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Research Article

Refining a Driving Retirement Program for Persons With Dementia and Their Care Partners: A Mixed Methods Evaluation of CarFreeMe™-Dementia

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Abstract

Objectives: We adapted the CarFreeMe™-Dementia program created by The University of Queensland for drivers in the United States. CarFreeMe™-Dementia aims to assist drivers living with dementia and their care partners as they plan for or adjust to driving retirement. This semistructured program focuses on driving retirement education and support. Topics include how dementia affects driving, lifestyle planning, stress management, and alternative transportation options. This study evaluated the feasibility, acceptability, and utility of the CarFreeMe™-Dementia intervention.

Methods: This pilot phase of the study included 16 care partners and 11 drivers with memory loss who were preparing for or adjusting to driving retirement. Participants completed 4–8 CarFreeMe™-Dementia intervention telehealth sessions. Online surveys (baseline, 1- and 3-month) and postintervention semistructured interviews informed evaluation of the intervention program using a mixed methods approach.

Results: This study established initial support for CarFreeMe™-Dementia in the United States. Participants indicated the program facilitated dialogue around driving retirement and provided guidance on community engagement without driving. Respondents appreciated the program's emphasis on overall well-being, promoted through lifestyle planning and stress management. They also reported the program offered practical preparation for transitioning to driving retirement.

Discussion: The CarFreeMe™-Dementia intervention, tailored to an American audience, appears to be a feasible, acceptable, and useful support program for drivers with memory loss (and/or their care partners) who are preparing for or adjusting to driving retirement. Further investigations of the efficacy of the CarFreeMe™-Dementia intervention in the United States, as well as in other countries and cultural contexts, are warranted.

Keywords: Alzheimer's disease, Caregiving, Observational studies, Qualitative methods

There are approximately 54.1 million drivers in America, 65 years old or older (National Highway Traffic Safety Administration, 2021). About 11.3% of all Americans over the age of 65 experience memory impairment in the form of Alzheimer's disease or related dementia (AD/ADRD; Hudomiet et al., 2018). Estimating the number of American drivers with AD/ADRD is difficult due to varying state licensing requirements and reporting standards (Vanderbur & Silverstein, 2006). However, studies suggest between 22% and 60% of Americans with mild cognitive impairment or diagnosed dementia still drive (Foley et al., 2000; Vaughan et al., 2015). This number is expected to grow given our aging population and this older cohort's expectations for continued driving (Mizenko et al., 2014; Naumann et al., 2014).

Dementia can progressively and significantly compromise critical aspects of driving safety, including awareness, attention, visual processing, reaction time, and decision-making (Brown & Ott, 2004; Chee et al., 2017; Fraade-Blanar et al., 2018). Dementia progression likely leads to earlier driving retirement as driving performance deteriorates more rapidly (Aksan et al., 2015; Ott & Daiello, 2010). Nevertheless, a dementia diagnosis does not indicate an immediate need for driving retirement (Versijpt et al., 2017).

Driving retirement can be difficult, as driving facilitates mobility, which often represents freedom and autonomy (Liddle et al., 2016; Sanford et al., 2019) and is a significant part of many Westerners' identity (Jetten & Pachana, 2012; Pachana et al., 2017). Sudden or unsupported driving retirement is associated with negative physical and mental health outcomes, including depression and social isolation (Chihuri et al., 2016; Qin et al., 2020).

Planning and supporting driving retirement for persons with dementia can be especially difficult considering dementia's impact on reasoning, comprehension, retention of new information, and the likelihood of anosognosia (i.e., the inability to recognize one's own memory loss; Albert, 2011; Moye et al., 2006). Conversations about driving retirement can be emotionally difficult for families and often have to be repeated (Jouk & Tuokko, 2017). There are currently few driving-specific decision aids for individuals with dementia (Carmody et al., 2015; Ho et al., 2021) or gold standard assessments of driver fitness (Rashid et al., 2020). Moreover, there is little systemic support provided by health care and social services to help people with dementia or their families navigate driving concerns (Marottoli & Coughlin, 2011). Additionally, medical professionals may have reporting mandates that can negatively impact their relationship with patients (Betz et al., 2016; Gergerich, 2016).

Evidence-based driving retirement support for persons living with dementia and their care partners (CPs) are few and limited in scope, such as support solely for CPs (Jouk & Tuokko, 2017; Stern et al., 2008) or individuals with revoked licenses (Dobbs et al., 2009). Thus, there is a need to identify effective strategies and create driving retirement programs to support persons living with dementia and their families (Andrew et al., 2015). A program that balances respect and autonomy by including the person living with dementia in the decision-making process of driving retirement is necessary (Livingston et al., 2017).

The University of Queensland Driver Retirement Initiative (UQDRIVE; Liddle et al., 2007), later renamed CarFreeMe™, is a seven-module psychoeducational, group-based program developed for older adults without cognitive impairment. CarFreeMe™ consisted of group meetings for 3–4 hr a week for 6 weeks to have discussions, speakers, and practical exercises on topics such as alternative transportation, lifestyle planning, and adjustment to loss and changes. Enrollment in CarFreeMe™ was associated with an increase in the use of alternative transportation, excursions from home, and satisfaction with transportation (Liddle et al., 2014).

Further research eliciting the driving retirement experiences of persons living with dementia indicated that family members often play an integral role and identified three key stages of driving retirement: growing concern (Preparing), crisis stage (Initiating driving retirement), and ongoing adjustment (Adjusting; Liddle et al., 2013, 2016). The findings led to CarFreeMe™-Dementia, an adaptation of CarFreeMe™, which focuses on drivers with dementia and their family members and is relevant for those in each stage of driving retirement. This adaptation added dementia education, including how dementia affects driving skills. A successful pilot trial in Australia demonstrated improvements in well-being, mobility, and transportation satisfaction (Scott et al., 2020). A larger scale evaluation is ongoing in Australia (see Scott et al., 2019).

In collaboration with the developers of the original programs, the University of Minnesota research team adapted the CarFreeMe™-Dementia intervention for use in the United States (U.S.), where driving is the principal mode of transportation for older adults and is particularly seen as synonymous with mobility and independence (Pristavec, 2018; Qin et al., 2020). This Phase I of a two-phase pilot study examines the feasibility, acceptability, and utility of the CarFreeMe™-Dementia intervention in the United States to assist persons with memory impairment and their families to manage the driving retirement transition.

Method

Recruitment

Recruitment efforts for CP-driver dyads were initiated in Minnesota in late September 2020. By the end of October 2020, eligibility was expanded to allow for either CPs or drivers to enroll individually. In February 2021, recruitment expanded nationally, and enrollment ended in May 2021. Recruitment strategies included sharing study information with the principal investigator's (J. E. Gaugler) registry of

dementia CPs interested in research opportunities; creation of a project website; word of mouth; and media distributed by local Area Agencies on Aging, memory clinic providers, and other community agencies. In addition, permission for contact was obtained via dementia-related webinars and educational outreach events. Research staff provided interesting contacts with study-related information via phone or email prior to initiating telephone-based screening and consent.

Inclusion and Exclusion Criteria

Participants included individuals with memory loss (and/or their CPs) who were either preparing for or adjusting to driving retirement. Preparing, Initiating, and Adjusting drivers are collectively referred to as "retiring drivers" (RDs). RDs were considered eligible if they: (a) had a diagnosis of AD/ADRD or the RD/CP expressed concern about their memory or cognition and (b) were considering or adjusting to driving retirement. CPs were eligible if they: (a) provided care to a person living with memory concerns or AD/ADRD and (b) the family was considering or adjusting to driving retirement.

The purposeful inclusion of those without diagnosed AD/ADRD allowed for the involvement of those with early-stage memory loss/cognitive impairment. All participants were required to live in the United States, be at least 21 years of age, and speak English. Additionally, participants were excluded if they: (a) resided in a nursing home; (b) initiated or changed dosing of a psychotropic medication in the past three months; or (c) had a mental illness in which symptoms were exacerbated in the last 6 months and not receiving ongoing treatment.

RDs were administered an adapted University of California, San Diego Brief Assessment of Capacity to Consent (Jeste et al., 2007). If unable to consent independently, the RD provided assent for participation, and a representative or CP completed consent on their behalf.

Intervention

Designed to be delivered by health professionals, the CarFreeMe™-Dementia intervention offers tailored psychoeducational coaching to help individuals with memory loss and CPs manage driving retirement across the continuum (Preparing, Initiating, and Adjusting). The goal was not to have RDs retire from driving, and for this reason, coaches did not make driving mandates. Instead, coaches encouraged participants to follow state laws and empowered participants to make decisions with their family and/or medical provider.

Two study coaches (with a PhD in clinical psychology and Doctor of Nursing Practice) reviewed the program modules and workbook and completed 10 1-hr training sessions with author (T. L. Scott), a coinvestigator and expert in CarFreeMe™-Dementia intervention delivery. CarFreeMe™ Consortium members provided consultation and oversight for the duration of the study. The coaches typically delivered the CarFreeMe™-Dementia program weekly via secure video conference in four to eight 1-hr sessions within a 3-month timeframe. During the first session, typically within 2 weeks of enrollment, participants were interviewed about their driving concerns, priorities for the program, and interests. Following the initial session, coaches guided participants through seven modules. An additional CP-only module was also offered.

The session content was semistructured and personalized, providing support for all stages of driving retirement (Liddle et al., 2013). For instance, the program educates Preparing drivers about how to decide when to retire, helps Initiating drivers manage their sense of loss, and supports Adjusting drivers by problem-solving ways to stay involved in activities. Seven module topics are specifically addressed: dementia education and associated changes that may affect driving, balancing independence and safety, coping strategies for adjusting to loss, experiences of RDs, alternative transportation options and problem-solving, lifestyle planning, and advocacy. Although coaches included the content of all modules, the number, order, and depth of coverage were determined by the participants' interests. Additional, or ad hoc, intervention sessions were delivered as needed. Program content was largely unchanged from the CarFreeMe™-Dementia program. Modifications included language changes and localized resources, using telehealth as the sole delivery method, and employing individual instead of group sessions. See Scott et al. (2020) for intervention details. This study was approved by the University of Minnesota IRB (Study 00009343).

Measures

A convergent parallel mixed methods design (i.e., the collection and analysis of qualitative and quantitative data concurrently) was used to examine the feasibility of program administration, its acceptance, and the utility of CarFreeMe™-Dementia over a 3-month period. Participants completed a baseline survey, follow-up surveys at one and three months, and a final semistructured interview. To decrease respondent burden, RDs received shortened surveys and some modified measures. Survey measures details are in Table 1.

Administrative feasibility: Recruitment, retention, and fidelity

Participant recruitment timelines and retention rates were noted. Study coaches completed a contact log to record session information and topics discussed. Author T. L. Scott reviewed the logs to ensure treatment fidelity. The research team reviewed this information during team meetings to monitor program delivery. Retention and session

Table 1. Summary of Assessment Measures Used in Phase I

	Description	Range
Measures for CP and RD		
Activities of daily living/ Instrumental activities of daily living (modified; Katz et al., 1963)	Twelve items assessing help required with activities	0–24
Assessment for readiness of mobility transition (AMRT; Meuser et al. [2013])	Twenty four items assessing readiness for driving retirement on emotional and attitudinal dimensions	0–90
Caregiver driving safety questionnaire (CDSQ; Iverson et al. [2010])	Ten items assessing history of crashes or traffic citations, including at-fault status, driving mileage, and driving practices	0–50
CarFreeMe™-Dementia intervention review checklists	Eight-item (RD) and 15-item (CP) on utility of the intervention content	0–40, 0–75
Mobility confidence questionnaire (Scott et al. [2019])	Nine-item (RD) and seven-item (CP) list assessing confidence in managing various aspects of driving retirement	0–90, 0–70
Driving retirement phase	Three items assessing what stage the RD was currently in (planning to retire, actively retiring, or already retired) and what actions they had taken toward driving retirement (e.g., limited driving and driving evaluation)	NA
Relationship closeness scale (RCS; Whitlatch et al. [2001])	Six items assessing relationship closeness between the CP and RD	0–19
Measures for CPs Only		
Cognitive impairment (Pearlin et al. [1990])	Eight items assessing the severity of memory loss, communication deficits, and recognition failures	0–32
Revised-memory and behavior problems checklist (Teri et al. [1992])	Twenty four items assessing dementia-related behavioral issues	0–96
Socioemotional support (Pearlin et al. [1990])	Eight items assessing the affective assistance provided by persons in their lives	0–30

Notes: The RD received simplified versions of several scales. CP = care partner; RD = retiring driver.

completion rates also served as indicators of feasibility and acceptability.

Intervention acceptability and utility

Participants received a review checklist measuring the extent to which the CarFreeMe™-Dementia program was useful to them (RDs 8 items, $\alpha = 0.90–0.91$; CPs 15 items, $\alpha = 0.78–0.90$). Using a five-point Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree), items assessed how well the program helped them adjust to driving retirement, identify alternative transportation solutions, and communicate feelings about driving retirement. An open-ended question asked participants to describe other ways the program was helpful or could be improved (see Table 3 for review checklist items). A semistructured interview elicited more detailed feedback. As able, CPs and RDs were interviewed separately to gather independent feedback. For full interview protocols, see Appendix A1 published as Supplementary Material online. Self-reported driving phase, preparedness for driving retirement, and driving retirement activities were assessed as further measures of utility and appropriateness for future study use. We hypothesized CarFreeMe™-Dementia would be feasible, acceptable, and useful for navigating driving retirement.

Analysis

Quantitative

Descriptive statistics were calculated for participant demographics. We conducted paired *t* tests to compare review checklist item score changes from 1-month to 3-month surveys, during and after the program, respectively. Percent agreement with each statement was also calculated based on the number of Likert responses at 4 (agree) or 5 (strongly agree). "Not applicable" responses were treated as missing and so resulted in a smaller sample for some comparisons. We also used paired *t* tests to compare continuous baseline and 3-month driving-related measure scores. All tests used a two-tailed significance cutoff of $\alpha = 0.05$. Exploratory analysis examined effects within and across surveys by Preparing and Adjusting groups.

Qualitative

Transcripts of the semistructured interviews ($N = 23$) and open-ended items on the review checklist were examined for themes answering the guiding question, "What affected the implementation and use of the CarFreeMe™-Dementia coaching for persons living with memory loss and their CPs?" Additionally, we probed for how the CarFreeMe™-Dementia program was helpful or not and what could be improved. Thematic analysis

was performed using the steps outlined by Braun and Clarke (2006). Codes were generated by identifying recurring responses among participant qualitative data and operationalized into overarching themes. Authors R. W. Birkeland, S. N. Ingvalson, K. W. Louwagie, L. L. Mitchell, and C. M. Peterson independently reviewed a subset of the data for commonalities and then discussed identified codes and examples. The authors evaluated the completeness and applicability of the initial codes to the second half of the data, finalizing the coding framework. Each transcript was coded by two coders in NVivo 12 to evaluate inter-rater reliability. Discrepancies were resolved by group consensus.

Integration of the quantitative and qualitative data occurred after the data were analyzed separately. We include supporting quantitative pre–post data from the intervention review checklists and driving outcomes throughout the qualitative results to highlight points of convergence with the themes on perceptions of the CarFreeMe™-Dementia program's feasibility, acceptability, and utility.

Results

Sample Characteristics

From three states, 16 CPs enrolled in the CarFreeMe™-Dementia study with 11 RDs enrolling as a dyad with their CP (N = 27). CPs were mostly female (n = 12, 75%) and spouses (n = 11, 70%) of the RDs, aged 63.6 years on average, and all were White. Half of the RDs were female (n = 8, 50%), aged 74.5 on average, and all were White. RDs had, on average, mild to moderate impairment, and 73% (n = 11) of RDs had an AD/ADRD diagnosis. In the past 3 years, 25% had been deemed at-fault for at least one motor vehicle accident. At the time of enrollment, half the RDs were in the Preparing for driving retirement phase, and half were Adjusting to retirement. See Table 2 for summarized demographics. Individualized information is available in Appendix A2.

Table 2. CP and RD Baseline Sample Characteristics

CP	*n*/mean	%/*SD*
Female	12	75.0
Age	63.6	10.3
White	16	100.0
Married	12	75.0
Bachelor's degree of higher	13	81.0
Annual Income of U.S. $80,000 or more	8	50.0
Employed	7	43.8
Spouse of care recipient	11	68.8
Social support	32.1	7.1
Relationship closeness (RCS)[a]	21.8	3.0
RD (reported by CP)	***n*/mean**	**%/*SD***
Female	8	50.0
Age	74.5	11.2
White	16.0	100.0
Married	11	68.8
Bachelor's degree or higher	9	81.0
Annual Income of U.S. $30,000 or more	9	56.3
Lives with CP	13	81.3
RD memory and behavior impairment	***n*/mean**	**%/*SD***
Diagnosed with AD/ADRD	11	73.0
Aware of memory concerns in years	4.4	3.5
Activities of daily living (ADL)[b]	8.5	5.2
Cognitive impairment (CI)[b]	10.1	5.6
Frequency—Memory and behavior problems checklist	10.1	4.1
RD driving characteristics	***n***	**%**
In last 3 years …		
Traffic violation	1	6.3
Involved in an accident	4	25.2
Been deemed at-fault in accident	4	25.2
Weekly miles driven		
0	9	56.3
1–25	2	12.6
26–50	2	12.6
51–100	1	6.3
100+	2	12.7

Notes: N = 16; CP = care partner; RD = retiring driver; *SD* = standard deviation; AD/ADRD = Alzheimer's disease or related dementia.
[a]Higher RCS = closer relationship to RD.
[b]Higher ADL and higher CI scores = more impairment.

Recruitment, Retention, and Fidelity

Despite an initial target of 20 participants or dyads, the research team made the decision to complete Phase I with 16 participant iterations due to time constraints exacerbated by coronavirus disease 2019 (COVID-19) delays and recruiting staff turnover. Figure 1 shows the flow of contacts throughout the study. All participants completed at least four intervention sessions (the minimum for program fidelity), averaging 7.6 for CPs and 6.6 for RDs, as they did not attend the CP-only session. Average session length was 64 min. Two participants completed one ad hoc session each, with an average duration 32.5 min. Contact logs indicated a high level of treatment fidelity. No adverse events were determined to have a relationship to the study.

Acceptance and Utility

After completing the program, nearly all CPs (93.8%) and all the RDs agreed that they would recommend CarFreeMe™-Dementia to others in a similar situation. Notably, participants had not completed the intervention when the 1-month survey was administered. Thus, the 3-month survey captures postintervention perspectives. Most CP review checklist items showed an increase in perceived utility for module topics and program goals from the 1- to 3-month review. See Table 3 for continuous score changes and results of significance testing. For conceptual

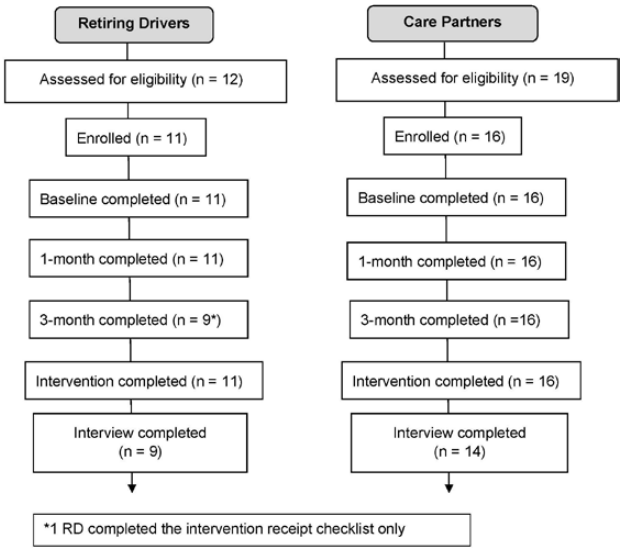

Figure 1. Participant flow CONSORT diagram.

clarity, percent agreement changes are detailed here. CPs reported statistically significant increases in agreement that CarFreeMe™-Dementia helped them maintain or improve community participation (56.3%→81.3%; CP item #4) and provided coping strategies for life after driving retirement (75.0%→100%; CP item #8).

Almost all RD utility scores increased, but none showed statistically significant changes (likely due to the small sample size). RDs indicated they felt less "supported through the experience of not driving" (88.9→66.7%; RD item #6) following program completion. However, CP perceptions of support increased significantly (66.7→81.3%; CP item #10). Alternative transportation utility remained relatively low for CPs at 1- and 3-months (58.3→61.5%; CP item #3) but increased for the RD (62.5→100%; RD item #2).

Although the focus of the Phase I pilot is feasibility, CPs reported Readiness of Mobility Transition scores improved significantly, indicating the utility of CarFreeMe™-Dementia for supporting their RD's preparation and/or adjustment to driving retirement (see Table 4). RDs' self-report of readiness of mobility Transition bordered statistical significance (p = .054), demonstrating agreement with their CPs' assessment of improved transition readiness.

Exploratory Ad Hoc Analyses

There were few statistically significant differences in treatment receipt and utility by RD driving phase (Preparing vs. Adjusting). Within the 1-month survey, Adjusting CPs reported more agreement with feeling emotionally supported adjusting to the loss of driving than Preparing CPs (p = .027; CP item #10). From 1- month to 3- months, Preparing CPs had a greater increase in agreement with exploring driving retirement experiences (p = .017; CP item #11). Additionally, Preparing CPs, who had lower baseline transition mobility scores, improved significantly more compared to Adjusting CPs (absolute score change: 15.1 [p = .03] compared to 11.1 [p = .06]).

Qualitative Themes on Acceptance and Utility

Themes from coded participant interviews and open-ended survey data are broadly categorized into benefits and considerations for future implementation. The average coding agreement was 94.0%. Quotes reflecting the themes are shared, and participant driving phase at enrollment is noted. Quantitative data are included to highlight how it converges or diverges from the qualitative experiences of the participants. Appendix A3 highlights additional exemplary quotes and converging quantitative measures.

Benefits

Benefits of CarFreeMe™-Dementia were categorized into six themes: (a) facilitation of productive dialogue, (b) practical preparation for adjusting to driving retirement, (c) acceptance of driving retirement, (d) improved well-being and lifestyle planning, (e) agency and dignity of the RD, and (f) emotional support from coaches.

Facilitation of productive dialogue.—CarFreeMe™-Dementia coaches provided a safe environment with an objective third-party perspective to help family members engage in tough conversations. As this CP noted, "Having another person, a neutral party, be there (helped). Sometimes these are difficult conversations for my sister and I to have with a parent, my mom, and so to have a third party it just gives it more credence" (ID501, Preparing CP).

With frequent opportunities for conversations about driving retirement, RDs became more comfortable with the topic: "Because the more I talked about it, the easier it became. In the beginning, who wants to talk about not driving and losing your license and everything that you did wrong … it became easier and less upsetting to me" (ID802, Adjusting RD).

CarFreeMe™-Dementia also facilitated collaborative decision-making and encouraged ongoing conversations outside of the program: "I was starting, and with (the coach)'s encouragement, to (have) some non-judgmental open conversations with my mom, trying to make a plan with her, not for her, to make her feel really in control of the process" (ID1201, Preparing CP).

Practical preparation for adjusting to driving retirement.—Participants found the driving safety education and potential barriers to driving retirement content useful: "What I especially like is the information is valuable for the non-driver and driver both as they navigate the changes" (ID801, Adjusting CP). Coaches collaborated on plans for monitoring unsafe driving and enacting incremental driving restrictions: "I knew what to look for as warning signs if the limited driving that he was doing

Table 3. CP and RD CarFreeMe™-Dementia Intervention Review

	1-Month			3-Month			Mean difference
CP—CarFreeMe™-Dementia helped me …	*M* (*SD*)	% Agree	NA	*M* (*SD*)	% Agree	NA	(95% CI)
1. Learn the importance of planning early for driving retirement	3.8 (0.8)	58.3	4	4.1 (.7)	83.3	4	0.3 (–0.2, 0.7)
2. Explore important aspects of planning early	4.0 (0.7)	76.9	3	4.0 (1.0)	86.7	1	0.0 (–0.7, 0.7)
3. Increase knowledge of or use of safe alternative modes of transportation such as bus, light rail, taxi	3.8 (1.0)	58.3	4	3.9 (1.2)	61.5	3	0.3 (–0.3, 0.9)
4. Learn ways to continue or increase participation in the community	3.4 (1.0)	56.3	0	4.0 (0.6)	81.3	0	0.6 (.1, 1.0)*
5. Develop strategies to help manage mobility	3.6 (0.9)	73.3	1	4.1 (0.7)	80.0	1	0.4 (–0.1, 0.9)
6. Better understand changes that can take place with dementia such as brain changes, behavior, thinking	4.2 (0.8)	81.3	0	4.4 (0.6)	93.8	0	0.2 (–0.2, 0.5)
7. Better understand the skills required for driving and how dementia affects those skills	4.1 (0.6)	86.7	1	4.1 (1.1)	86.7	1	0.1 (–0.5, 0.7)
8. Become aware of coping strategies for adjusting to life without driving	3.8 (0.7)	75.0	0	4.5 (0.5)	100.0	0	0.8 (0.3, 1.3)**
9. Learn about or express concerns and feel validated related to grief/loss of the experience of driving	3.9 (0.8)	73.3	1	4.4 (0.7)	87.5	0	0.5 (–0.1,1.2)
10. Be supported through an emotional adjustment to the loss of driving (autonomy, independence, etc.)	3.7 (0.6)	66.7	1	4.3 (0.9)	81.3	0	0.6 (0.1,1.1)*
11. Explore others' experiences with retiring from driving	3.6 (0.7)	60.0	1	3.9 (0.9)	75.0	0	0.4 (0.0, 0.8)
12. Learn how to set goals	3.9 (1.1)	56.3	0	4.3 (0.8)	81.3	0	0.4 (–0.1, 0.9)
13. Learn ways to conserve energy	3.4 (1.1)	40.0	1	3.7 (0.7)	56.3	0	0.2 (–0.3, 0.7)
14. Overall: I would recommend CarFreeMe™-Dementia to others in a similar situation as my relative	4.3 (0.6)	93.8	0	4.7 (0.6)	93.8	0	0.4 (0.1, 0.8)*
15. Overall: I would recommend CarFreeMe™-Dementia to others in a similar situation as I am	4.2 (0.6)	93.3	1	4.7 (0.6)	93.8	0	0.5 (0.1, 0.8)*
	1-Month			3-Month[a]			Mean difference
RD—CarFreeMe™-Dementia helped me …	*M* (*SD*)	% Agree	NA	*M* (*SD*)	% Agree	NA	(95% CI)
1. Plan for when I will not drive anymore	2.8 (1.5)	33.3	4	4.4 (0.7)	85.7	5	1.0 (–1.3, 3.3)
2. Find other ways to get around such as the bus, light rail, taxi, rides from friends or family, etc.	3.3 (1.4)	62.5	4	4.1 (0.3)	100.0	3	1.0 (–1.0, 3.0)
3. Continue to participate in my community	3.8 (0.9)	70.0	2	4.3 (0.5)	100.0	2	0.5 (–0.3, 1.3)
4. Learn more about dementia and changes that can happen in my brain and in my day-to-day life	3.7 (0.9)	60.0	2	4.1 (0.6)	90.0	2	0.3 (–0.3, 0.8)
5. Express my feelings about not driving anymore (such as grief, relief, etc.)	3.7 (1.0)	72.7	1	4.2 (0.7)	88.9	3	0.4 (–0.1, 0.8)
6. Be supported through this experience of not driving anymore	4.1 (0.9)	88.9	2	4.0 (0.9)	66.7	1	–0.4 (–1.3, 0.5)

Table 3. Continued

RD—CarFreeMe™-Dementia helped me …	1-Month			3-Month[a]			Mean difference
	M (*SD*)	% Agree	NA	*M* (*SD*)	% Agree	NA	(95% CI)
7. Hear stories about others who had retired from driving and how they adjusted	3.6 (0.9)	55.6	3	3.7 (0.5)	66.7	3	−0.2 (−1.2, 0.9)
8. Overall: I would recommend CarFreeMe™-Dementia to others in a similar situation as I am	4.0 (0.4)	90.9	1	4.3 (0.5)	100.0	2	0.2 (−0.1, 0.6)

Notes: CP *N* = 16; RD *N* = 11. Likert scale 1 = strongly disagree, 2 = disagree, 3 = neutral, 4 = agree, 5 = strong agree; % Agree = agree or strongly agree and does not include the participants responding "not applicable" (NA). Paired *t* test data may show other mean differences given its constraints. CP = care partner; RD = retiring driver; *SD* = standard deviation; CI = confidence interval.
[a]*n* = 9 RD.
**p* < .05; ***p* < .01.

should stop, and it gave me the confidence to assess if he was still driving safely" (ID1001, Adjusting CP).

Coaches also helped identify alternative transportation options (e.g., friends and community transit) that participants may not have known about or considered an option. As this RD noted, "But now, this is something new that I'm realizing that there are friends that would be willing to and whereas before, I wouldn't even think of contemplating that" (ID502, Preparing RD). Quantitative results also indicate RDs and their CPs felt more prepared to adjust to driving retirement after the intervention (e.g., improved readiness for mobility transition scores and RDs indicated more agreement with the checklist item "CarFreeMe™-Dementia helped me plan for when I will not drive anymore"). Moreover, 100% of CPs agreed the program helped them "become aware of coping strategies for adjusting to life without driving" at the 3-month follow-up. This item had the largest increase in score from 1 to 3 months (p = .006).

Acceptance of driving retirement.—CarFreeMe™-Dementia helped RDs and their family members accept the need to transition to driving retirement. Participants who were struggling with adjustment to driving retirement felt that the program affirmed their decision to retire. Even if they had not been completely on board to start, the extended discussion "was a kind of a softening way of making me understand" (ID1302, Adjusting RD). The program helped some by framing driving retirement as a part of the aging process:

> I think it helped her feel more positive about having that reinforced and discussed about safety and that it's normal as you age for her age level that people make this decision. It's not just her, many people, and I think it's just helped her feel more accepting. (ID201, Adjusting CP)

At the same time, the program increased CP confidence and ability to support the RDs' eventual retirement. A CP explained the perspective she gained:

> It was really helpful in thinking of this next part of not driving doesn't have to be, for lack of better words, like a death sentence … that we can reframe it and think of what are some new skills and benefits that can maybe come out of this. (ID1201, Preparing CP)

Survey data showed mobility confidence scores improved for both the CPs and RDs. However, the RD change only bordered on statistical significance (p = .053; see Table 4).

Improved well-being and lifestyle planning.—CarFreeMe™-Dementia participants reported improved well-being and appreciated lifestyle planning. Participants described using sessions to process and reduce driving-related stress, which, in turn, improved their mood. A CP noted a typical session, "Was really great for (RD), and then just to have this regular time to talk about the driving issues and also about just being more engaged in life really had a positive effect on her" (ID201, Adjusting CP). Participants also said they used the relaxation techniques the coaches shared.

The program's focus on lifestyle planning and goal setting went hand-in-hand with improved wellness. This CP reflected:

> We talked about activities and like of all the things you could be doing, you know, what's important to you … to help make sure that we're focused on what's important in the limited time that we have, and don't worry about the things that aren't. (ID101, Preparing CP)

A few participants, more often the RD, reported experiencing stress, particularly at the onset of the intervention. This CP reported, "Initially it caused some reexamination and depression … Because it reminded her that she can't do it anymore." However, some also relayed that having these conversations ultimately helped "because she was able to communicate … maybe some of her thoughts and feelings, and she understood why you would need to consider retirement" (ID1101, Adjusting CP). RDs also reported being more able to express their feelings about not driving by the program's end (72.7%→88.9%; RD checklist item #5).

Table 4. CP and RD Driving-Related Measures Over Time

	Baseline *M* (*SD*)	3-Month *M* (*SD*)	Mean difference (95% CI)
CP self-report			
Mobility confidence questionnaire	47.2 (10.9)	51.0 (9.9)	3.8 (–3.9, 11.5)
RD (reported by CP)			
Stopped driving, *n* (%)	9 (56.3)	10 (62.5)	
Otherwise, considering driving retirement, *n* (%)	2 (12.5)	2 (12.5)	
Driving retirement activities, *n* (%):			
Driving evaluation	3 (18.8)	4 (25.0)	
Talking with family or other support	7 (43.8)	8 (50.0)	
Talking to their doctor or other health care provider	8 (50.0)	10 (62.5)	
Limiting their driving (e.g., daytime and local roads)	10 (62.5)	9 (56.3)	
Other	6 (37.5)	5 (31.3)	
Driving and safety questionnaire[a]	30.5 (8.8)	32.9 (6.3)	0.9 (–1.7, 3.6)
Readiness for Mobility Transition[b]	86.6 (16.5)	73.8 (21.6)	–12.9 (–20.6, –5.1)**
RD self-report			
Mobility confidence questionnaire	67.6 (14.6)	71.1 (9.0)	7.0 (–0.1, 14.1)
Stopped driving, *n* (%)	7 (58.3)	5 (55.6)	
Otherwise, considering driving retirement, *n* (%)	1 (8.3)	1 (8.3)	
Driving retirement activities, *n* (%):			
Driving evaluation	1 (8.3)	3 (25.0)	
Talking with family or other support	6 (50.0)	7 (58.3)	
Talking to my doctor or other health care provider	6 (50.0)	5 (41.7)	
Limiting my driving (e.g., daytime and local roads)	7 (58.3)	5 (41.7)	
Other	3 (25.0)	1 (8.3)	
Driving and safety questionnaire[a]	27.4 (7.3)	27.0 (7.8)	1.4 (–2.9, 5.7)
Readiness for mobility transition[b]	77.8 (13)	66.0 (16.5)	–11.0 (–22.3, 0.3)

Notes: CP *N* = 16; RD *N* = 9 except 3-month (*n* = 8). Data are mean (standard deviation) unless noted. CP = care partner; RD = retiring driver; *SD* = standard deviation; CI = confidence interval.

[a]Lower scores = safer.

[b]Lower scores = more prepared.

**$p < .01$.

Agency and dignity of the RD.—The intervention aimed to treat the RD with dignity and respect, emphasizing the importance of including them in the decision-making process and not dictating driving changes. This RD underscored the importance of having a voice in the decision, "(The coach) made us feel like this decision was ours and gave us the tools to evaluate, which it should be. We're adults, and we shouldn't have somebody treating us like a two-year-old" (ID1002, Adjusting RD).

The intervention also empowered RDs to remain active in the community without driving. They felt more confident about being able to go where they needed to go:

> I knew that I could get out. I didn't feel that I was locked in. I knew I could get out, make a phone call, and someone would pick me up and take me where I wanted to go, somehow, some way. (ID802, Adjusting RD)

This was also reflected in RD agreement that CarFreeMe™-Dementia helped them continue to participate in their community (100% at 3-month; RD checklist item #3).

Emotional support from the coaches.—Participants enjoyed talking with the program coaches. They combined educational content with personalized support and validated the impact of driving retirement, offering opportunities for emotional processing. One CP shared, "To talk to somebody else about it, not me, and that helped him go through, and kind of see it more full circle and just process the information and the feelings. The feelings needed to be processed" (ID801, Adjusting CP). Their RD similarly shared: "It reinforced the decision that I'd already made … (The coach) was helpful in getting through the pain of giving up my driver's license" (ID802, Adjusting RD). CPs reported statistically significant increases in feeling "supported through an emotional adjustment to the loss of driving" (CP checklist item #10), but as noted, RD scores declined after program completion (RD item #6).

Flexibility and tailoring.—The semistructured CarFreeMe™-Dementia program emphasizes tailoring session content to meet the emotional and resource needs of each participant. This flexibility was especially important

for participants who were still driving and initially uncomfortable discussing driving retirement. As one CP relayed, "We had to approach it kind of delicately because there was a lot of denial and I think that (the coach) worked that into it really well" (ID401, Preparing CP). Driving discussion reticence is also reflected in some lower perceived review checklist scores at 1-month. Aging-related content also helped integrate natural considerations for driving retirement. One CP reported at the 1-month follow-up that "We have not yet reached the driving issues. Saving them for last. We have concentrated on issues related to adjusting to getting old in general" (ID402, Preparing RD), and another remarked that "This program is so much beyond just the loss of driving" (ID301, Adjusting CP). The variety of topics and tailorable nature of CarFreeMe™-Dementia session content were imperative to successful program delivery and engagement.

Implications for future CarFreeMe™-Dementia implementation

Participants indicated two perceived issues with CarFreeMe™-Dementia: (a) timing was not ideal and (b) alternative transportation content was not helpful.

Timing.—By design, the evaluation of the program included participants at all stages of the driving retirement decision. The consensus among participants, especially those who were adjusting to rather than preparing for retirement, was that they wished they had experienced the program earlier, noting "the program would best help those who are just starting to decide whether to quit driving. The information is valuable regardless but would have a stronger impact very early on in the decision-making process" (ID801, Adjusting CP).

This was also seen in the treatment review item regarding early planning, which had the most "not applicable" responses. A couple of participants thought it was too early in the process for an immediate application but said the information would be useful in the future.

Alternative transportation.—Many participants said discussion of more traditional alternative transportation (e.g., public transit) or even rideshare services was not a realistic option for them. For some, their geography meant limited availability of these services (e.g., rural or suburban locations). Other CPs shared reluctance regarding unsupervised travel: "I'm thinking, if my husband can't drive anymore, I'm certainly not going to put him on a bus, you know?" (ID901, Preparing CP). Still, some participants appreciated the information about local community bus routes that serve individuals with disabilities or medical issues.

At the same time, RDs reported that their perspectives on alternative transportation had expanded, noting increased awareness and acceptance of asking friends or family for rides (see practical preparation theme). This empowerment also boosted their feelings of agency and produced more realistic expectations: "It definitely made me aware of all the different choices that I have and which choices I really don't have" (ID402, Preparing RD). These facets are also reflected in the 3-month treatment review checklist: CPs reported less utility for alternative transportation (61.5% agreement with item #3), while 100% of RDs indicated the program helped them find other ways of getting around and continue to participate in their community (items #2 and #3).

Discussion

Driving retirement is often a difficult life transition that is not routinely addressed by health care or other aging support services, leaving RDs and their families to navigate this transition largely on their own (Betz et al., 2014). As the U.S. population ages and more older drivers develop dementia, strong and practical support for RDs and their family is needed. The CarFreeMe™-Dementia intervention is a unique, tailored psychoeducational program designed to support RDs and their CPs in all phases of the driving retirement continuum.

Based on participant feedback, as well as the perfect retention and intervention completion rates, CarFreeMe™-Dementia was an acceptable and feasible driving retirement intervention for use in the United States Similar to its precursor, the Australian UQDRIVE intervention (Gustafsson et al., 2012), participants expressed that CarFreeMe™-Dementia facilitated driving retirement preparedness, acceptance of driving retirement, and continued engagement with the community after driving retirement. The current study demonstrated that remote delivery to individuals or dyads can provide similar benefits to the Australian interventions.

Survey and interview feedback strongly indicated the CarFreeMe™-Dementia program was useful to drivers preparing for, and adjusting to, driving retirement. While overall receipt scores indicate the program was equally beneficial to these groups, exploratory analyses indicated they may gain value from it, such as Adjusting CPs feeling more emotionally supported in adjusting to the loss of driving or Preparing CPs appreciating exploring driving retirement experiences. Qualitatively, participants noted the program might be particularly helpful to those preparing for driving retirement, indicating the importance of connecting families to CarFreeMe™-Dementia early, as well as offering the program throughout the driving retirement process.

Participants appreciated session content tailored to their specific needs and location and the flexibility to discuss other aging and dementia-related issues as they arose. Although participants may not have had the chance to share their experience with peers in a group setting (Gustafsson et al., 2011), the one-on-one delivery of the U.S.-modified CarFreeMe™-Dementia allowed for greater personalization and individualized emotional support. Sessions offered a supportive and open forum with a neutral third party that facilitated emotional processing and productive dialogue about driving retirement for what were often difficult

conversations (Jouk & Tuokko, 2017). The RDs especially valued the emphasis on their agency and voice in decision-making. In line with the criteria outlined by Sanford et al. (2020) meta-synthesis of driving retirement experiences of persons living with dementia, CarFreeMe™-Dementia appears to meet the needs of RDs living with dementia and CPs alike by providing individualized practical planning support, facilitating communication, valuing the RDs' autonomy, and validating the emotional difficulty of the transition.

Contrary to the Australian UQDRIVE participants (Gustafsson et al., 2011), most American participants did not find value in discussing the use of public transportation. This differentiation may result from varying cultural norms, as well as the availability of public transportation. Concerns about the difficulty individuals with memory loss might experience utilizing public transportation were also frequently noted. However, American RDs appreciated the normalization of asking friends, family, and neighbors for rides as alternatives to driving.

Regarding feasibility, we had some initial difficulty recruiting participants. The COVID-19 pandemic likely affected recruitment as participating in a driving retirement program was not a priority for many who were understandably preoccupied with health concerns and other lifestyle changes. Driving retirement was also not as relevant for some due to restricted excursions during the pandemic. To enhance recruitment, we expanded outreach efforts and inclusion criteria to allow for participants from across the United States, as well as allowing RDs and CPs to enroll alone rather than as a dyad.

Implications for Follow-up Research

Results from this study suggest that further investigation of CarFreeMe™-Dementia is warranted. The study team initiated a second phase of the feasibility and acceptability evaluation with a target of 50 participants (or dyads) in the fall of 2021. Informed by the current study, we incorporated participants' recommendations, such as dedicating more time to addressing particular issues (e.g., insurance and delivery services). In the final session, coaches will reiterate key information, such as red flags for unsafe driving. As some RDs reported not feeling as supported a month after the intervention was completed, coaches will emphasize the availability of ad hoc coaching sessions and impress upon family members the importance of their continued support of the RD throughout the driving retirement process. If the high level of acceptability, feasibility, and perceived utility are maintained in Phase II, we anticipate CarFreeMe™-Dementia will have sufficient preliminary evidence to warrant larger-scale efficacy testing of the intervention in the United States

Strengths and Limitations

As this was a pilot study, the sample size was small, which limited our ability to identify statistically significant quantitative changes during program participation, especially with RD self-reported outcomes. A larger sample size would also allow for further discriminant testing by RD driving phase. A major strength of the study is the inclusion of the RD voices, which are often excluded from dementia care research (Gaugler et al., 2019). Furthermore, RDs and family members could join as a dyad or alone, providing the opportunity for individuals with reluctant partners to participate. Telehealth delivery supported nationwide enrollment and facilitated safe interactions during the COVID-19 pandemic.

Conclusion

Development and evaluation of programs that offer support for persons living with dementia who are navigating driving retirement are necessary given how emotionally and logistically difficult this transition often is. CarFreeMe™-Dementia appears to be an acceptable, feasible, and useful intervention supporting RDs with memory loss and their CPs across the continuum of the driving retirement transition. With few existing support programs, CarFreeMe™-Dementia establishes the potential for an effective individualized psychoeducational intervention that facilitates collaborative driving retirement discussions between persons living with dementia and their families.

Supplementary Material

Supplementary data are available at *The Journals of Gerontology, Series B: Psychological Sciences and Social Sciences* online.

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Conflict of Interest

J. Liddle, N. A. Pachana, L. Gustafsson, and T. L. Scott are authors and/or intellectual property contributors of the CarFreeMe™ Programs, which are owned by The University of Queensland (UQ). UniQuest Pty Ltd, on behalf of UQ, is responsible for commercializing the CarFreeMe™ Programs worldwide. The authors have no share or ownership of UniQuest. Proceeds from commercialization of the Programs provide funding for continuing

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Author Contributions

C. M. Peterson supervised study coordination, conducted data analysis, and authored the manuscript. R. W. Birkeland and K. W. Louwagie provided intervention administration, data analysis, and contributed to writing of manuscript. S. N. Ingvalson provided study coordination, data analysis, and contributed to writing of manuscript. L. L. Mitchell offered consultation during study and contributed to data analysis and manuscript editing. T. L. Scott provided intervention training and manuscript editing. J. Liddle, N. A. Pachana, and L. Gustafsson provided editing support. J. E. Gaugler designed study, provided general study oversight, and edited manuscript.

References

Aksan, N., Anderson, S. W., Dawson, J., Uc, E., & Rizzo, M. (2015). Cognitive functioning differentially predicts different dimensions of older drivers' on-road safety. *Accident Analysis and Prevention*, **75**, 236–244. doi:10.1016/j.aap.2014.12.007

Albert, M. S. (2011). Changes in cognition. *Neurobiology of Aging*, **32**(1), S58–S63. doi:10.1016/j.neurobiolaging.2011.09.010

Andrew, C., Traynor, V., & Iverson, D. (2015). An integrative review: Understanding driving retirement decisions for individuals living with a dementia. *Journal of Advanced Nursing*, **71**(12), 2728–2740. doi:10.1111/jan.12727

Betz, M. E., Jones, V. C., & Lowenstein, S. R. (2014). Physicians and advance planning for "driving retirement." *The American Journal of Medicine*, **127**(8), 689–690. doi:10.1016/j.amjmed.2014.03.025

Betz, M. E., Scott, K., Jones, J., & Diguiseppi, C. (2016). "Are you still driving?" Metasynthesis of patient preferences for communication with health care providers. *Traffic Injury Prevention*, **17**(4), 367–373. doi:10.1080/15389588.2015.1101078

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, **3**(2), 77–101. doi:10.1191/1478088706qp063oa

Brown, L. B., & Ott, B. R. (2004). Driving and dementia: A review of the literature. *Journal of Geriatric Psychiatry and Neurology*, **17**(4), 232–240. doi:10.1177/0891988704269825

Carmody, J., Traynor, V., & Steele, A. (2015). Dementia, decision aids and general practice. *Australian Family Physician*, **44**(5), 307–310. https://www.racgp.org.au/afp/2015/may/dementia,-decision-aids-and-general-practice/

Chee, J. N., Rapoport, M. J., Molnar, F., Herrmann, N., O'Neill, D., Marottoli, R., Mitchell, S., Tant, M., Dow, J., Ayotte, D., Lanctot, K. L., McFadden, R., Taylor, J. P., Donaghy, P. C., Olsen, K., Classen, S., Elzohairy, Y., & Carr, D. B. (2017). Update on the risk of motor vehicle collision or driving impairment with dementia: A collaborative international systematic review and meta-analysis. *The American Journal of Geriatric Psychiatry*, **25**(12), 1376–1390. doi:10.1016/j.jagp.2017.05.007

Chihuri, S., Mielenz, T. J., DiMaggio, C. J., Betz, M. E., DiGuiseppi, C., Jones, V. C., & Li, G. (2016). Driving cessation and health outcomes in older adults. *Journal of the American Geriatrics Society*, **64**(2), 332–341. doi:10.1111/jgs.13931

Dobbs, B. M., Harper, L. A., & Wood, A. (2009). Transitioning from driving to driving cessation: The role of specialized driving cessation support groups for individuals with dementia. *Topics in Geriatric Rehabilitation*, **25**(1), 73–86. doi:10.1097/01.TGR.0000346058.32801.95

Foley, D. J., Masaki, K. H., Ross, G. W., & White, L. R. (2000). Driving cessation in older men with incident dementia. *Journal of the American Geriatrics Society*, **48**(8), 928–930. doi:10.1111/j.1532-5415.2000.tb06889.x

Fraade-Blanar, L. A., Hansen, R. N., Chan, K. C. G., Sears, J. M., Thompson, H. J., Crane, P. K., & Ebel, B. E. (2018). Diagnosed dementia and the risk of motor vehicle crash among older drivers. *Accident Analysis and Prevention*, **113**, 47–53. doi:10.1016/j.aap.2017.12.021

Gaugler, J. E., Bain, L. J., Mitchell, L., Finlay, J., Fazio, S., Jutkowitz, E., Banerjee, S., Butrum, K., Fazio, S., Gaugler, J., Gitlin, L., Hodgson, N., Kallmyer, B., Le Meyer, O., Logsdon, R., Maslow, K., & Zimmerman, S. (2019). Reconsidering frameworks of Alzheimer's dementia when assessing psychosocial outcomes. *Alzheimer's and Dementia*, **5**, 388–397. doi:10.1016/j.trci.2019.02.008

Gergerich, E. M. (2016). Reporting policy regarding drivers with dementia. *Gerontologist*, **56**(2), 345–356. doi:10.1093/geront/gnv143

Gustafsson, L. A., Liddle, J. M., Lua, S., Hoyle, M. F., Pachana, N. A., Mitchell, G. K., & McKenna, K. T. (2011). Participant feedback and satisfaction with the UQDRIVE groups for driving cessation. *Canadian Journal of Occupational Therapy*, **78**(2), 110–117. doi:10.2182/cjot.2011.2.6

Gustafsson, L. A., Liddle, J., Liang, P., Pachana, N., Hoyle, M., Mitchell, G., & McKenna, K. (2012). A driving cessation program to identify and improve transport and lifestyle issues of older retired and retiring drivers. *International Psychogeriatrics*, **24**(5), 794–802. doi:10.1017/S1041610211002560

Ho, M. -H., Chang, H. R., Liu, M. F., Chien, H. -W., Tang, L. -Y., Chan, S. -Y., Liu, S. -H., John, S., & Traynor, V. (2021). Decision-making in people with dementia or mild cognitive impairment: A narrative review of decision-making tools. *Journal of the American Medical Directors Association*, **22**(10), 2056–2062. doi:10.1016/j.jamda.2021.06.034

Hudomiet, P., Hurd, M. D., & Rohwedder, S. (2018). Dementia prevalence in the U.S. in 2000 and 2012: Estimates based on a nationally representative study. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, **73**(Suppl. 1), S10–S19. doi:10.1093/geronb/gbx169

Iverson, D. J., Gronseth, G. S., Reger, M. A., Classen, S., Dubinsky, R. M., & Rizzo, M. (2010). Practice parameter update: Evaluation and management of driving risk in dementia. *Neurology*, **74**(16), 1316–1324. doi:10.1212/WNL.0b013e3181da3b0f

Jeste, D. V., Palmer, B. W., Appelbaum, P. S., Golshan, S., Glorioso, D., Dunn, L. B., Kim, K., Meeks, T., & Kraemer, H. C. (2007). A new brief instrument for assessing decisional capacity

for clinical research. *Archives of General Psychiatry*, **64**(8), 966–974. doi:10.1001/archpsyc.64.8.966

Jetten, J., & Pachana, N. (2012). Not wanting to grow old: A Social Identity Model of Identity Change (SIMIC) analysis of driving cessation among older adults. In J. Jetten, C. Haslam, & S. A. Haslam (Eds.), *The social cure: Identity, health and well-being* (pp. 97–113). Psychology Press.

Jouk, A., & Tuokko, H. (2017). Development of "down the road": An interactive toolkit about driving cessation for dementia caregivers. *Educational Gerontology*, **43**(10), 499–510. doi:10.1080/03601277.2017.1355669

Katz, S., Ford, A. B., Moskowitz, R. W., Jackson, B. A., & Jaffe, M. W. (1963). Studies of illness in the aged. The index of ADL: A standardized measure of biological and psychosocial function. *Journal of American Medical Association*, **185**, 914–919. doi:10.1001/jama.1963.03060120024016

Liddle, J., Bennett, S., Allen, S., Lie, D., Standen, B., & Pachana, N. (2013). The stages of driving cessation for people with dementia: Needs and challenges. *International Psychogeriatrics*, **25**(12), 2033–2046. doi:10.1017/s1041610213001464

Liddle, J., Haynes, M., Pachana, N., Mitchell, G., McKenna, K., & Gustafsson, L. (2014). Effect of a group intervention to promote older adults' adjustment to driving cessation on community mobility: A randomized controlled trial. *Gerontologist*, **54**(3), 409–422. doi:10.1093/geront/gnt019

Liddle, J., McKenna, K., & Bartlett, H. (2007). Improving outcomes for older retired drivers: The UQDRIVE program. *Australian Occupational Therapy Journal*, **54**(4), 303–306. doi:10.1111/j.1440-1630.2006.00614.x

Liddle, J., Tan, A., Liang, P., Bennett, S., Allen, S., Lie, D., & Pachana, N. (2016). "The biggest problem we've ever had to face": How families manage driving cessation with people with dementia. *International Psychogeriatrics*, **28**(1), 109–122. doi:10.1017/S1041610215001441

Livingston, G., Sommerlad, A., Orgeta, V., Costafreda, S. G., Huntley, J., Ames, D., Ballard, C., Banerjee, S., Burns, A., Cohen-Mansfield, J., Cooper, C., Fox, N., Gitlin, L. N., Howard, R., Kales, H. C., Larson, E. B., Ritchie, K., Rockwood, K., Sampson, E. L., & Mukadam, N. (2017). Dementia prevention, intervention, and care. *Lancet*, **390**(10113), 2673–2734. doi:10.1016/S0140-6736(17)31363-6

Marottoli, R. A., & Coughlin, J. F. (2011). Walking the tightrope: Developing a systems approach to balance safety and mobility for an aging society. *Journal of Aging and Social Policy*, **23**(4), 372–383. doi:10.1080/08959420.2011.605655

Meuser, T. M., Berg-Weger, M., Chibnall, J. T., Harmon, A. C., & Stowe, J. D. (2013). Assessment of Readiness for Mobility Transition (ARMT): A tool for mobility transition counseling with older adults. *Journal of Applied Gerontology*, **32**(4), 484–507. doi:10.1177/0733464811425914

Mizenko, A. J., Tefft, B. C., Arnold, L. S., & Grabowski, J. G. (2014). *Older American Drivers and Traffic Safety Culture: A LongROAD Study (Technical Report)*. AAA Foundation for Traffic Safety. https://aaafoundation.org/older-american-drivers-traffic-safety-culture-longroad-study/

Moye, J., Karel, M. J., Gurrera, R. J., & Azar, A. R. (2006). Neuropsychological predictors of decision-making capacity over 9 months in mild-to-moderate dementia. *Journal of General Internal Medicine*, **21**(1), 78–83. doi:10.1111/j.1525-1497.2005.00288.x

National Highway Traffic Safety Administration. (2021). *Older population: 2019 data Traffic Safety Facts*. (Report No. DOT HS 813 121). National Center for Statistics and Analysis. https://crashstats.nhtsa.dot.gov/Api/Public/ViewPublication/813121

Naumann, R. B., West, B. A., & Sauber-Schatz, E. K. (2014). At what age do you think you will stop driving? Views of older U.S. adults. *Journal of the American Geriatrics Society*, **62**(10), 1999–2001. doi:10.1111/jgs.13050

Ott, B. R., & Daiello, L. A. (2010). How does dementia affect driving in older patients? *Aging Health*, **6**(1), 77–85. doi:10.2217/ahe.09.83

Pachana, N. A., Jetten, J., Gustafsson, L., & Liddle, J. (2017). To be or not to be (an older driver): Social identity theory and driving cessation in later life. *Ageing and Society*, **37**(8), 1597–1608. doi:10.1017/S0144686X16000507

Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *Gerontologist*, **30**(5), 583–594. doi:10.1093/geront/30.5.583

Pristavec, T. (2018). Social participation in later years: The role of driving mobility. *The Journals of Gerontology, Series B: Psychological Sciences and Social Sciences*, **73**(8), 1457–1469. doi:10.1093/geronb/gbw057

Qin, W., Xiang, X., & Taylor, H. (2020). Driving cessation and social isolation in older adults. *Journal of Aging and Health*, **32**(9), 962–971. doi:10.1177/0898264319870400

Rashid, R., Standen, P., Carpenter, H., & Radford, K. (2020). Systematic review and meta-analysis of association between cognitive tests and on-road driving ability in people with dementia. *Neuropsychological Rehabilitation*, **30**(9), 1720–1761. doi:10.1080/09602011.2019.160311

Sanford, S., Rapoport, M. J., Tuokko, H., Crizzle, A., Hatzifilalithis, S., Laberge, S., & Naglie, G. (2019). Independence, loss, and social identity: Perspectives on driving cessation and dementia. *Dementia*, **18**(7–8), 2906–2924. doi:10.1177/1471301218762838

Sanford, S., Naglie, G., Cameron, D. H., & Rapoport, M. J. (2020). Subjective experiences of driving cessation and dementia: A meta-synthesis of qualitative literature. *Clinical Gerontology*, **43**(2), 135–154. doi:10.1080/07317115.2018.1483992

Scott, T., Liddle, J., Mitchell, G., Beattie, E., & Pachana, N. (2019). Implementation and evaluation of a driving cessation intervention to improve community mobility and wellbeing outcomes for people living with dementia: Study protocol of the "CarFreeMe" for people with dementia program. *BMC Geriatrics*, **19**(1), 66. doi:10.1186/s12877-019-1074-6

Scott, T., Liddle, J., Sidhu, R., Mitchell, G., Beattie, E., Gustafsson, L., & Pachana, N. (2020). Adaptation of the CarFreeMe driver retirement intervention to provide driving cessation support to older people living with dementia. *Brain Impairment*, **21**(3), 247–258. doi:10.1017/BrImp.2020.16

Stern, R. A., D'Ambrosio, L. A., Mohyde, M., Carruth, S., Tracton-Bishop, B., Hunter, J. C., Hellyar, C., Olshevski, J., Daneshvar, D. H., & Coughlin, J. F. (2008). O3-07-01: At the crossroads: Development and evaluation of a dementia caregiver group intervention to assist in driving cessation. *Alzheimer's*

and Dementia, **4**(4S_Part_5), T173–T173. doi:10.1016/j.jalz.2008.05.459

Teri, L., Truax, P., Logsdon, R., Uomoto, J., Zarit, S., & Vitaliano, P. P. (1992). Assessment of behavioral problems in dementia: The revised memory and behavior problems checklist. *Psychology and Aging*, **7**(4), 622–631. doi:10.1037//0882-7974.7.4.622

Vanderbur, M., & Silverstein, N. (2006). *Community mobility and dementia: A review of the literature* (DOT HS 810 684; pp. 1–48). Alzheimer's Association Public Policy Division and National Traffic and Highway Safety Administration. https://one.nhtsa.gov/people/injury/olddrive/CommMobilityDementia/pages/CurrentScr-StatePolicy.htm

Vaughan, L., Hogan, P. E., Rapp, S. R., Dugan, E., Marottoli, R. A., Snively, B. M., Shumaker, S. A., & Sink, K. M. (2015). Driving with mild cognitive impairment or dementia: Cognitive test performance and proxy report of daily life function in older women. *Journal of the American Geriatrics Society*, **63**(9), 1774–1782. doi:10.1111/jgs.13634

Versijpt, J., Tant, M., Beyer, I., Bier, J. -C., Cras, P., De Deyn, P. P., De Wit, P., Deryck, O., Hanseeuw, B., Lambert, M., Lemper, J. -C., Mormont, E., Petrovic, M., Picard, G., Salmon, E., Segers, K., Sieben, A., Thiery, E., Tournoy, J., & Ivanoiu, A. (2017). Alzheimer's disease and driving: Review of the literature and consensus guideline from Belgian dementia experts and the Belgian road safety institute endorsed by the Belgian Medical Association. *Acta Neurologica Belgica*, **117**(4), 811–819. doi:10.1007/s13760-017-0840-5

Whitlatch, C. J., Schur, D., Noelker, L. S., Ejaz, F. K., & Looman, W. J. (2001). The stress process of family caregiving in institutional settings. *Gerontologist*, **41**(4), 462–473. doi:10.1093/geront/41.4.462