

Research Article

# Automated Vehicles for People With Dementia: A “Tremendous Potential” That “Has Waystogo” —Reports of a Qualitative Study

Shabnam Haghzare, PhD,<sup>1,2,\*</sup> Elaine Stasiulis, PhD,<sup>3,4</sup> Ghazaleh Delfi, MASc,<sup>2</sup> Hodan Mohamud, BSc,<sup>2</sup> Mark J. Rapoport, MD, FRCPC,<sup>5,6</sup> Gary Naglie, MD, FRCPC,<sup>7,8</sup> Alex Mihailidis, PhD,<sup>2,9</sup> and Jennifer L. Campos, PhD<sup>2,10</sup>

<sup>1</sup>Institute of Biomedical Engineering, University of Toronto, Toronto, Ontario, Canada. <sup>2</sup>KITE—Toronto Rehabilitation Institute, University Health Network, Toronto, Ontario, Canada. <sup>3</sup>Institute of Medical Science, University of Toronto, Toronto, Ontario, Canada. <sup>4</sup>Rotman Research Institute, Baycrest Health Sciences, Toronto, Ontario, Canada. <sup>5</sup>Department of Psychiatry, Sunnybrook Health Sciences Centre, Toronto, Ontario, Canada. <sup>6</sup>Department of Psychiatry, University of Toronto, Toronto, Ontario, Canada. <sup>7</sup>Department of Medicine and Rotman Research Institute, Baycrest Health Sciences, Toronto, Ontario, Canada. <sup>8</sup>Department of Medicine and Institute of Health Policy, Management and Evaluation, University of Toronto, Toronto, Ontario, Canada. <sup>9</sup>Department of Occupational Science and Occupational Therapy, Institute of Biomedical Engineering, University of Toronto, Toronto, Ontario, Canada. <sup>10</sup>Department of Psychology, University of Toronto, Toronto, Ontario, Canada.

\*Address correspondence to: Shabnam Haghzare PhD, Institute of Biomedical Engineering, 500 University Ave. Institute of Biomedical Engineering, University of Toronto, Toronto, ON M5G 2A2, Canada. E-mail: [Shabnam.Haghzare@mail.utoronto.ca](mailto:Shabnam.Haghzare@mail.utoronto.ca)

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## Abstract

**Background and Objectives:** The prospect of automated vehicles (AVs) has generated excitement among the public and the research community about their potential to sustain the safe driving of people with dementia. However, no study to date has assessed the views of people with dementia on whether AVs may address their driving challenges.

**Research Design and Methods:** This mixed-methods study included two phases, completed by nine people with dementia. Phase I included questionnaires and individual semistructured interviews on attitudes toward using different types of AVs (i.e., partially or fully automated). Interpretative phenomenological analysis was used to assess participants' underlying reasons for and against AV use. The participants' identified reasons against AV use informed the focus group discussions in Phase II, where participants were asked to reflect on potential means of overcoming their hesitations regarding AV use.

**Results:** The results showed that people with dementia might place higher levels of trust in fully automated compared to partially automated AVs. In addition, while people with dementia expressed multiple incentives to use AVs (e.g., regaining personal freedom), they also had hesitations about AV use. These hesitations were based on their perceptions about AVs (e.g., cost), their own abilities (i.e., potential challenges operating an AV), and driving conditions (i.e., risk of driving in adverse weather conditions).

**Discussion and Implications:** The findings of this study can help promote the research community's appreciation and understanding of the significant potential of AVs for people with dementia while elucidating the potential barriers of AV use by people with dementia.

**Keywords:** Automated vehicles, Dementia, Driving, Focus group, Qualitative analysis

## Background and Objectives

### The Potential of Automated Vehicles as Assistive Technologies

Automated vehicles (AVs), defined as vehicles that can automate some or all driving tasks, are expected to enhance mobility and thereby the health and well-being of populations who traditionally lack appropriate access to accessible transportation (Crayton & Meier, 2017; Dean et al., 2019). Among such populations are people who live with driving-restrictive medical conditions such as dementia, the symptoms of which often result in progressive declines in one's driving ability (Harper et al., 2016; Vehicles, 2015). Different stages (i.e., mild, moderate, and severe) and types of dementia (e.g., Alzheimer's disease and vascular dementia) can respectively exhibit as varying degrees and different forms of decline (e.g., motor and/or cognitive) in the driving abilities of people living with dementia. As such, while the diagnosis of dementia does not automatically revoke one's driver's license, the driving fitness of people with dementia is often required to be assessed regularly and ultimately, as dementia progresses, people with dementia are required to stop driving completely (Carr & Ott, 2010). If AVs are able to help sustain the safe driving of people with dementia or at least a subpopulation of them, they can have significant benefits for both the public, people with dementia, and their circle of care (Dicianno et al., 2021; Knoefel et al., 2019). These benefits include enhanced road safety, the potential decreased cognitive load of driving for people with dementia who still drive, and/or continued access to safe mobility for people with dementia who no longer drive. As such, AVs could potentially help avoid/delay the well-established adverse health consequences of driving cessation for people with dementia ranging from faster cognitive decline to higher risks of morbidity and institutionalization (Chihuri et al., 2016; Choi et al., 2014; Freeman et al., 2006).

The speculations around AVs' usefulness for people with dementia are based on the functionalities of current commercially available AVs and the anticipated functionalities of future AVs. The highest level of current commercially available AVs is Partially Automated Vehicles (PAVs; Level 2 Automation), which provide steering and brake/acceleration support to the driver, but the driving responsibility remains with the human driver at all times. To complement PAV functionalities, the human driver is required to supervise PAV's functions, to steer, brake, or accelerate as needed (e.g., when the control limits of the PAV are reached) to maintain safety (SAE International, 2021). However, the ultimate objective of the AV industry is to reach Fully Automated Vehicles (FAVs; Level 5 Automation; SAE International, 2021; currently in testing) that can drive the vehicle under all conditions with no need for human input, and potentially no means for even allowing human input (e.g., no steering wheel). If used as assistive technologies for people with dementia, the different levels of driving

assistance provided by each Level of AV could potentially correspond to a certain level of assistance required by people with dementia living with different stages of dementia.

### The Potential Barriers of Utilizing Automated Vehicles as Assistive Technologies

The evolution of AVs from PAVs (Level 2) to FAVs (Level 5) has been an incremental advancement of both technological implementation and public adaptation (NHTSA, 2013). Correspondingly, policy and infrastructure are also anticipated to be reformed incrementally such that they can (a) ensure a safe transition from nonautomated vehicles/PAVs to FAVs and (b) ensure the maximal realization of AVs' promise of accessible mobility and enhanced social equity (Dean et al., 2019). However, recent studies have identified compounding barriers toward realizing the potential of AVs to enhance population-specific access to mobility (Crayton & Meier, 2017; Pettigrew et al., 2019; Yang & Coughlin, 2014). These potential barriers include (a) the dominant role of the private sector in leading the AV development efforts, resulting in AV design that prioritizes commercial goals rather than accessibility goals; (b) a lack of in-depth appreciation among decision-makers in AV development about the implications of AVs for populations who traditionally lack accessible transportation; and (c) a paucity of relevant population-specific data that can be used to inform decisions on AV development and deployment models to increase accessibility (Kelley, 2017; Pettigrew et al., 2019). Considering these barriers, using AVs as assistive technologies for people with dementia as a means to enhance their access to mobility has been an unrealized potential. A first step toward exploring the potential of AVs as assistive technologies is to capture the requirements, needs, and preferences of end-users, in this case, people with dementia (Boger et al., 2017).

### Current Study

To help address the current lack of data on the views of people with dementia on AV use, the current mixed-methods study adopted an exploratory approach guided by the following objectives: (a) to assess the effects of AV type (PAVs vs. FAVs) and driving conditions/tasks (e.g., long distances, night-time, heavy traffic, adverse weather; parallel parking, unprotected left turn) on the AV acceptance of people with dementia and (b) to assess and characterize the perspectives of people with dementia toward using PAVs/FAVs.

## Research Design and Methods

### Participants

Prior to the individual interviews, the study's consent form, followed by a capacity-to-consent assessment tool was

administered to the participants. The assessment tool was adapted from Jeste et al. (2007), in which a participant's capacity to consent is assessed based on their understanding and appreciation of the study protocol. As such, the capacity assessment tool includes probing questions about the study protocol, and it is administered after presenting participants with information pertaining to the study protocol in the consent form. In this study, all participants were deemed eligible to consent.

Nine persons living with dementia were recruited through online advertisements (see Table 2 for participant demographics and characteristics). Participants were eligible to participate if they were fluent in English, and self-identified as a person with a formal diagnosis of dementia. The protocol was approved by the University of Toronto Research Ethics Board (#38808).

### Study Design and Setting

This exploratory study encompassed two consecutive phases. Phase I included the completion of questionnaires and semistructured individual interviews, and Phase II included focus group sessions. Both phases were conducted using a video-conferencing platform and were audio-recorded. A mixed-methods design was chosen to allow for an in-depth exploration of participants' experiences and opinions. The two-phase design of the study was chosen in consideration of the potential sensitivity of the topic of driving cessation for some people with dementia (hence the individual sessions in Phase I), while aiming to explore the potential heterogeneity of opinions and experiences of people with dementia (hence the focus groups in Phase II). Phase I sessions were carried out with one participant at a time (i.e., nine sessions) to allow for exploration of individual experiences and in-depth conversations about AV functionalities based on the individual's level of familiarity with AVs. Among the nine participants, eight agreed to continue to Phase II. Phase II included two focus group sessions, which included three and five participants, respectively. Phase II of the study allowed for a more in-depth conversation, and to gather, compare, and contrast the thoughts and ideas of participants on the subject of AV use. A stakeholder advisory committee, including a person living with dementia and a care-partner, was consulted in the design of both phases of the study and the design of the instruments. Table 1 provides an overview of the instruments used in this study.

### Procedure

During the individual interviews (Phase I), the History Questionnaire and AV Familiarity Questionnaire were administered to participants by a research assistant, which respectively included questions on participants' driving and diagnosis history, and their familiarity and experience with AVs. To provide participants with the knowledge of PAVs and FAVs needed to answer the questions

that followed, they were presented with PAV and FAV functionality briefings and the participants' understanding of the briefings were confirmed through follow-up questions. These two briefings were each followed by the interview components relating to Usefulness and Acceptance of first the PAVs, followed by the FAVs. The Cognitive Walkthrough interview was the final component of Phase I. After the completion of all nine individual interviews, and the curation of the focus group discussion points based on the interviews, participants were randomly assigned to and participated in one of the two focus groups (Phase II).

### Data Analysis

To qualitatively assess the participants' responses to the open-ended questions, audio recordings of the semistructured interview sessions were first automatically transcribed and then manually corrected verbatim by two members of the research team. Interpretative phenomenological analysis (IPA) was used to assess the data (Smith & Shinebourne, 2012). IPA is a qualitative approach that aims to provide detailed examinations of personal lived experience and to offer insights into how a given person, in a given context, makes sense of a given phenomenon; here, the use of PAVs/FAVs. Based on the study's research question on the views of people with dementia of PAV/FAV use, IPA was deemed suitable as it focuses on an individual's personal perception or account of a phenomenon, as opposed to an attempt to produce an objective statement about the phenomenon itself (Smith & Shinebourne, 2012). In addition, IPA focuses on sense-making of a phenomenon through a joint effort of the participant and the researcher, which in this study was reflected in the conversational approach taken by the study team in the interviews and the focus groups, and the coding process, which was focused on the experience of each individual. In an iterative process, the initial codes were searched, and the two sets of codes generated by the two study members were compared to create a coding framework. Guided by the IPA approach, the coding framework included annotation that not only represented the interview content, but also reflected the researchers' impression of whether the participants, through their statements, were voicing a benefit, a concern, or a suggestion to overcome their concern toward future AV use. The discrepancies were resolved by discussion between the two study members. Consequently, the transcripts were recoded using the coding framework, and the codes were grouped into recurring patterns (or "themes"). Subsequently, related themes were grouped into categories and organized into a high-level mapping describing the conceptual connections between categories (Figures 3–6). The data during analysis was managed using NVivo 12. The trustworthiness of the qualitative analysis (Lincoln & Guba, 1985) was achieved by employing procedural rigor strategies such as comparing the coding of the text data completed by two members of the research

**Table 1.** Overview of the Instruments Used in This Study

Title	Description
Study Phase I	
History questionnaire (Online Supplementary Material Section A)	A questionnaire recording participants' demographics, driving and health history, and diagnosis of dementia.
AV familiarity questionnaire (Online Supplementary Material Section B)	A questionnaire with two 3-point Likert scale questions on the level of familiarity and experience with a current commercially available AV, Tesla Autopilot. Specifically, the questions asked, "How familiar are you with Tesla Autopilot?" and "How much experience do you have with Tesla Autopilot?" Participants were asked to rate their familiarity/experience with the Tesla Autopilot from zero (i.e., not familiar/no experience), to three (i.e., familiar/experienced).
PAV/FAV functionality briefing	An information sheet including plain language summaries and a table describing the automation functionality and the driver's responsibilities in PAVs/FAVs. These descriptions included tables adapted from <a href="#">Seppelt et al. (2018)</a> , showing the allocation of driving responsibilities between the PAV/FAV and the driver.
PAV/FAV acceptance questionnaire and interview (Online Supplementary Material Section C)	Questionnaire: A questionnaire including three items of <i>trust in</i> , <i>perceived safety of</i> , and <i>intention to use AVs</i> . The questions were adapted from the validated Autonomous Vehicle Acceptance Model Questionnaire ( <a href="#">Hewitt et al., 2019</a> ) and summarized using three 4-point Likert scale questions. Interview: After each question, when applicable, participants were asked to elaborate on their answers. PAV/FAV versions: The questions were repeated as related to PAVs and FAVs separately, but in each case, the questions were framed differently to reflect PAV or FAV use.
PAV/FAV usefulness questionnaire and interview (Online Supplementary Material Section D)	Questionnaire: A questionnaire was created to capture perceived usefulness of PAVs/FAVs among people with dementia in mitigating their potential driving challenges, with two sections thematically related to: (a) challenging driving <i>conditions</i> (e.g., night-time and heavy traffic) and (b) challenging driving <i>tasks</i> (e.g., left turns and backing up the car). The conditions/tasks were chosen to represent situations commonly avoided by older adults ( <a href="#">Tuokko et al., 2014</a> ). Participants were asked whether, in the context of nonautomated driving, they "avoid driving" in a particular driving condition or performing a particular driving task. If they responded "yes," the subsequent question asked whether they "would still avoid driving if they used a PAV/FAV" for each condition and task. Participant 9, who no longer drove, was asked to answer these questions reflecting on the time frame after their diagnosis, before they gave up driving. Interview: Specific to each driving condition/task, the participants were asked to reflect on the reasons why they would/would not avoid each task/condition using a PAV/FAV. PAV/FAV versions: Two versions of the AV Usefulness Interview were implemented and used, as applicable to PAVs and FAVs.
FAV trip—Cognitive walkthrough interview	A cognitive walkthrough is a task-specific usability inspection method, in which the participant is guided through a sequence of actions, for instance using a storyline, as a formalized way of imagining the users' thoughts and actions ( <a href="#">Mahatody et al., 2010</a> ). The objective of the Cognitive Walkthrough of an FAV trip was to allow participants to reflect on the usefulness of FAVs to address their potential challenges in the entirety of a trip, even when the FAV is fully performing all driving tasks for the person with dementia. This included aspects of the trip beyond simply the act of driving, such as leaving their residence to get to the car, traveling to the intended destination, engaging in the intended activity, and returning home. Two brief scenarios were described to the participants, in which they were asked to mentally walk through the actions required for them to take a trip to a grocery store using a FAV. In both scenarios, participants were asked to reflect on the potential obstacles that they may face from leaving their home, to using the FAV, finding the grocery store, and finding their way back home. The second scenario differed only in that the participants were asked to consider a situation in which the automated system disengages due to a system failure.
Study Phase II	
Focus group discussion points	The discussion points used in the focus groups were based on the comments made by the participants in the interviews that specifically referred to suggestions as to their proposed means of overcoming their hesitations toward PAV/FAV use.

Notes: AV = automated vehicle; PAV = partially automated vehicle; FAV = fully automated vehicle.

team (S. Haghzare and G. Delfi) and engaging in ongoing discussions about the codes and their relation to emergent themes, which facilitated reflexivity and bracketing off research preconceptions. Other techniques included prolonged engagement with the participants and the substantive literature, which contributed to the study's credibility, and maintaining an audit trail that consisted of field notes, transcripts, codes, definitions, and mappings to achieve dependability (Nowell et al., 2017).

## Results

### Results of the Questionnaires

#### Participant characteristics

Table 2 describes the demographics, driving status, diagnosis, and prior familiarity/experience of the participants (age min = 63 and age max = 80) with commercially available AVs (i.e., Tesla Autopilot). The participants included both current drivers and past drivers.

#### PAV versus FAV acceptance among people with dementia

Figure 1 describes participants' ratings of their PAV and FAV acceptance with relatively high overall ratings for both PAV and FAV use across the three items of *trust*, *perceived safety*, and *intention to use*. In addition, participants have rated FAVs higher across all three items compared to PAVs.

#### The influence of driving conditions and tasks on the intended self-regulatory behavior of people with dementia when using PAVs/FAVs

In the Usefulness Questionnaires, participants were asked whether they currently "avoid driving" using nonautomated vehicles and whether they "would avoid" driving using PAVs or FAVs in various driving conditions/tasks. As shown in the first three rows of Figure 2, none of the participants avoided backing up the car, driving long distances, or driving in clear daytime conditions during nonautomated driving. However, for the remaining seven driving conditions/tasks, there was at least one participant who avoided nonautomated driving. In total, there were 12 instances where participants reported self-regulating their nonautomated driving in specific driving conditions/tasks, which are shown with the colors light gray, dark gray, and black in Figure 2. In one third of instances (4/12 instances; light gray), participants reported that PAV use would change their self-regulatory behavior (i.e., they would no longer avoid driving if using PAVs), which were specific to conditions/tasks of heavy traffic, highway, and parking the car. In another one third of instances (4/12 instances; dark gray), participants reported that only an FAV would change their self-regulatory behavior to no longer avoid driving, specifically for the conditions/tasks of driving at night, bad weather, on highways, and parking the car. In another one third of instances (4/12 instances; black), participants noted that neither a PAV nor an FAV

**Table 2.** Factors Characterizing Participants ( $N = 9$ )

Variable	$M (SD)$	$n$
Age	66.00 (5.63)	
Sex		
Female		2
Male		7
Familiarity with Tesla		
Not familiar		2
Slightly familiar		6
Familiar		1
Experience with Tesla		
No experience		8
Some experience		1
Experienced		0
Years of driving experience	45.11 (11.33)	
Time since diagnosis (counted from 2021), years	6.22 (2.77)	
Driver's license status		
Valid		7
Valid—Conditional		1
Expired		1
Revoked		0
Driving frequency		
Every day		5
Sometimes		2
Never		2
Dementia type		
Vascular		3
Alzheimer's		2
Mixed Alzheimer's/vascular		1
Frontotemporal		1
Unknown		2
Dementia stage		
Mild		4
Mild to moderate		1
Moderate		2

Note:  $SD$  = standard deviation.

would change their self-regulatory behavior, and that, regardless of the vehicle's automation, they would still avoid driving, specifically for the conditions/tasks of driving in unfamiliar areas, turning left at intersections, in bad weather, and in heavy traffic.

### Results of the Interviews

Figure 3 presents a high-level overview of the four categories of the themes extracted in the interviews and in the focus group sessions and the connections among the four identified categories. Namely, Category 1 includes themes that describe participants' self-reported incentives to use PAVs/FAVs, and Category 2 includes themes that describe participants' self-reported hesitations toward PAV/FAV use, both of which were described by the participants as contributing factors to their overall acceptance of PAVs/FAVs. Category 3 includes the themes that were identified as *underlying factors* (or

sources) of participants' incentives/hesitancies to use PAVs/FAVs. Finally, Category 4 includes themes describing the means proposed by the participants to potentially overcome their hesitancies toward PAV/FAV use, which could positively influence their acceptance of PAV/FAV use.

**The incentives for people with dementia in using PAVs/FAVs and the factors underlying these incentives**

Figure 4 summarizes participants' incentives to use PAVs/FAVs (i.e., Category 1: white column on the right) and maps each incentive to its identified underlying factor (i.e., Category 3: dark gray column on the left). As shown in Figure 4, all the incentives for PAV use noted by the participants were also noted for FAV use (1.6–1.8), but participants highlighted unique incentives for FAV use compared to PAV use (1.1–1.5). Two underlying factors of participants' incentives to use PAVs/FAVs were identified, which included AV characteristics and benefits to self and care-partners.

*AV characteristics.*—The perceived “safety” of FAVs in comparison to human drivers was described by some participants as a characteristic of FAVs that contributes to

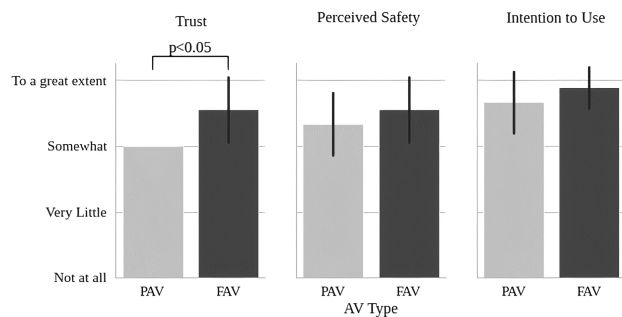
their positive attitudes toward FAV use, and leads to their notion of regarding FAVs as “a safety tool” (see Figure 4, Quote 1).

While the safety of FAVs was often compared to the safety of a typical human driver, some compared FAV's performance to their own driving, and considered it a safer option in comparison: “I cannot make a trip safely. My mind draws blank. I would trust a fully automated because it takes the driving away from me and it does it itself.” Participants highlighted the importance of FAV's perceived relative safety compared to their own driving safety by describing their concerns about endangering the safety of other road-users when they drive: “It's not about me getting hurt, it is about me hurting somebody else. I couldn't live with myself if I did something to hurt somebody else.”

Some participants attributed their perceived safety of FAVs to their “faith in the government and that they [the government] would make sure that things are safe for that [FAV use] to occur,” noting that “if it [a FAV] passes the government's safety standards, I think I would be comfortable with that [FAV].” While some participants were only comfortable trusting the decisions of the government as “[an] independent third party to make that determination” on FAV's safety, some participants were even comfortable trusting the AV manufacturers:

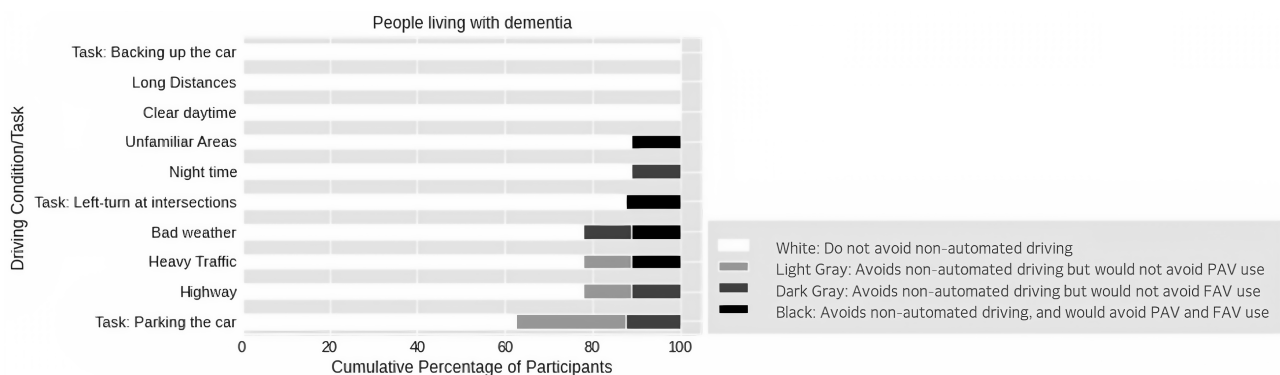
From what I've heard and read, the companies involved have gone to great expense to make sure that all of the vehicles are safe, and of course that's to their advantage because if they have problems with their automated vehicles getting into accidents, etc. that's gonna give them a lot of bad publicity. So, I think that's one thing that they are going out of their way to give top priority to—safety features. So, I feel confident that they [FAVs] are completely safe.

*Benefits to people with dementia and care-partners.*—The second underpinning of the incentives of people with dementia to use PAVs/FAVs was identified as



**Figure 1.** Comparison of the ratings of people with dementia of their acceptance of PAVs and FAVs for trust, perceived safety, and intention to use.

Notes: AV = automated vehicle; PAV = partially automated vehicle; FAV = fully automated vehicle. The bar chart shows the average response and error bars represent standard deviation of participants' ratings.



**Figure 2.** A stacked bar chart of the percentage of people with dementia (n = 9) who avoid driving with nonautomated vehicles and who would avoid using PAVs, and/or FAVs, separated by driving conditions/tasks.

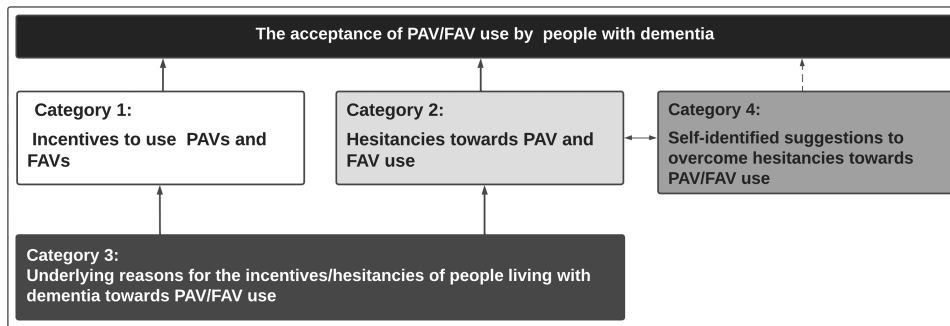
Notes: PAV = partially automated vehicle; FAV = fully automated vehicle.

the technology’s benefits to people with dementia and their family care-partners. While participants described unique benefits of FAV use compared to PAV use (Figure 4; 1.2–1.5), they also described benefits that were applicable to both PAV and FAV use (Figure 4; 1.6–1.7).

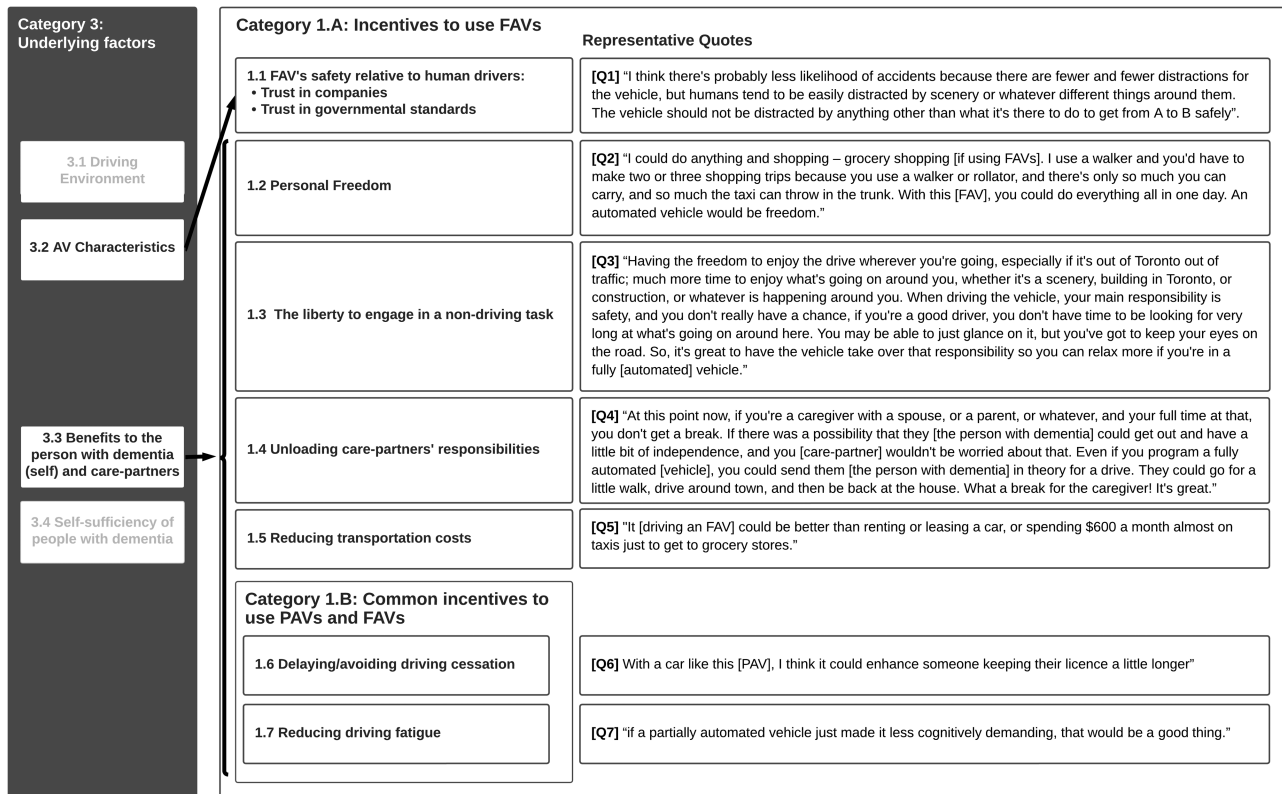
FAVs’ unique benefits for the person living with dementia and care-partner.— The first FAV-specific benefit compared to PAVs described by the participants was regaining “personal

freedom,” which was emphasized as a significant potential benefit to some people with dementia: “for people that don’t have freedom, that freedom means everything.” Some participants noted how FAVs could help lift the limitations of their everyday lives that had been introduced by their transition to nondriving (see Figure 4, Quote 2).

The freedom anticipated as a benefit of using FAVs was also characterized by some participants as the autonomy to make and execute travel plans independently:



**Figure 3.** General map of the connections among the four categories of the identified themes. Notes: PAV = partially automated vehicle; FAV = fully automated vehicle. The detailed information about the themes in each category and the connections between categories are presented in Figures 4–6.



**Figure 4.** Mapping of the themes identified as the incentives for PAV/FAV use among people with dementia, associated underlying factors, and representative quotes. Notes: AV = automated vehicle; PAV = partially automated vehicle; FAV = fully automated vehicle. The opaque boxes in the gray column on the left are the themes identified in the analysis as underlying factors that are not relevant to incentives for people living with dementia to use AVs but to hesitancies of people living with dementia to use AVs.

I will be able to, for instance, go sky-diving. I'm now booked with something called [a sky-diving company] ... If I had a car, I could just zip along the highway, go to [the sky-diving company], take my jump, and come home.

The second unique benefit of FAV use for people with dementia compared to PAVs was described by the participants as having the liberty to engage in a nondriving task while the FAV is in control of driving. Although most participants noted that they would still want to be involved with the driving tasks when the FAV is in control, and they "wouldn't take [their] eyes off [the road] for a second," the option or liberty to engage in a nondriving activity (e.g., "listening to audio books," "carrying on a conversation") that may otherwise result in "distracted driving," even momentarily, was considered a benefit by the participants (see Figure 4, Quote 3).

The third unique benefit of FAV use compared to PAV use described by the participants was FAV's potential benefits for family care-partners because "the transition from having the ability to get yourself around to having to depend on others to help you get around, that's a significant problem. And it's not [a problem] just for the people who have dementia, but it's also [a problem] for their care-partners, or their families, or their friends, or whoever people they end up relying on for assistance." So, "something that can help care-partners manage their situation is very worthwhile." Having a parent who lived with dementia and witnessing the other parent caring for the parent with dementia, another participant shared that they "got very strong, passionate feelings about caregivers. So, if a care-partner or a caregiver can be relieved of the responsibility of transporting people with dementia, that I think takes some of the responsibilities off of the care partner and would relieve them of some stress." Additionally, participants shared their worry for care-partners' well-being as a stressor for themselves: "I worry more about the effect [of dementia] on my wife than I do about the effect on me, and I really hope that my wife survives my trip through dementia, and things like this—an automated vehicle that takes some burden off of caregivers and care-partners—can help. There are all kinds of damage that's done by dementia. So, if there's ways to protect the survivors, then I'm very, very keen on that" (see Figure 4, Quote 4).

The fourth and final unique benefit of FAVs compared to PAVs described by the participants was its potential to reduce transportation costs for people with dementia when "renting or leasing a car" as opposed to "spending \$600 a month almost on taxis just to get to grocery stores," which may or may not be applicable depending on the accuracy of the participant's estimated cost of AVs. This was of special importance to those participants who had to incur high transportation fees because they lived in rural settings, and those who due to "concurrent health issues" other than dementia, were not able to use public transport and did not find accessible transportation services as convenient

because "they [the transportation services] are late an hour sometimes, and people are left waiting in wheelchairs."

PAVs' and FAVs' common benefits for the person living with dementia.—Two common benefits of PAV and FAV use were identified by the participants. The first common benefit was considered their potential to delay/avoid driving cessation. Considering "being able to drive, a gift," this benefit was voiced by participants with a range of driving abilities, those who are "not capable of driving in certain conditions now," those who anticipate that they are "gonna have to stop driving some time," or those who have already stopped driving, but "would go get it [their drivers' license] again if such a vehicle becomes available."

While the potential benefit of delaying/avoiding driving cessation was noted for both PAV and FAV use, participants highlighted that PAVs and FAVs might provide them with different levels of benefits. Namely, PAVs were often considered to help *delay* driving cessation, while FAVs were considered by some participants to help *avoid* driving cessation. In case of PAVs, for instance, one participant noted that: "With a car like this [PAV], I think it could enhance someone keeping their license a little longer," while adding that "even with a [partially] automated vehicle, if my judgment was impaired, I would still stop driving." In comparison to PAVs, FAVs were considered to be a longer-term solution: "I have to quit driving as my diagnosis gets worse, and I've been told that it gets worse, and a fully automated vehicle would solve that" because "fully automated vehicle would take the onus away from me [the person with dementia] and put it on itself."

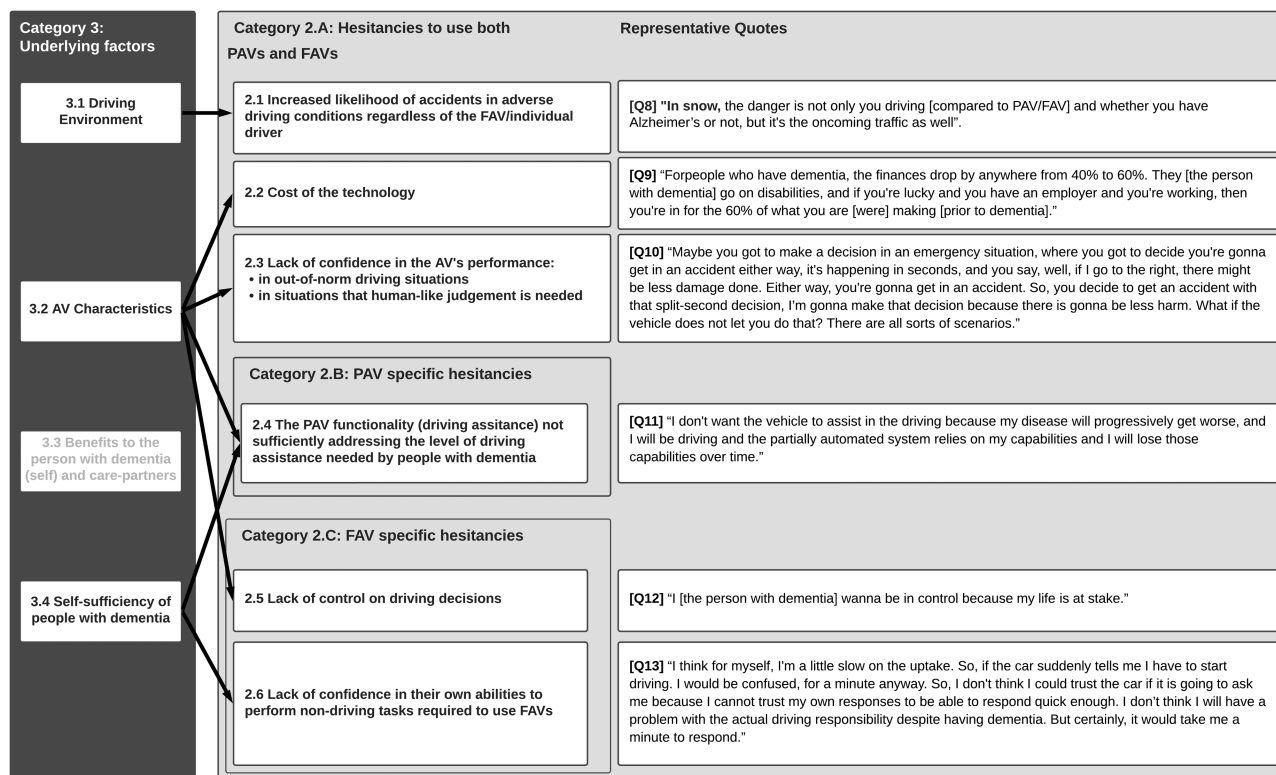
The second common benefit of PAV and FAV use for people with dementia were identified by the participants as the potential convenience of avoiding fatigue during driving, especially for long distances. For some participants, the underlying difficulty with nonautomated driving was "cognitive fatigue" and as such, they concluded that "if a partially automated vehicle just made it less cognitively demanding, that would be a good thing." Similarly, other participants anticipated that "it [a PAV] would definitely cut back on the fatigue," or that "the automated [FAV] will let me [the person with dementia] sit back and relax."

#### The hesitations of people with dementia regarding using PAVs/FAVs and the factors underlying these hesitations

Figure 5 summarizes the themes identified as participants' hesitations toward PAV/FAV use (Category 2: gray column on the right) and maps them to their identified underlying factors (Category 3: dark gray column on the left).

*The hesitations of people with dementia toward both PAV and FAV use.*—The first identified hesitancy of





**Figure 5.** Mapping of the themes identified as the hesitancies toward both PAV and FAV use among people with dementia, associated underlying factors, and representative quotes.

*Notes:* AV = automated vehicle; PAV = partially automated vehicle; FAV = fully automated vehicle. The opaque boxes in the gray column on the left are the themes identified in the analysis as underlying factors that are relevant to hesitancies of people living with dementia to use AVs but to incentives for people living with dementia to use AVs.

participants toward PAV and FAV use was specific to their use under challenging driving conditions (e.g., traffic and adverse weather) or their use to perform challenging driving tasks (e.g., parallel parking or parking in tight spots). Most participants noted that they would still avoid using PAVs/FAVs in the challenging conditions/tasks that they avoid with a nonautomated vehicle because of "higher likelihood of accidents in these situations" where for instance "the danger is not only you driving [compared to PAV/FAV] and whether you have Alzheimer's or not, but it's the oncoming traffic as well."

In addition, participants also highlighted hesitancies toward AV use applicable to both PAVs and FAVs that were rooted in the AV characteristics as perceived by the participants. These hesitancies included concerns about the cost of the technology and the participants' lack of confidence in the performance of PAVs/FAVs in "out-of-norm situations." The cost of the technology was regarded as a barrier toward AV use, especially for people with dementia who "could lose [their] license at any point," and as such, were uncertain about the return on investment, meaning that, depending on its length, the duration that an AV could extend their safe driving period before complete cessation may not be worth the cost. For instance, a participant described an occasion when they had to make a similar decision:

I remember I blew my motor, and I chose to put another motor in rather than get a new car because I could lose my license in a year. It used to be two years between assessments, and then they moved it up to one year.

Furthermore, other participants noted that the financial aspects of purchasing/using an AV may be a potential barrier for many people with dementia because "For people who have dementia, the finances drop by anywhere from 40% to 60%. They [people with dementia] go on disabilities, and if you're lucky and you have an employer and you're working, then you're in for the 60% of what you are [were] making [prior to dementia]."

The second identified hesitancy toward AV use that was common for both PAVs and FAVs was participants' lack of confidence in the performance of PAV/FAVs, especially in "out-of-norm situations" or in situations where "human-like judgement is needed" (see Figure 5, Quote 10).

*The hesitancies specific to PAV use.*—Participants noted that they would hesitate to use PAVs because they deemed PAVs' driving functionalities insufficient to meet the current or future level of driving assistance they would require to be able to drive safely: "I don't want the vehicle to assist in the driving because my disease will progressively get worse, and I will be driving and the partially automated system

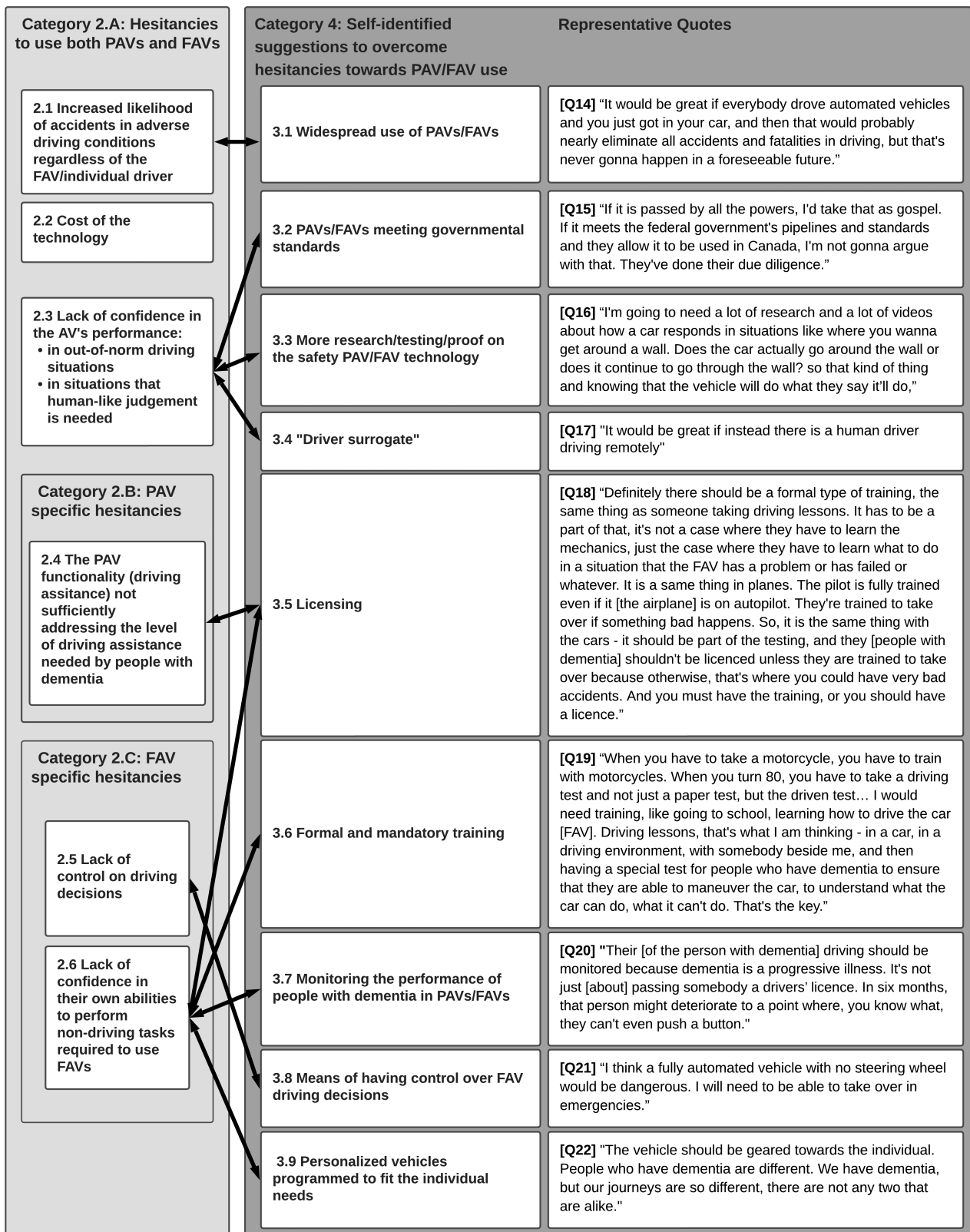


Figure 6. Mapping of the suggestions of people with dementia to overcome their hesitancies toward PAV/FAV use. Notes: AV = automated vehicle; PAV = partially automated vehicle; FAV = fully automated vehicle.

relies on my capabilities and I will lose those capabilities over time.”

*The hesitations specific to FAV use.*—The first FAV-specific hesitancy identified among the participants was their reluctance to relinquish driving control to the FAV altogether, highlighting that “I [the person with dementia] wanna be in control because my life is at stake.” Other participants conditioned their trust in FAVs on “the assumption that I [the person with dementia] can override anything any time I want” or that they would use an FAV “as long as there is a switch to turn it [the FAV] off.” When participants were reminded that based on the definition of FAVs, their future designs may not have a means for drivers to interfere with FAVs’ driving decisions, the participants regarded that as “dangerous”: “I think a fully automated vehicle with no steering wheel would be dangerous. I will need to be able to take over in emergencies.”

The participants’ second type of hesitancy to use FAVs was rooted in their lack of confidence in their own abilities to carry out the nondriving tasks (e.g., “programming the destination” or “remembering the pin to the car”), noting that “That’s really hard for people with dementia. For me, numbers and routines were the first to go.” Similarly, when queried about the possibility of having to take over driving control from the AV if requested, most participants voiced that they are not entirely confident in their current abilities to take over driving control from an AV if they are requested to do so (see Figure 5, Quote 13).

#### Self-identified potential means of overcoming hesitations toward PAV/FAV use

During the interviews and further during the focus groups, participants described some potential suggestions that could help mitigate their hesitations toward PAV/FAV use, which were grouped under Category 4. Figure 6 provides a list of the themes in Category 4 mapped to the underlying causes of hesitation of people with dementia toward PAV/FAVs use. For instance, some participants noted the widespread use of PAV/FAV as a possible way of ensuring the safety of PAVs/FAVs under all driving conditions (see Figure 6, Quote 14). This is while some participants highlighted the need for “governmental standards” and conditioned their acceptance of AVs on the AVs meeting such governmental standards (see Figure 6, Quote 15). Other participants indicated that they would require more testing and/or evidence to gauge “whether or not this [PAV] is something that would protect me enough at the stage of my life with the condition that I have,” and to ensure that “the vehicle [FAV] will do what they [the manufacturers] say it’ll do” (see Figure 6, Quote 16).

A potential means of overcoming the lack of confidence in AV’s performance was described to be the alternative of having a “remote human surrogate driver.” In this alternative scenario, instead of the AV system, a human driver is remotely controlling the vehicle. While realistically there

may be multiple technical barriers to the realization of this proposed idea, having a human driver who is “driving remotely using a simulator” instead of the person with dementia was considered a better alternative than being driven by an AV, and it was described to alleviate the concerns of people with dementia about AV’s performance in “out-of-norm” driving situations.

Licensing and mandatory training for people with dementia to use AVs were noted as two possible means of relieving participants’ concerns about their lack of confidence in their own abilities to drive in PAVs and to perform nondriving tasks required to use FAVs (see Figure 6, Quote 18). Specifically in terms of potential AV training for people with dementia, the participants suggested specific training programs for people with dementia, such as “hands-on” training because “people who have cognitive impairments don’t remember certain steps” (see Figure 6, Quote 19).

Related to the suggestions of having special licensing and training requirements for AV use of people with dementia, some participants highlighted the need to “monitor” the driving performance of people with dementia “because dementia is a progressive illness. It’s not just [about] passing somebody a drivers’ license. In six months, that person might deteriorate to a point where, you know what, they can’t even push a button. I can’t ... I cannot even change my TV stations where everyone can change TV stations.”

Another suggestion voiced by most participants was AV personalization through “individualized vehicles” or vehicles that are “geared towards the individual” because “people who have dementia are different. We have dementia, but our journeys are so different, there are not any two that are alike.” Participants described potential features of such personalized AVs, for instance, “the ability to save the address to the grocery store or home or wherever” such that they can automatically program the destination when the person with dementia “just verbally says grocery store. Or on the way back I [the person with dementia] would tell it [FAV] to get back home. Just a single word.” Another feature of such personalized AVs was described as the ability to store “medical information” on the person with dementia or having the means to contact the care-partner(s) in case of emergencies.

## Discussion and Implications

For the purpose of evaluating the potential usefulness of AVs as assistive technologies for people with dementia, the current mixed-methods study aimed to explore the views of people with dementia on AV use. Specifically, questionnaires were used to assess the potential differences in participants’ trust in, perceived safety of, and intention to use PAVs and FAVs under different driving conditions and for different driving tasks. The results indicated that people with dementia might have significantly higher levels of trust in FAVs compared to PAVs. This finding supports Molnar et al.’s projections that AVs with different levels

of automation may have varying levels of benefits for older adults or those living with driving-restrictive medical conditions (Molnar et al., 2005). Similar notions of the greater perceived benefits of FAVs for people with dementia compared to PAVs were also observed in the results of our qualitative analysis, where people with dementia highlighted additional incentives for FAV use compared to PAV use, including personal freedom, liberty to engage in nondriving tasks, and unloading family care-partners' responsibilities. The latter was congruent with the findings of previous research on care-partners perspectives of AV use by people with dementia in their care, where compared to PAVs, FAVs were deemed more useful by family care-partners of people with dementia in unloading their caregiving responsibilities (Haghzare et al., 2022). Similarly, people with dementia noted different levels of benefits for PAVs versus FAVs in helping their transition to nondriving. Specifically, people with dementia noted that while PAVs may help *delay* their driving cessation, FAVs may help *avoid* their driving cessation. In other words, PAVs could help people with dementia who still drive to drive safer, while FAVs could help with the independent transportation of people with dementia who are giving up driving or who no longer drive. While a theoretically justifiable hypothesis, future research is warranted to objectively confirm/negate the relative advantage of FAVs versus PAVs in enhancing the driving safety of people with dementia. In fact, considering the current lack of evidence on the safety of AV use of any type by people with dementia, the most critical step for future research is to evaluate the safety of using different AV levels by people with dementia. Only once evaluated and verified, the anticipated self-reported benefits of AV use by people with dementia (e.g., personal freedom) would be applicable. This is especially important because extrapolating from the literature on nonautomated driving of people with dementia, there is a high likelihood of a gap between the subjective, self-reported driving abilities/habits and the objective evaluation of the driving abilities/habits of people with dementia (Eby et al., 2012; Silverstein et al., 2011), which could be applicable to the self-reported PAV and FAV use of people with dementia as well. Beyond PAVs and FAVs, these evaluations should include AV levels such as SAE Level 3 which require the driver to take overdriving control when the AV can no longer drive. While in this study, people with dementia subjectively deemed their abilities insufficient to safely perform driving take-overs in AVs, more evidence is needed to objectively characterize the fitness of people with dementia at different severity levels to take overdriving control in AVs. AV testing among people with dementia can additionally help inform governmental standards on AV development, specific AV designs, and AV licensing and training for people with dementia, which are not only required to ensure the accessibility and safety of AVs for people with dementia but were also highlighted in this study by people with dementia as a potential means to overcome their hesitations to use AVs. AV testing among

people with dementia could also help alleviate the concerns of care-partners identified in previous research pertaining to potential challenges that people with dementia in their care may face when using AVs (Haghzare et al., 2022).

In future research evaluating the safety of AV use by people with dementia, the underlying factors of hesitations/incentives for people with dementia to use AVs identified in this study (themes in Category 3) can be used as variables that should be strategically controlled. These factors include the driving environment, AV characteristics (e.g., AV level), and the driving abilities of people with dementia, all of which could potentially influence the safety of AV use by people with dementia and, therefore, should ideally be considered in policies around AV use by people with dementia. A lack of rigorous consideration of these potentially influencing factors in future research and policies pertaining to AV use by people with dementia could pose risks either to road safety or to realizing the potential of AVs for this population. For instance, overgeneralizing any findings confirming the safety of using a certain AV type, under certain driving conditions, by people with dementia with the certain type(s) and stage(s) of dementia to all AV types/driving conditions/people with dementia could pose serious risks to road users and public safety. On the other hand, by not identifying AV designs that could potentially help some people with dementia to drive safer, at least in certain driving conditions, we risk ignoring the potential life-changing benefits of AVs for people with dementia.

Proactive policies are necessary to encourage AV evaluation among people with dementia. In the absence of such policies, a true or perceived lack of commercial incentives for the AV industry may hinder the efforts toward identifying and realizing the potential of AVs for people with dementia. This is especially true because the safety-critical nature of AV evaluations among people with dementia could make them an effortful undertaking that should be carried out in the presence of a trained specialist (e.g., occupational therapist), preferably in controlled settings (i.e., high-fidelity driving simulators) to ensure safety, followed by on-road settings to rule out any potential implications of the controlled setting (e.g., simulation sickness) on the driving evaluations of people with dementia. In addition, policies will also be key in the subsequent steps following AV evaluations among people with dementia to ensure that the testing outcomes are appropriately integrated into standards, services, and AV designs. For instance, in the current subjective evaluation of the views of people with dementia of AV use, some people with dementia considered the AV cost as one of the reasons why they would be hesitant to use AVs while others living in rural areas, identified financial advantages of AV use if the cost is lower than the transportation costs, they have to incur for using taxis. This finding highlights the role of promoting appropriate service delivery models and AV-ownership models in realizing the potential of AVs as assistive technologies. Without appropriate policy enforcements, AVs may perpetuate the current

societal inequalities in access to transportation systems (Pettigrew et al., 2019). For instance, without policies encouraging considerations of cost or accessibility of AVs, the private AV-ownership models could take dominance over the car-sharing models, which could mean that AVs as assistive technologies, even if realized, will only benefit a subpopulation of people with dementia who can purchase and own AVs.

While the current study took an exploratory approach to capture and account for the experiences of each participant and their views on AV use, the major limitation of the study is its small number of participants and the deliberate permissiveness of the inclusion criteria across different subpopulations of people with dementia. In particular, the study included people with dementia with varying stages and types of dementia, level of community engagement, level of care received by family-care partners, and driving ability/history. This is while, each of the noted characterizing factors of people with dementia may have implications on their adoption of AVs, and they each warrant future research. For instance, all but one person with dementia who participated in this study still drove, and were mostly self-identified to be in earlier stages of dementia, which hinders the external validity of the findings across people with dementia with various stages and types of dementia and, therefore various levels/types of decline (e.g., cognitive and/or motor declines). Furthermore, considering the quotes from the participants, many participants were knowledgeable about AVs, which may not be true for the general older adult population or people with dementia. In addition, participants in this study exhibited self-awareness about their current or projected decline in driving skills (e.g., expecting to have to give up automated driving due to progression of dementia). However, not all people with dementia, especially those in later stages of dementia, exhibit the same insights about their driving skill declines (Brown et al., 2005; Starkstein et al., 2006).

Another limitation of the study could be that while the study's procedure was designed to confirm the understanding of the participants of the PAV/FAV functionality briefings, there were no procedures in place to ensure the retention of the information about PAVs and FAVs among people with dementia who may be subtle to forgetting that information. On the other hand, it is likely that in the absence of proper regulations and licensing around AV use by people with dementia, the study's procedure could reflect and project the reality of AV use by people with dementia where people with dementia would be thrust into using AVs after only being presented with information about PAV and/or FAV functionality. Aside from the study's limitations, the identified themes in this study can serve as the basis of future survey-based research that aims to capture the views of a larger sample of people with dementia strategically selected based on their type/stage of dementia and their driving status. In addition, some of the means identified by people with dementia to overcome

their hesitations toward AV use, such as AV personalization and the ongoing monitoring of the driving performance of people with dementia could be translated into prototypes of in-vehicle technologies, where the accessibility and usability of these features should be further assessed among a larger sample of people with dementia.

## Conclusions

The people with dementia in this study shared the public's enthusiasm about AVs' tremendous potential for them in enhancing road safety, returning/maintaining their personal freedom, delaying/avoiding their driving cessation, and unloading family care-partners of some of their caring responsibilities. However, people with dementia voiced concerns about the safety of their AV use, which stemmed from concerns about their self-sufficiency in operating AVs, concerns about AV performance, and the fitness of AV functionality to their needs. People with dementia also identified barriers such as cost to their intention to use AVs. A combination of evidence-based governmental standards and licensing and training requirements directed toward AV use by people with dementia, and AV designs specific for people with dementia were identified as potential means of overcoming their hesitations toward AV use. These findings highlight that, in the presence of AV technology designs and AV delivery/ownership models that fit the needs and preferences of people with dementia, AV use can be an acceptable solution among people with dementia to enhance/prolong their driving safety. However, confirming the possibility and consequently, realization of this vision is contingent on two steps: (a) extensive evaluation of the safety of AV use among people with dementia (b) followed by AV personalization and the cocreation of AV service delivery models for people with dementia. As such, the realization of the potential of AVs for people with dementia will not be achievable without proactive joint efforts among people with dementia and their care-partners, the research community, private sector, and policymakers.

## Supplementary Material

Supplementary data are available at *The Gerontologist* online.

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## Conflict of Interest

None declared.

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