

“Don’t mention the ‘D’ word”: Dementia and driving retirement in rural NSW, a qualitative case series.

Rural Research Capacity Building Project - June 2011

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Table of Contents

Acknowledgements	3
Acronyms	3
Definitions	3
Abstract	4
Executive Summary	5
Introduction	8
Background	8
Research questions	11
Methodology	11
Methods	12
Participants	14
Findings	15
Study limitations	27
Conclusions	27
Recommendations	27
References	29
Appendices	33

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Acronyms

ACAT.....	Aged Care Assessment Team
CACP.....	Community Aged Care Package
GP	General Practitioner
NCAHS	North Coast Area Health Service
MNCLHN	Mid North Coast Local Health Network
OT	Occupational therapist
RTA.....	Road and Traffic Authority
RN	Registered Nurse

Definitions

Dementia is a syndrome that can be caused by a number of progressive disorders that affect memory, thinking, behaviour and the ability to perform everyday activities. Alzheimer's disease is the most common type of dementia. Other common types of dementia include vascular dementia, dementia with Lewy bodies and fronto-temporal dementia (1).

Disability is a universal human experience. It is the negative aspect of functioning and can be understood in terms of impairment to body structure and function, restriction in activity and limitation to participation. Physical and social environmental factors influence the experience of disability (2).

Personhood is "a standing or a status that is bestowed on one human being by another in the context of relationship and social being" (3) p 8.

Stigma is a mark of disgrace or discredit that sets a person aside from others (4).

Abstract

Background: The inevitable transition from driver to passenger following dementia diagnosis threatens psycho-social well being. The prediction of a 'Tsunami' of dementia for the north coast of NSW warrants exploration of driving retirement experiences in rural areas where there is little public transport, great distances to travel and a notorious stretch of the Pacific Highway.

Aims: This project aimed to increase understanding of the experiences of people with dementia, their family and carers and other key decision makers living in a rural area in relation to driving retirement.

Method: This project used qualitative methods. Case studies were developed from in-depth semi structured interview data and from a review of medical records of participants with dementia. The data was coded and emergent themes linked to theoretical frameworks. Participants were six people with dementia, their family and carers and those who they identified as involved in their driving retirement (including general practitioners, aged care assessment team nurses and occupational therapist, a community case manager, a medical specialist, and a NSW roads and traffic authority manager).

Results: Major themes about driving retirement were derived from the data.

- **No-one did anything!** Participants with dementia and their families and carers described a lack of support and guidance from authorities, and health professionals described a lack of time, resources, collaboration and clear guidelines to inform clinical decisions and interventions.
- **I was like a cornered rat.** Participants described anger, anxiety and conflict with potential or actual damage to relationships.
- **No-one faced me.** Participants with dementia felt that they were not included in decision making during driving retirement and that their emotional needs were not met. Clinicians described lack of time, resources and the skills to provide person centered care.
- **I felt like I had had my arm cut off.** Participants described a loss of independence and difficulty functioning within the structural and institutional environment.
- **Don't mention the 'D' word.** Participants with dementia described experiences of outsider status, stigma and deviance.

Conclusions: There is a lack of guidance and planning for driving retirement in dementia care and inadequate resources to address the conflict, loss of identity and loss of independence associated with driving retirement.

Keywords: Dementia, driving, stigma, personhood, disability

Executive Summary

The problem

The prevalence of dementia is rapidly increasing in Australia as the population ages. It is estimated that at present, one out of four people over the age of 85 in Australia have dementia. (5) The number of people with dementia in NSW is projected to increase from 84,000 in 2009 to 341,000 in 2050. This equates to an increase of 410%. It is estimated that by 2050, Coffs Harbour, Tweed and Port Macquarie will be among the top ten State Electoral Divisions with the highest prevalence of dementia in NSW. The number of people with dementia in the region defined by the previous North Coast Area Health Service is projected to increase from 8,080 in 2009 to 35,295 in 2050, a growth factor of 336.8% (5). Planning to address the personal and social implications of living with dementia is of increasing importance.

Dementia is characterised by progressive deterioration in cognition. As the underlying disease progresses, cognitive impairment will affect driving skills to a point where it is no longer safe to drive. Continuing to drive past this point poses obvious risks of accident and injury to self and others (6). However studies indicate that driving cessation also threatens health and wellbeing, with associated costs and burdens. Dependence, depression, entry to residential care, social isolation and increased family carer stress and transportation burden are recognised as negative psycho-social risks associated with driving retirement (7–10). Living in rural areas with greater distances to travel and poor access to public transport may further increase transportation costs and the risks of decreased activity participation and social isolation following driving retirement.

The response

Health professionals and community services including general practitioners, allied health, practice nurses, dementia support services and aged care assessment teams (ACATs) often come into contact with people with dementia at this vulnerable time and are well placed to target interventions to reduce these risks. Driving retirement is one area that has been identified in the literature as requiring better preparation and planning (7) (11-14).

Recommendations

Families and people with dementia:

- Discuss driving soon after diagnosis and make a plan in collaboration with the GP. Ask for practical and emotional support.

Health Professionals:

- Encourage families and people with dementia to plan for driving retirement and implement strategies to minimise the risks of social isolation, depression and decreased activity participation following driving retirement.

- Educate people with early dementia and families about how cognitive impairments impact on driving ability, explain the increased risk of accidents and encourage voluntary driving retirement.
- Use written information, take time, involve families and use other strategies to compensate for cognitive impairments in order to include the person with dementia in discussions and decisions as appropriate and do not allow a label of dementia to overshadow personhood.
- Acknowledge the significance and the loss involved in driving retirement.
- Offer referral to Alzheimer's Australia support and information services.
- Provide support to people with dementia and families to deal with grief and loss if appropriate and screen for depression following driving retirement.
- Provide support and advice regarding strategies for families to manage any conflict that may arise during driving retirement.

Government:

- Provide clearer national guidelines regarding medical fitness to drive with regard to dementia, based on evidence, including guidelines for appropriate cognitive assessments, recognising the cumulative impact of health conditions.
- Fund short term case management at the vulnerable time of driving retirement to assist people with dementia to access existing alternate transport and to promote participation in activities of daily living.
- Increase the number of CACPs or similar individualised services that provide on going flexible transport and assistance with participation in community life.
- Conduct a broad community education program to better prepare older people for driving retirement.

RTA:

- Provide information to the community about the process to follow after a diagnosis of dementia with regard to drivers licencing.
- Investigate the validity of the current road test with regard to assessing people with dementia's ability to drive safely.

The project

These recommendations are based on the results of a two year qualitative research project funded by the Clinical Education and Training Institute, Rural Directorate (15). This project addressed the following questions:

1. What are the experiences of people with dementia, their close families or carers and other key decision makers in regard to driving retirement in a rural setting on the mid north coast of NSW in 2009-2010?
2. What are the key information and support needs for these people?

This qualitative descriptive case series involved semi-structured interviews with six people with dementia who had given up driving within the last 12 months and a close family member or carer, and then additional interviews with other support and decision makers identified during the initial interview. The North Coast Area Health

Service (NCAHS) medical records of the people with dementia were reviewed to identify whether there had been any health professional interventions with regard to driving retirement. Participants were recruited using purposive sampling in order to select information rich cases (16). Participants with dementia were identified through a variety of sources: the local Alzheimer's Association support worker, a community health worker, a community service provider and a medical specialist.

Findings

Five major themes emerged through thematic analysis of the data:

- **No-one did anything!**. Participants with dementia and their families and carers described a lack of support and guidance from authorities and health professionals described a lack of time, resources, collaboration and clear guidelines to inform clinical decisions and interventions.
- **I was like a cornered rat.** Participants described anger, anxiety and conflict with potential or actual damage to relationships. Health professionals, family and carers felt a conflict between being an advocate for the person with dementia and being responsible for the safety of the person with dementia and the rest of the community. Fear of conflict was a major concern.
- **No-one faced me.** The majority of participants with dementia felt that they were not included in the process of deciding that it was time to retire from driving and that their emotional responses to the loss of independence and identity were not acknowledged or addressed. Family and carers described challenges in adjusting to changing relationships. Health professionals described lack of time and resources to include people with dementia and to focus on retained abilities.
- **I felt like I had had an arm cut off.** People with dementia described activity and participation limitations resulting from interactions between impairments and aspects of the social, institutional and physical environments such as a lack of individual alternate transport which prevented some of the participants with dementia from continuing social and leisure activities.
- **Don't mention the 'D' word.** Participants with dementia felt devalued and marginalized. People with dementia interpreted licence cancellation as a social sanction for being a 'bad' driver, rather than a consequence of a medical condition that increases the risk of accidents. Health professionals described a reluctance to use the term 'dementia'.

Conclusion: This project describes experiences of six people with dementia, their family, carers and others involved in their driving retirement, and identifies themes across their stories. These themes suggest the need for clearer pathways for driving retirement with better collaboration between decision makers with efforts both to reduce the stigma related to dementia and to protect personhood. This could be described as creating a physical, social and institutional environment that promotes inclusion and function as well as safety.

Introduction

The primary purpose of this study was to better understand the personal experiences of people with dementia, their family, carers and other key support and decision makers during the process of driving retirement in a rural area in NSW. The secondary purpose of the study was to identify the practical support, emotional support and information needs of these people in regard to driving retirement. This project was completed through the Rural Research Capacity Building Program of the Clinical Education and Training Institute, Rural Directorate, which aims to foster research skills in rural clinicians (15).

Background

The 'Tsunami' of dementia (17)

The risk of developing dementia increases with age. As a consequence the number of people with dementia is rapidly increasing in Australia as the population ages. (1) The number of people with dementia in NSW is projected to increase from 84,000 in 2009 to 341,000 in 2050. This equates to an increase of 410%. It is estimated that by 2050, Coffs Harbour, Tweed and Port Macquarie will be among the ten State Electoral Divisions with the highest prevalence of dementia in NSW. The number of people with dementia in the region defined by the previous North Coast Area Health Service is projected to increase from 8,080 in 2009 to 35,295 in 2050, a growth factor of 336.8% (5). Adequate planning to address the personal and social implications of living with dementia is of increasing importance. Driving retirement is one area that has been identified in the literature as requiring better preparation and planning. (7) (11-14).

Dementia and disability

Dementia is an umbrella term for a syndrome of progressive cognitive decline resulting from pathology that affects the brain. Different pathologies result in different patterns of cognitive impairment. For example, Alzheimer's disease, the most common pathology, is characterised by memory and language impairments early on in the disease process. Other pathologies may present first with other cognitive impairments such as speed of information processing, executive function or visual perceptual impairment (18). Dementia may be accompanied by impairments caused by other pathologies such as musculoskeletal or hearing impairments. Impairment is one aspect of the concept of disability described in the International Classification of Disease Functioning and Health (2002) (2).

Disability is a universal human experience. It is the negative aspect of functioning and can be understood in terms of impairment to body structure and function, restriction in activity and limitation to participation. Physical and social environmental factors influence the experience of disability (2),(19). Disability theorists and advocates have emphasised that physical disability is perpetuated through a disabling environment and more recently this idea has been applied to dementia (20) (21). The environment includes institutional as well as structural features,

including allocation of resources, time, workforce skills and community attitudes (19).

Dementia is an example of how the experience of disability is not limited to a small group of people, and how disability can be experienced for a period of time throughout life.

Dementia and driving retirement

Driving retirement and dementia is a much-debated topic (22). The benefits of maintaining independence in community activities such as shopping, banking, and participating in social and leisure activities must be balanced against the risks of injury to self and others through motor vehicle accident. Although it is inevitable that people with dementia will eventually stop driving, it is generally accepted that people with mild dementia may be able to drive safely for a time until their cognitive impairments begin to diminish their driving skills as there is no definitive evidence at what point crash rate is increased in comparison to the rest of the population (6-7),(9),(23). In contrast, some authors dispute this lack of evidence and using clinical reasoning believe that people with a diagnosis of dementia should not drive as cognitive impairments such as decreased speed of information processing and switching of attention, and reduced memory increase the risk of getting lost or having an accident to an unacceptable level. (24-25).

Transition from driver to passenger increases the risks of negative psychosocial outcomes including social isolation, premature entry to residential care, depression, decreased participation in activities of daily living and increased transportation responsibilities for carers (7-10). Exploring the experiences of people with dementia may assist understanding of how these negative outcomes occur.

Health professionals and driving retirement

In NSW licensed drivers are legally required to disclose their diagnosis of dementia to the RTA. To retain a licence they must submit a medical report indicating that they are fit to drive. All people, with or without a medical condition must submit this same form annually from age 75 and either pass an RTA driving test biannually or accept a modified licence (for example a licence with distance restrictions) (7). National standards guide doctors in the decision as to whether a person is medically fit to drive (26). On the medical form a doctor can recommend retention of a full licence or a modified licence, or if unsure, refer for either an RTA driving test or an occupational therapy (OT) driving assessment. General practitioners often refer to a medical specialist for an opinion as to whether a person is fit to drive rather than refer for a practical driving test.

The literature has identified a need for more effective clinical interventions with regard to driving retirement for older people including a need for more supportive interventions for people with dementia to avoid some of the negative psychosocial outcomes associated with driving retirement such as isolation, depression and loss of independence (7). Studies have identified a lack of clarity about the process (7), (10), (23), (27). Health professionals including GPs, ACATs, specialists, social workers (SWs) and OTs are sometimes involved in driving retirement decisions and support (22), (28), (31) but are not all satisfied that they are “doing a good job” (29-

30). Interventions include assessments, giving advice and written information to individuals and families and counselling and support for families.

In America, psycho-educational group programs to assist people with dementia and their carers with driving retirement have been developed, evaluated and found to assist adjustment to driving retirement (12), (32). A randomised control trial has reported improvements in carer perception of self-efficacy, preparedness, and communication following attendance of four group sessions (32). In a mixed methods study people with dementia and carers attended driving retirement groups and results indicated a reduction in negative psycho symptoms (12). In Australia, researchers from the University of Queensland (UQ) have developed a community program (UQdrive) to prepare and support older people through the process of driving retirement. These programs aim to raise awareness and promote planning for driving retirement. They offer information and intensive support in a weekly group setting, and address emotional and lifestyle adjustment (14). The UQdrive group is currently being evaluated in a randomised control trial. Researchers at UQ are currently also analysing data from a qualitative project with people with dementia in regard to their needs related to driving retirement but have not investigated experiences in a rural setting (33).

Dementia and rural driving retirement

Lack of transport options and greater distances to travel have been identified as issues in studies of driving retirement in rural areas highlighting the effect that the social and physical environment has on the experiences of individuals (7), (10), (30). There appears to be a complex interaction between clinical, social and demographic factors informing decisions about driving retirement. Studies indicate that decision makers consider where the person with dementia lives, their social supports and transport options as well as their impairments and health conditions when providing advice about driving (7) (30) (35).

Rural driving may differ from city driving in the types of risks posed and capabilities required. Driving in the country is typically thought of as less demanding than peak hour city driving however in NSW, 66% of all fatal crashes occur on country roads (34). Rural driving typically has lower traffic volume, varied road conditions and can be high speed. People with dementia living in rural areas are likely to have different experiences of driving than those living in an urban area.

Alzheimer's Australia has identified a lack of access to health and support services for people with dementia living in rural Australia (36). People with dementia and families who cannot access health professional assessment and advice about driving retirement or ongoing community services to promote community engagement and participation following driving retirement, are arguably at a disadvantage.

Study setting

This study was conducted in part of the mid north coast of NSW. The region has a subtropical climate. The traditional agricultural industries are dairy farming, beef cattle and forestry. Manufacturing and tourism are now important in the region (37). The largest town in the study area had a population 26,353 in 2006 and there are four other towns and several villages in the surrounding area (38-39). There are

three companies that run bus services throughout the study area, three inter city trains that each run north and south once a day and intercity coach services. There are no taxi services in two of the villages. There is a Home and Community Care (HACC) community transport service that provides individual transport and shopping buses in parts of the sub region and there is non emergency health related transport (40). The study area is traversed by a notorious stretch of the Pacific Highway (41). In 2009, 27 people were killed in car crashes on the Pacific Highway in NSW. Of these 27 people, six were killed on the highway in the study area (34). RTA data does not include whether or not a driver involved in a crash had dementia.

Mid North Coast Local Health Network clinicians have regular opportunities to provide brief interventions to people with dementia and those involved in their lives. Although the literature has established that people with dementia are at risk of negative psycho-social outcomes following driving retirement, less is known about the experiences of people with dementia during the transition from driver to passenger. Some of the respondents to the Alzheimer's Australia NSW survey regarding driving in 2010 were people living in rural and remote areas (7). However driving retirement experiences of people with dementia living in rural NSW have not been explored in depth.

Research questions

1. What are the experiences of people with dementia, their close families or carers and other key decision makers in regard to driving retirement in a rural setting on the mid north coast of NSW in 2009-2010?
2. What are the key information and support needs for people with dementia, their families, carers and decision makers leading up to, during and in the months following driving retirement in a rural area in NSW?

Methodology

The primary researcher is a female occupational therapist employed in an ACAT in the mid north coast of NSW with no previous research experience. The researcher chose a qualitative description case series design with the intention of linking personal stories to existing theories in the area of disability and dementia through thematic analysis. Qualitative description can be useful to explore the needs of vulnerable groups such as people with dementia and their carers, as it focuses on the lived experiences of individuals (42). Case study research enables investigation of complex systems in real life, and is suited to the development of clinical practice (43). Qualitative case study research allows exploration of 'the case' from different perspectives and by collecting different types of data that adds to the richness of the information and strength of the analysis (44).

Person centred care, an established approach in dementia care, was influential in the choice of methodology. Person centred care values people with dementia as individuals, attempts to view the world from their perspective and aims to create a positive psychosocial environment (45). There is growing recognition that people with dementia are quite often aware of their situation and can contribute important insight about their experiences and needs (46). A framework for dementia research has been suggested by proponents of "person centred care". This framework

identifies three overlapping research domains: subjective experience, socio cultural context and interactional environment (46). The proposed project is largely within the domain of subjective experience. Building on the notion of person centred care, writers have developed the term "relationship centred care" This concept encourages us to view the person with dementia within the context of their important relationships (45).

As an occupational therapist involved in driving assessment the researcher is considered an active participant in the research project. The researcher is drawn to the theoretical perspective that understands that people are constantly creating social structure through actions and interactions and trying to make sense of experiences (47).

Methods

Ethical issues: Approval for this study was obtained from the North Coast Area Health Service Ethics Committee 22/10/2009, NCAHS HREC No. 477N.

Sampling strategy: Participants were recruited using purposive sampling in order to select 'information rich' cases (16). The inclusion criteria for the participants with dementia was: a diagnosis of dementia, living in the community (not residential care), retired from driving within the past 12 months, living in one of the more rural areas of the local health network and being in close contact with a family member or carer. During recruitment the inclusion criteria was broadened from 'living with a carer' to 'being in close contact with a carer'. This enabled inclusion of another male participant with dementia.

The researcher attempted to recruit participants with dementia from a variety of referrers in order to ensure a diverse range of experiences. These referrers were general practices, community health occupational therapists, the Alzheimer's Association carer support group and dementia support worker, two local community aged care package providers, and a medical specialist involved in dementia diagnosis and care. The researcher first contacted potential referrers (other than the specialist) by telephone, described the project and invited them to assist in identifying potential participants. Initial phone contact was followed up by email or letter and phone call. The specialist was approached in person at the hospital clinic.

Six people with dementia who met the inclusion criteria were identified. One person was identified through the local dementia support group, three people were identified through the local specialist clinic, one person was identified by a community occupational therapist and one person by a community service provider. No potential participants were identified through GPs. All of the potential participants with dementia identified agreed to participate. Recruitment ceased at this point due to perceived time and abilities of the researcher to complete a comprehensive analysis of a complex data set within the available time.

Family and carers of potential participants with dementia were first contacted by the referrer and given a participant information sheet by either the referrer or by mail by the researcher. The researcher then telephoned and spoke to the carer to describe the project and to explain what participation would entail. The fact that participation was voluntary and that the project was separate from the researcher's work in the

ACAT was emphasized to all potential participants. The carer was asked to discuss participation with the person with dementia. The person with dementia and their carer were asked to decide whether they would like to be interviewed separately or together. All of the people with dementia and their carers agreed to participate. Written consent to participate was gained from both the person with dementia and the carer at the time of the interviews. Before gaining consent the researcher again explained the purpose of project and discussed participation with the person with dementia and their carer to confirm that they understood what they were consenting to.

Prior to the project, the researcher had had brief contact with one of the participants with dementia. (The researcher had organised installation of a hand-rail in 2008) The researcher had completed two driving assessments with one other participant. This participant was included as they were the only participant who had had an OT driving assessment and the researcher was seeking to describe a variety of experiences.

During the interviews with the person with dementia and their carers other key support and decision makers were identified, and consent gained to contact some of these people for further interviews. These people were initially contacted by telephone and mailed a participants information sheet. Written consent was gained either in person or in the case of the telephone interviews by fax or mail.

Data collection: Data was collected through semi-structured interviews with open-ended questions. The interviewer used an interview guide with topic headings (see appendix 1). The researcher conducted the interviews with the exception of one. In order to further capture the researchers own experiences of driver assessment with people with dementia, a co-worker interviewed the researcher. The co-worker was another occupational therapist working for the NCAHS who was experienced in conducting interviews, aged care and driving issues. The interviews with all of the people with dementia were conducted in their homes. Three carers were interviewed with the person with dementia in the home and two of these carers also spoke afterwards by phone. One carer chose to be interviewed at the local health campus. One carer chose a telephone interview. The specialist, ACAT workers, caravan park manager and occupational therapist were all interviewed at the Health Campus. Three GPs were interviewed by telephone and one GP was interviewed at their home. The RTA manager was interviewed at the local RTA office. The interviews ranged in length from 15 minutes to approximately 90 minutes. Participants were given a phone number to contact the interviewer at a later date if they would like to make further comments. Demographic information of the participants with dementia was collected including age, gender and address. The interviews were audio recorded. Interviewees were not offered a transcription of the interview. Pseudonyms were allocated to all participants. There were no repeat interviews.

Medical records of the people with dementia held by NCAHS were reviewed to identify any health professional interventions in regard to driving. Co-morbidities were noted.

Data analysis: Data was analysed by qualitative thematic analysis. A coding framework was developed and themes identified. The researcher transcribed all of the interviews verbatim. Transcripts were read and data was categorised and coded

in a word document table. Coding attempted to capture significant statements, any emerging themes and their possible meanings. This process was repeated for the interviews with carers and those with other decision makers. The three tables were compared in regard to emerging themes. The coded data was also sorted manually and from that three A3 'mind maps' developed. The interview data of two case studies, a summary of the case study stories (appendix 2), examples of coding and over arching themes were given to two other occupational therapists, both novice researchers, working in the MNCLHN to read and discuss to broaden the developing analysis. Emerging themes were discussed during telephone mentoring sessions (approximately 12 sessions). The mentor encouraged the researcher to reflect on personal reactions and meanings attributed to statements in the interviews and to record these immediately following interviews and while analysing data. Participants were given a copy of findings. Four participants provided feedback regarding findings. One repeated concerns about the danger of driving on the Pacific Highway while the other three indicated that they did not want to modify the findings.

Participants

In this section the participants and their transport options are briefly described.

Case study one: Simon is a 79 year old man. He was interviewed with his wife, Barbara. Other key decision makers interviewed were Sam, his current GP, Jan, an ACAT Registered Nurse (RN) and Nick, an OT. Simon does not use any community or public transport, his wife drives. Alternate transport available in their town includes taxi, community transport and a bus service.

Case study two: Grace is a 91 year old woman. She was interviewed with her brother and sister-in-law, Tom and Robin, with whom she lives. Other key decision makers interviewed were Francis, her GP and Jan, an ACAT RN. One key decision maker, an RTA on road assessor, was not given permission by their employer (RTA Central office) to participate and Chris, an RTA manager agreed to be interviewed about the process of on road assessment and their own past experiences as a driving assessor. Grace attends a day centre and Tom and Robin provide transport to daily activities. Alternate transport available in their town includes the school bus and community transport.

Case study three: Margaret is an 80 year old woman. She lives with her son and daughter-in-law, Rob and Judy. She was interviewed alone and Judy was interviewed separately. Other key decision makers interviewed were Lee, her GP and Kerry, a medical specialist. Margaret attends a social support group. Margaret does not use community or public transport. Her family drive her to activities. Alternate transport available in their town includes taxi, a bus service and community transport.

Case study four: Violet is a 74 year old woman who lives alone. She was interviewed alone and her carer, Karen, who is a caravan park manager was interviewed separately. Other key decision makers interviewed were Leslie, an ACAT RN, Kim, her Community Aged Care Package (CACP) case manager and Kerry, a medical specialist. The CACP provides transport for Violet and at times she catches a taxi. Alternate transport available in locality includes taxi, bus and community transport.

Case study five: May is an 81 year old woman. She lives with her husband, Jim, who also has dementia. May was interviewed with her daughter, Colleen. Other key decision makers interviewed were Ray, her GP, Kim, her CACP case manager and Kerry a medical specialist. The CACP provides transport for May. Alternate transport available in the locality includes community transport and a school bus.

Case study six: Mick is a 79 year old man. He lives alone. He was interviewed alone and his brother, David was interviewed separately. Other key decision makers interviewed were Ray, his GP and Kim, his CACP case manager. The CACP provides transport and at times David drives him. Alternate transport available in the locality includes community transport and a bus service.

All participants were from a rural background with ARIA scores (accessibility/remoteness index of Australia) ranging from 2.34 to 3.28 indicating some restrictions on accessibility of some goods, services and opportunities for social interaction (48). Five of the participants had moved within the last three years. Of these, two had moved to be closer to services, two had moved to live with family and one had moved as part of an itinerant lifestyle. Of the two who had moved to live with family, one had moved within the same town and one had moved to a more remote locality. Distance between current address and local post office ranged from 850 m to 9.9 km, with the median being 5.1 km. while distances to the major town in the sub region were greater, ranging from 4.7 km to 60.2 km, with the median being 44.9 km. Distances were obtained from Google maps (49).

In summary, six people with dementia, seven carers, one CACP case manager, one RTA staff member and eight health professionals were interviewed

Findings

Five interconnecting themes were identified from the data. These themes were:

- **No-one did anything!** Participants with dementia and their family and carers described a lack of support and guidance from authorities, and health professionals described a lack of time, resources, collaboration and clear guidelines to inform clinical decisions and interventions.
- **I was like a cornered rat.** Participants described anger, anxiety and conflict with potential or actual damage to relationships.
- **No-one faced me.** Participants with dementia felt that they were not included and that their emotional needs were not met. Clinicians described lack of time, resources and the skills to provide person centered care.
- **I felt like I had had my arm cut off.** Participants described a loss of independence and difficulty functioning within the structural and institutional environment.
- **Don't mention the 'D' word.** Participants described experiences of outsider status, stigma and deviance.

Theme one: No-one did anything!

Families, carers, health professionals and people with dementia reported a lack of any clear plan during driving retirement. Participants with dementia and their families and carers described a lack of support and guidance from authorities when they sought help. This was confusing and frustrating.

It's like jumping off rooftops, there was no, no flow... Rather than that happen to someone else, I would rather have, not a meeting, but a sequence of melding the process, not cotton wooling the decisions that have been made against you...perhaps a bit of dialogue with the RTA. (Simon)

We weren't quite sure of the pathway and there was I think a degree of confusion...how do we get this (driving assessment) happening and who funds it? Does the RTA fund it? (Sam)

Health professionals described a lack of time, adequate guidelines and resources to address driving retirement.

I don't think we ever have enough time to fully and comprehensively case manage someone with dementia (during driving retirement) because I think it is complex and it does involve talking to a lot of different people and it does involve putting together little pieces of the jigsaw. (Leslie)

Health professionals described difficulty at times deciding as to whether the person with dementia was fit to drive. The GPs and specialist reported that the Austroads medical standards for licensing and clinical management (26) gave limited guidance for clinical decisions for people with dementia.

The main problem I have is being sure in my own mind whether it is appropriate to stop (them) driving and I think some stronger, firmer guidelines, simple guidelines... The clear ones are clear... The middle range ones, the grey area ones are a bit disconcerting, and sometimes I am just not sure... (once sure) I do what's right, it doesn't worry me. (Ray)

Concerns about isolation and lack of services in more rural areas delayed action.

(When making the decision about fitness to drive)... you always worry about the trucks...that's always something I consider and also the windy way out back...(but also) there's a big question about their ability to access services, you really don't want to isolate them...If they were living in town you might say...you shouldn't be driving...(but) they've got to be able to get into town because there is no public transport. (Sam)

In many of the cases the GP referred the person with dementia to another health professional or the RTA for assessments. General practitioners reported two main reasons to refer on, firstly for an opinion as to whether the person with dementia was still safe to drive and secondly to maintain the therapeutic relationship if their licence was cancelled.

I referred her on to make that final assessment ...I didn't really make that decision that she couldn't drive, I actually handed it over to someone else...We often try to be the advocate for the patient and driving is sometimes something they don't like to give up easily... and you can strain the doctor patient relationship...(Lee)

People with dementia and families described confusion regarding the reason for referral.

I lost a lot of faith in doctors... You know, if you go to a doctor and he says I'd like you to see Dr so-and-so, and they refer you to another doctor well there's got to be a good reason for them sending me to a specialist or someone like that! I would like to know exactly why! Why am I going to this specialist, why are they sending me? (Margaret)

Despite multiple referrals and assessments, carers in most of the case studies reported that they had not had enough support and guidance from health professionals. They described confusing pathways of care and poor dialogue between health professionals, the RTA and carers resulting in feelings of frustration and confusion. Grace's brother, Tom felt that "they left it up to us". Simon and Barbara described a devastating experience of being referred from one person to the next, anxiously awaiting appointments, undergoing multiple assessments and then with no warning having Simon's licence cut up in public at the local RTA office. May's carer described difficulty organising appointments as a carer at a distance with miscommunication about the reason for appointments. Family and carers perceived that difficulties negotiating the system were due in part to being inexperienced. Violet's carer described great difficulty communicating with health professionals due to privacy laws.

Two family carers experienced less frustration and more satisfaction with the pathway. These carers were proactive and directed the process, enlisting the GP as an ally early on and planning ahead for driving retirement.

I had a good long talk with his local doctor up there and I said "Well how are we going to do it? And I said well we'll just do it very tentatively, we won't sort of break his heart and say you can't drive anymore, we'll let him run his race on it...and I spent a lot of time up there with him. (David)

So I went to see Lee ahead of time and I said "Look, I'm just giving you a bit of warning, we're going to be coming in"...So he said "Alright, what we'll do is we will refer her to the aged care assessment team". (Judy)

Aged care assessment team staff described practical difficulties with assessments including lack of time and difficulty organizing appointments with people with dementia. Leslie drove a forty minute journey to find that Violet had forgotten the appointment and had gone out. ACAT staff also described lack of ongoing involvement with people after assessment.

I didn't see him in between time ..., it's not very much time to spend with people and after I don't really know what is going on, I wonder what is happening, I don't know, I wonder whether they are driving or not. (Nick)

I never get any feed back from the doctor...having informed the GP (that the person has a significant cognitive impairment and is still driving) I don't hear anything of it. (Jan)

Carers described an immense relief to have someone that they could rely on for ongoing assistance and advice once they had a Community Aged Care Package (CACP). This was in stark contrast with their experience looking for guidance before case management.

It (the CACP) was an absolute godsend for her because she is now getting the care that she needs...and the only person who, and I'm not knocking anyone, maybe I just didn't ask the right questions, the only person I can give any credit to giving me the information I now know is Kim. (Karen)

Carers reported that they were not given any written information about dementia or driving. None of the health professionals interviewed were aware of the written resources available including the Alzheimer's Association help sheets. Two carers reported that they had done their own research about dementia and driving using the internet and the library.

Some of the people with dementia and all of the health professionals and families interviewed agreed that preparation and collaborative planning would have helped. Health professionals agreed that involving family in assessment and planning was essential and that case management was often needed.

But the plan is the way to go. I think a planned approach and sometimes when you've done that it becomes clearer what the pathway should be. (Kerry)

Theme two: I was like a cornered rat.

Participants described conflict and fear of conflict throughout the driving retirement. Roles changed and relationships were stressed.

Health professionals based in smaller towns described strong community connections and some long term multidimensional relationships with clients.

I've looked after Grace for 26 years and I also looked after her husband...we had a good relationship and...I always thought that she was very much like my mother, always out and about...but it became evident that she couldn't drive, and it was really, really hard! (Francis)

Health professionals and carers described conflict between being an advocate for the person with dementia and being responsible to the rest of the community. Both health professionals and families spoke of potential and actual damage to relationships when their role changed from ally to perceived adversary.

You don't want to harm the doctor patient relationship in one sense but in another sense you've got to do something about it. (Francis)

We used to be absolute best friends and she used to adore me and I adored her. I thought, I thought she as just the most magnificent lady you know...and she said to me one day "You're not the person I thought you were" because sometimes I just have to say no, you can't do this, you can't do that. (Judy)

Family members described great anxiety and conflict when trying to stop the person with dementia from driving in the time leading up to licence cancellation.

I used to try to just get in the drivers seat, and that was hard, but he'd always want to drive and we'd both be vying for the drivers seat. I was still able to drive at that stage. (May in reference to her experience with her husband Jim)

She had many binges, accidents, um, getting to the point that we were quite worried about not just for her safety but for other peoples safety... I did manage to get the keys off her because...she had quite a nasty accident where she actually hit the side of her own house... she was getting more and more agitated because she knew I had the keys. (Karen)

Health professionals described being the brunt of anger when people with dementia initially rejected the decision that they should not drive.

I suggested ... that perhaps he ought not to be driving and he got very cross, raised his voice and told me I had no idea... he had been driving for years and never had an accident and he got really very, very angry. (Leslie)

In contrast, May accepted the decision made by health professionals without anger although she was frustrated by her loss of independence.

I was rather expecting it (licence cancellation) I think and you know you just hope things will happen and they don't...It's frustration more than anything else...I mean I'm sure the right thing was done. (May)

Carers reported arguments and outbursts of anger when the person with dementia had their licence cancelled. Participants with dementia agreed that they had been distressed and angry with the person who made the decision and those around them.

I was more aggressive, more argumentative...my whole life had been kerbed...I was like a cornered rat. (Simon)

...I was angry. I really wanted to PUNCH their lights out! (Violet)

People with dementia reported that the decision did not seem fair and the reasons difficult to understand and accept.

Well I think if you could explain it in such a way but I can't quite follow or fathom how memory impairment comes into my driving. (Margaret)

However in some cases family described avoiding conflict with the person with dementia by presenting driving retirement in a positive light.

I took it on myself to ask Grace if I could drive her around from now on...it was just a sort of mutual arrangement. (Tom)

In the early days he would become aggressive I said "bro there's no need for you to go out...this is our baby, this is your farm"...and you know he settled down...he doesn't seem to have an interest in driving because I've got everything in place for him where he doesn't need to drive... I've got his meals in place, I've got carers calling there and he's quite happy. (David)

This case series highlights anxiety, anger and conflict in driving retirement experiences. People with dementia may react defensively in anger to a sudden threat to their independence and self concept. Carers and health professionals are

often the brunt of this anger. Carers may experience ongoing conflict when the person with dementia continues to reject, or forgets, that they should not drive. Support to manage intrapersonal and interpersonal conflict and provision of alternate transport and social contact are key information and support needs.

Theme three: No-one faced me.

Most of the participants with dementia felt that they were not included in the process of deciding that it was time to retire from driving and that their emotional responses to the loss of independence and identity were not acknowledged or addressed. Families and carers described challenges in adjusting to changing relationships but a deep commitment to protecting personhood. Health professionals described lack of time, resources and the skills to include people with dementia in planning for driving retirement.

People with dementia felt that they were left out of the decision that they should not drive and would have preferred someone to take time to face them personally and to explain what was happening.

They didn't face me and say "Well your time is up and you should be giving up driving now". No one faced me and said lets go and have a driving test. (Violet).

I wasn't asked! (Grace)

May and Margaret felt that although they were told directly that they should no longer drive the decision was not given enough gravity, but brushed over quickly.

He left till he was going to say, no, I don't think that you should be driving. (May)

In contrast, Mick felt that he had made his own decision to stop driving. He reduced his driving slowly over a period of time as alternate transport was introduced and was not aware that his brother had influenced his decision.

No, well I've cut down on me driving...It was my decision...I thought well, within meself, I'm not confident. (Mick)

Family, carers and health professionals agreed that driving retirement was difficult to talk about with the person with dementia. Of the GPs interviewed, only Sam felt that he had faced the issue with the client directly. Jan (ACAT RN) had counseled Simon not to drive on the Pacific Highway. Lack of time, fear of negative emotional reactions and the person with dementia's difficulty understanding and remembering were the major reasons why the people with dementia were not included in planning. Health professionals described discomfort and difficulty talking about bad news. One GP described a desire to develop the skills to continue a relationship with clients with dementia, protecting personhood while being honest.

I find it really, really hard to tell them. I'm getting better at telling people bad news...I think I'm just going to have to say 'Look, I've known you a long time and look you've trusted me on a lot of things and I think you're going to have to

trust me, I'm asking you to trust me in this, I am concerned about you driving'
(Francis)

Health professionals and family reported that although it was difficult they did try to talk about driving retirement, Successful strategies were characterised by taking time, aiming for voluntary driving retirement, avoiding conflict, planning ahead, collaborating with the GP, emphasising what the person could still do, explaining the risks, comparing the problem to other impairments such as vision, having a relationship of respect and trust and using humor.

Look, sometimes people can come in angry and hostile and you go through it with them and they still hate it but I think as long as you do it in a pleasant reasonable way, rational not too autocratic way, they are generally accepting of it and people shake hands on the way out I think most people are accepting at the end of the day. (Kerry)

I often associate it with other medical problems as well, if they've got poor vision, poor hearing, if their mobility is not great I try to focus on that rather than saying straight out your memory's not great you shouldn't be driving. (Leslie)

I think, and I am probably a little helped by the fact that I am aged myself and therefore I can put it in the context of 'we', so I say "We aren't going to be able to drive forever"...and people will tell you that they have been driving for 50 years or 60 years and I say "That's great, wonderful, get out now while you're ahead". (Kerry)

Participants with dementia described feelings of anger, powerlessness, grief, hurt, failure, frustration and confusion during the process of driving retirement.

...feeling like a black curtain was being drawn across my life...like I'd been suddenly emptied, it made my head spin" (Simon)

Well I suppose a sense of failure really...one more thing you can't do, It's frustration more than anything else (May)

I was so off the planet, I was angry! (Violet)

Well I felt terrible because I liked my driving (Grace)

(Not driving) makes me feel incapable (Margaret)

Violet and May spoke of driving retirement as one of multiple losses. No health professional interventions regarding emotional adjustment were reported. As Violet stated "no one came near me."

Family and carers reported mixed emotions characterised by empathy with the feelings of the person with dementia. Two carers were brought to tears during the interview when recalling the experience of their loved ones licence being cancelled.

It was shattering...like the end of life really...just belittling...not being allowed to drive. (Barbara)

Of the carers interviewed only Barbara was aware of the existence of the Alzheimer's support group. Despite this grief and anxiety, carers reported that they were nonetheless relieved that the person with dementia was not going to drive, it was the process that was distressing.

(I felt) in some ways...relieved, because we were concerned about mum and dads safety on the roads... I didn't necessarily disagree with the decision, but I wasn't prepared for the decision at that time. (Colleen)

Family and carers expressed concerns that the person with dementia had difficulty accessing medical treatment for depression following driving retirement. Kim had been told by a health professional that people with dementia do not get depression. General practitioners reported that they did not usually screen for depression in people with dementia, but did treat depression with medication when apparent.

Ah yes, I probably haven't followed (screening for depression) up as closely as I guess I should. (Lee)

I just feel so sorry for her...nobody should have to go through that...there should be more help for people who are on their own...Look, she would not be eating, she would be just sitting in her house and she would be one of those people that could pass away and no one would know. (Karen)

This case series illustrates that driving retirement is a time when personhood is vulnerable, and therefore a critical time in person centred dementia care. Personhood involves being part of a group and being involved in the process of life (3). Well-being includes experiencing and expressing emotions, asserting desires and maintaining self respect (51). Health professionals require time and skills to include people with dementia and families in driving retirement decisions and to focus on retained abilities. Specialised counseling or other interventions that assist adjustment to loss and promote retained abilities as well as screening and treatment of depression are key support needs.

Theme four: I felt like I had had an arm cut off.

Case study participants described experiences of disability. Loss of licence was described as a loss of independence and autonomy and figuratively as a loss of a limb.

I felt like I had had an arm cut off (Simon)

People with dementia described activity limitations and participation restrictions resulting from interactions between impairments and aspects of the social, institutional and physical environment. For example, a lack of flexible, alternate transport. Just as a person who uses a wheelchair may experience discrimination when there is no ramp at a railway station, a person with dementia may experience discrimination when they cannot access alternate transport due to memory and planning impairments.

Areas of impairment often associated with dementia include memory, speed of information processing, language, executive functions, attention, visual perception and co-morbidities (hearing and vision, mobility and endurance). Activity limitations

from the case series included remembering an appointment, ringing a taxi, and talking about being depressed. Participation restrictions from the case series included being involved in the decision to stop driving, accessing alternate transport for social and community activities, experiencing the loss of driving retirement and adjusting to this loss emotionally.

As stated above, most of the participants with dementia felt that they did not participate in planning to stop driving. Aspects of the environment that limited participation in planning included lack of time and support allocated for planning, anxiety about potential conflict, lack of written information to compensate for memory impairment, and the confusing nature of the process described above.

Difficulty accessing health professionals was reported in the case studies. Two of the people with dementia, Violet and Margaret were new to the area and did not remember the name of their GP or involvement with them. Kerry described Violet as a wanderer, a person unsettled and at risk of *“falling through the cracks”* missing out on medical care and services. Kim reported Violet’s difficulty waiting in surgeries for appointments, and difficulty liaising with health professionals *“they just don’t understand”*. General practitioners reported difficulty accessing psycho-geriatric specialist services in the area. Karen reported that they waited for over six months for an appointment, despite feeling as though they were in crises. Simon and Barbara had to travel to Sydney to see a neuropsychologist.

Psycho-geriatrics! (Name of specialist) is a nightmare to get into, but he does a very good job. It is (hard) considering there are only two specialists in our area and the volume of people in that age grouping it’s no wonder it’s a bit of a wait. (Sam)

Participants in most of the case studies identified a lack of appropriate alternate transport as a major problem following driving retirement.

(There is) nothing here, this is deadsville...it’s a long way there and you either walk or get a taxi, and that’s expensive. (Violet)

Particularly where I am, public transport’s disgusting and non-existent! (Ray)

The Alzheimer’s Association NSW has recommended taxi concessions for people with dementia (7), however it is relevant to note that May, Mick and Grace lived in localities with no taxi service, a relatively common occurrence in rural areas.

Well there’s the school bus, but you don’t really want to be up and ready to go that early (May)

Case study participants reported successfully using individualised alternate transport such as community transport, CACPs and taxis where available. Participants also relied on families. May relied on the CACP for transport but found that *“...being stuck out here you need a lot of time to do a little”*. Kim agreed that there was never enough time allocated in a CACP (approximately five hours a week) to meet the needs of people with dementia living in a rural area.

Some of the people with dementia felt that they had become isolated since driving retirement. Some had family available to drive them every day and one had a CACP but was not motivated to go out. The people with dementia who had CACPs described the workers as being both friends and employed staff.

She's a lovely lady and she doesn't live far from here and she rang and she said well, we'll go shopping if you're right today and I say yes alright and she says 'I'll come and pick you up at such and such a time,' see and I say "Yes alright, that's fine". (Violet)

Within the last three years five of the six people with dementia had moved house. Simon and Mick had moved into town to be closer to services. Grace and Margaret had moved to live with family and Violet had moved as a continuation of her itinerant lifestyle. Moving to be near services or family could be regarded as moving to a more enabling environment.

Most carers spoke about the person with dementia decreasing their participation in activities of daily living following driving retirement despite offering transport. Conversely Tom, Graces brother, spoke about Grace being as busy as ever because he and his wife were able to drive her to activities every day. David and Judy were concerned that it was hard to find social and leisure activities that Mick and Margaret were able to do. Alzheimer's Australia has called for increased government funding for social inclusion programs, focusing on the retained abilities of the person with dementia to enable access to main-stream community life (51).

This case series highlights the need for an enabling social, physical and institutional environment to compensate for impairments and promote participation both in planning for driving retirement and in social and community activities following driving retirement.

Theme five: Don't mention the 'D' word.

Margaret is really into stigma and appearances. It's all about appearances. She had no intentions of driving but she doesn't like the fact that she has been told she can't. I mean it's a lot easier to choose not to than it is to be told you can't. (Judy)

Stigma is a multidimensional concept. In broad terms stigmatisation is a social process involving an adverse social judgment leading to devaluation and exclusion. It is the negative effect of a label (4). Labelling, stereotyping, prejudice, discrimination and forms of oppression including marginalisation are all facets of the concept. Health stigma occurs when this social judgment is based on "an enduring feature of identity conferred by a health problem which is medically unwarranted."(52) p. 441. Stigma related to dementia has received attention in the literature recently. (51, 53-58) In their report completed in 2010 Alzheimer's Australia NSW chose the following definition of stigma:

A social process or related personal experience characterized by exclusion, rejection, blame or devaluation that results from experience or reasonable anticipation of an adverse social judgment about a person or group identified with a particular health problem. (51) p. 6.

Case study experiences highlight aspects of stigma related to dementia identified in the literature including an overlap with the stigma related to aging, fear around diagnosis, institutional rather than intentional marginalisation, stigma by association and feelings of shame and devaluation. (51,53) In addition, driving retirement experiences included perceived deviance as people with dementia felt that by losing their licence they were being marked as having done something wrong as well as being different. This was perceived to be unfair, and contributed to anger.

All of the case study participants with dementia spoke of their experiences in the context of ageing and decline. '*...one more thing you can't do*' (May). Dementia and driving retirement were experienced as markers of a steady progression towards dependence, loss of mental capacity and potentially loss of dignity and personhood. The 'double whammy' of experiencing the stigma related to aging and the stigma related to dementia has been identified in recent literature (53).

The journey from being, from being normal people to reaching the age when (you) have to have that (fit to drive) tick from the GP (Simon)

The reluctance of applying and accepting the label of dementia was evident in the case studies. One carer asked the researcher not to use the "scary word" and carers and health professionals interviewed avoided using the term dementia directly with the people with dementia. While all of those with dementia reported that they had problems with their memory and word finding, only Simon talked about his diagnosis of dementia.

Looking at that (neuro-psychological) report, and the previous tests that I had done and the vascular dementia diagnosis...(the specialist said) "I suggest he does not drive". (Simon)

He thinks that I might have a sl... they always try to cut it right back, a slight memory impairment or something and therefore I should not be on the road. (Margaret)

The specialist interviewed agreed that there is fear associated with the diagnosis.

It's worse than telling people they've got cancer really because you are telling them they have got a progressive incurable condition... so I think we need to be pretty sure. (Kerry)

Some GPs reported that they use softer terms such as "*the forgetfuls*" or down played the issue and referred on to a specialist for diagnosis if necessary telling the client it was "*a routine thing in these cases*". Reluctance to diagnose has been recognized in the literature and in part attributed to the stigma related to dementia. (56) (58) (59). Stigma is more common with health conditions that affect the mind (4).

Many participants recalled their experiences of cognitive assessments as stressful and in some way as unfair judgments of their ability to drive.

...as though I was being put under the microscope ...picked up like a butterfly and pinned down...a CIA interrogation...judged. (Simon)

May described the cognitive assessments as *'little IQ tests'*, which she did not relate to her ability to drive. She and Margaret felt that they were not prepared for assessments and were not told of the significance of the outcome. In contrast Simon was aware of the significance of the assessment and felt extremely stressed while waiting for appointments.

Margaret, Simon, Grace and Violet talked about being good drivers with long experience and good driving records. Having their licence cancelled seemed unfair and should only have happened after failing a practical driving test or being booked for speeding or causing an accident. Grace did not recall any assessments although she had had cognitive assessments and an RTA driving test. Mick was also not aware of any assessments.

Simon, Margaret and Violet described feeling devalued and marginalised during driving retirement. Licence cancellation was interpreted as a social sanction for being a 'bad' driver, rather than a consequence of a medical condition that increased the risk of accidents. The difference between perceiving licence cancellation to be the result of a medical condition and perceiving licence cancellation to be the result of bad driving reflects the distinction between stigma (an ontological deficit) and deviance (a moral deficit) (52). Licence cancellation compounded their sense of outsider status.

He was pronounced unfit to drive without any concrete evidence, we were both close to tears...she might as well have told him to stand and be shot. (Barbara)

I'm not capable and yet I've been driving all those years and never had a ticket even...I thought I was doing a good job and then I was pushed aside you may as well say and I was pretty hurt (Violet)

In contrast May reported that she understood that her health and age were the reasons why she should not drive, and Mick reported that it was his own decision not to drive. Simon, Margaret and violet described rejecting the idea that they were bad drivers and also the advice to stop driving

Knowing that I was still capable which combated the...their diagnosis of me, so I, I couldn't, I wouldn't agree with them. It was a defense (Simon)

Grace's brother, Tom, *"thought she was a good driver"* but went to the GP when others told him that she should not drive due to dementia. The GP sent Grace for an RTA driving test. The RTA manager interviewed, Chris, stated that the RTA driving assessor would not have known that Grace had dementia. Chris stated that the RTA relies on the GP to make the decision regarding whether a medical condition might make someone unsafe to drive. Grace passed the driving test. Health professionals interviewed agreed that although a practical driving test for people with dementia appears a fair and valid test of driving skills, these tests do not take into account fluctuating abilities, the risk of getting lost, ability to deal with emergencies and other strategic and tactical aspects of driving (25). Licence cancellation despite passing an RTA test appears discriminatory. This highlights the need recognised in the literature for an RTA driving test for people with dementia or a clinic based assessment of fitness to drive with greater face validity (7).

This case series illustrates the presence of stigma related to dementia. Stigma related to dementia is linked to our fear of loss of dignity and personhood. Stigma related to driving retirement is also linked to the perception of being marked as a bad driver. Stigma reduction in this area requires education and institutional change to provide the resources needed to avoid unintentional discrimination and marginalization. For example, people diagnosed with dementia, as well as their families, may require specialized psychosocial interventions to adjust to loss. People with dementia may require assistance to access alternate transport and support to continue to participate in community activities. Broad community education is needed to build the attitude that driving retirement is not a sanction but a responsibility and to encourage voluntary timely driving retirement.

Study strengths and limitations

This was a small local study with the researcher working in both the geographical and clinical area. This adds an intimate insider knowledge of the area. Experiences of driving retirement are very varied and it is likely that this small study did not reach data saturation. None of the participants in the current study were people from culturally and linguistically diverse groups, Indigenous or younger people with dementia so care must be taken in generalising these findings to these population groups or to urban centres.

Conclusion

This case series has examined the experiences of six people with dementia their carers and others involved in their driving retirement in a rural setting on the mid north coast of NSW in 2009-2010 and described themes derived from their stories. These interconnected themes suggest that key support and information needs include the need for clearer pathways for driving retirement with better collaboration between decision makers with efforts both to reduce the stigma related to dementia and to protect personhood. Driving retirement can be a difficult transition and planning and support are needed to manage the conflict and losses experienced. The need for investment in a physical, social and institutional environment that promotes inclusion, function and safety is highlighted by these six stories.

Well I have lost the interest now and I am a bit hurt and afraid...I don't like it, it's a bit much, but it has happened and it wasn't a good way...but anyway, that's life I suppose (Violet)

Recommendations

Families and people with dementia:

- Discuss driving soon after diagnosis and make a plan in collaboration with the GP. Ask for practical and emotional support.

Health Professionals:

- Encourage families and people with dementia to plan for driving retirement and implement strategies to minimise the risks of social isolation, depression and decreased activity participation following driving retirement.
- Educate people with early dementia and families about how cognitive impairments impact on driving ability, explain the increased risk of accidents and encourage voluntary driving retirement.
- Use written information, take time, involve families and use other strategies to compensate for cognitive impairments in order to include the person with dementia in discussions and decisions as appropriate and do not allow a label of dementia to overshadow personhood.
- Acknowledge the significance and the loss involved in driving retirement.
- Offer referral to Alzheimer's Australia support and information services.
- Provide support to people with dementia and families to deal with grief and loss if appropriate and screen for depression following driving retirement.
- Provide support and advice regarding strategies for families to manage the conflict that may arise.

Government:

- Provide clearer national guidelines regarding medical fitness to drive with regard to dementia, based on evidence, including guidelines for appropriate cognitive assessments, recognising the cumulative impact of health conditions other than dementia on fitness to drive.
- Fund short term case management at the vulnerable time of driving retirement to assist people with dementia to access existing alternate transport and to promote participation in activities of daily living.
- Increase the number of CACPs or similar individualised services that provide on going flexible transport and assistance with participation in community life.
- Conduct a broad community education program to better prepare older people for driving retirement.

RTA:

- Provide information to the community about the process to follow after a diagnosis of dementia with regard to drivers licencing.
- Investigate the validity of the current road test with regard to assessing people with dementia's ability to drive safely.

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Appendix 1

Introduction

This is a research project funded by the NSW Institute of Clinical Services and Teaching. I work in the local ACAT as an occupational therapist, but this project is separate to my work in the ACAT. I am interested in dementia and have met a number of people with dementia through work and also family and friends. My aim is to better understand the experiences of people with dementia and people around them in regard to giving up driving. I am interviewing people in the more rural areas of our local community.

Consent

Thankyou for agreeing to be interviewed. Your willingness to talk about your experiences is much appreciated.

Use of information from the interviews and storage of data.

Confidentiality

The interview will take up to an hour, and we can stop at any time that you want to.

I might also make some notes while we talk.

I will refer to my list of questions to make sure that I have not forgotten anything.

Test the recorder.

Interview guide and example questions (Person with dementia)

Events leading up to and at the time of driving retirement:

Can you tell me what happened that led to you handing in your driving licence?

What were the main reasons why you stopped driving?

Did your doctor or someone else help you with the decision? How did they do this?

Do you feel that you were involved in the decision?

Can you tell me how you felt when you handed in your licence?

After driving retirement and up to the present:

Activity participation

Has your life changed since you stopped driving?

Can you tell me about your leisure and social activities at present? What do you do most days?

Are there any activities that you have given up because you can no longer drive?

Relationships

Has not being able to drive changed the way that you relate to family or friends? Do you think that they see you any differently?

Transport

Can you tell me about any alternate transport that you use? Do you use taxis? Community transport? Buses? Does someone drive you where you want to go?

What sort of transport would you like to have available here?

Where would you go if you were still able to drive?

Mood

Has your doctor or any other health professional asked you about how you are feeling now that you do not have a driving licence?

How do you feel right now about your situation?

Interview guide and example questions (Carer)

Events leading up to and at the time of driving retirement:

Can you tell me what happened when (persons name) gave up driving, what led to the decision, who was involved and what they did?

How were you and (persons name) involved in the decision?

Can you tell me how you felt at the time?

Did your doctor or any other health professional talk to you about driving and dementia? What did they tell you?

Did anyone help you and (persons name) make plans to stop driving before it came to the crunch? Did you feel prepared?

Were you been given any written information or advice about driving and dementia? If so, how helpful was it?

After driving retirement and up to the present:

Has your life changed since (persons name) gave up driving? Can you tell me about how it has changed?

Relationships

Do you think that your relationship with (persons name) has changed since they stopped driving?

Has (persons name)s relationships with other people (friends/neighbours/family) changed at all since they were not able to drive? In what way?

Activities

Since (persons name) has not been able to drive, has there been any activities that he/she has had to give up? How do they spend their days now in comparison to a year ago?

Has your daily and weekly routine changed since (persons name) stopped driving? What do you do now that you did not need to do a year ago?

Transport

What alternate transport options are there in this area?

Do you think it would help if there was other transport available here? What sort of transport would you like to have available here?

Can you tell me about the types of support (persons name) has if he/she wants to go out?

Mood

Do you think that not being able to drive has affected (persons name)s mood? In what way? Has (persons name) been offered any counselling or support? How do *you* feel now about your situation? Have you been offered any counselling or support about how you are feeling?

Interview guide and example questions (GP/other decision maker)

Can you tell me how you were involved in the decision for (persons name) to stop driving?

Planning for driving retirement

Would you say that you were involved in a making a plan for (persons name) to stop driving before it came to the crunch?

Do you feel that you get enough information and time to be involved in planning for driving retirement?

Were you able to get any information or support from any other person?

Are you aware of any services or other health professionals that might help plan for driving retirement?

Did you have any written information or resources to help you?

This is a resource from the USA do you think this might be useful to use in your practice?

Assessment

Who do you think is best placed to make the decision in cases like this? GP? family? Person with dementia? Geriatrician? Other specialist? RTA?

What factors do you take into account when advising people with dementia to stop driving?

Do you find the Aus roads medical guidelines useful?

Do you think that the fact that we are in a rural area affects the decision making in any way?

Can you tell me how you feel when you have to make these decisions?

Trying to avoid negative consequences eg depression/carer stress/isolation

Driving retirement has been identified as a significant risk factor for depression, do you think there is anything that could be done about this?

What do you think about screening clients with dementia for depression and their carers for stress?

Who could you refer to provide support, counselling or alternate transport when you know your (patient/client) is going to lose their licence?

Ideally

What do you think would help in future situations like this?

Given that people with dementia eventually stop driving, what steps do you think could be taken to make this process better for all involved?

Rurality Do you think living in a rural area makes it any easier or more difficult for you and your (patients/clients) in regard to driving retirement?

Appendix 2

Case study stories in brief

Simon

Simon lives with his wife Barbara in a coastal town in NSW. He is a retired technician, 79 years old and has a history of cardiovascular disease. Simon has been driving since he was 15 and has been a competent and careful driver. He has driven 'all over Australia' with Barbara as the navigator. Simon was diagnosed with vascular dementia in 2004. In 2006 a specialist referred him to a neuropsychologist for cognitive assessment. The neuropsychologist recommended an OT driving assessment. The referring specialist passed this advice on to the GP, and the GP wrote this on the RTA medical form and gave the form to Simon. Barbara and Simon lived 30 km out of town and so they decided to go to the RTA on their way home from the GP to find out what to do with the form. The RTA officer asked Simon for his licence and without warning cut it in half at the counter. They were both shocked and angered. Simon's licence was downgraded to a learner licence with the condition of driving only with a licenced driving instructor until the OT assessment. Barbara made inquiries and found an OT driving assessor, Nick.

Simon passed the driving assessment and changed GPs. The next time that he was required to have an OT driving assessment, Barbara was 'wise' to the situation and went into the RTA to ask them to 'make it a little less traumatic', which they did, putting a tiny nick in the corner quietly and giving it back to him to put in his wallet. Simon passed his driving reassessment; Barbara took lessons and slowly began to take over the driving.

Simon described great distress and anxiety waiting for assessments and doctors appointments "like an actor waiting to go on stage" as well as discomfort during the actual assessment. The medical record indicates that Simon had multiple assessments, and very little advice or intervention about planning for driving retirement.

Grace

Grace is 89 years old. She learnt to drive as a young married woman to help her husband deliver cars, and she enjoyed driving well into her eighties. She retired from driving in October 09. Her cognitive impairment became apparent following a hospital admission in February 08. Her GP, Francis, had looked after her for 26 years and deeply respected her spirit and independence, describing her as a person with a busy schedule and "always an absolute delight". However "the dementia set in" and her brother and sister-in-law, Tom and Robin started to hear comments from others in the community that Grace should not be driving. Tom spoke to Francis who organised an RTA age test. Although Tom thought that Grace was a good driver and there had been no actual incidents, they were concerned about a particular intersection that Grace had to negotiate when leaving her street. Grace passed the test in August 09.

Francis also referred Grace for an ACAT assessment. Jan, the ACAT RN met with Grace, Tom, Robin and Francis in October 09 and completed a general assessment. He noted that her memory was not too problematic at present, that she had a 15km distance restriction on her licence, and that Grace agreed to be guided by her family and Francis to give up her licence when the time came. Soon after this Tom asked Grace to come and live with him and Robin. In regard to driving retirement Tom felt that the Francis "left it up to us" and the Francis agreed that "the family did the job". Tom asked Grace "if he could drive her around

from now on...it was just a sort of mutual arrangement". Although Grace agreed to this, Tom felt that he would have liked more support and advice at the time from an authority.

Grace felt that she was left out of the decision to stop driving, but would not want to drive now. She continued all of her social activities with the support of Tom and Robin. Grace's cognition is continuing to deteriorate and when interviewed her memory and language difficulties were very apparent.

Margaret

Margaret lives with her son and daughter-in-law, Rob and Judy, on a small property. She moved a year ago from her own home in a town in another area on NSW. Margaret is 80 years old and was diagnosed with dementia at 78. Judy reported that four years ago the family had started to receive phone calls about Margaret driving dangerously with reports of incidents such as speeding and tailgating and overtaking a school bus in unsafe conditions. They talked to Margaret about these incidents, went with her while she drove, and thought that she drove well. However incidents continued to occur and then Margaret drove off the road and hit a tree. "Somebody doxed her in" and the RTA sent a medical form to her GP for completion. Margaret has five children and there was concern within the family as to whether she should keep her licence as she would be isolated if she could not drive. The GP was reluctant to tick the 'fit to drive' box, but the family persuaded him to allow Margaret to have a conditional licence with a 20km distance restriction in day light hours only. Margaret's memory worsened and the family decided she was not safe living alone. Following a hospitalisation for elective surgery they persuaded her to move, which she did, leaving her car behind. Margaret asked for her car repeatedly, and so eight months later it was brought up so that she could sell it. Before her 80th birthday she received an RTA medical form for completion. Judy went to see the new GP, Lee, to prepare him and to ask him not to allow Margaret to drive. Lee referred Margaret to a specialist who counselled her not to drive and wrote to the RTA recommending licence cancellation. Judy intercepted a "horrible" letter from the RTA to Margaret that directed her to surrender her licence. Rob took Margaret in to the RTA and they very sensitively cancelled her licence and gave her an ID card.

Margaret relies on family for transport as she has no support services in place and no access to public transport. She does not have her own friends locally and Judy reported that it was difficult to find something that Margaret wants to do. Judy reports considerable carer stress.

Violet

Violet lives alone in a caravan park outside a small coastal town. She is 75, widowed and has no contact with her family. She is now supported by a Community Aged Care Package (CACP) and the managers of the park. A CACP provides case management and practical support with activities of daily living. The experience of Violet's driving retirement caused great distress to the park managers, Karen and her family, as they were thrown into a situation of responsibility with no support or guidance. Violet already had dementia when she came to live in the park. This was Karen's first experience of dementia. Violet had no GP, no family and no community support services. Karen and the park residents soon noticed that Violet had difficulty with driving. The removalist drove Violet's car to the park. When Violet did drive she drove erratically, driving on the wrong side of the road, cutting across sites and having multiple minor accidents.

Karen helped Violet to find a GP and asked her what to do about Violet and, in particular, her driving. The GP told Karen to take the car keys, and later to sell the car. Karen did this reluctantly after Violet ran into the side of her mobile home closely followed by another serious incident where she became frightened and stopped suddenly on a bridge, causing a traffic jam. Karen went to all the local car yards but one, asking them not to sell another car

to Violet. Unfortunately Violet went to that one car yard and bought herself a new car. Karen went back to the GP for help, however the GP declined to write to the RTA but did refer Violet to a specialist. Karen was able (with much effort and after another accident) to persuade Violet to sell the second car. Although the GP referred Violet to a specialist due to staff shortages the specialist did not see Violet for many months, by which time Violet was no longer driving as she had no car.

In looking for assistance, Karen contacted the local community health service who referred Violet to ACAT. Leslie, the ACAT RN, tried to visit Violet three times before she managed to find her at home and felt frustrated by this. Leslie assessed Violet just after the second car had been sold and recommended a Community Aged Care Package (CACP) to provide case management and assistance with transport, shopping and social support. Violet did not wait long for a CACP to become available.

May

May lives with her husband a few kilometres from a small country town. They have support from two CACPs and their three daughters visit regularly despite living 2, 4 and 10 hours drive away. May learnt to drive in 1952 and enjoyed driving, but drove only locally over the months before her licence was cancelled. Jim has Alzheimer's disease and May experienced Jim's driving retirement a few years ago, and then more recently her own. May believed that her GP and the specialist decided together that she was "not with it enough to drive" before she was assessed by the specialist. Her health was poor. The specialist visited her at home, and told her that she should not drive. Colleen, May's daughter, and Kim, her CACP case manager were with her. Watching May receive the news Kim felt "gutted". Colleen was surprised that the appointment was about fitness to drive as she had organised the referral for an ACAT assessment of eligibility for a CACP.

Colleen felt that since giving up driving May was missing out on incidental social interaction, and had less choice and freedom in her life. There is no taxi service and the only public transport is the school bus at 7 am. Although May has friends, she does not like to be dependent on others. Having a CACP helps, however May feels that it is her poor health that has limited her social and community activities. Being in a rural area the CACP hours are stretched.

May has accepted the decision and thought that her GP, Ray, did not want to talk to her directly as it was a difficult decision. However, she feels a "sense of failure". May thinks that although it is very hard, the best person to decide when it is time to retire from driving is the individual, not the GP and not the RTA. As her GP put it driving retirement is "a realisation...another reminder in the ageing process."

Mick

Mick lives alone on the edge of a small rural town. He has support from a CACP and from his brother, David, who lives down the coast but visits every three or four weeks. He is 79 years old and has lived in the area many years but moved into town at the instigation of his brother who saw that he was not managing on a more isolated property. When David realised that Mick was starting to advance in his dementia and to become lost when driving he spoke to the doctor, Ray, and they decided to restrict the distance he was permitted to drive. Ray was happy to go along with David's plans for Mick to make a slow transition from driver to passenger.

David spent a lot of time with Mick settling him, organising services and telling him he didn't need to drive anymore. He has slowly accepted this and does not want to drive now as he has no need and he does not have the confidence.

At first David didn't know anything about dementia but did his own research to understand why Mick was suspicious and aggressive. He learnt to take things slowly and carefully. Mick feels that it was his own decision to stop driving. David feels that he has grown a lot closer to Mick through the experience. They have spent more time together and Mick has grown to trust David.

David now relies on a CACP to assist Mick. Before Mick had a CACP he was driving up to accompany Mick to appointments, to mow the lawn and monitor Mick's well being. Mick's CACP case manager, Kim, found the process of taking over Micks case management and transport quite easy because David did so much preparation with Mick, and because Mick trusts David. Mick now regards the workers as friends.