Review for IP Journal

Review of "Developing the Driving and Dementia Roadmap: A Knowledge-to-Action Process"

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Key Highlights

- This study introduces the Driving and Dementia Roadmap (DDR), a web-based toolkit designed to support individuals with dementia and their carers in navigating the challenging transition from driving to non-driving. It features tailored resources, including conversation guides, transportation planning worksheets, and emotional support tools, accessible through user-specific portals.

- The DDR was developed using the adapted KTA framework, combining systematic evidence synthesis and stakeholder input. This iterative process ensured that the toolkit was user-centered, practical, and aligned with the theoretical Transtheoretical Model for behavioral transitions.

- The DDR addresses a critical gap in dementia care by offering a scalable, person-centered intervention that transforms theoretical knowledge into actionable support. It enhances accessibility and usability with a direct-to-user format, meeting both emotional and practical needs while advancing dementia care research.

Main Review

Transitioning from driving to non-driving is a significant life change that profoundly affects the independence, social identity, and emotional well-being of individuals with dementia. This process is one of the most challenging aspects of dementia care, with far-reaching implications for health, social engagement, and overall quality of life (Holden and Pusey, 2021). For older adults with dementia, ceasing to drive is often associated with negative health outcomes, including increased risks of depression, anxiety, social isolation, and reduced mobility, which further complicate their care and daily living. Family and friend carers also face considerable challenges during this transition, experiencing feelings of guilt, frustration, and resentment, especially when adequate support systems and resources are lacking. Caregivers frequently bear the responsibility of monitoring, assessing, and facilitating this sensitive process, often without the necessary tools or training to navigate it effectively. The

absence of reliable assessments for driving fitness, insufficient education for healthcare providers, and societal discomfort in addressing such emotionally charged issues further complicate the situation.

Decades of research on dementia and driving cessation have provided valuable insights, emphasizing the importance of early discussions, shared decision-making, and practical support to facilitate this transition (Scott *et al*., 2020). While interventions such as toolkits, healthcare-provider-led programs, and decision aids show promise, their limited accessibility and scope hinder widespread impact. Key challenges include a scarcity of evidence-based interventions and tools that address the emotional and logistical complexities of driving cessation. Usability, accessibility, and trustworthiness remain significant barriers for resources intended for individuals with dementia and their carers. Many existing tools are heavily reliant on healthcare providers, limiting their accessibility and reach. The absence of reliable screening measures for driving fitness further complicates the issue. Family caregivers often feel unprepared and unsupported in navigating the legal and emotional challenges of this transition (Rapoport et al., 2019; Sanford et al., 2016). Additionally, the persistent "knowledge-to-action (KTA) gap" (Graham et al., 2006) highlights the failure to translate research into practical, user-friendly tools. This gap, coupled with a lack of resources addressing the emotional toll of driving cessation and limited alternative mobility options, underscores the urgent need for innovative, evidence-based, and user-centered solutions.

Stasiulis et al. (2023) explicitly addresses the gap between theoretical knowledge on driving cessation and its practical application by developing a resource designed to support decision-making and emotional adjustment for individuals with dementia and their family carers. The study employs a multi-phased methodology of the adapted KTA framework (See Figure 1):

1. Knowledge Creation involved two key parts:
- **Development of the Driving and Dementia Intervention Framework (DD-IF)**: Systematic reviews, meta-syntheses, and qualitative studies provided evidence and stakeholder perspectives to design a comprehensive framework addressing the practical and emotional aspects of driving cessation, this Transtheoretical Model of behavior change informed the framework's structure.
- **Early Version of the DDR Toolkit**: Existing resources were curated and aligned with the DD-IF, resulting in a draft toolkit containing tools such as worksheets and videos, tailored to various stages of the driving cessation process.

2. Action Cycle focused on adapting and refining the toolkit through iterative stakeholder engagement. Key activities included:
- **Stakeholder Feedback:** Input from individuals with dementia, carers, and healthcare providers informed content, design, and delivery improvements.
- **Preliminary Testing and Refinement:** The prototype was evaluated and adjusted to enhance accessibility, usability, and relevance.
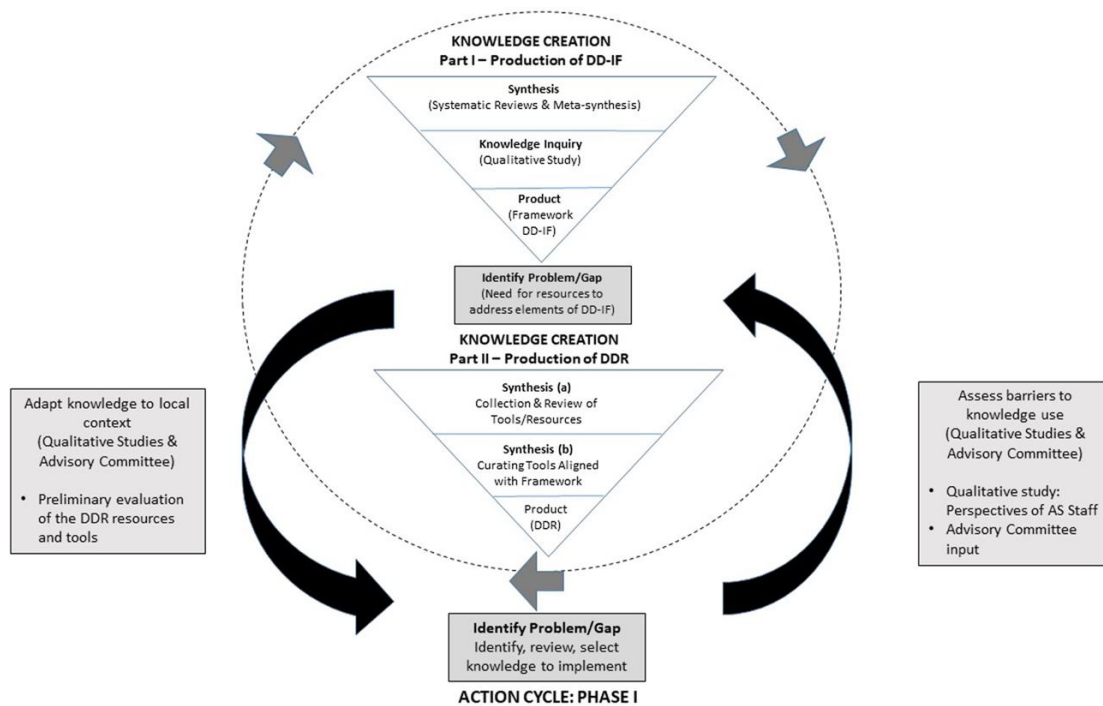
Figure 1. Adapted KTA Framework.

The DDR makes significant contributions to dementia care, aligning with contemporary principles that emphasize holistic, person-centered support. By adopting a direct-to-user format, the DDR reduces dependence on healthcare professionals, thereby increasing accessibility and scalability. Its foundation in the adapted KTA framework ensures a systematic and evidence-based approach to knowledge translation, while the integration of the Transtheoretical Model addresses behavioral changes associated with driving cessation. Continuous input from individuals with dementia, family carers, and healthcare providers enhances the toolkit's relevance, usability, and adaptability. Additionally, the innovative two-phase knowledge distillation process bridges gaps in existing resources, enabling the DDR to effectively address user needs and adapt to local contexts.

Despite its strengths, the DDR has notable limitations. Its web-based format assumes both internet access and digital literacy, which may exclude older adults in rural or underserved areas. Additionally, the evaluation of the toolkit relies heavily on subjective feedback, limiting its empirical robustness and generalizability. While the DDR addresses emotional challenges associated with driving cessation, its resources in this area are less comprehensive compared to interventions like CarFreeMe, which incorporate professional facilitation for more tailored support.

What distinguishes the DDR is its self-directed approach, which enhances scalability by empowering individuals and their carers directly. Unlike CarFreeMe, which relies on professional guidance, or the "Driving and Dementia Toolkit" (Byszewski *et al.*, 2013), which primarily targets healthcare providers, the DDR focuses on the specific needs of individuals with dementia and their carers. This innovative approach ensures

the DDR complements existing resources while tackling broader challenges of accessibility and usability.

Overall, the DDR represents a promising advancement in supporting persons with living with dementia. Its integration of the adapted KTA framework and emphasis on stakeholder-driven design ensure a strong balance between scientific rigor and practical applicability. However, addressing challenges such as digital accessibility and the need for comprehensive empirical validation is crucial to expanding its reach and effectiveness. By refining these areas, the DDR has the potential to become a widely adopted and transformative resource for individuals with dementia and their carers.

For further reading:

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Byszewski, A., Aminzadeh, F., Robinson, K., Molnar, F., Dalziel, W., Man Son Hing, M., ... & Marshall, S. (2013). When it is time to hang up the keys: the driving and dementia toolkit–for persons with dementia (PWD) and caregivers–a practical resource. *BMC geriatrics*, *13*, 1-5. https://doi.org/10.1186/1471-2318-13-117

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Rapoport, M., Yamin, S., Vrkljan, B., Tuokko, H., Sanford, S., Stasiulis, E., ... & Naglie, G. (2019). Perspective from the field: designing the driving cessation in dementia intervention toolkit (DCD-IT). *The American Journal of Geriatric Psychiatry*, *27*(3), S185-S186. https://doi.org/10.1016/j.jagp.2019.01.099

Scott, T. L., Liddle, J., Pachana, N. A., Beattie, E., & Mitchell, G. K. (2020). Managing the transition to non-driving in patients with dementia in primary care settings: facilitators and barriers reported by primary care physicians. *International Psychogeriatrics*, *32*(12), 1419-1428. https://doi.org/10.1017/S1041610218002326

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