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Young onset dementia and driving cessation: a scoping review of lived experiences

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Abstract

Background Driving cessation is one of the most challenging life transitions, associated with multiple negative consequences for individuals living with late-onset dementia. This paper extends the literature as to date there is no published review that details the experiences of people living with young onset dementia (“YOD”).

Methods A comprehensive search of the literature was conducted using the scoping review methodology.

Results Ten studies were included for full text review of 1634 initially identified through database searching. The results of the included articles indicated areas of concern for people living with YOD and their family members including, loss of independence; role change; threat to self-identity; feelings of isolation, grief; acceptance; predictors of driving cessation.

Conclusion There is a lack of robust evidence related to driving cessation and the experiences of people living with YOD. No published paper reported psychosocial interventions specifically targeted at supporting persons with YOD through driving cessation.

Keywords Driving, Driving cessation, Young onset dementia, Scoping review, Lived experience, Intervention

Introduction

Dementia causes progressive impairments to memory, executive function, motor skills, attention, and other cognitive functions that are essential for safe driving [1]. As such, driving cessation is an inevitable consequence of a dementia diagnosis [1]. Research has demonstrated that for older people living with a dementia diagnosis, driving cessation is a challenging life transition, associated with multiple negative consequences for individuals, including increased risk of depression, anxiety, loneliness, and isolation [2].

Driving is an important instrumental activity of daily life for older people [3], a way to access services and social activities [4]. People with young onset dementia (diagnosed before age 65 years, “YOD”) may be uniquely affected by driving disruptions given their relatively greater financial, occupational, and familial responsibilities [5, 6]. That is, driving cessation may impact an individual’s continued employment or ability to contribute to household chores.

Without access to transportation, individuals with dementia may become increasingly isolated and reliant on family members or caregivers for transportation, which can limit the person with YOD’s ability to maintain their social connections and engage in activities outside the home. Social isolation can lead to a decline in physical and mental health, including increased depression and anxiety, and more rapid cognitive decline [7]. Therefore, supports needed to address these unique challenges are likely to be different to those provided for older people.

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The predominance of research to date has focused on older people living with dementia [8, 9] and these data lack applicability for young people with dementia. Understanding the unique lived experiences of people with YOD confronting driving cessation may guide design and delivery of age-appropriate support programs. The aim of this review was to synthesise the available literature to identify what is known and what is not known about the lived experiences of people with YOD and their care partners when confronting driving cessation, and to explore the availability of interventions to support driving cessation in this population. Our research questions were:

- What are the lived experiences of people with young onset dementia and their care partners/family members regarding driving and driving cessation?;
- What is the available evidence for the effectiveness of psychosocial programs to support people living with young onset dementia and their care partners when giving up driving?

Method

Information sources and search strategy

A comprehensive search of the literature was conducted using the scoping review methodology prescribed by Arskey and O'Malley [10] to gain an understanding of the research that has been conducted to date. A search strategy was developed to identify studies about driving cessation among people with YOD. The search was conducted in December 2022, and updated in December 2023, in MEDLINE, CINAHL, PsycINFO, Scopus, ProQuest, the Cochrane Database, and Google Scholar. Reference lists of all included papers were hand-searched for additional records. The following search terms were used:

("Dementia" OR "Alzheimer" OR "frontotemporal" OR "Pick" OR "Lewy*" OR "semantic" OR "cortico-basal degeneration" OR "progressive supranuclear palsy" OR "progressive aphasia" OR "cognitive impairment")*
 AND
("Young" OR "Young* onset" OR "Early onset" OR "presenile")*
 AND
"Driv" OR "driving cessation" OR "driving retirement" OR "transport" OR "mobility".*

Eligibility criteria

This review included English-language papers published since 1998, reporting research investigations or evaluation examining experiences related to driving cessation that include or are written by people living with young

onset dementia and/or their care partners/family members. We kept the breadth of sources broad because our initial scoping search revealed a lack of research in this area. Systematic and other literature reviews, study protocols, opinion pieces, and papers not available in English were excluded.

Study screening and data extraction

One author (BWH) screened all titles identified by the searches and removed irrelevant papers. Two reviewers (BWH and BK) screened abstracts and full texts for eligibility based on the criteria previously described. Disagreements regarding inclusion were resolved upon discussion of two reviewers. In total, 10 papers met the criteria and were included in our review (see Fig. 1).

Two reviewers (RJ and TM) extracted the data using a data extraction spreadsheet that was piloted with five papers before finalisation and continuation with the remaining papers. Independently extracted data was cross-referenced for accuracy, and disagreements between authors were resolved by checking with a third author (TS). Extracted data included first author, title, year, country, study aim, study design, number of participants, participant details, data collection method, intervention or activity assessed (if applicable), outcomes reported, results, and conclusions. We planned a narrative approach to presenting the results, given a great degree of variation in designs and heterogeneity in the outcomes across the retrieved studies. To achieve this, we used content analysis procedures, focusing on extracting relevant data, grouping them together by meaning, and synthesising them into coherent, consistent, relevant, and clearly defined themes. To ensure rigour of the data extraction, data charting, and theme identification process, the research team convened regularly to discuss and resolve any ambiguities.

Results

Identification and selection of included studies

A total of 1631 records were retrieved through database searching and three records were identified via reference list review. A total of 1226 records were retained for screening after duplicates were removed. Following title and abstract screening, 44 articles remained for full text review. A total of 34 articles were excluded because they did not meet the inclusion criteria as shown in the Fig. 1 PRISMA flow diagram [11]. Ten studies met all criteria. Papers included qualitative descriptive studies ($n=9$), and retrospective record reviews ($n=1$). Papers were from the United Kingdom ($n=5$), the United States ($n=1$), Australia ($n=2$), Sweden ($n=1$), and Italy ($n=1$). Year of publications spanned from 2004 to 2023. These

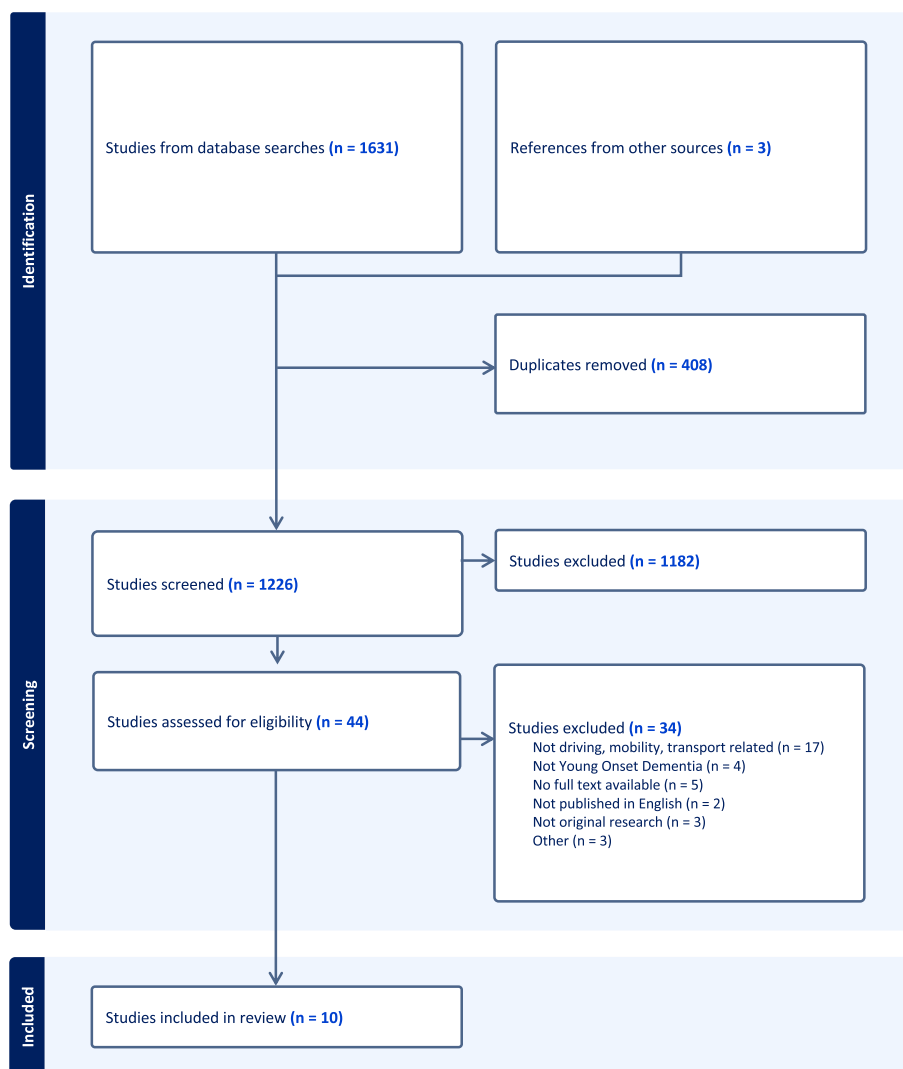


Fig. 1 Flow diagram showing identification of studies for inclusion in this review according to PRISMA guidelines [11]

studies included 248 participants in total, although only two studies, focused specifically on driving cessation.

Characteristics of included studies

Table 1 summarises key characteristics for all included studies. Of the ten included studies, two focused specifically on driving. The remaining eight examined the broader lived experiences of individuals with YOD, including the impacts on their social, occupational, and daily lives, as well as on the family members of individuals with YOD. Although driving and driving cessation were not the main focus of these studies, the data extracted from them highlighted driving cessation as a significant challenge post-diagnosis. The results indicated the following areas of concern for people living with YOD and their family members: loss of independence; role

change; threat to self-identify; feelings of isolation, grief; acceptance; and predictors of driving cessation. Loss of independence was commonly reported as being of most concern across the included articles.

Loss of independence

People living with YOD report that they require support from family and friends to assist them in their daily activities once they have ceased driving [12, 15, 16, 19, 20]. Studies reported loss in relation to no longer being able to drive, losing independence and becoming reliant on someone for driving, which was a significant challenge to individuals as well as their family members who must take over driving [15, 16, 20]. Former drivers face significant challenges in accessing their communities when they must rely on a partner or family member for transportation.

Table 1 Summary information of included studies

Author, year, country	Aims	Design	Sample size and characteristics	Data collection method	Outcomes reported	Results	Conclusions
1. Beattie et al., 2004 [12] United Kingdom	Demonstrate how interviews can be conducted with younger people with dementia	Qualitative, cross-sectional descriptive	N= 14 Participants under 65 years of age who were using services and had received a diagnosis of dementia (36% female)	Semi-structured in-depth interviews	Subjective experiences and perceptions of people with young onset dementia	Four themes were derived from the data: (1) the general experience of having dementia; (2) dementia diagnosis; (3) the importance of age; and (4) risk and danger issues. The risk and danger issues theme included discussions about driving. There were apparent tensions between professionals' and carers' reported perceptions of risk and danger in relating to driving, and the desire of those living with YOD to maintain independence	Currently, risk appears to be defined by health and social care professionals, with little or no involvement of the younger person with dementia. Moreover, assessment of risk is fraught with complexities. The findings of the present study supported previous assertions that driving capabilities in people living with YOD require an interdisciplinary approach. Involving younger people with dementia in the process of defining risk may contribute considerably to this area of risk assessment and management. Ultimately, this may lead to a service that improves their lives by allowing these individuals to remain autonomous for as long as possible, as opposed to reducing opportunities to be independent and travel based on flawed perceptions of risk and danger

Table 1 (continued)

Author, year, country	Aims	Design	Sample size and characteristics	Data collection method	Outcomes reported	Results	Conclusions
2. Chirico et al., 2021 [13] Italy	To understand how family and social relationships are affected by YOD to provide adequate care and services designed upon both patients and family's needs, and to be able to provide recommendations that inform clinical practice and service improvements from a family perspective	Descriptive (qualitative interviews)	N= 38 Family carers who had a relative with a YOD diagnosis of any type (26 Spouses, and 12 adult children) (68.4% female)	Semi-structured interviews	Subjective experiences of family members living with and caring for a person with YOD	It was reported that people with YOD had trouble accepting their condition and difficulty in seeking help. Further, there was a lack of information regarding where participants could obtain help, for those who did receive such information, they found that services were not equally distributed, with no dedicated transport to attend these services Additionally, a change in family roles was reported when a person with YOD stopped driving, and their partner may have had to assume a new role such as driving their children to school	Family relationships were significantly challenged due to dementia and delays in diagnosis increased family conflicts. Family members described lower quality of relationship, increased social isolation and loneliness, and increased dependence of the person living with YOD, with a gradual shift of roles and responsibilities. The psychosocial consequences are broader and less evident than in late-onset dementia, such that effective support and care should be based on a 'whole family' approach. Greater public knowledge and understanding about YOD, involving mass media, might contribute to avoid family self-isolation while promoting social connectivity, increased support at the policy level, and better emotional and practical support

Table 1 (continued)

Author, year, country	Aims	Design	Sample size and characteristics	Data collection method	Outcomes reported	Results	Conclusions
3. Clemerson, Walsh, & Isaac, 2014 [14] United Kingdom	To provide an exploration of individuals' subjective experiences of young-onset Alzheimer's disease	Descriptive (qualitative interviews)	N= 8 Participants under the age of 65 years diagnosed with Alzheimer's Disease (12.5% female)	Semi-structured interviews	Subjective experiences of young onset dementia	Four themes and ten sub-themes emerged. (1) Disruption of the life-cycle, (1.1) am too young, (1.2) Loss of adult competency, (1.3) Reviewing life expectations, and (2) Identity, (2.1) Alzheimer's disease: a threat to self, (2.2) Holding on, (2.3) Redefining self, and (3) Social orientation, (3.1) Disconnection and isolation, (3.2) Reconnecting, and (4) Agency, (4.1) Powerlessness and loss of agency, (4.2) Regaining control. The themes represented participant's lived experiences and ways of coping with AD, and a disruption to an expected life cycle. Driving was raised under theme 2.2. Participants used techniques that minimised past skills and placed greater importance on preserved skills, adjusting to and compensating for losses and directly denying change. Specifically, changes around having to give up driving and how hard that change was, even for someone who never had great driving abilities, were noted	The experiences of living and coping with young onset Alzheimer's disease (AD), where there is a socially constructed concept of the individual's sense of their predicted life trajectory, and ability to achieve specific age-related goals were limited and as such disrupted life-cycle expectation. The coping strategies identified, such as re-stabilizing self, reconnecting with others, regaining control and reviewing life, helped with regaining a sense of feeling competent at typical mid-life tasks. Younger people with AD felt too young to be living with dementia and their strategies to cope were conceptually different to those in older age groups. There was need to develop specialist services for younger people with dementia, and opportunities for where this population can continue to contribute to wider society, helping to fulfil expected age-related tasks

Table 1 (continued)

Author, year, country	Aims	Design	Sample size and characteristics	Data collection method	Outcomes reported	Results	Conclusions
4. Griffin et al., 2016 [15] United Kingdom	To elicit the views of people with behavioural-variant frontotemporal dementia ('FTD') regarding their experiences of living with this diagnosis	Descriptive (qualitative interviews)	N= 5 People with a diagnosis of probable behavioural-variant FTD (Ages 46–62, 40% female)	Semi-structured interviews	Subjective experiences and perspectives from people with probable behavioural-variant FTD	<p>Bewilderment and relationship to others were two themes that emerged from the various interviews. Within these two themes, there were three main categories related specifically to driving; (1a) <i>Bewilderment – Awareness of change</i>: One participant described their previous love of driving and their multiple cars in relative detail in relation to his explanation of not driving anymore</p> <p>(1b) <i>Bewilderment – Threats to self</i>: Another participant reportedly was accepting of their diagnosis and medications but seemed to experience a threat to their sense of self/independence from the impact of losing their driving licence</p> <p>(2) <i>Relationship to others – Coping with threats to self</i>: another participant reported difficulty in losing their driving licence. The difficulty was not on a practical level, but rather on an emotional level, as they explained that getting around by bus was easy for them. Stopping driving was difficult for them due to feeling reliant on others especially given that they did not perceive their driving ability to be compromised by dementia. The same participant also gave a detailed descriptive account of failing a driving assessment, rationalising that their driving was merely 'different' to how other people drive 'these days'. The same participant also didn't believe the assessors were qualified to make a judgment about licence removal, as they were not medically qualified</p>	<p>The article explored the subjective experiences of those living with FTD.</p> <p>Two main themes were discovered, <i>Bewilderment</i>, which reflected how participants presented with an awareness of changes in their lifestyle and behaviour, and <i>relationships with others</i>, which reflected the difficulties that occurred with participants having to rely on another person.</p> <p>Regarding driving, more often acceptance of driving cessation was impacted by a love of cars, a loss of independence, and feeling unfairly assessed and blaming others for licence removal</p>

Table 1 (continued)

Author, year, country	Aims	Design	Sample size and characteristics	Data collection method	Outcomes reported	Results	Conclusions
5. Harris, 2004 [16] United States of America	To explore lived experiences of persons with YOD and to give voice to their experiences	Descriptive (qual interviews + focus groups)	N= 23 Younger individuals (<65) with dementia (57% female)	Focus groups, face-to-face interviews, and online interviews	Participants experiences of living and coping with YOD	Three themes emerged from the participants narratives: (1) Issues of self-hood and self-esteem; with multiple aspects of people's identity affected, including no longer being able to drive. (2) Changing relationships within an entire family structure, i.e. a ripple effect occurred throughout the family due to the diagnosis occurring at such a time in the family lifecycle, where the participants held multiple roles within the family, e.g., partner, adult to young children, child to aging adult, etc. (3) Off-time dependency: especially in western society, i.e. where it is judged harshly for an adult, under 65yrs old to be seen as dependent on another	Due to their stage in family life cycle and younger age, people with YOD have additional stressors. The ramifications of dementia on their family members and themselves are known to younger adults; there is also a need to discuss these concerns with their peers

Table 1 (continued)

Author, year, country	Aims	Design	Sample size and characteristics	Data collection method	Outcomes reported	Results	Conclusions
6. Hutchinson, 2018 [17] Australia	To improve understanding of the societal influences impacting individuals living with a cognitive impairment under 65 years and their family members	Descriptive (qualitative interviews) (Doctoral dissertation)	N= 35 People living with YOD (5), spouse caregivers (6), children and young people in families (17), and health and social care providers who had experience supporting families living with YOD, including children (7)	Semi-structured interviews	Lived experiences of individuals with YOD and family members	Chapter 6 concluded that the creation of a family-focused services model would allow for the family unit to live and function well together during the dementia progression, and it would enable participation and engagement in the community. In this chapter, one participant reported feeling a disconnect from her family. She spoke about the loss of meaningful activities and a feeling of connection related to her historical place within the family due to having a suspended licence	A common theme found throughout this Doctoral dissertation research was a lack of understanding and significant unmet needs for people living with YOD and their families, where it was considered that the social model of disability might contribute to reframing the way people consider dementia and thus drive social change. In Chapter 6, the impacts of YOD on the family unit were discussed and the need for greater social inclusion, societal acceptance and enablement were highlighted. Further, poorer family relationships and stress were linked to negative outcomes for families adapting to dementia, ineffective communication, and a lack of connectedness for all family members, compounded by a lack of information and formal support

Table 1 (continued)

Author, year, country	Aims	Design	Sample size and characteristics	Data collection method	Outcomes reported	Results	Conclusions
7. Johannessen & Möller, 2013 [18] Sweden	To find out how people experience living with early-onset dementia, and to assess the implications for practice and the development of further services	Descriptive (qualitative interviews)	N= 20 Persons with YOD (40% females)	Qualitative interviews	Subjective experiences of living with dementia	Intrapsychic challenges emerged as a theme regarding driving, i.e., the sadness of losing a licence, or the idea of one day losing a licence was a great loss to many of the participants. They had either felt too unsafe to drive or had been told by someone that they should no longer drive. They complained about no longer being able to participate in various activities due to being restricted from driving. While others felt an unease about driving, however, continued to drive in a more cautious and focused manner. There were reports of others avoiding high traffic areas, or adjusting to the change and relinquishing the driving role to a spouse. A feeling of hopelessness was described by some in relation to no longer being able to drive	Participants described the experiences and changed they had with living with a dementia diagnosis. This included various losses, e.g., becoming a non-driver, issues that restricted them from the types of activities they wished to participate in, and no longer having the opportunity of going to work, nor daily contact with colleagues. Participants also experienced issues of feeling like they were no longer apart of society, and unable to keep in touch with the current society. These varying degrees of loss also included the sense of general awareness around driving and lack of understanding of driving assessment scores, as a result of the disease

Table 1 (continued)

Author, year, country	Aims	Design	Sample size and characteristics	Data collection method	Outcomes reported	Results	Conclusions
8. Papon-Young et al., 2012 [19] United Kingdom	To develop an action plan based on a problem or problems identified by people with YOD	Descriptive (qualitative interviews & discussion groups)	N= 8 Diagnoses of YOD was > 6 months ago	Qualitative interviews and discussion groups	Experiences of living with dementia	<p>Eleven themes were generated from analysis of transcripts. Only one theme related to driving, i.e., (1) Age-related difficulties. One participant felt that there were strong significant differences for people diagnosed with dementia before 65 years old, compared to those diagnosed at an older age. Due to differences in commitments, such as loss of employment, income, and driving, leading to changing roles and responsibilities, e.g., for their children</p>	<p>The findings suggest that the perception that life was over following diagnosis needs to be changed, and an incongruence of people receiving a dementia diagnosis was often associated with those in their 80s was discussed. However, driving was only mentioned briefly, discussing the differences between being diagnosed under 65 years old versus being diagnosed at an older age</p>

Table 1 (continued)

Author, year, country	Aims	Design	Sample size and characteristics	Data collection method	Outcomes reported	Results	Conclusions
9. Scott et al., 2023 [20] Australia	To explore the lived experiences and expressed needs of people living with YOD who are adjusting to life without driving	Descriptive (qualitative interviews)	N= 18 People living with YOD (10) and care partners (8)	Semi-structured interviews	Lived experiences from persons with YOD and care partners of persons with YOD	Four themes were generated from the analysis of transcripts across both people living with YOD and care partners of those living with YOD, these include: (1) losses and burdens, (2) the unique challenges of YOD, (3) coping and adjustment, and (4) how to meet needs	The findings suggest there is a large range of impact that occurs to persons living with YOD going through driving cessation, and on their care partners. Their lived experiences show that this critical time period, of driving cessation, requires support, education, and programs, which are currently limited, specifically for persons with YOD. Additionally, that persons with YOD have a specific set of difficulties due to their younger age, such as family responsibilities, financial challenges, and navigating work intensified by the life changes associated with the cessation of driving

Table 1 (continued)

Author, year, country	Aims	Design	Sample size and characteristics	Data collection method	Outcomes reported	Results	Conclusions
10. Velayudhan et al., 2018 [21] United Kingdom	To determine the prevalence and factors affecting driving cessation in individuals with and without dementia aged under 65 years	Chart review	N = 225 total (79 YOD) Patients aged less than 65 years assessed at the Younger Person's Memory Service (YPMS) within the Mental Health Service for Older People from 2000–2010, (females = 25% of total group, 39% for YOD group)	Semi-structured interview to assess cognitive functions, functional abilities, and behavioural symptoms, neuroimaging, Participants or carers providing information regarding driving cessation	Frequencies, descriptive statistics related to driving cessation	40.5% (32/79) of people with YOD stopped driving. Most did so voluntarily (27/32, 17 women, 10 men. 59.4% of people with YOD who stopped driving were women 25.5% of people with YOD who continued driving were women $p < 0.001$). No association was found between driving cessation and alcohol use ($p = 0.253$, $\chi^2(1) = 5.36$), current smoking (0.658, $\chi^2(1) = 3.27$), head injury ($p = 0.345$, $\chi^2(1) = 2.13$), presence of anxiety symptoms ($p = 0.44$, $\chi^2(1) = 0.61$) or depressive symptoms ($p = 0.82$, $\chi^2(1) = 0.05$) YOD and driving cessation was found to be partially mediated by deficits in praxis (0.7536, 95% CI 0.1834 – 1.401, $p = 0.0099$) and less impaired comprehension (-0.59 , 95% CI -1.23 — -0.119 , $p = 0.024$)	Women were found to be more cautious and more easily persuaded to stop driving by health professionals and/or family, whereas men tended to believe they were more competent to drive fearing the loss of independence, they felt it was more shameful to admit an inability to drive – hence less likely to cease driving A significant predictor of driving cessation in people with YOD was a deficit in praxis People with less impaired comprehension (i.e., those who were more aware of their safe driving capacity) were more likely to stop driving

This loss of independence is particularly pronounced in rural and regional areas, where scarcity of public transport exacerbates the challenges [13, 20].

Additionally, decisions about driving and stopping driving might be imposed on the person living with YOD, such as when health professionals' or care partners' main focus was on issues of risk and danger. It appeared that such risk assessments were not always conducted with a client's best interests in mind. For example, some individuals may lose their independence earlier than necessary – be it driving privileges or lone public transport travel – due to proxy assessments deeming it 'too high risk,' potentially reflecting stigma-related biases [12, 13, 20].

Role Change

The changes in roles after driving cessation affected both the person living with YOD and their family member [12, 13, 15, 16, 18–20]. These studies emphasise the unique challenges of giving up driving for people living with YOD, highlighting that their needs are vastly different from those of older adults. They emphasised that younger individuals face the loss of employment, and income alongside increased stress due to responsibilities such as caring for children, managing a mortgage, and running a business.

Dependency on a partner who is still driving, difficulties with adjusting to being a former driver, and allowing a partner take over the driver role were added challenges for people living with YOD and their partners [13, 16, 18]. When a person with YOD ceases driving, it can increase the caregiving tasks of their family members. Additionally, people with YOD may find it extremely difficult to no longer contribute to running the household, such as by driving their younger children to activities [16, 19, 20].

Threat to Self-Identity

Self-identity may be disrupted after driving cessation for people living with YOD [14–16, 20]. People with YOD struggled with losing their own identity and saw themselves as no longer being a productive member of society after licence removal [16, 20]. Scott and Colleagues [20] report how care partners perceive the impact on the self-identity of individuals who have had to quit their job due to a driving disruption. As one care partner described how the removal of their mother's licence affected their mother's ability to maintain her own small business, and how losing her small business, "was like her losing part of her identity" [15, daughter, p.4]. Another described their care partner's identity loss in terms of 'masculinity,' stating, "when him and I went into [licencing 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]"... he said "and now you've gone

and cut off my balls." – "that's just the way he felt" [15, wife, p.4].

One way to cope with the threat to identity and regain a stable sense of self may be through cognitive dissonance, by downplaying the importance of driving or one's driving capabilities, to divert blame away from the disease itself. For example, if a person did not pass their fitness to drive assessment, they might attribute it to outdated driving techniques they were taught, rather than the disease itself [14, 15].

Feelings of isolation, grief

Once people living with yod ceased driving, their activities were considerably reduced, which created feelings of isolation [17, 18]. The inability to independently get to places diminished people's social lives, leaving them feeling isolated [8, 18]. For persons living in rural areas, driving cessation can result in feelings of isolation and a sense that the person's life has ended. Studies described participants experiencing a profound sense of loss and disconnection from their communities and families. While families may be at work all day, these individuals are often sat at home, alone, watching cars pass by [17, 20].

Feelings of grief followed driving cessation for some individuals with YOD according to included studies [18, 20]. The forfeiture of a driving licence, or even the idea of it, was described as experiencing a great loss. Grief was sometimes mentioned when discussing the decision to give up a driver's licence [18, 20]. Participants may have accepted that they felt too unsafe to drive or they may have been told by someone that they should no longer drive, but after driving cessation, nevertheless experienced feelings of sadness and hopelessness at not being able to continue [18, 20].

Accepting a diagnosis of YOD

Accepting a diagnosis of YOD can be especially hard for younger people due to the belief that dementia is an older person's disease; this can affect how people's driving cessation journey can differ. For example, if someone does not accept their YOD diagnosis, they are more likely to continue driving without recognising the risks, making the process of driving cessation more challenging for both them and their family members. For example, "It took over 1 year before we sought help. He didn't accept the condition, he still used to drive" [17, wife, p.2245].

Predictors of driving cessation

Women were found to be more cautious about driving and more easily persuaded to stop driving by health professionals and family members, according to one study where 59.4% of people living with YOD who stopped driving were women [21]. Whereas men tended to believe

that they were more competent, fearing the loss of independence, and felt it was more shameful to admit their inability to drive – hence were less likely to cease driving according to Velayudhan and colleagues [21]. A significant predictor of driving cessation in people living with YOD was a deficit in praxis. People with less impaired comprehension (i.e., those who were more aware of the limits of their driving abilities) were more likely to stop driving.

Programs to support people living with YOD through driving cessation

Our second question was “What is the evidence for the effectiveness of psychosocial programs to support people living with young onset dementia and their caregivers when giving up driving?” We found little evidence across the retrieved articles of supported psychosocial programs that directly addressed the emotional challenges of driving cessation or offered alternative transport services, for people living with YOD. Additionally, Chirico and colleagues [13] reported a lack of professional services providing the types of needed information for services to persons with YOD/care partners. Elaborating that it appeared to be by chance whether patients and care partners were given such information. Additionally, there were issues with some services being unequally distributed across cities, or not being available at all in places, which meant that persons with YOD had to rely solely on family members/care partners for transport in the absence of such dedicated transport services.

Scott and colleagues [20] found it challenging for both care partners and persons with YOD to access information and support programs after diagnosis [20]. Care partners raised the need for person-centred approaches to support, rather than information leaflets, which were considered less useful [20]. Peer-to-peer support for driving cessation was highlighted as especially helpful. For example, a buddy system and regular telephone contact with someone who has already experienced the process of driving cessation could provide valuable support for those newly diagnosed who have to stop driving.

Discussion

This scoping review sought to determine the experiences of people living with YOD and their care partners regarding driving and driving cessation. Additionally, we sought to assess the evidence for the effectiveness of psychosocial programs to support people living with YOD and their care partners when giving up driving. This was the first paper to synthesise the experiences of people living with YOD directly related to driving cessation. Given that only ten studies were included, with only two studies that focused specifically on driving cessation, this

review highlights the narrow scope of research that has been conducted about the experiences and needs of people with YOD. Further, the review identified no existing interventions to address the challenges of driving cessation that are specifically targeted for people with YOD.

The analysis of our first question revealed some common experiences related to driving cessation for people living with YOD, including loss of independence, change in family role, threat to self-identity, feelings of isolation, acceptance, grief, and predictors of driving cessation. These findings are consistent with research relating to older people with dementia, where driving cessation was associated with significant declines in physical and social functioning, and poorer physical and mental health outcomes [22]. Driving cessation is consistently cited as one of the most challenging milestones in the lived experience of dementia, representing a profound shift in the breadth of everyday life [23, 24]. The accessibility of transport alternatives varies and is affected by the infrastructure available in the person's location, their financial means, availability of formal and informal care, and other factors [25]. As such, the impacts of driving cessation can be inequitable and disproportionately burden those already at risk for poorer outcomes.

While similar issues and challenges related to driving cessation have been raised by older people with dementia, the circumstances, and contexts for people with YOD are unique. Anosognosia (i.e., lack of insight) and impulsivity, which are common in forms of dementia that emerge in midlife, pose major risks for driving safety [26]. This lack of insight can make it difficult for individuals to understand the necessity of stopping driving, leading to conflicts and additional challenges for family members. Consequently, driving cessation further disrupts the family dynamics, compounding the grief associated with a diagnosis of YOD. Younger people with dementia generally experience symptom onset at a time of high professional, familial, and financial responsibility [27]. Driving cessation can be a barrier to employment and early workforce departure is a source of major ongoing financial burden for the person with YOD and their family [28]. People with YOD may have caring responsibilities for both children and ageing parents, and inability to drive limits the caring contributions that can be made. These care responsibilities may then compound on the person with YOD's primary caregiver (e.g., their spouse). As such, driving cessation should be understood as a contributor to the whole-family burden that more commonly occurs for people with YOD than for older people with dementia [29].

In relation to our second question, we found no evidence of psychosocial programs for specifically targeted toward people living with YOD for driving cessation.

However, there are general programs available, including self-guided resources [30, 31], decision-making tools for stopping driving [32, 33], and care-provider delivered interventions to facilitate driving retirement for older people [34] and older people living with dementia [8]. Despite the recognised importance of addressing the unique social challenges of people faced by people with YOD [5, 6], there is a lack of studies that have specifically addressed the supports and services needed to facilitate the transition from driving to non-driving in this population.

Strengths and limitations of the scoping review

Given the limited research available on this topic thus far, we deliberately maintained broad search parameters to encompass a wide range of studies, irrespective of their specific focus or research design, with the objective of capturing all related literature. This review highlights the lack of empirical evidence on the lived experience of people with YOD and their family members. For example, only two of the included studies focused exclusively on driving, however only one of these captured lived experiences, the other was a chart audit of prevalence and factors affecting driving cessation. In addition, it is important to note that the results presented for ‘accepting a diagnosis of YOD’ and ‘predictors of driving cessation’ are each based on findings from a single study. A further limitation may be that, by excluding non-English articles, we have missed research findings, perspectives, and cultural nuances relevant to the objectives of this review.

Conclusion

To date, the majority of research on driving cessation has primarily focused on older people with dementia, which may overlook the unique lived experiences of people with YOD. More comprehensive research is needed to inform the development and implementation of support programs tailored to the specific age-related needs of people with YOD.

Abbreviations

YOD Young onset dementia

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Authors' contributions

TLS and MC designed the study. BWH accessed databases and performed the initial search strategy. BWH and TLS assessed retrieved articles for eligibility and quality. and BWH assessed quality, TLS, RJ and TM performed data extraction. All authors contributed to the writing and editing of the manuscript.

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Availability of data and materials

All data generated or analysed during this study are included in this published article and its supplementary information files.

Declarations

Ethics approval and consent to participate

Ethical approval from a Human Research Ethics Committee was not sought as this was a scoping review of the published literature.

Consent for publication

N/A.

Competing interests

The authors declare no competing interests.

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