. 3)

(iv) Interactive functions of tools

• 3 x tools had interactive functions

(Driving Decisions Workbook)

“Yeah, I like the checklists and I like the one that gave the summary at the end.”

(Driving decisions workbook) (Group B, Interview 2, p. 17)

“I think they need a few key questions asked and they should make the decision based on that and not go through a multitude of questions like an exam on a subject at university.”

(Driving Safety while Aging Gracefully) (Group C, Interview 2, p. 10)

(v) Format of the tools

• 4 x tools available as pdf documents and on the internet

(At the Crossroads)

“’Well it didn’t seem to apply to bloody Australia much. A lot of it seemed to apply to bloody places overseas and that, yeah.’”

(At the cross roads) (Group G, Interview 2, p. 10)

“The only confusion … where they talked about turning left and it should have been right, … and I thought, just a minute, … ah yes, OK, we’re talking America. [Because left and turns are easy for us and I thought, what are they on about?] And there wasn’t much in here about roundabouts and I think roundabouts are the one thing that really confuse the elderly.”

(Driving Decisions Workbook) (Group A, Interview 2, p. 2)

Discussion

• Strengths of study
  – One of a very few studies where the end user and potential end user evaluated consumer driving assessment tools for over-55s

• Limitations of study
  – Sample size included only a small number of drivers with dementia

Implications for Practice

• Policy makers could raise awareness of these tools to potentially increase rates of appropriate retirement from driving for people with dementia

• Practitioners could use these tools to more effectively enhance the process of a decision to retire from driving for people with dementia
Conclusion

- Lack of awareness about consumer driving assessment tools for over-55s and specifically dementia
- Most important element of a tool is to acknowledge the sensitivity and complexity of the decision to retire from driving for a person with dementia
- Delivery format needs to reflect the contemporary information needs of over-55s including interactive internet resources
- Findings from the study will inform the development of a new Australian consumer-focused driving decision support tool for people with dementia

References

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