

Research Article

The Paradox of Dementia and Driving Cessation: “It’s a Hot Topic,” “Always on the Back Burner”

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Abstract

Background and Objectives: Despite the well-recognized difficulty that persons with dementia and family carers experience in the decision making and transition to nondriving, there are few interventions and resources to support them. As part of our ongoing research to develop a driving cessation toolkit that addresses this gap, we sought to examine the context-specific factors relevant to its effective implementation in settings that support older adults with dementia.

Research Design and Methods: A qualitative descriptive approach was used to explore the perspectives of Alzheimer Society (AS) staff in their work of supporting people with dementia and family carers within the context of driving cessation. Individual in-depth interviews were conducted with 15 AS staff members in 4 Canadian provinces. Data were examined using interpretative thematic analysis.

Results: The study results revealed an overarching paradox that despite the importance of driving cessation in people with dementia, it continues to be largely avoided at the individual and system levels. This is explored via the themes of (a) paradox of importance and avoidance identified in AS settings; (b) lack of awareness and understanding about dementia and driving among people with dementia and family carers; (c) distress and avoidance rooted in ongoing system issues; and (d) moving driving cessation to the “front burner.”

Discussion and Implications: Viewed through the emerging social health paradigm, which focuses on the social and emotional consequences of dementia, our results highlight the urgent need to mobilize our communities, medical education systems, and transportation authorities to finally resolve the dementia and driving cessation paradox.

Keywords: Social health, Family carers, Toolkit, Challenges, Alzheimer Society

Driving cessation has been well established in the literature as being a complex and difficult decision and transition for drivers with dementia and their family to make (Adler, Rottunda, & Dysken, 1996; Andrew, Traynor, &

Iverson, 2015; Lucas-Blaustein, Filipp, Dungan, & Tune, 1988; Sanford, Naglie, Cameron, & Rapoport, 2018). It is a multifaceted issue replete with tensions including the imperative to ensure public safety and the personal safety

of people with dementia while preserving their independence, social connectedness, and quality of life (Arai, Arai, Mizuno, Kamimura, & Ikeda, 2017; Carr & O'Neill, 2015; Perkinson et al., 2005). The aging of the population and the increasing prevalence of dementia bring an added urgency to this matter (Alzheimer Society of Canada, 2016). The emergence of the social health paradigm in dementia, which emphasizes the individual's capacity to live well in their social adaptation to the challenges posed by dementia, offers further impetus to address the problem of driving cessation (Arai et al., 2017; Vernooij-Dassen, Moniz-Cook, & Jeon, 2018).

The significance of driving for older adults cannot be underestimated. It is a practical necessity and the main mode of transportation for adults over the age of 65 (Munro, 2016). In addition to meeting the functional needs of older adults such as shopping and medical appointments, driving provides connections to social activities, a sense of security, and aesthetic pleasure (C. B. Musselwhite & Haddad, 2010; Sanford et al., 2019). Adverse psychosocial and health consequences for people with dementia include loss of independence, increased burden on family carers (Sanford et al., 2018), lower activity levels, social isolation, depression, and higher rates of institutionalization and mortality (Chihuri et al., 2016). Recent research focused on the symbolic aspects of driving cessation has brought added attention to the emotional impact of driving cessation for older adults (Pachana, Jetten, Gustafsson, & Liddle, 2017), including adults with dementia (Sanford et al., 2019). Disruptions to identity, loss of independence, and changed roles are tied to feelings of grief and anger (Sanford et al., 2019) as well as to perceptions of being older and less valued (Jetten & Pachana, 2012; Pachana et al., 2017). For men, the affective impact of driving cessation may be even more intense as suggested by research indicating that older men are less likely than women to cease driving (Baines, Au, Rapoport, Naglie, & Tierney, 2016), experience more depression post driving cessation (Ragland, Satariano, & MacLeod, 2005), and tend to associate driving with their status and social roles (Musselwhite & Shergold, 2013).

Determining the point when safe driving has become significantly compromised for people with dementia is a challenge for drivers with dementia and family carers who may not understand how dementia impacts driving (Liddle et al., 2013), as well as for primary care physicians whose in-office clinical assessments for dementia are inadequate indicators of fitness to drive (Molnar, Patel, Marshall, Man-Son-Hing, & Wilson, 2006). Although primary care physicians are largely expected by family carers to play a role in the decision-making process (Adler, 2010; Adler, Rottunda, & Kuskowski, 1999; Andrew et al., 2015; Perkinson et al., 2005), many are reluctant to raise this topic (Andrew et al., 2015). Studies indicate that primary care physicians lack knowledge and confidence about how to approach the topic of driving cessation, and are concerned about its negative

impact on their relationship with patients (Rapoport et al., 2018; Sinnott et al., 2018). Similarly, family carers avoid talking to people with dementia about stopping to drive because of their fear of family conflict and negative emotional reactions (D'Ambrosio, Coughlin, Mohyde, Hunter, & Stern, 2009). As a result, the process of deciding to stop driving is often abrupt (Adler & Kuskowski, 2003) and characterized by crisis (Byszewski, Molnar, & Aminzadeh, 2010; Liddle et al., 2013), further heightening emotional distress for people living with dementia and their families (Scott, Liddle, Pachana, Beattie, & Mitchell, 2019; Sinnott et al., 2019).

Early planning for driving cessation is considered to be an effective way to lessen some of the negative impacts of driving cessation by facilitating readiness to the practical (e.g., awareness of alternative transportation options) and emotional changes (e.g., loss and grief), thereby easing the transition to nondriving (Liddle et al., 2013; Sanford et al., 2018; Scott et al., 2019; Sinnott et al., 2019). While interventions to support persons with dementia and family carers' adaptation to life postdriving are emerging (Supplementary Table 1), there remains a limited number of driving cessation interventions and resources, geared to persons with dementia, their family carers, and primary care physicians (Byszewski et al., 2013; Rapoport, Cameron, Sanford, & Naglie, 2017; Sinnott et al., 2018).

To help address this gap and facilitate driving cessation discussions, we are developing a web-based, evidence-informed driving cessation toolkit to support people with dementia, family carers, and health care providers in the decision-making process and transition to nondriving. The toolkit is a curated collection of materials and resources (e.g., guidelines, videos, and assessment tools) designed to meet the practical and emotion-based needs of this target audience. The development of this toolkit will be described in an upcoming paper. We aim to first implement the toolkit in Canadian branches of the Alzheimer Society (AS), the leading nationwide community organization for education and support of people with dementia and their family carers. As part of our ongoing research involving key stakeholders to further develop the toolkit and to create strategies for its implementation, our objective in this study was to examine the context-specific factors relevant to its effective implementation in settings that support older adults with dementia. Specifically, we asked participants about their perceptions of the key challenges that drivers and former drivers with dementia and their family carers face in their geographical regions; how these challenges were addressed; and the main gaps that exist in supportive programs that address driving cessation.

Methods

Study Design

A qualitative descriptive approach (Bradshaw, Atkinson, & Doody, 2017; Sandalowski, 2000) was used to provide a direct and rich exploration of the perspectives of AS staff in their work of supporting people with dementia and family

carers within the context of driving cessation. Within the interpretive process, the researcher stays close to the data, and the produced account is described in everyday terms (Sandalowski, 2000). Qualitative description is considered particularly useful in health care research where insights gleaned from informants' views are used for intervention development and refinement (Neergaard, Olesen, Andersen, & Sondergaard, 2009).

Setting and Participants

The study included 15 participants from eight AS organizations across Canada, located in British Columbia, Manitoba, Nova Scotia, and Ontario. Purposive sampling strategy involved selecting sites in diverse regions in Canada that served urban and rural communities. Executive directors of AS organizations were first contacted by the research team to ascertain their organization's interest in participating in the study. An E-mail template was provided to agreeable directors, inviting staff members who they deemed as most appropriate to take part in the study, in consideration of the study's focus on dementia and driving. Ethical approval was received from the Baycrest Health Sciences Research Ethics Board (#38-15). Written consent was obtained from each participant. To ensure confidentiality, pseudonyms were used, and the data presented do not identify the work location.

Data Collection

All 15 participants were first asked to review the resources and tools in a preliminary online version of the Driving Cessation in Dementia Resource Toolkit (DCDRT) either on their own or in a webinar led by the researchers. In-depth interviews were conducted with each participant via telephone as most participants were located outside the geographical region of the host research institution. Interviews were approximately an hour long and were guided by a semistructured interview protocol (Supplementary Table 2). The interview focused on how regional and AS organizational resources and supports addressed (or not) the challenges that drivers and former drivers with dementia and their family carers experienced. Interview questions were derived from our intent to explore context-specific factors that could impact the implementation success of the DCDRT and were informed by implementation science principles (Bauer, Damschroder, Hagedorn, Smith, & Kilbourne, 2015). Participants were asked to describe the types of challenges their clients faced, details about available services and programs, and perceived gaps, including reasons for those gaps. As is characteristic of qualitative interviews, the format of the interview was conversational, thus enabling topics to be brought up by participants to be further explored. Field notes were maintained throughout the data collection process.

Analysis

All interviews were transcribed verbatim from the digital audio-recordings and entered into NVivo 12 qualitative analysis software for the purpose of managing and organizing the textual data. Transcripts were reviewed to ensure the accuracy of the transcribed text. Data were analyzed using interpretive thematic analysis, following the guidelines outlined by Braun and Clarke (2006). A constructivist approach was taken whereby the social contexts and structural conditions were considered in how patterns identified in the data were produced. The goal of interpretive thematic analysis is to develop latent levels (i.e., underlying ideas, assumptions, and conceptualizations) of analysis and interpretation that build on patterns identified in the semantic (i.e., explicit) content (Braun & Clarke, 2006). After familiarizing themselves with the data via reading and rereading the transcripts, E. Stasiulis coded the entire data set and B. Sivajohan and a research assistant coded subsets of the data, according to a codebook that was simultaneously developed and revised as analysis progressed. Coding and subsequent categories and themes were generated directly from the data in an inductive approach as well as guided by the research questions (Supplementary Figure 1). Rigor conceptualized in qualitative methodology as trustworthiness (Lincoln & Guba, 1985), was achieved by comparing coding among researchers (E. Stasiulis and B. Sivajohan) and the research assistant; peer debriefing via ongoing discussions of the themes with the research team; "thick" or adequate description of the study context and sample; prolonged engagement with the study phenomenon; and an audit trail comprised of field notes, transcripts, coding framework, analytic memos, and maps. Discrepancies were attended to via discussion and resolution. Higher-level themes were developed from the collated codes, based on patterned responses and collections of meaning. Themes were further revised through a process of mapping and checking for coherency and alignment with the data set.

Results

Participants included 15 staff members from AS organizations in four Canadian provinces (British Columbia, Manitoba, Ontario, and Nova Scotia). Eight participants were from four different sites in Ontario, three from two sites in British Columbia, two from two sites in Manitoba, and two from one site in Nova Scotia. Only one participant was male. Ten participants occupied coordinator roles (provincial, regional, education, and client services), two served as family support workers, two worked in memory clinics, and one was a provincial program director (Table 1). All performed functions in overseeing or delivering education and support to persons with dementia, family carers, and health care providers, enabling them to "have an opportunity to view things from many different angles," as stated

Table 1. Participant Demographics

Participant	Sex	Role	Time at AS	Geographic region
ASP01	Female	Provincial coordinator	12 years	Urban and rural
ASP02	Female	Provincial coordinator	2½ years	Urban and rural
ASP03	Female	Program coordinator	5 years	Urban and rural
ASP04	Female	Occupational therapist in memory clinic	2 years	Urban
ASP05	Female	Program director	14 years	Urban and rural
ASP06	Female	Coordinator of client services	9 months	Urban and rural
ASP07	Female	Education coordinator	7 months	Urban
ASP08	Female	Regional coordinator	3½ years	Rural
ASP09	Female	Education manager/coordinator	6 months	Urban
ASP10	Male	Social worker and team lead	5 years	Urban
ASP11	Female	Support and education coordinator	1 year	Urban
ASP12	Female	Family support coordinator	15 years	Urban and rural
ASP13	Female	Education coordinator	13 years	Rural
ASP14	Female	Social worker in memory clinic	12 years	Rural
ASP15	Female	Family support worker	5 years	Rural

Note: AS = Alzheimer Society.

by a participant (ASP03). Programs and services they were involved with encompassed telephone information and helplines, individual counseling, educational workshops, support groups, and community presentations.

The results revealed an overarching paradox that despite the recognized importance of driving cessation in people with dementia, it continues to be often avoided as a topic of discussion at the individual level and to be neglected at the system level. We outline this paradox in the following themes: (a) its recognition in AS settings as a “hot” topic that is met with resistance; (b) how a lack of awareness and understanding about dementia and driving contributes to fear and delay among people with dementia and family carers; (c) how distress and avoidance are rooted in on-going system issues; and (d) the importance of bringing driving cessation to the “front burner” to resolve the paradox (Table 2).

Paradox of Importance and Avoidance Identified in the AS Settings

All participants regarded driving cessation in dementia as a major concern in their everyday work with people with dementia and family carers. They described driving cessation as a “hot topic” because it generated passion, frustration, and fear, and because it is considered to be an important topic that, as one staff member (ASP15) stated, “comes up a lot ... more than anything.” The significance of driving cessation was reflected in participants’ enthusiasm for participating in the study:

That’s why I got quite interested in being a part of this. Because I think it’s a big thing that comes up and people don’t often know how to deal with it. This is not just speaking for people living with dementia, but also for family members who support them. (ASP10)

Yet, at the same time, driving cessation was also identified as a neglected subject.

It’s so important to address this. ... [It] has always been on the backburner for some reason, as I don’t think it’s been identified as what a huge loss it is for people. (ASP11)

Participants reported that their clients with dementia and family carers avoided talking about driving until: they were in a crisis instigated by being informed by their physician or the Ministry of Transportation that the driver with dementia must cease driving; and/or family carers were distressed about their family member’s unsafe driving. AS staff members were contacted for help, mainly by family carers when as one participant (ASP06) stated, “It’s well beyond the time that their family members should be driving and they’re at the point where this is an emergency and need strategies of how to deal with this.”

Efforts within AS organizations to introduce the topic of driving cessation earlier at the individual and programming levels were often met with resistance.

I know in my individual support visits, it’s often me bringing it up. And you can just see on people’s faces when you start to talk about driving. Like, they don’t want to go there. (ASP12)

Participants reported that workshops or webinars focused on driving in the context of dementia were usually poorly attended. Only sessions on driving held in conjunction with other community organizations and including topics related to aging that were not dementia-specific had a good turnout. AS participants attributed this response to people avoiding the topic of driving:

And that probably got our biggest bang for the buck, because people were attending for all sorts of other reasons, so then they heard the message ... because it’s

Table 2. Themes With Illustrative Quotes

Major themes	Subthemes	Illustrative quotes
(1) Paradox within AS settings	(1a) Driving cessation as a “hot topic”	<p>“And, it’s a hot topic for us, because people are very passionate and frustrated when it happens to someone they know, or to themselves.” (ASP15)</p> <p>“It’s a hot topic, driving. People are very worried about their driver’s licence. (It’s) very important.” (ASP14)</p> <p>“Our first challenge is the conversation about driving cessation. (It) doesn’t usually happen until there’s a problem, until there’s a report to the Ministry of Transportation.” (ASP14)</p>
	(1b) Avoidance at the individual level	<p>“We have our info line that would be more helping through it step-by-step. But it’s not proactive, it’s reactive. We often don’t get calls until there’s a real crisis situation. Somebody is driving even though they got a letter in the mail saying they shouldn’t drive and what do we do?” (ASP03)</p> <p>“It’s an avoidance thing. So, I’m curious to see if we get, kind of an average number of people out to that workshop (on driving and dementia), or if it will be really small cause people don’t want to go there.” (ASP14)</p> <p>“Often times driving is an issue, but ... there may be other bigger issues that they’re dealing with. It’s not always at the forefront of the challenges.” (ASP07)</p>
	(1c) Avoidance at the programmatic level	<p>“If the conversation around retiring from driving was earlier, rather than after they’ve lost their licence, at a memory clinic, or at their doctor’s office, then, it would probably be less alarming. It’s still going to be hard and they’re still going to have to grieve that loss and be challenged with all of the transitions that come. ... It’s not going to prevent them from living fully, if they know what to do, if they know what their options are. So, it’s that front end informing people what it could be like, so they’re not so fearful of when it happens.” (ASP15)</p>
	(1d) Importance of early conversations	<p>“You try to use reasoning and it doesn’t work, as it would with somebody who had good insight. ... And, people would still have the emotional turmoil of not being able to drive, but, if they could understand why. They have medical challenges that make it unsafe for them to drive and why that is such a big concern. It’s still difficult, but it’s easier to try and ease them into, ‘Okay, well what else can we do?’ But, if their brain’s not able to give that information, then, it can sometimes end up being a real battle with families, because families are trying to encourage somebody not to drive and they just won’t hear it. Sometimes, it ends up being ... well, you’ve had a couple of accidents.” (ASP13)</p>
(2) Lack of awareness and understanding		<p>“It’s a really difficult topic to bring up for people living with dementia and for caregivers, as well. For people with dementia it’s really difficult to consider giving up driving and from what I’ve heard a lot of people don’t realize that they will eventually have to give up driving.” (ASP02)</p> <p>“Frequently, families don’t think about driver cessation if they are observing memory loss unless it’s really affecting activities to daily living. By then it could be too late to be thinking about driving.” (ASP05)</p> <p>“A lot of people I have spoken with think that being a co-pilot is okay. ‘They’re driving fine as long as I’m with them and I tell them where to go’. So, even having those conversations earlier rather than later on, I think would be [helpful]. ...” (ASP06)</p>
		<p>“There seems to be a lack of consistency, which is really frustrating for people. To one extreme where the doctor just takes it away, right away. No driving assessment, no options given, to the extreme where it’s not even talked about. And, the family get frustrated because they want the doctor to address that issue.” (ASP08)</p> <p>“Another key challenge is inconsistency among family doctors on addressing driving. Some family physicians report to the Ministry right away. Other family physicians seem not to be concerned about their responsibility to report at all, which when you get people together ... like in some of our support groups, people come together and share their stories. And, it becomes pretty apparent that there isn’t consistency. And, so, then there gets to be a feeling of unfairness.” (ASP14)</p>
(3) System-level issues	(3a) Inconsistencies with primary care physicians’ approaches	<p>“Just not knowing what the process is to have driving assessed. Whose responsibility is it? Is it doctors? Is it the family members? Who do they go to, to talk to about that?” (ASP08)</p>
	(3b) Confusion about reporting and assessment processes	

Table 2. Continued

(3c) Lack of accessible driving assessments	<p>“And, so, we’ve had people literally get upset when we talk about this, because they don’t believe that they were fairly treated. And, that they’re very well capable of driving, even now, when you know that they’re not, right. But, that’s where the drivers really get that sense that I’ve not been fairly and duly assessed.” (ASP11)</p> <p>“The Ministry says, ‘Okay, well there might be a problem. If you want to keep driving, you need to demonstrate your ability to drive safely.’ So, then the person has to go to assessment centers approved by the Ministry. They cost between \$500 and \$700 out of pocket, by the driver. So, for people with low income that’s a barrier ... [and] is the end of driving. The other thing is that we don’t have a [Ministry-approved] assessment center in [town in rural area]. So, people have to go out of their community to take a test, which adds to the feeling, ‘That it’s not fair.’” (ASP14)</p> <p>“When people do get reported, I think a lot of people would like to do a driving assessment but for whatever reason they’re like, ‘No I’m not paying that much.’ Some people can’t afford it, some people can but they’re like, ‘I’m not paying that money and not risking getting it back.’ So, I think it’s just lack of knowledge of what’s out there and helping people guide them through that process.” (ASP04)</p>
(3d) Lack of alternative transportation	<p>“We have very little, if any, alternative driving solutions in rural areas. There isn’t a taxi that goes out 45 minutes out of town, or an hour out of town, or two hours. And, if there isn’t a family member living close by, who can take time off work, it just becomes really difficult to get around. So, they end up driving a lot longer than, I think, what is safe. But, they just feel like they do not have a choice ... they just keep on driving.” (ASP08)</p> <p>“There’s the reality piece of, ‘I don’t drive. My husband is the one who drives. We’re in a rural community. I’m completely isolated if he’s not driving. That’s why I do always drive with him’. ... It’s one thing if my neighbour, two doors down from me can drive versus my closest neighbour who is two kilometers away.” (ASP12)</p>
(4) Bringing driving cessation to the front burner	<p>(4a) Easy to access and flexible</p> <p>“Some people don’t want to talk to people. They’re not ready and it’s a hard topic. So, maybe just having that readily available online for the public so that they can look at it at their own leisure and get some ideas that way because they are doing their own research.” (ASP06)</p> <p>(4b) To guide through emotional and practical transitions</p> <p>“And offer emotional support and ... how does one plan their life around it? What are the options? How does one plan around it? So, I think a potential resource where people may, uh, have ... may have a little bit of a guideline, can go quite a long way.” (ASP10)</p> <p>“And, it would be important that you have a role transition from the perspective of the person with dementia. So, like, ‘What does it feel like to be a passenger in the car for the first time, when you used to always do the driving when you’re with your wife?’ ‘What does it feel like to have to rely on other people for transportation?’” (ASP14)</p> <p>“I just talked to a gentleman, he’s very young, 63, and he’s not collecting pension yet. And yet he’s had to give up his driver’s licence, and was still employed full-time. He had to give up his career. And, you know, he just had tears in his eyes. He was being so brave in saying that he wanted to do the responsible thing. He wanted to not put anyone at risk. But, he just had such a loss of independence. And, so, how do ... you know, how to support people in that respect, I think, is one of the key issues for sure.” (ASP08)</p>
(4c) To start the conversation early	<p>“We serve a growing number of people with mild cognitive impairment. So, there is this opportunity with those folks to have these proactive driving conversations. They might not go on to develop dementia and so they might not need to retire from driving ... but they’re at higher risk and they might. As we serve those people more and more, there’s this opportunity to have proactive driving conversations.” (ASP12)</p> <p>“Having those conversations as a community-wide thing, as opposed to dementia-specific thing ... and I think that having conversations about driver cessation with the population at large is good ... it’s that whole thing about causing older adults themselves to think about, ‘Is it safe for me to keep on driving, or should I be looking at other ways of doing this?’ It’s important to have the adult children of people thinking about it long before the problem is totally there, with the public education issue about public safety, not just a dementia issue.” (ASP05)</p>

Note: AS = Alzheimer Society.

not a topic people really want to go there on. You almost have to have it around something that, “Okay, well since I’m there, I’ll hear this” as opposed to “Yes, I’ll go and sit through this willingly.” (ASP05)

Education workshops devoted only a small portion of their sessions to the topic of driving cessation because it was not a concern for attendees who did not drive, and it was one of many other issues related to the dementia experience.

However, in support groups that provided spaces for people to share their emotional experiences, driving cessation was often an issue that was spontaneously discussed. Most frequently, support and education about driving occurred in one-on-one interactions between AS participants and their clients, usually in a time of urgency and crisis.

Positioned in a largely reactive role of supporting clients was concerning for participants because there were fewer opportunities to help prepare people with dementia and family carers for what some considered to be the “trauma” of transitioning to nondriving. This trauma was observed to be especially salient for men, because as one participant (SP11) explained, “It’s something that really defines who they are and what supports the family.” While participants acknowledged that early conversations about driving cessation would not necessarily make the transition to nondriving stress-free, they agreed it would help “smooth out some of those initial wrinkles” and in the worst cases it would ease the trauma that some people experienced. Preparing people with dementia and family carers for the practical and emotional challenges of driving cessation was seen as a way to diminish fear and facilitate an engaged life for people with dementia postdriving cessation. Furthermore, delaying the driving cessation conversation increased the likelihood that drivers with dementia might lack insight about their medical condition and thus the capacity to understand the implications of continued driving. In these cases, participants reported that the distress experienced by people with dementia and their family carers intensified, often precipitating a crisis in trying to prevent their family member from driving:

We had this poor lady in. She’s 89 years old. Very globally impaired, and when the doctor told her he had to report, it was like we had killed her child. Like, it was hell—yelling at us, slapping our hands down. Definitely, there’s global impairment and poor insight. But had that conversation started earlier with her, from the family doctor, from the family. ... (ASP04)

Lack of Awareness and Understanding About Dementia and Driving

A pervasive lack of awareness and understanding about the relationship between dementia and driving was identified as contributing to clients’ distress and delay in considering driving cessation. Participants reported that some clients seemed surprised that they would have to stop driving. For others, despite or perhaps because driving was such an integral part of their everyday lives, the impact of not driving was something they had not considered, and hence it came as what one participant (ASP10) described as “a big shock.” He explained that clients were “sort of saying, ‘I didn’t think there was so much involved in it, because I was so used to just getting in my car and going for a

drive.’” Participants also noted that for some people with dementia and family carers, their lack of knowledge about how dementia can impact driving contributed to delays in thinking about driving cessation. They described “myths” that clients held about being safe, such as if they drove “within town limits” or if family carers acted as “copilots,” directing the driver with dementia where to go.

Distress and Avoidance Rooted in Ongoing System Issues

According to participants, some of the fear, confusion, frustration, and subsequent avoidance that people with dementia and family carers associated with driving cessation were rooted in ongoing system-level issues. These included physicians’ varied approaches to driving cessation, the confusion around reporting and assessment, obstacles to accessing assessments, and the lack of alternative transportation. Not surprisingly, the lack of dialogue about driving cessation in physicians’ offices was partly attributed by AS staff to people’s fear of losing their license and the perceived stigma that could accompany it.

The biggest thing with drivers is just that it’s not talked about. So it’s not talked about in the family doctor’s offices. It’s not being brought up. It’s sort of like this hush-hush subject. Part of the problem is where people are fearing it and they’re so afraid to talk about it. (ASP04)

As one participant suggested in the account below, physicians’ approach to discussing driving cessation was a critical factor in whether the conversation took place and the impact it had on people with dementia and family carers’ fear and resistance.

A lot of people are so fearful that it’s, “Okay I have this diagnosis. They’re going to take my license.” And just having the doctors explain, “It’s something to look towards in the future. It will be a gradual thing.” I think if that was implemented and discussed with the doctor, people would be less resistant and less fearful. (ASP06)

Participants reported that physicians varied widely in how they dealt with this topic, with some consistently raising the issue of driving, but mostly avoiding it and/or immediately informing their patients that they must cease driving at the point of a dementia diagnosis. These inconsistencies were a source of frustration and distress for participants’ clients who described learning about how other drivers with dementia were treated differently by their doctors. Participants surmised that a lack of education and training about driving issues, as well as physicians’ perceived risks of liability and damage to the therapeutic relationship, contributed to diverse clinical approaches to this issue:

I’ve heard about those who are really good about it and they sit down and they explain why they are

recommending to the Ministry [of Transportation]. Or, they have conversations with the family to gage the right time to do that suggestion to the Ministry that the person shouldn't be driving, instead of just as soon as the diagnosis happens. And then I hear people who say, they received a diagnosis and then, two minutes later, the doctor said, "Give me your license." And, then, the other spectrum where the person shouldn't be driving, the family is saying to the doctor, "Please. This person should not be driving." And, the doctor won't. I don't know whether they're educated very well on how to deal with it. (ASP13)

In conjunction with the inconsistencies of physicians' approach to driving cessation, participants identified the lack of clarity around reporting and driving assessment as a significant challenge for physicians as well as for people with dementia and family carers. Without valid assessment measures and consistent reporting standards, primary care physicians were left in what one participant (ASP05) described as, "a kind of gray zone for physicians to make decisions about, should they or shouldn't they [report]?" Similarly, family carers were reported as being confused about who was responsible for the assessment process, and people with dementia were fearful that talking with primary care physicians would mean losing their license.

Obstacles to accessing specialized off- and on-road driving assessments due to high costs and distant locations of driving assessment centers hindered participants' efforts to help their clients assert their rights in determining their ability to drive safely, further adding to clients' frustration and sense of being treated unfairly. This was a concern to people with dementia who needed to prove that they were capable of continued driving and for those who wanted the opportunity to dispute their physicians' report to the Ministry. As one participant (ASP14) stated, "For people with low income that's a barrier ... and is the end of driving."

The systemic lack of alternative transportation, particularly in rural areas, was also viewed as posing a significant challenge to people with dementia and family carers' consideration to stop driving and in participants' efforts to support them. Several AS staff members served rural clients and hence had first-hand knowledge about this issue. They considered their clients' concerns and fears about losing their driver's license as "legitimate" because of the ensuing isolation that would occur once they stopped driving. Only a few rural communities offered subsidized transportation services for people with disabilities. Most rural clients had no access to alternative transportation, thus placing them in desperate situations where as a participant (ASP01) stated, "it's almost begging for you to cheat as far as driving." Without potential solutions to people with dementia's and family members' transportation needs, AS staff members were limited in their capacity to support them. Suggestions for getting around were not always viable and offering

support groups that their clients did not have transportation to get to was considered "cruel."

Moving the Topic of Driving Cessation to the Front Burner

Study participants stressed the importance of bringing awareness and information about driving cessation to people with dementia, family members and to the wider community as a means to address the challenges they identified. They recommended resources aimed at supporting the emotional impact of driving cessation; providing strategies for family carers and health care providers to initiate conversations; and providing information about region-specific driving regulations, including material directed specifically to people with dementia. AS staff also endorsed having resources available online to meet the diverse needs of people with dementia and family carers at varied stages in their dementia journey and for people who are not involved with AS organizations. The point at which people with dementia and family carers first learned that driving must cease was identified by participants as a key time when resources were needed for them to provide practical and emotional support to their clients who suddenly were no longer driving.

Participants also stressed the need for proactive measures and resources to start the conversation about driving cessation as early as possible, which included targeting people with mild cognitive impairment and engaging the wider community. "Planting the seeds" to alert people about the upcoming possibility of having to stop driving could aid in the preparation and planning of this major transitional event.

Discussion

Findings from this study reiterate some of the main challenges in driving cessation and dementia that have been reported in research studies for the past three decades (Adler et al., 1996; Adler, Rottunda, & Dysken, 2005; Lucas-Blaustein et al., 1988; Sanford et al., 2018). While our study results are not new, they bring additional empirical evidence to the AS of Canada's assertion, as reported by McCracken, Caprio-Triscott, and Dobbs (2001), that driving cessation remains one of the "toughest issues" in dementia care. The paradox of driving cessation as a "hot" but neglected topic was acutely apparent within the context of AS settings, and perpetuated by people with dementia and family carers who resisted participants' attempts to address this issue. The fact that this avoidance occurred even within the supportive environment of AS staff who have expertise in dementia reflects, as participants identified, the depth of their clients' fears and lack of understanding about driving and dementia (Adler et al., 1996; Scott et al., 2019). Participants' admonition that early conversations

and planning for driving cessation are integral to easing the fear and distress of transitioning to nondriving for people with dementia, is well recognized in the driving and dementia literature (Byszewski, Molnar, & Aminzadeh, 2010; Liddle et al., 2016; Sanford et al., 2018; Scott et al., 2019). Despite this recognition and recommendations to support people with dementia and their families in the decision-making process and transition to nondriving (Andrew et al., 2015; Chacko et al., 2015; D'Ambrosio et al., 2009; Sanford et al., 2018), our study findings indicate that prevailing individual, family, and system-level gaps continue to hinder this objective.

The neglect in addressing issues related to driving cessation at the system level is paradoxical considering the touted importance in the dementia literature of attending to the challenges of driving and dementia. Participants identified three main areas of concern that underpinned the fear, frustration, and subsequent avoidance their clients experienced with respect to driving cessation: people with dementia's lack of confidence and knowledge about how to approach driving cessation; the lack of accessible driving assessments and guidelines on the reporting process; and the lack of alternative transportation options, particularly in rural areas. These system gaps mirror those that predominate in the early and more recent literature. For example, early studies reported on the importance of primary care physicians providing information to their patients and family carers about the impact of dementia on driving as well as their involvement in the decision-making process (Adler et al., 1996, 1999; Adler & Kuskowski, 2003). Later research additionally emphasized the need to provide education and training to physicians to address their reluctance in engaging in discussions with patients about this sensitive topic (Byszewski, Molnar, & Aminzadeh, 2010; Sanford et al., 2018; Sinnott et al., 2018). However, study participants' reports of their clients' negative experiences of how primary care physicians approached and managed driving cessation suggests that education and training imperatives are not being consistently actualized.

Similarly, earlier literature reviews on driving and dementia conducted by Odenheimer (1993), Adler and colleagues (1996), and Lloyd and colleagues (2001) stressed the "critical" need to develop standardized guidelines outlining the roles and responsibilities of health care providers about processes of assessment and reporting. They also urged policymakers, clinicians, and community leaders to work together to develop affordable alternative transportation options for former drivers with dementia. More recent reviews and studies, including this study's findings, indicate that these issues are not yet resolved. Although national Canadian guidelines were recently updated, they are limited because they do not provide concrete suggestions for determining collision risk for drivers with dementia or how to support them through the transition process (Rapoport et al., 2018). The lack of alternative transportation options continues to be documented

in the literature (Silverstein & Turk, 2015) and reported by study participants as a pressing issue, posing significant barriers to people with dementia's willingness to give up driving (Sanford et al., 2018) as well as primary care physicians' likelihood of discussing driving cessation with their patients (Scott et al., 2019).

The recent introduction of the social health concept to dementia care research (Dröes et al., 2017; Vernooij-Dassen & Jeon, 2016; Vernooij-Dassen et al., 2018), which focuses on the emotional and social consequences of dementia, brings the driving and dementia dilemma to the forefront. Social health is derived from Huber and colleagues' (2011) revised concept of the World Health Organization's definition of health, which involves a shift from its inert construction as a "state of complete physical, mental and social well-being" to a more vibrant concept of "health as the ability to adapt and to self-manage" (p. 2). It asserts that people with medical conditions, such as dementia, can achieve a state of well-being in balancing the opportunities and limitations posed by their physical state in the midst of social and environmental obstacles (de Vugt & Dröes, 2017). This concept counters the dominant biomedical emphasis on deficits and the accompanying stigma and negative discourse that largely surrounds dementia (de Vugt & Dröes, 2017). Specifically, the dimensions of social health include: (a) "people's capacity to fulfill their potential and obligations," (b) "the ability to manage their life with some degree of independence," and (c) "the ability to participate in social activities" (Huber et al., 2011, p. 2). Extending Dröes and colleagues' (2017) operationalization of these dimensions for people with dementia to the context of driving cessation entails: (a) fulfilling their capacity to participate in shared decision making via early planning; (b) helping them to adjust to and manage the practical and emotional consequences of driving cessation by providing education, support, and strategies to enhance their strengths and capabilities; and (c) maintaining their involvement in meaningful activities and social relationships via alternative transportation strategies. Locating driving cessation in dementia within the social health paradigm not only adds credence to attending to the social dimensions of this issue, but it also offers a more balanced approach that emphasizes the remaining capacities of people with dementia to live a quality life post driving cessation.

As viewed through the lens of social health, interventions at the system level can help to halt the cyclical and paradoxical pattern of driving cessation urgency and avoidance. The stigma and negative discourse associated with dementia (Mitchell, Dupuis, & Kontos, 2013) and driving cessation underpins people with dementia and family carers' fears and evasion of this topic, and contributes to primary care physicians' reticence to discuss driving cessation. Without these discussions, early planning is pre-empted, and the unaddressed consequences of driving cessation continue to perpetuate the cycle of distress and fear. Purposeful silence may reinforce these emotions and the stigma associated

with dementia and its accompanying losses, including driving cessation (Patterson, Clarke, Wolverson, & Moniz-Cook, 2017). However, if primary care physicians are better equipped to address drivers with dementia's emotional and practical concerns via education and training and with accessible alternative transportation options in place, some of the negative outcomes that impede driving discussions would be minimized—thus disrupting the paradoxical sequence of urgency and avoidance.

Early discussions about driving cessation can also offer more viable opportunities for people with dementia to engage in shared decision-making. Involving people with dementia in the decision of when and how to stop driving while their insight is more robust optimizes their capacities to make choices, a key aspect of social health (Mariani, Vernooij-Dassen, Koopmans, Engels, & Chattat, 2017). Reliable, accurate, and accessible driving assessments that can clearly delineate when driving is no longer safe would impart respect for the limitations and capabilities of people with dementia, instilling for them a sense of fairness (Andrew et al., 2015). Finally, as study participants stressed, the provision of information and resources to support people with dementia throughout all stages of the driving cessation process is critical to enhancing people with dementia's knowledge, strengths, and capabilities during this major transition period (Sanford et al., 2018). Extending information about dementia and driving to the wider community via educational forums on driving safety, as suggested by participants, as well as public awareness campaigns could help to normalize driving cessation as a topic more easily discussed (Lloyd et al., 2001). The Dementia Friendly Community Movement (<https://www.dfamerica.org/>) is one example of an initiative that aims to foster the inclusion and community engagement of people with dementia. In acknowledging people with dementia's abilities and disabilities and the factors that impact their adaptation to their changing life worlds as nondrivers, the social health concept opens spaces for interventions that bring driving cessation to the “front burner” and promote the social health of people living with dementia (Vernooij-Dassen & Jeon, 2016).

Study Limitations

A study limitation is that the sample did not include the perceptions of people with dementia and their family carers. However, as supporters and educators to this group, AS staff provide a uniquely combined individual and expansive view of the state of driving cessation in dementia. In addition, study findings aligned with the substantive literature on driving and dementia, demonstrating credibility and transferability. A more detailed exploration of the system-level issues was not within the scope of this study. Another limitation is that because we were only able to obtain the perspectives of one male participant, we cannot comment on any possible gender-based differences in AS staff's perceptions of their experiences.

Conclusion

As more than three decades of research including this study indicate, driving cessation in dementia continues to assume a “back burner” position at both the micro and macro level, despite the considerable distress it holds for individuals with dementia and their family carers. The significant implications of this neglect were foreshadowed 22 years ago by O'Neill (1997, p. 71) who stated, “The whole issue of dealing with driving cessation parallels how we succeed or fail in helping our patients deal with the reality of the deficits caused by dementia.” While evidence suggests that we have indeed failed so far in this regard, the emerging attention to the social dimensions of dementia may bring renewed resolve and directives to address the driving cessation dilemma. The collective will to mobilize our communities, medical education systems, and transportation authorities to finally attend to the driving and dementia paradox has never been more urgent.

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Conflict of Interest

None reported.

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