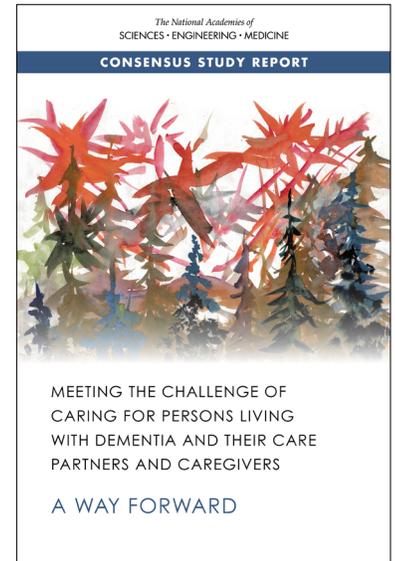




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Meeting the Challenge of Caring for Persons Living with Dementia and Their Care Partners and Caregivers A Way Forward

Millions of people in the United States and globally live with dementia, and many desire support in leading meaningful and rewarding lives, maintaining independence and agency, enjoying activities of interest, sustaining social relationships, and connecting to familiar environments and communities. To live well with dementia, people need care, services, and supports that reflect their values and preferences, build on their strengths and abilities, promote well-being, and address needs that evolve as cognitive impairment deepens.



Persons living with dementia co-manage their care with or rely on the support of a wide range of care partners and caregivers, including spouses, other family members and friends, and direct care workers in homes or residential care settings. While dementia care has improved since the 1970s, many still lack access to high-quality care and are not living as well as they might. Disadvantaged groups, especially racial and ethnic minorities, still face challenges in access to care, services, and supports, due to deep and persistent inequities.

At the request of the National Institute on Aging (NIA), the National Academies of Sciences, Engineering, and Medicine convened an ad hoc expert committee to assist NIA and the broader dementia community in (1) assessing the evidence on care interventions for persons living with dementia and caregivers, (2) informing decision making about which interventions should be broadly disseminated and implemented, and (3) guiding future actions and research.

The committee's primary source of evidence was an Agency for Healthcare Research and Quality (AHRQ) systematic review of the available evidence on care interventions for persons living with dementia and their care partners and caregivers. The committee also considered additional evidence and input, including perspectives from persons living with dementia, care partners, and caregivers.

ASSESSING THE STATE OF THE EVIDENCE

While hundreds of dementia care interventions have been tested in randomized controlled trials (RCTs), assessing the evidence to learn what is effective, for whom, and in what circumstances is challenging. The committee concluded that the evidence needed to inform decisions about policy and the implementation of specific

interventions broadly—including prioritizing the many interventions that could be helpful but require resources—is limited. This is partly due to inherent complexity. Dementia care interventions often involve multiple components and can be implemented at multiple levels and in diverse contexts, which can impact their effectiveness. In addition, persons living with dementia and their care partners and caregivers are as diverse as the general population—representing different ages, genders, races, ethnicities, sexual orientations, and disabilities—and their needs change as cognitive impairment progresses.

Importantly, the AHRQ systematic review and the committee’s analysis also highlight limitations in the existing research base that can be addressed. While some interventions have been tested in large RCTs and are beginning to be implemented more broadly in various communities, many more have only been tested in academic settings with fewer participants not representative of the diverse population of persons living with dementia. Over time, standards for research have become more rigorous; older studies often did not meet current standards. This progress is not yet fully reflected in the overall body of literature assessed in the AHRQ systematic review.

INTERVENTIONS READY FOR IMPLEMENTATION IN REAL-WORLD SETTINGS WITH EVALUATION

The AHRQ systematic review identified no interventions that met its criteria for high-strength or moderate evidence of benefit and two types of interventions with low-strength evidence of benefit, which incorporate many of the core components of care, services, and supports listed in Box 2. Collaborative care models use multidisciplinary teams that integrate medical and psychosocial approaches to care. The AHRQ systematic review found low-strength evidence that such models benefit quality of life, quality indicators, and emergency room visits. REACH (Resources for Enhancing Alzheimer’s Caregiver Health) II is a multicomponent intervention that supports family care partners and caregivers through a combination of strategies (e.g., problem solving, skills training, stress management, support groups, information and education, role playing). The AHRQ review found low strength evidence that REACH II and its adaptations reduce caregiver depression. For both collaborative care and REACH II interventions, additional studies show benefits on a wide range of other outcomes, although the evidence was not sufficient to reach conclusions on effectiveness for these outcomes, generally due to inconsistent findings across studies.

Both collaborative care models and REACH II and its adaptations are already being implemented in a variety of settings with promising results. Notably, REACH II has been studied in and adapted for diverse populations to a greater extent than is usual in the field. **The committee concluded that the evidence is sufficient to justify implementation of these two types of interventions in a broad spectrum of settings, with evaluation conducted to continue expanding the evidence base to inform future implementation.** Additional research on other promising interventions is needed to develop better ways of meeting the urgent needs of persons living with dementia and their care partners and caregivers. For a full list of the committee’s recommendations, see the Recommendations insert.

Beyond collaborative care models and REACH II, the AHRQ systematic review found insufficient evidence to support conclusions about benefits for all other interventions. This does not imply these interventions are ineffective. Instead, it reflects the high uncertainty given the limitations of the evidence base and the approach used in the AHRQ systematic review to support conclusions on readiness for broad dissemination and implementation.

These conclusions do not call into question fundamental aspects of high-quality dementia care, services, and supports. Rather, they suggest a need for additional research on specific interventions. In the meantime, organizations, agencies, communities, and individuals can use the guiding principles (see Box 1) and the core components of care, services, and supports (see Box 2) to immediately improve dementia care. Individuals and families may also want to experiment with activities such as listening to music and dancing that, when tailored to personal interests and preferences, can provide pleasure with little potential harm.

BOX 1 GUIDING PRINCIPLES FOR DEMENTIA CARE, SERVICES, AND SUPPORTS

These principles can guide ideal care, services, and supports for persons living with dementia and their care partners and caregivers. Unfortunately, their application is currently limited.

- Person-centeredness
- Promotion of well-being
- Respect and dignity
- Justice
- Racial, ethnic, sexual, cultural, and linguistic inclusivity
- Accessibility and affordability

BOX 2 CORE COMPONENTS OF CARE, SERVICES, AND SUPPORTS FOR PERSONS LIVING WITH DEMENTIA AND THEIR CARE PARTNERS AND CAREGIVERS

Several existing frameworks describe core components of ideal dementia care. The components below are designed with the participation of the individuals involved; managed throughout the course of the condition; and adjusted to the changes experienced by persons living with dementia and their care partners and caregivers:

- Detection and diagnosis
- Assessment of symptoms to inform planning and deliver care, including financial and legal planning
- Information and education
- Medical management
- Support in activities of daily living
- Support for care partners and caregivers
- Communication and collaboration
- Coordination of medical care, long-term services and supports, and community-based services and supports
- A supportive and safe environment
- Advance care planning and end-of-life care

A BLUEPRINT FOR FUTURE RESEARCH

The committee offered a blueprint for future research including methodological improvements aimed at limitations frequently found in the current evidence base, as well as approaches that can complement RCTs to better understand complex dementia care interventions and the systems in which they operate. The blueprint prioritizes research that promotes equity, diversity, and inclusion, as well as focusing on the priorities of persons living with dementia and their care partners and caregivers. It also emphasizes providing the evidence necessary to make inclusive decisions and implement interventions in the real world, including expanding the focus on community- and policy-level interventions.

CONCLUDING REMARKS

Studying dementia care interventions is challenging and complex, and the body of evidence is complicated to interpret. Two types of interventions are supported by sufficient evidence for implementation in real-world settings with evaluation to continue to expand the evidence base. Given current major deficits in care, services, and supports, providing these interventions to those who could benefit would be a step forward. Still, research should continue to develop and evaluate other potentially promising interventions. The committee's recommendations provide a path forward for building a more robust evidence base by using rigorous, cutting-edge methods that are inclusive, equitable, and yield critical information for real-world implementation. This information can be employed throughout the field by early-career researchers and others who want to harness new approaches to better support persons living with dementia and their care partners and caregivers in living as well as possible.

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