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QUALITATIVE PAPER

A qualitative study exploring the experiences and needs of people living with young onset dementia related to driving cessation: ‘It’s like you get your legs cut off’

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Abstract

Background: driving disruptions have significant impact on individuals living with dementia, their care partners and family members. Previous studies show that for older people with dementia, stopping driving is one of the hardest things that they cope with. To date, no studies exist that address the expressed needs and experiences of people living with young onset dementia (YOD) who are adjusting to life without driving, whose needs are not well understood and whose needs might be expected to differ from those of older people with dementia.

Methods: a multi-perspective, qualitative descriptive phenomenological approach was undertaken. A topic guide was developed in consultation with lived experience experts. In-depth interviews ($n = 18$) with 10 people with YOD and eight family caregivers were conducted, to elicit lived experiences in relation to changing and cessation of driving. Interviews were recorded and transcribed verbatim. Data were analysed using a hybrid approach, employing deductive and inductive coding.

Results: core findings reflected the impact and coping strategies employed by people with YOD and their care partners across four themes: (i) losses and burdens, (ii) the unique challenges of YOD, (iii) coping and adjustment and (iv) how to meet needs.

Conclusions: driving disruptions often come at a time when people living with YOD are likely to have significant financial and family commitments, or they/their partners may be employed or raising a family, negatively impacting individual’s roles and self-identities. Intervention to support emotional and practical adjustment and reduce social isolation is essential for coping.

Keywords: young onset dementia, automobile driving, primary care, cognitive disorders, qualitative, older people

Key Points

- Driving cessation is a significant life transition.
 - Driving disruptions present unique social challenges to people with young onset compared with late onset dementia.
 - People with young onset dementia and their families require support for practical and psychological needs after driving cessation.
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Background

Driving disruptions have significant impact on older people living with dementia, their care partners and family members. Driving cessation is identified as one of the most difficult challenges faced by older people with dementia [1, 2] and a complicated area of practice by health care professionals [3]. Driving is an important instrumental activity of daily living [4], signaller of autonomy, independence and a way to access the community [5]. Accordingly, the transition to non-driving comes at significant personal cost, including increased risk of depression, anxiety, loneliness and isolation [6, 7].

Despite a growing body of research, gaps remain about the experiences of people living with young onset dementia (YOD), any dementia diagnosed before the age of 65 [8]. YOD affects up to 3.9 million people worldwide and accounts for up to 10% of all dementias in Australia [9, 10]. While the symptoms of dementia may be similar regardless of age of onset [11], for people with YOD, the diagnosis usually comes at a time when they have significant financial and family responsibilities, are likely to be employed full-time, have a care partner who is employed full-time, paying off a home, caring for children and/or their ageing parents [12]. The symptoms of YOD can adversely affect these roles, relationships, self-identities and individuals' self-worth [13, 14].

Maintaining social relationships, social participation and meaningful engagement is vital for preserving cognitive and emotional health across the lifespan. For people with YOD, sudden changes in life circumstances, such as loss of employment and occupational engagement, and relationship strain, can lead to social isolation [13, 14]. Restricted community mobility resulting from loss of driving privileges can further intensify isolation. The aims of this study were to identify issues, needs and experiences related to driving changes for people living with YOD, through in-depth interviews with those affected, people living with YOD and their family members.

In Australia, as with most other countries, drivers with a diagnosis of dementia must undergo some form of medical fitness to drive assessment to determine if an individual is fit to drive. According to the Australian and New Zealand Society for Geriatric Medicine 2022 position statement [15], drivers with mild dementia may drive safely for a limited time but require regular review of safe driving capacity, at least 12 monthly. People with moderate or severe dementia are deemed unsafe to drive.

Driving is a complex task requiring a range of cognitive and psychomotor capacities that are affected by dementia, visuospatial skills, memory, judgement and decision-making, attention, executive function and reaction time [16]. Therefore, at some point, all drivers with dementia must stop driving. Investigating the needs and experiences related to driving cessation according to those with lived experience of YOD offers health professionals and researchers a deeper understanding to inform interventions that support coping and adjustment to driving loss.

A scoping of the literature suggests that this study is the first published study to explore the lived experiences and expressed needs of people living with YOD who are adjusting to life without driving [17]. The research questions were: (i) what are the lived experiences for people living with YOD related to driving and giving up driving? and (ii) what needs or issues should be addressed in relation to supporting driving and driving cessation according to people living with YOD and their family members?

Method

Study design, setting and participants

A descriptive phenomenological methodology [18] was undertaken using semi-structured interviews for data collection. A flexible approach to understanding a potentially individualised and complex issue underpinned the research design to allow for the elicitation of key shared aspects of the lived experience of driving cessation, while also considering the individuality of each person's experience. Semi-structured interviews were recorded with participants' consent, de-identified, transcribed verbatim and analysed using a hybrid approach [19].

Participants were (i) people living with YOD and (ii) partners or family members of people living with YOD ('care partners'). Inclusion criteria were, people with YOD and care partners who resided in the community and had lived experience related to driving and driving cessation (including planning to stop or having stopped). A purposive stratified sampling approach was used, intended to include a variety of age, gender and location (metropolitan and regional/rural areas). Participants were recruited via a range of sources including support groups, dementia research database (StepUp for Dementia), health professional networks, social media and newsletters. Recruitment continued until a range of participant perspectives could be included. However, no potential participant who volunteered to take part and met inclusion criteria was excluded from participating.

Procedure

Participants responded to a brief survey to provide basic demographic and descriptive information either online before, or at interview. Key interview questions were e-mailed prior to interview to help participants recall and communicate what they wished to. Interviews were conducted by the first author (T.L.S.), a psychologist with lived experience of dementia and driving, and an experienced interviewer with no prior relationships or familiarity with the participants prior to the study. Interviews were held from 2020 to 2022. Interviews were conducted by teleconference (e.g. Zoom) or telephone, based on participants' locations and preferences, audio-recorded and later transcribed verbatim for analysis. In the case of videoconference, only audio files were provided for transcription.

Data analysis

Transcriptions were analysed using a hybrid approach [18]. This approach employs a method of deductive and inductive coding and was considered appropriate since there is existing literature on the challenges of driving cessation for older people with dementia; however, there is no published study from the perspectives of people with YOD. Thus, theory- and data-driven codes were developed.

Familiarity with the data involved listening to interviews and revising transcripts several times by the first author (T.L.S.), searching for key, shared aspects of the lived experience of driving cessation, while also considering the individuality of each person's experience. Similarities and areas of consensus between the two groups of participants' data, people living with YOD and care partners, were emergent at this stage, and subsequently combined in thematic analysis.

A code manual was created, and codes were assigned to units of data: phrases, sentences and paragraphs. Data-driven codes were developed in addition to theory-driven codes, where the latter did not sufficiently describe the content. Data coding was an iterative process, i.e. new codes were discovered, or existing codes were altered, and coding continued until consistency in shared experiences was observed. This initial coding of data was reviewed and assessed for suitability by two researchers (T.L.S. and D.R.), by reviewing transcript segments assigned to codes. Themes were discovered based on repeated patterns in the coded text and were corroborated by two raters (D.R. and J.L.) by exploring the interaction of text, codes and themes before theme labels and definitions were finalised.

Rigour

To achieve rigour, we employed several strategies, including accurate documentation of participant responses, all interviews were recorded and professionally transcribed verbatim and we employed multiple data sources including transcripts and interviewer's memos. Additionally, we held regular peer-checking meetings to discuss our interpretations and ensure consensus on a logically sound interpretation and maintained an audit trail to track all decisions and changes made during the analysis process.

Ethical considerations

This study was approved by The University of Queensland Human Ethics Committees (#2018000257; #HE000232). All participants were provided with an Information Sheet and given time to consider consent, before being contacted for interviews. Verbal informed consent was obtained and audio-recorded before interviews started.

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Findings

The findings represent the integration of perspectives of 18 participants, 10 people living with YOD, aged 50–74 years ($M = 62$, $SD = 7.4$, 50% female), ex-drivers ($n = 5$) or still driving but contemplating stopping ($n = 5$), and eight care partners, aged 45–85 years ($M = 63.5$, $SD = 11.9$, 75% female) of people living with YOD who were ex-drivers ($n = 7$) or still driving ($n = 1$). The self- and proxy-reports describe people with varying types of YOD, including Alzheimer's (33%), vascular (28%), Lewy body (22%), frontotemporal (11%) and mixed (6%), who had been diagnosed on average 2.5 years prior to interview, ranging from 1 to 4.5 years. All participants' demographic characteristics are shown in Table 1. Unique identifiers are used. Four overarching themes were identified from interviews: (i) losses and burdens, (ii) the unique challenges of YOD, (iii) coping and adjustment and (iv) how to meet needs. Table 2 shows themes, definitions and example segments from transcripts.

Themes and example statements derived from the analysis

Theme 1: losses and burdens

A series of intense losses

Overwhelmingly the topic of discussions focused on grief and loss experienced as a consequence, or potential consequence, of no longer driving. This was by far the most salient of topics raised by participants living with YOD and care partners and related to the impact of no longer driving on an individual's independence, freedom, role, identity and social connectedness. While some participants with YOD had already stopped driving, for others, the experience of loss was expressed in terms of their concerns for the future. As one participant, still driving, expressed 'Without a licence, my life would change tremendously' (RD08).

The negative emotions associated with changes in driving status were described as so intense for individuals that worsening of depressive symptoms and preoccupations with death and suicide followed. 'I miss the, the freedom to do what I want, when I want. At times, when you're sitting at home here for weeks and not being able to go anywhere, . . . you just want to sort of go—if this is all life's got to offer me now, ah, I might as well go and end it, and that's the way I feel a lot of times' (RD04).

The concept of freedom encapsulated a feeling of having no boundaries, no rules, total independence in decision-making, to go 'where I want, when I want, just because I want to' (RD06).

The difficulty in the transition from a highly valued role, 'driver', to non-driver was raised in relation to being the main driver in the household or being a contributing driver within the family unit. Stopping driving precipitated a series of losses for some participants living with YOD including cessation of work and feeling less involved in family roles.

Table 1. Characteristics of participants.

Retired/retiring driver (RD)							
ID	Age	Male/female	Lives with/or alone	Geographic location	Still driving? Yes/no	Alternative driver/s at home? Yes/no	Main driver (is/was)? Yes/no/shared
RD01	50	Female	Partner and children	Metro	No	Yes	Shared
RD02	55	Female	Partner and children	Regional	Yes	Yes	Shared
RD03	62	Male	Partner and children	Metro	Yes	Yes	Yes
RD04	63	Male	Partner and children	Rural	No	Yes	Yes
RD05	63	Male	Partner	Metro	No	Yes	Yes
RD06	69	Female	Partner	Metro	No	Yes	No
RD07	74	Male	Partner	Metro	Yes, not at night	Yes	Yes
RD08	68	Female	Alone	Regional	Yes	No	Yes
RD09	54	Female	Child	Metro	No	Yes	Yes
RD10	62	Male	Partner& child	Metro	Yes	Yes	Yes

Care partner (CP)							
ID	Age	Male or female	Lives with person with YOD Yes/no	Geographic location	Person with YOD driving? Yes/no	Relationship to person with YOD	Is/was person with YOD main driver? Yes/no/shared
CP010	58	Female	Yes	Regional	No	Spouse	Shared
CP011	58	Female	Yes	Rural	No	Spouse	Shared
CP012	60	Female	Yes	Metro	No	Spouse	Shared
CP013	69	Male	Yes	Metro	No	Spouse	No
CP014	45	Female	Yes	Metro	No	Child	Yes
CP015	72	Female	Yes	Metro	Yes	Spouse	Yes
CP016	85	Male	No	Metro	No	Parent	Yes
CP017	61	Female	Yes	Metro	Yes	Spouse	Shared

She had her own business, and driving was a huge part of that. . . . so to have to quit work was huge and extremely difficult for her, and then to realise that part of the reason she had to quit work is because she knew she just could not handle driving the highways anymore, . . . all these things just kind of were lumped together sort of in a ball in the beginning; the not working and the not driving at the same time. . . . definitely, it was like her losing part of her identity (CP014).

The feeling of lost control and impact on social roles including masculinity was described. One care partner stated ‘. . . when him and I went into [licensing authority] and he handed in his licence and he said, “You know, you’ve—you’ve cut off my legs”. “And then a couple of weeks later we sold his ute [utility truck]” . . . “And now you’ve gone and cut off my balls”.—“that’s just the way he felt” (CP010).

Impact on social isolation and participation

The person with YOD loses social connections following loss of employment and ability to connect to the community, together with loss of contact from friends and family following a diagnosis of dementia. A care partner described,

‘upon diagnosis, you already lose so many friends, I feel like . . . her social life took a hit long before she quit driving’ (CP014). Driving cessation impacts community mobility, further minimising social engagements, especially if there are limited alternatives available, ‘unfortunately, I think . . . it did affect her ability to get to social outings, but unfortunately, because of the Frontotemporal Dementia diagnosis, there was already less outings—people don’t know how to deal with it’ (CP014).

Avoiding and living with new burden

Participants with YOD described experiencing driving cessation as a burden to others, not wanting to put family members out for seemingly trivial trips they would previously have done themselves: ‘this is my illness and I don’t want to put people out—just because I want to go down the shop’ (RD04).

‘Having to rely on people’ (RD06), particularly, family members, was a common concern for the retired driver, ‘I wait, wait, wait, wait all the time’ (RD09), as well as care

Table 2. Themes, definitions and example statements.

Themes and definitions	
Losses and burdens	
<p>This theme describes the grief and loss and feelings of burden experienced by both persons with YOD and care partners, as a consequence or potential consequence of no longer driving. Participants' discussions focused on the impact of no longer driving on an individual's independence, freedom, roles, identity and social connectedness.</p> <p>Care partners described their own losses related to loss of their own valued activities, roles, independence and intimate relationships, along with feelings of strain with taking on a partner's transport and social support needs.</p>	<p>... I sat down and I told [partner], I went, well, that's it, no licence so I might as well just curl up and die somewhere (ID RD04).</p> <p>Taking a driver's licence off of someone is taking their identity off them (CP012).</p> <p>... now he is 100 percent reliant on having somebody else take him ... even if it's—it's just, 'Look, I just need to go and get a spray can of paint'. you know, so, 'Oh, right, okay, well hang on a minute while I finish a load of washing' (CP010).</p> <p>I took you to the morning melodies at church, I took you to the city to go to lunch with ... , and then I took you to the doctor and then I took you back to the church for a trivia night and a casserole night, so that was four activities that I was driving you and then waiting for you to finish or whatever. It gets a bit much sometimes (CP012).</p> <p>I find it difficult to get away on my own, simply because [RD] has got nothing else to do ... I feel like I've lost my independence too (CP010).</p>
'Basically, everyone I know is at work'; the unique challenges of YOD	
<p>This theme highlights the unique experiences of people with YOD who were occupationally and socially active prior to diagnosis and driving cessation and wanting to continue to retain their mobility post driving cessation. The inconvenience of scheduling and planning and the lack of spontaneity that is at odds with the lifestyle of peers and personal expectations had a strong impact.</p> <p>This theme also reflects the stigma and shame experienced by those with YOD, in relation to licence removal, and having a diagnosis of dementia, seen as 'an older person's disease'.</p> <p>Participants with YOD described the impact of no longer driving as something that made them feel older than they were and out of sync with peers and society.</p> <p>Choosing to stop driving before a decision was imposed enabled some to avoid embarrassment and exert control.</p>	<p>... basically everyone I know is at work (RD01).</p> <p>it's limited her independence for activities in that she can't just jump in the car and go down to the shops, spontaneous stuff (CP013).</p> <p>... he cannot sit at home on his own, he needs people around him and people that don't have dementia around him so I have gone out into the community as much as I can, and locally, and found suitable activities to stimulate him (CP012).</p> <p>Can you imagine your life if every time you went out, you had to call somebody to book to come and pick you up? There would be no spur of the moment, I will pop down the shop and get that or if something happens to the kids, I will dash up and sort something out for the kids. It's well, hang on I will see if I can get somebody to get me there and that's not independence by any means (RD08).</p> <p>Driving's been a part of your life for so long—and when that goes it's, yeah, you're lost and you suddenly then sit there and go, I'm only 62 and I—I'm not that old, or am I? (RD04).</p> <p>I reckon, it was—it's easier for me, in a way because I voluntarily handed it [licence] in, but if you had the police come up to you and go, 'You're no longer driving Sunshine', that would be a real hit in the guts ... where I did it voluntarily and—so the impact of such isn't as bad. Yeah, like I said, I still miss it, I miss it a lot and, yeah, my heart goes out for those people who had them taken off them (RD04).</p>
Coping and adjustment	
<p>This theme describes the process of transitioning to driving cessation, experienced as a time of intense emotions, that sometimes stay intense and sometimes move towards acceptance.</p> <p>Topics included decision-making, discussions around driving, driving assessments and adjustment to the decision. Safety, loss of confidence and feelings of regret were discussed in relation to driving cessation and feelings of anxiety and unfairness were associated with driving assessments.</p> <p>There seemed to be no consensus or easy way to assess medical fitness to drive that would not create anxiety and would feel valid to all participants.</p>	<p>it's like you get your legs cut off. ... (RD04).</p> <p>... safety for him and for other people on the road, and for anyone who he had in the car with him because he didn't think he had a problem (CP011).</p> <p>Arguments arise when I say she shouldn't drive to a certain place (CP013).</p> <p>None of the controls were like a normal car that I have driven ... I went to take the handbrake off and there was no handbrake, I said to him, 'Where's the handbrake?' and he said, 'Oh you just press that button' and I said, 'You're kidding me, you are expecting me to become a pilot and drive a car that doesn't have normal controls like a car that most of us would be driving?' (RD08).</p> <p>... that I have to go to my GP and then my GP, who's never been in a car with me ever, and not likely to ever be in a car with me, looks at me and I look at her and I go, 'Look, if I felt in any way I was a risk on the road ... ' ... I would be the first to go, 'I have to stop driving because I do not want to be at all responsible for causing an accident'. I mean, many able-bodied people have accidents ... and if I felt that I was starting to make mistakes, you know, I'd self-diagnose there and go, oh, you know, I just shouldn't be driving (RD01).</p>
How to meet needs	
<p>Participants with YOD and care partners identified areas of need to support driving and driving cessation, and strategies used to improve their outcomes. Topics included preparation, education, accessing information and supports, better driving assessments, alternative transport options and support groups.</p> <p>Dementia-specific groups were seen not only as a valuable source of information and support but as facilitating connections with others who have shared experiences. The need for such connections was identified by those living rurally, although the logistical challenges with organising this in isolated communities was acknowledged.</p> <p>Attention to acceptance of fitness to drive decisions through involving trusted people was also recommended.</p>	<p>if the early detection was perfected maybe there would be more time for people to get used to the idea that they're probably going to have—not be able to drive (CP010).</p> <p>I've been diagnosed with early onset Alzheimer's, what's my duty of care—to notify someone and who do I notify and how do I go about it? (RD010).</p> <p>you see, where we are we're so isolated it's, even if you arranged, ... where they can get together and, you know, ... that they're not alone, they're not the only ones that have had to do this, had to hand licences in ... but to do that you'd have to, like, arrange a bus or something to go around and pick up all the ones in the country to take them there ... it would be a logistics nightmare to organise all that ... (RD04).</p> <p>... so I think if you can say you can't drive and obviously be very empathetic, you know; this is awful, we know that it's terrible, these are the reasons why, but here's some things we're going to do to try and ease the burden of not having a driver's licence anymore (CP014).</p> <p>... it is very hard to get the person to accept it. For them to actually recognise that they have diminished in that capacity. That's where they need the support of people that, whose opinions they respect (CP012).</p>

partners, 'now he is 100 percent reliant on having somebody else take him' (CP010).

Care partners described a change in their own activities and roles following the person with YOD retiring from driving. One participant said 'there are lots of things that I can't do anymore because I have to work my life around his appointments' (CP010), also expressing a desire to participate in activities on their own, 'they say "stay and have a go" and I just politely said, "This is my respite... I don't want another activity that I have to do with my husband"' (CP011). However, this can only be achieved when there is suitable support available. 'I still try to get out and, you know, ... it is all very much reliant on ... have I got someone at home or nearby who can drive? Just in case something happens. Because if I've got no one then I can't go ...' (CP010). Some care partners experienced a feeling of guilt at pursuing activities outside of the carer role, 'it's a real escape for me. But I feel guilty every time I go because it's usually a day ... almost a whole day away ...' (CP011). The nature of providing transport support could be time consuming and tiring, 'it all gets a bit much sometimes' (CP012). Some care partners indicated they purposefully do not share the impact 'A lot of days it becomes an act. I say, I'm happy to drive you wherever you want to' (CP011).

Theme 2: 'Basically, everyone I know is at work'; the unique challenges of YOD

This theme included concepts related to the unique experiences of living with dementia according to a younger population. Individuals with YOD were comparing their own experience of life after driving to their expectations of what they thought their life would be like, as well as to what they thought the experiences of older people with dementia and peers who do not have dementia would be. The adjustment to finding ways to keep busy and people to socialise with during the day was challenging for people who led very active lives before driving cessation: '... the difficult thing for me is, I'm only 50—and I've been working since I was, you know, forever. And my circle of friends and workmates ... basically everyone I know is at work' (RD01).

The requisite change to daily life patterns seemed to be at odds with how participants thought retirement should work, as one person with YOD, currently driving, relayed, '... spontaneity is the thing, now we are retired, not being able to do what want to do when we want to do it, that will be a big change' (RD03), a care partner anticipating the impact of driving loss on her recently retired spouse 'I would hate him to be sitting watching Netflix 24/7. That would be quite tough for him but also it will be really tough for me' (CP017).

Loss of income and unplanned early retirement placed additional financial strain on individuals with YOD, limiting their ability to afford everyday travel expenses after driving cessation. Alternatives to driving were described as incompatible with continuing the preferred levels and patterns of activities and expectations for these participants with YOD,

'Occasionally I will get a taxi ... but of course there is still the cost involved ... and I can't afford \$40 a day on an aged pension' (RD08). Furthermore, community transport was not always an option because of costs and availability: '... it's expensive for one; two, you can't always get it when you want it ...' (RD08).

In certain situations, it was assumed that individuals with YOD would be capable of using public transportation since they may seem physically fit and healthy enough to do so. While some participants with YOD described easier access to public transport, they expressed a lack of confidence in using timetables and knowing where to get on and off and that 'catching a bus would be an anxiety nightmare' (RD01).

When public transport is not suitable and always relying on family and friends is not the preferred way to stay engaged in activities, people may elect to rely on transport from service providers. However, disappointment and frustration arose because of the unreliability of such an alternative to meet the greater transportation needs of people with YOD, 'Three weeks in a row I sat outside waiting for somebody to pick me up to take me to craft ... they just don't seem to care' (RD06).

For participants with YOD experiencing additional exclusion, including those living in rural locations, the impact of driving cessation was particularly arduous, as they did not have options available to others, and did not fit local services arranged around disability and aged care requirements. For example, age-appropriate support groups, 'I have no play friends ... and even when I go to the Alzheimer's Association and catch-up with them, I'd be the youngest' (RD01). The challenges of accessing services in rural locations was identified, 'out here, unless you jump on a kangaroo's back, you've got no public transport, and so you're relying a lot on friends and family, and they can't be there all the time because they've got their own things to do so you could go weeks just sitting at home' (RD04).

Theme 3: coping and adjustment

A major concern for all participants with YOD and care partners was a lack of available support for helping someone cope with the process of, and after, driving cessation. Key experiences to be navigated within the process included monitoring safety, decision-making, formal assessment and adjusting lifestyles.

Managing safety, navigating discussions and decisions

Importantly, safety concerns were commonly reported by participants with YOD in relation to making the decision to stop driving, 'being told to stop means you're probably not doing it very safely already' (RD010). Others cited a loss of confidence and anxiety as a precursor to cutting back or stopping, 'I often ask my children to take me, because of the stress of trying to find where I've parked my car—and navigating back and forward through a very unfamiliar environment becomes more difficult' (RD01).

For some participants with YOD, independently making the decision to stop driving was important, ‘I’d much rather give up driving than be told to stop ... it’s finding that right point’ (RD010), ‘I just made the decision ... I didn’t ask, I knew that I wasn’t safe on the road, so I just stopped’ (RD07). However, this decision to stop was often followed by a feeling of deep regret, ‘it was my decision to hand my licence in and, ah, I do regret it’ (RD04), hurt, ‘It really hurts, but I’ve done the right thing’ (RD06), and longing, ‘I made that decision on behalf of everybody else who’s got to drive on the roads ... you feel like your life has come at an end, because I sit at the front and watch cars go up the highway’ (RD04).

Discussions around driving and driving cessation were often fraught with emotion and some participants described arguments that arose when restrictions on driving were imposed by family members. One care partner participant recalled the ‘main tipping point’ as an argument with their grandson, who was involved in the decision-making and monitoring of driving, ‘and [RD] sort of had an argument with him and [Grandson] said, “No, you are not driving”. So ... he unscrewed this bottle of water and threw it at [Grandson], and then stormed off’ (CP010).

Despite the emotion involved, participants with YOD were mostly open to discussing driving cessation with family, friends and health professionals, but also acknowledged that whereas there are people they can talk to about it, there were few people to share the experience with, ‘Yeah, I’ve got, a psychiatrist ... who I see quite regularly. I’ve got counsellors who, I see quite regularly ... there’s [partner] and, my daughter, she cops an earbashing a fair bit. Both, yeah, there’s people around I can talk to but sometimes they don’t understand. That’s the thing. You know, you can tell them how you feel—but unless you’ve been there and— or doing that, you don’t know how that person is actually feeling ...’ (RD04).

Some people with YOD appeared to develop an eventual recognition and acceptance over time that the right decision was made, if recognition of the magnitude and meaning of the loss was present. As one care partner recalled, ‘he was probably scared and emotional and—and worked up. ... when we talked about it later, he was just like, “You know, I’ve driven so many miles all my life in trucks and tractors and headers and cars and things, you know, you can drive”’ (CP011).

The role and impact of assessment

A range of ways of monitoring and deciding about medical fitness to drive were reported. Some participants, those with YOD and care partners, described a strong belief that an individual’s driving fitness should be determined on a case-by-case basis and that removing a person’s licence upon diagnosis of a dementia, as some had experienced, was unreasonable, ‘immediately the doctor said “you have a dementia” then said “and you can’t drive anymore”, and it stopped overnight sort of thing’ (CP16). Although, not all agreed, as one retired driver with YOD indicated, ‘I think once you’ve

been diagnosed your licence should be taken off because you don’t know what your brain’s going to do next’ (RD04).

Despite a desire for individualised decisions, the impact of fitness to drive assessments was felt by drivers and care partners. The strangeness of the test, feeling unable to prepare for it and being scrutinised by two people were raised as adding to the difficulty of the experience. Being fully informed of the process of driving assessment was highly valued and may mitigate some of the anxiety felt, ‘the [assessor] who was going to do the test, was good and told me everything that had to happen ...’, which informed a decision to choose not to have an on-road test on balance. ‘I would never have gone through that ... I didn’t want to fail, so I just gave it up. ... a bit of pride here’ (RD06). Although this positive experience was not shared by some, as one participant with YOD framed it as ‘a horrible experience, really horrible’ (RD08). While others, elected to avoid the experience of an on-road assessment and embarrassment of potential licence cancellation by taking control of the decision to stop, ‘She wanted to do it on her own, on her own terms, not when someone else tells her she couldn’t do it’ (CP013).

Theme 4: how to meet needs

Accessing information and support

Challenges in accessing information and support were common concerns across both groups of participants. Regarding the legal responsibilities of driving following diagnosis, ‘it was very difficult because nobody tells you what to do and what your responsibilities are ...’ (RD010). Another participant stated they had no knowledge about services, supports and concessions and only became aware when they attended a YOD group, ‘Nobody tells you the support unless you get into a group like YOD group ... they said’, ‘Oh, have you got this card, and have you got that card?’ (RD050).

Some participants took on an active advocating role themselves within dementia-specific groups. As one participant with YOD described their role in supporting those who were newly diagnosed, ‘... we work with other people with dementia, who are newly diagnosed and just ring them on a regular basis and maintain a buddy system type thing’ (RD08). While another care partner participant spoke of advocating more broadly within the community, ‘[partner] is really passionate about making people aware that young people like him that look fit and healthy and strong can have, something like this and still be able to be out and about in the community’ (CP011).

Educating people about the effects of dementia on driving safety, so that people are more likely to accept when they should stop driving, was suggested, ‘if we had someone who listened to us and was preparing us for a diagnosis of early onset dementia ... people like us could have been – prepared perhaps’ (CP011).

Having a plan and a system of supports in place that facilitates continued participation in life and maintenance of hope before removing someone’s driving privileges was recommended, ‘so they don’t feel like you’ve just taken my

licence and now what am I going to do, you know? ... To give them hope instead of just sucking all the hope and leaving them with no tools, nothing' (CP014).

Given the impact of the lack of appropriate transport, people would benefit from supports for building transport skills, continued community participation and providing feedback to improve transportation. Care partners, whose lives may also be significantly disrupted, discussed the need for person-centred approaches to finding and trying out alternative transports, 'don't just give someone a brochure and hope they read it ... you've got to have a program organised too' (CP013). The potential benefit of practicing alternative transports in a supported way was highlighted, 'I could probably learn how to call a cab or an Uber and practice it and write notes and do that, and then I'd probably feel quite confident ... get my children to write notes for me to say, so you phone this number or you save that URL and get the app on your phone and—do this and this' (RD01).

Discussion

Previous research has explored the unique social challenges and issues for people living with YOD and their families, and this study focused on those related to driving and driving cessation. In addition, we were interested in what lived experience experts perceived as acceptable ways of supporting those needs.

The critical role that driving plays in individuals' identity, lifestyle and independence can be seen in participants' grieving for their former driving role. The negative emotions associated with changes in driving status may become so intense for individuals, placing them at a greater risk of worsening of depressive symptoms and preoccupations with death and suicide. Families also struggled with the perceived and experienced burdens and role changes required by driving cessation. Research with older people living with dementia indicated the vital and challenging roles of families, and the consideration of the relationship and family within supports [20, 21].

While there are shared aspects of driving cessation in terms of challenges and needs with older people with dementia [3, 7, 22], and groups experiencing driving cessation (e.g. TBI) [23], there were some unique experiences related to driving changes with YOD. Participants with YOD spoke about how the ability to drive was strongly tied to identity and how they believed others perceived them, along with substantial fear and stigma related to even discussing driving issues. Importantly, participants indicated that because of their age and patterns of participation, changes to driving were linked with immediate changes to activity levels, participation in essential and valued roles and social exclusion. For younger people who may be navigating work, family responsibilities and unplanned financial changes—this may precipitate their feeling of not being part of society or not sharing experiences with their peers [12, 14, 24]. Participants with YOD described not feeling part of their peer group and also not feeling part of dementia-specific social or service-related networks. It is well known that once

diagnosed, people with YOD may lose friends [25], driving cessation may then have a compounding effect on people's social connectedness since they can no longer easily access the community or participate socially if they rely on family who may still be working themselves. Given that driving cessation has a documented impact on social identity, perceptions of self and ageing, and social isolation [2, 26], this indicates an important need in supporting people with YOD and their care partners with driving cessation. Specialised and individualised supports to maintain identity, maintenance of peer networks and creation of new ones are indicated.

Getting out and about in the community is important for the well-being of people living with dementia, and having access to suitable transport options is crucial in supporting this [27]. Considering these needs, along with the isolation and lack of belonging felt by participants, in creating support services, including transportation support is recommended. Future developments in transportation technologies, for example, may support this group, if their needs are considered in their development.

While the safety considerations identified in research and policy [15] were acknowledged by participants, the vexed issue of assessing fitness to drive was also raised as a major concern within the driving cessation process. Participants indicated that blanket cessation of driving because of diagnosis was not generally welcomed, as is supported by local and international guidelines [15, 28]. However, many noted a lack of acceptance, perceptions of unfairness and high levels of stress related to in-office or formal on-road testing of driving ability. It may be impossible to find a way of getting clear perspectives on personalised fitness to drive that is acceptable to everyone, and the perception from some participants with YOD that they will know when they are unsafe is not supported by road safety research [29–31]. However, the importance of clear communication, support during the process and compassionate engagement is needed and valued. Support for families and health professionals to encourage them to have the difficult conversations [3, 32, 33], including sharing the grief and loss and intense emotions seems necessary.

This research indicates that it is possible that while generally improving supports for people who cease driving for any reason and at any age might help this group, it is likely that some specialised supports are required. Age-appropriate support programmes are required to support social needs of people after driving retirement, a recent international Delphi study identified this need more generally in terms of care programmes [34].

People living with YOD indicated that peers or people in their cohort were wanted to share the emotional aspects, to spend time with and to exchange strategies and ways of getting things done. Given that a diagnosis of dementia may occur close to the time of driving cessation for people with YOD (or in some cases, at the same time), support for dementia literacy and life planning at this time may be valuable. People living with YOD and their families may benefit from clear information about legalities and responsibilities, nature of changes to driving performance

related to dementia and strategies for feeling comfortable with the decision, or adjusting to it over time. Support to learn how to use alternative transport and to find ways to preserve engagement with social networks, valued roles and out of home activities and responsibilities are needed. Additionally, ways to contribute to improving things for others in the future were also raised by some participants. The existence of driving cessation programmes with other groups (e.g. [7, 35]) may provide a useful scaffold, along with these findings, to co-adapt the programme with people living with YOD, their care partners and supporters.

Strengths, limitations and future directions

An important strength of this study is that it draws on a range of lived experience, integrating the perspectives of people with YOD who are driving or have stopped driving, and care partners of persons with YOD. This study also had an even representation of the perspectives of male and female driver-/retiring drivers with YOD. A limitation is that this study did not include non-English-speaking participants. Future research should explore the perspectives from a culturally and linguistically diverse group of participants.

Conclusions

The findings demonstrate the wide-ranging impact that driving changes may have on an individual living with YOD and care partners. These lived experience perspectives highlight that driving disruption and driving cessation support are a critical period of need for people living with YOD and their support persons. For younger people with dementia navigating work, family responsibilities and unplanned financial changes, feelings of fear and uncertainty about their future may be intensified by driving cessation-related life changes and associated perceived devaluation.

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