

Care Interventions for People Living With Dementia and Their Caregivers

Evidence Summary



Main Points

- An intensive multicomponent intervention with education, group discussion, in-home and phone support sessions, and caregiver feedback for informal caregiver support (i.e. discrete adaptations of REACH II), may improve informal caregiver depression at 6 months. (low-strength evidence)
- Collaborative care models (i.e. Care Ecosystems or discrete adaptations of the ACCESS models) may improve people living with dementia (PLWD) quality of life. (low-strength evidence) The literature does not allow for further determination of whether the very small to small average effects applied to all enrolled PLWD or if larger effects were concentrated in an unidentified subgroup.
- Collaborative care models (i.e. discrete adaptations of the ACCESS model) may improve system-level markers, including guideline-based quality indicators and reduction in emergency department visits. (low-strength evidence)
- For all other outcomes and interventions, we found the evidence was insufficient because the uncertainty of the evidence was too high to draw conclusions.
- We found little information to determine whether interventions are equally appropriate for or have been successfully adapted to other race/ethnic cultures within the United States, rural communities/communities with low resources, or specific populations of PLWD, such as people with Down syndrome or complex presentations of dementias.



Background and Purpose

The aging of the U.S. population and the concurrent rise in the number of adults living with dementia underscore the urgent need for a systematic review of the available evidence for care interventions for PLWD and their formal and informal caregivers. The National Institute on Aging commissioned such a review from the Evidence-based Practice Center Program at the Agency for Healthcare Research and Quality. Dementia



affects about 5 million U.S. adults 65 years and older (with disparities by race and ethnicity), and that number may grow to almost 14 million by 2060.^{1,2}

The goal is to understand the evidence base for effective care interventions, and to assess the potential for broad dissemination and implementation of that evidence. Subsequently, a National Academies of Sciences, Engineering, and Medicine committee of experts, established at the request of the National Institute on Aging, will use the evidence findings delivered in this report to help develop its own independent recommendations regarding which care interventions are supported by sufficient evidence to be widely disseminated and implemented, as well as to identify research gaps.



Methods

The methods for this systematic review follow the Agency for Healthcare Research and Quality Methods Guide for Effectiveness and Comparative Effectiveness Reviews.⁹ See the review protocol (<https://effectivehealthcare.ahrq.gov/products/care-interventions-pwd/protocol>) and the full report of the review for additional details. We searched Ovid Medline, Ovid Embase, Ovid PsycINFO, CINAHL, and the Cochrane Central Register of Controlled Trials (CENTRAL) to identify randomized controlled trials, nonrandomized controlled trials, and quasi-experimental designs published and indexed in bibliographic databases through October 2019.



Results

We identified 9,217 unique references, 894 of which were eligible for our review, comprising 627 unique studies with an additional 267 companion publications. We sorted eligible studies into 37 major intervention categories. Approximately 60 percent of the literature emerged from research conducted outside of the United States.

While the literature was highly diverse, we found little information to determine whether interventions are equally appropriate for or have been successfully adapted to other race/ethnic cultures within the United States, with only a handful of studies providing sufficient inclusion of African-American or Hispanic/Latino populations. Interventions for rural communities were found to be even more rare in the literature. Additionally, the many countries in which care interventions were evaluated were almost exclusively high-resource, with very few low-resource countries represented. Finally, few studies gathered the granular detail necessary for a deeper understanding of the applicability of the interventions. Many important groups were rarely studied, including people with Down syndrome, who are living longer and who overall experience higher rates of dementia than the general population, and individuals with complex presentations of dementia.

We found low-strength evidence that one multicomponent intervention for informal caregiver support, REACH II (comprised of education, group discussion, in-home and phone support sessions, and caregiver feedback), may improve caregiver depression.³⁻⁵ Collaborative care models based on the ACCESS or Care Ecosystems models may

improve quality of life for PLWD⁶⁻⁹ and health system-level markers, including improvements in guideline-based quality indicators^{7,8} and reducing emergency room visits.⁶ For all other interventions and outcomes, we found the uncertainty of the evidence was too high to draw conclusions. The vast majority of studies had small sample size, were pilots that had not undergone traditional efficacy testing, and/or had high risk of bias, and provided insufficient evidence to draw conclusions.

Limitations

As stated, the goal of the review was to understand the evidence base for effective care interventions for PLWD and their caregivers in order to assess the potential for broad dissemination and implementation of that evidence. All decisions about the review methodology followed from this goal, which has implications for our findings. Therefore, some specific approaches for a particular intervention, or even whole classes of interventions, may not have been captured. Similarly, we may have missed some community services and support approaches such as tool kits, referral services and links, or awareness-raising outreach.

Because we excluded studies with fewer than 10 participants per study arm, we may not have identified some interventions with only very preliminary research. Our approach to risk of bias assessment was generous, relative to how risk of bias is assessed in more targeted systematic review topics. This is in part due to the unusually varied studies included in this review as well as the complexity of the condition and the care approaches.

Furthermore, included studies had methodological problems such as low subject retention, widely varying measures of success, and relatively small size trials that may have lacked the power to detect benefits. These problems stem from well-recognized challenges in researching these populations; therefore, we erred on the side of assessing a body of research as insufficient rather than ineffective. Additionally, given the progressive nature of dementia and the anticipated increase in care needs over time, it may be difficult to identify improvement in caregiver burden. The goal may in fact be to slow the rate of burden—and studies may be underpowered to detect such a small effect.

Finally, given the breadth of the topic, our systematic review is naturally reductionist in nature. That is, small but true differences may exist between many of the categories we summarized into our outcomes.

Implications and Conclusions

Ultimately, we uncovered very little evidence to support interventions and programs for active, widespread dissemination because evidence was insufficient to draw conclusions about the effects of the vast majority of interventions studied.

Dementia care research has been slow to incorporate key elements of rigorous intervention design. Until relatively recently, many dementia care intervention studies were not held to reporting standards (e.g. the Consolidated Standards of Reporting Trials

statement), pre-registration of trials, data safety and monitoring boards, or other standards more common in other areas of clinical science. As a direct result, despite a few positive findings, our global conclusions, largely similar to past reviews,¹⁰ are that the amount of high-quality evidence is insufficient to draw firm conclusions about interventions.

In order for Federal funders and stakeholders to expedite the translational pipeline of idea development to implementation, as they aim to do, critical improvements are needed in dementia care research. Only with such improvements will we be able to draw clearer, less ambiguous conclusions related to efficacy.



References

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Full Report

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