



Translation, Dissemination, Implementation, and Scaling Up of Effective Care, Services, and Supportive Approaches for Persons with Dementia and Their Caregivers

Background Paper

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Additional information can be found at the Summit website (<https://aspe.hhs.gov/national-research-summit-care-services-and-supports-persons-dementia-and-their-caregivers>) or the National Alzheimer's Project Act website (<https://aspe.hhs.gov/national-alzheimers-project-act>). The opinions and views expressed in this report are those of the authors. They do not necessarily reflect the views of HHS, the contractor or any other funding organization.

Introduction

More than 5 million Americans live with dementia, and the number of people with Alzheimer's disease, the most common cause of dementia, is projected to increase to 13.8 million persons by 2050 (Hebert, Weuve, Scherr, & Evans, 2013; National Institute on Aging [NIA], 2016). Dementia affects a person's cognitive function, behavior, and ability to perform everyday activities such as shopping, paying bills, and managing medications (Alzheimer's Association, 2016; NIA, 2016). People with dementia and their family caregivers face great difficulties in coping with and managing the condition (Alzheimer's Association, 2016). Currently, no pharmacological treatments exist that can prevent, cure, or significantly delay the onset or progression of Alzheimer's disease or of other diseases that cause dementia (Cummings, Morstorf, & Zhong, 2014; NIA, 2016; United States Department of Health and Human Services [HHS], 2016b).

Rigorous research has shown, however, that some nonpharmacological interventions can have positive effects for people with dementia and their family caregivers (Gitlin, Marx, Stanley, & Hodgson, 2015; National Academies of Sciences, Engineering, and Medicine [NASEM], 2016). Unfortunately, although these evidence-based interventions are proven effective in research settings, they have not been widely translated to community settings across the United States (Gitlin et al., 2015; Kales, Gitlin, & Lyketsos, 2014; Maslow, 2012; NASEM, 2016). This background paper summarizes the research on the translation, dissemination, implementation, and scaling up of effective care, services, and supportive approaches for persons with dementia and their caregivers.

Translation and Implementation

Translation studies of evidence-based interventions help to determine if interventions can be effective when implemented outside the often-rarified research setting used to originally test them. Translation of evidence-based interventions for people with dementia and their caregivers from a research study to the larger community is complex, requiring consideration of several factors.

- *Funding*--Funding for translating evidence-based dementia care interventions has been limited to a few sources. Funders of translating dementia care interventions to home and community-based settings include the Administration on Aging's Alzheimer's Disease Supportive Service Program (ADSSP) and Alzheimer's Disease Initiative-Specialized Supportive Services, United States Department of Veterans Affairs, and the Rosalynn Carter Institute for Caregiving and its funding partner Johnson & Johnson (Gitlin et al., 2015; HHS, 2016a, Maslow, 2012). Most of these studies are focused on demonstrating effectiveness and do not include more detailed analyses of which groups benefit most from these programs and which providers are best suited to implement various interventions (Maslow, 2012).
- *Selecting an intervention*--Several factors are involved in organizations selecting an intervention to be translated to a community. These factors include whether the intervention fits with the mission of the translating agency, the agency's other programs, and the way the agency delivers services (Nichols et al., 2016; Prohaska & Etkin, 2010); whether the implementation requirements are manageable and within the resources of the agency (Bass & Judge, 2010); if there are well-defined procedures that describe how

to deliver the intervention (Bass & Judge, 2010; Horner & Blitz, 2014; Nichols et al., 2016; Prohaska & Etkin, 2010); and if research-based evidence indicates that the intervention is effective for the target population (Bass & Judge, 2010). In addition, a recent study on translation studies of evidence-based interventions through the Administration for Community Living's ADSSP found that grantees also considered geographic proximity of the original researcher when choosing an intervention for translation (Gould et al., 2017). A final consideration is whether there will be ongoing financial support from third-party funders of the intervention.

- *Partnering with community organizations and key stakeholders*--Translating an intervention into a community often takes the work of many stakeholders and community partners. Partners need to have expertise related to the intervention; resources for recruitment; sufficient and appropriate settings for the translated program; information and delivery systems capable of tracking and performing the intervention (Bass & Judge, 2010; Bertram et al., 2015; Glasgow, Lichtenstein, & Marcus, 2003; Krist et al., 2012; Prohaska & Etkin, 2010); and the ability and willingness to allocate these resources for the translation project (Horner & Blitz, 2014).
- *Recruiting participants*--Recruiting people with Alzheimer's disease or other dementias has proven difficult for some translation studies. Potential participants may not meet the eligibility criteria for the study, may be unwilling to participate because of the time commitment or stigma associated with dementia, may not understand the potential benefits of such studies, or may not yet be diagnosed with dementia (Gould et al., 2017; Maslow, 2012). Many participants do not want to be involved in a research study, in part because responding to researchers' questions can be time consuming. It is important to ensure that there are enough potential participants in the target community for whom the program outcomes are relevant (Bertram et al., 2015; Scheinholtz, 2010) and whose culture, values, and preferences make them likely to use the program (Bass & Judge, 2010; Horner & Blitz, 2014).
- *Intervention staff*--Sufficient staff at involved agencies who have the necessary expertise to implement the translated program (Bass & Judge, 2010; Bertram et al., 2015; Horner & Blitz, 2014; Nichols et al., 2016; Teaster, 2011) and whose culture and professional and personal values make them likely to accept and continue to deliver the program after the translation study has ended (Horner & Blitz, 2014) is critical. However, finding community services providers who have adequate education and experience and the needed interpersonal skills to provide evidence-based interventions for people with dementia and their caregivers can be challenging (Maslow, 2012). Although original research studies may use intervention staff with high educational qualifications and skills, staff implementing these interventions in community-based translations may not have similar backgrounds (Bass & Judge, 2010). In some instances, staff from more varied disciplines with lower level credentials deliver interventions compared to the original intervention (Gould et al., 2017). However, the prior academic and work experience may not be as important when working as an interventionist as program-specific training (Bass & Judge, 2010).
- *Monitoring fidelity*--Maintaining fidelity helps ensure that the delivery of a translated intervention is consistent with the original evidence-based intervention (Gitlin et al., 2015; Sherman & Steiner, 2016). Variations exist in the methods used for measuring fidelity. Some fidelity monitoring strategies include regular communication with

intervention staff, checklists and forms for data tracking, visits to or recordings of the training sessions by experienced trainers, and participant evaluations (Hughes et al., 2016). Several ADSSP grantees used the original researcher as a resource to monitor program activity and maintain fidelity. In addition to providing education on the intervention, some of these researchers provided training specifically on how to maintain intervention fidelity. Maintaining fidelity for the grantees was not always easy because the elements of the intervention are sometimes not well described in the research literature or depend on the clinical expertise of the intervention developer. Intervention manuals were an important tool to codify an intervention and maintain fidelity (Gould et al., 2017).

- *Intervention modifications*--Although maintaining fidelity to the original intervention is important in translation studies, modifications may be appropriate and necessary to adapt the intervention to real-world settings. Modifications can be made to accommodate needs of the target population, better fit the translation setting, or accommodate budget and resource constraints (Gitlin et al., 2015; Gould et al., 2017; Maslow, 2012). Modifications to the original intervention may be needed to improve contextual fit and acceptance and use of the translated program (Bass & Judge, 2010; Bradley et al., 2004; Gitlin et al., 2015; Scheinholtz, 2010). For education and support interventions, some specific types of modifications include changes in eligibility requirements, the number of sessions offered or length of sessions, session location, delivery mode, treatment elements, and interventionist training (Gitlin et al., 2015; Gould et al., 2017). Balancing the need for changes with maintenance of essential components of the original intervention is a frequently identified tradeoff (Gitlin et al., 2015; Horner & Blitz, 2014; Nichols et al., 2016).
- *Evaluating the translated program*--Data gathered from a translation evaluation provide critical information to adjust or justify how a program is implemented. Modifications can be made to improve aspects of the program that are not achieving desired results and positive aspects can be continued. Positive evaluation results also may provide an opportunity to garner support for future funding of the program (Paone, 2015). In addition to more academic measures, selecting outcomes meaningful to agency administrators and people who could use the translated program is critical (Bass & Judge, 2010; Horner & Blitz, 2014; Prohaska & Etkin, 2010; Scheinholtz, 2010). Cost and cost-effectiveness are likely to be important to agency administrators and improved ability to manage daily activities, and reduced behavioral symptoms are likely to be valuable outcomes to people with dementia and their family caregivers (Gould et al., 2017).

Dissemination and Scaling Up

Successful dissemination and scaling up of effective interventions for people with dementia and their caregivers relies on several factors. Additional replications conducted across various settings and different communities would assist in establishing that a program can work with multiple populations (Gitlin et al., 2015; Prohaska & Etkin, 2010).

Although most interventions are not disseminated widely, some programs have managed to be replicated in several settings. For example, a statewide dissemination effort of the Reducing Disability in Alzheimer's Disease was conducted in Ohio, where project staff developed a replication handbook that complemented the original researcher's original intervention manual

(Gould et al., 2017). The development of this replication handbook and accompanying cost estimates were required as part of ADSSP evidence-based translation grants (HHS, 2009). Two programs--Benjamin Rose Institute on Aging's BRI Care Consultation™ and Rosalynn Carter Institute's Resources for Enhancing Alzheimer's Caregiver Health--have been disseminated to 20 or more sites across the country (Wiener et al., 2016). The developer for BRI Care Consultation™ reported that the agency is licensing other sites and providing ongoing consultation, refresher training, and fidelity monitoring for those sites.

Sustainability

The lack of stable, ongoing, and sufficient funding to sustain evidence-based programs that have achieved positive outcomes in translation projects is a major barrier to sustaining these programs over time. Time-limited demonstration grants have been the primary source of funding for translation projects, and the projects often struggle to find other funding sources to maintain the projects after the grants end (Bass & Judge; 2010; Gitlin et al., 2015; Krist et al., 2012).

The current health and long-term services and supports system is not structured to fund the delivery of evidence-based interventions (Gitlin et al., 2015). However, there are a few instances of evidence-based interventions for people with dementia and their caregivers that have found ways to obtain ongoing funding. For example, three home health care agencies and two private agencies obtained Medicare reimbursement for the Skills₂Care intervention, and the National Family Caregiver Support Program funded the delivery of Skills₂Care in five Area Agencies on Aging (Maslow, 2012). Securing such financial support can be time consuming, and maintaining funding can require ongoing efforts by researchers and others. After initial federal funding ended, ADSSP interventions were most commonly sustained through Titles III-D (Disease Prevention and Health Promotion Services) or III-E (National Family Caregiver Support Program) of the Older Americans Act (Gould et al., 2017; Maslow, 2012). In most cases, Medicare, Medicaid, and commercial insurance reimbursement is not available.

Strategies to Improve Translation and Dissemination

Because interventions may be more effective at a specific disease stage or for groups of people, it can be difficult to know which intervention to use for specific people with dementia or their caregivers (Gitlin et al., 2015; Maslow, 2012). An intervention classification system would allow for a better understanding of the programs, similarities and differences between programs, and help identify research gaps (Gitlin et al., 2015; Maslow, 2012). A classification system could include categories for what is involved in each program, the target population for each, and the types of issues addressed (Maslow, 2012). Beyond a classification system, research is warranted on which groups of people with dementia could benefit from these interventions, such as those with early-onset dementia, late-stage dementia, non-Alzheimer's dementias, racial and ethnic minorities with dementia (Maslow, 2012), and individuals with intellectual and developmental disabilities (Courtenay, Jokinen, & Strydom, 2010).

An important focus for the future is creating replication guides that allow communities to implement interventions. Reports on effective interventions for people with dementia and their caregivers often do not include enough information to replicate the intervention in the community, so translation is difficult (Gitlin & Hodgson, 2015).

Finally, although many academic studies focus on “soft” impacts, such as caregiver burden, fewer studies assess “hard” impacts, such as reduced hospitalization, emergency room and nursing home use. These aspects of programs are important in translation research to determine the financial feasibility of each intervention and to appeal to future funders, such as health systems and health plans (Gitlin et al., 2015).

Conclusion

Moving evidence-based interventions for people with dementia into communities requires several steps. Translation studies help to determine if evidence-based interventions that have shown effectiveness in a research setting can show similar results in communities. To translate such interventions, factors include funding, collaborating with community organizations, modifying the intervention to fit real-world settings while also staying true to the original intervention, and evaluating results. Although evidence-based interventions for people with dementia and their caregivers have shown positive effects, to date they have not been widely translated into community-based settings.

Specific research on evidence-based interventions as they relate to specific groups of people with dementia and their caregivers is lacking. Future research efforts could include identifying subgroups of people with dementia who could benefit from these interventions. Development of a classification system for evidence-based programs could also help advance the field. Such a classification system could allow for a more complete understanding of evidence-based interventions that are most beneficial to people with dementia in various stages of the disease and with differing life circumstances.

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