

**Dementia Caregiver Intervention Research Now and into the Future:  
Review and Recommendations**

Laura N. Gitlin, Ph.D., FGSA, FAAN,<sup>1</sup> Eric Jutkowitz, Ph.D.,<sup>2</sup> & Joseph E. Gaugler, Ph.D.<sup>3</sup>

<sup>1</sup>College of Nursing and Health Professions, Drexel University

<sup>2</sup>Department of Health Services, Policy and Practice, School of Public Health, Brown University

<sup>3</sup>Division of Health Policy and Management, School of Public Health, University of Minnesota

This work was supported in part by the National Institute on Aging (NIA) of the National Institutes of Health under Award Number U54AG063546, which funds NIA Imbedded Pragmatic Alzheimer’s Disease and AD-Related Dementias Clinical Trials Collaboratory (NIA IMPACT Collaboratory). The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

This paper was commissioned for the Workshop on Challenging Questions about Epidemiology, Care, and Caregiving for People with Alzheimer’s Disease and Related Dementias and their Families. The workshop was convened by the Board on Behavioral, Cognitive, and Sensory Sciences on October 17, 2019, in Washington, DC with support from the National Institute on Aging. Opinions and statements included in the paper are solely those of the individual author, and are not necessarily adopted, endorsed, or verified as accurate by the Board on Behavioral, Cognitive, and Sensory Sciences or the National Academy of Sciences, Engineering, and Medicine.

Dr. Gitlin was also supported in part by the National Institute on Aging grants (Dementia Behavior Study R01AG041781; and Improving Support for Family Caregivers in Adult Day Services: The Adult Day Plus Trial R01 AG049692)

We thank Daniel Scerpella, Research assistant, Drexel University; Dr. Karolina Bryl, Post-doctoral Fellow, Drexel University; and Marie Dellapina, MS, Research assistant, Drexel University, for their assistance with literature reviews.

## EXECUTIVE SUMMARY

This paper, prepared for the National Academies of Science, Engineering, and Medicine Decadal study, reviews an extensive body of research on interventions that support family and formal caregivers of persons living with dementia (PLwD) in order to generate research recommendations that advance scientific inquiry in this area. To identify recommendations for the next generation of caregiver intervention research, our paper sought to answer three broad questions: 1) what is the state of the science of dementia caregiver (family and formal) intervention research?; 2) what are the key findings from caregiver (family and formal) intervention studies (nonpharmacological and pharmacological); and 3) what are the key limitations and gaps in the extant literature? Organized in three sections, this paper first provides foundational knowledge from which to understand caregiver intervention research including a brief discussion of nomenclature and a summation of the 50+ year historical record of research in this area. Next, we describe the methodologies used to identify reviews (scoping, meta-analyses and systematic reviews) and present a synthesis of this extensive literature. Our multiple review of reviews focuses on research conducted in the past two decades in both the United States and globally, and which evaluated nonpharmacological interventions for family and formal caregivers as well as trials of pharmacological treatments for PLwD reporting outcomes for family caregivers. Lastly, based on a synthesis of the evidence, we present conclusions and key recommendations for future research.

Using the NIA Stage Model for Behavioral Interventions to locate existing caregiver interventions along their developmental pathway, we find that most interventions for family caregivers (>200) have been tested only at the efficacy stage with very few subsequently tested in pragmatic trials or translated for delivery in care settings. Similarly, for formal caregivers,

studies are at a formative stage of their development having been tested in settings but with no data concerning long term effects and sustainability of approaches. Taken as a whole, this review of reviews of interventions studies reveals a duality; on one hand, there are many caregiver support interventions that are efficacious and buttress psychosocial wellbeing in family caregivers that can be implemented now in care settings. Yet, on the other hand, intervention studies have methodological (but fixable) flaws, small effect sizes, do not address all of the documented unmet needs of families across the disease trajectory, and samples do not reflect the diversity of caregivers (geographically, racially, ethnically) nor are outcomes of importance to different stakeholders examined. Furthermore, it is challenging to compare interventions across studies due to nomenclature confusion and the lack of linking proven interventions to disease stage and understanding the clinical significance of interventions and their outcomes given that many studies do not adequately describe their samples or interventions. While there are fewer tested interventions for formal caregivers, a similar pattern emerges. There is evidence that approaches providing education and skill building are effective in enhancing efficacy and care quality, yet it is unclear whether interventions for formal caregivers are fully integrated in workplaces and sustained, and not all concerns and needs of health providers are addressed in existing programs. For example, formal caregivers who also provide care at home to PLWD or a child with significant needs have heightened distress and are at higher risk for depression than their counterparts, yet supportive interventions for this at-risk group do not exist.

This state-of-the-science indicates great progress, yet nevertheless, much room for improvement including changing methodologies and paradigms by which interventions are advanced and tested. In question is the theory-base of most interventions and their overreliance on stress-process frameworks and consequently their narrow focus on symptom reduction

outcomes (e.g., burden, depression, upset) in contrast to strength-based approaches and outcomes of resilience, adaptation, and family functioning. Echoed throughout the long history of caregiver intervention research up to the present are three key themes: there is evidence, existing evidence is not embedded in real world care settings, and the need to strengthen and develop more evidence using different rigorous methodologies. This reflects the experience both within the United States and worldwide and applies to interventions for both family caregivers and formal providers. In response to this state-of-the-science, we offer three broad recommendations to advance this area of inquiry that can build a strong body of evidence and which has potential to make a real impact in the lives of family and formal caregivers. These broad areas include: conducting caregiver intervention research differently; engaging in implementation research to bring the evidence to real settings; and developing new interventions that address unmet needs of diverse caregivers and across the disease trajectory. For each of these areas, we provide multiple and specific research suggestions.

Overall, caregiver (family and formal) intervention research is critical to the advancement of comprehensive dementia care. This is a highly promising area of inquiry, the results of which have the high potential to improve quality of life, alleviate the burdens of dementia and strengthen the abilities of caregivers to provide dementia care. In order to realize the potential of this area of inquiry, multiple research fronts must be pursued and new frameworks and methodologies are an imperative.

## INTRODUCTION

### **Box 1. Snapshot of Caregiving at Home for an Individual with Moderate Stage Dementia**

Since her husband was initially diagnosed with dementia (four years ago), Mrs. Smith is having increasing difficulty managing her husband's physical and cognitive declines and behavioral symptoms including trying to leave home, repetitive vocalizations, rejection of needed help, and anxiety. Medications have not been effective, had negative side effects and were discontinued. His physician and neurologist told the Smiths that "nothing can be done." Thus, Mrs. Smith has been on her own. By chance, Mrs. Smith learned of the Alzheimer's Disease Association from a neighbor and was able to obtain helpful printed information; she also used the help line a few times, but she has not been interested in support groups. Mrs. Smith is unaware of community services and as such they do not receive in-home help nor does Mr. Smith attend adult day services. Mrs. Smith had to stop working so she could care for her husband full time. Because of this, their finances are strained. The Smith's adult children live far and are unable to provide daily support. Mrs. Smith feels increasingly isolated and depressed. She is not sure how to manage daily care challenges nor engage her husband and she is concerned about their rapidly diminishing quality of life.

Mrs. Smith is one of the over 16 million Americans who provide extraordinary care to a relative, in this case her husband, living with Alzheimer's Disease or a related disorder (AD/ADRD; Alzheimer's Association, 2019, Box 1). Since most people living with dementia (PLwD) reside in their own residence or the home of a family member, close to 90% of long term care and supports is typically provided by one or more family members (O'Shaughnessy 2014). Families who live nearby or at a long distance also provide care (MetLife, 2011) with an estimated 1.4 million to 2.3 million long-distance caregivers (Alzheimer's Association, 2012).

There is no question that families have and will continue to provide long-term care for PLwD; this has been true historically, it is the case currently, and will be the situation into the future (Gitlin et al., 2019; Gitlin & Schulz, 2012; Pruchno & Gitlin, 2012). Family involvement

in care provision is a global phenomenon occurring across socioeconomic levels, race and ethnic groups, and in low, middle and high-income countries (Shahly et al., 2013; World health organization, 2014). In the United States, there is a strong societal expectation and implicit demand that families assume responsibility for providing episodic and long-term care to PLwD. Furthermore, dementia is a disease of disparities with more women affected, more women providing care, and higher prevalence rates of dementia among African Americans and Latin Americans. These are important considerations in the evaluation of intervention research.

The economic value of caregiving is extraordinary. In 2018, caregivers of PLwD provided an estimated 18.5 billion hours of unpaid assistance, valued at \$290 billion (U.S. Department of Labor, Bureau of Labor Statistics, 2018, <https://www.bls.gov/opub/mlr/2018/home.htm>). Of the \$350,174 lifetime cost caring for a PLwD, families incur the brunt (70%) of the economic outlay (\$225,140) with the rest paid for through Medicare and Medicaid (Jutkowitz et al., 2017).

Providing care to PLwD differs in important ways from providing care to individuals with serious illness who are cognitively intact. Compared to non-dementia caregivers, dementia caregivers tend to provide more assistance with instrumental and self-care activities, monitor health and medication taking, assist with mobility challenges, episodic and care transitions and care coordination and advocacy including communicating with health professionals (Riffin, Van Ness, Wolff, & Fried, 2017). An ample body of research has also documented the dramatic increase in care responsibilities that occur with disease progression. This includes but is not limited to managing complex clinical symptoms (e.g., functional decline, behavioral symptoms) along with co-morbidities, coordinating and involving other family members in care provision

and providing extensive hands-on assistance, as in the case of the Smiths above (Jutkowitz et al., 2017, Jutkowitz et al. in press).

In response to the multi-faceted roles and long-term involvement of families, an extensive body of research has emerged over the past 50 years that documents both the positive and detrimental effects of dementia caregiving. This literature consistently shows that with disease progression, family members themselves are at risk for depression, burden, distress, missed days at work, financial distress, hospitalizations, social isolation, and/or cognitive decline (Jutkowitz et al., 2017; Pinquart & Sorensen, 2003; Sorensen, Duberstein, & Pinquart, 2006). Caregivers are impacted at each point along the disease trajectory. Recent research indicates that even at pre-clinical and mild cognitive disease stages, family members report worry and anxiety and may initiate care in the form of accompaniment to medical visits, coordination of appointments or help with finances (Wolff et al., 2018). Similarly, with residential placement, many caregivers continue to experience depression and distress and are often involved in care coordination and hands-on assistance. Upon death of the PLwD, some caregivers experience complicated grief.

Given the in-depth involvement of family members and the associated financial, psychological, and physical costs of caregiving, supporting family caregivers and addressing their different needs along the disease trajectory is a major public health imperative; this is the case now and will be into the future. Furthermore, the impending shortage of available family caregivers in the upcoming decades raises additional concerns as to how best to support PLwD and the role of a healthcare workforce (Gaugler & Kane, 2015). Equally, health professionals providing care to PLwD confront similar challenges as families. Burn out, stress and anxiety are common experiences (Marx, et. al., 2017). There is broad consensus that supporting families



and formal caregivers must be part of comprehensive dementia care.<sup>1</sup> Given the 2025 world-wide goal for treatment(s) that prevent, delay disease progression and/or improve dementia care,<sup>2</sup> we are at a critical juncture in which we must take stock of what is effective and what is not in order to explicate future directions for caregiver intervention research that can positively contribute to, improve and rapidly advance comprehensive dementia care.

This paper, prepared for the National Academies of Science, Engineering, and Medicine decadal study, reviews an extensive body of research on interventions that support family and formal caregivers of persons living with dementia (PLwD) in order to generate research recommendations that advance scientific inquiry in this area. To identify the next generation of caregiver intervention research, our paper sought to answer three broad questions: 1) what is the state of the science of dementia caregiver (family and formal) intervention research?; 2) what are the key findings from caregiver (family and formal) intervention studies (nonpharmacological and pharmacological); and 3) what are the key limitations and gaps in the extant literature? Organized in three sections, this paper first provides foundational knowledge from which to understand caregiver intervention research including a brief discussion of nomenclature and a summation of the 50+ year historical record of research in this area. Next, we describe the methodologies used to identify reviews (scoping, meta-analyses, and systematic reviews) and present a synthesis of this literature. Our review of reviews focuses on research

---

<sup>1</sup> We define comprehensive dementia care as coordinated care provided across the disease trajectory and which addresses a range of treatment goals (medical, social and quality of life) that change with disease progression and includes assuring safety and well-being for both the person living with dementia and their family members as well as supporting formal caregivers with appropriate education and skills training(Gitlin & Hodgson, 2018).

<sup>2</sup> As of this writing, results of Biogen's Phase 3 trial of aducanumab, an investigational infusion treatment for early Alzheimer's disease, were released, showing a slowing of cognitive decline for individuals at an early disease stage. The consequences of treatment on quality of life, over time and for caregivers, have not been examined. Although treatment that slows disease progression is important, it will not in itself address familial and formal provider needs to provide long-term care. Even with the possibility of treatments such as aducanumab, the necessity for supporting family and formal caregivers will persist.

conducted in the past two decades in both the United States and globally, and which evaluated nonpharmacological interventions for family and formal caregivers as well as trials of pharmacological treatments for PLwD reporting outcomes for family caregivers. Lastly, based on a synthesis of the evidence, we present key recommendations for future research and conclusions.

## BACKGROUND

### What Should We Call Family Members Providing Care?

Caregiver intervention research is necessarily dependent upon how we define and frame the term “caregiver.” Yet, how we identify, label, define, study and involve families as “caregivers” in interventions is not straightforward. There are important differences in how a “caregiver” has been defined in studies, reports and legislation. The language used to refer to and define “caregiver” impacts study inclusion criteria, who self-identifies and volunteers for a study, as well as who may be eligible to receive an evidence-based care and supportive service based on policy and legislation or guidelines imposed by a health care organization or community-based service. Thus, nomenclature is an essential ingredient to caregiver intervention research and must be fully understood in order to move forward with the next generation of caregiver intervention inquiry. A study of nomenclature was a strong recommendation of the first National Research Summit on Care and Services and has been a focus of subsequent NIH research summits on Alzheimer’s Disease and Related Disorders (Gitlin, Maslow, & Khillan, 2018).

Variations in terminology used to refer to families providing care to an older adult reflect differences in disciplinary frameworks, historical and point in time referents, cultural innuendos, preferences, location/place/care setting, legislation as well as the science of caring. Table 1 and

2 are illustrative of the complexity of the term. Table 1 lists some of the key terms used to refer to families in medical encounters which structure the nature of their inclusion (or not) as care partners.

[Table 1]

Table 2 illustrates the way in which “caregiver” has been variably defined by advocacy groups and legislative acts targeting family members. The terms used to describe family involvement continue to evolve with more recent references to this group as a “care partner,” “carer”, or “support person.” These terms reflect a paradigm shift from the view of the PLwD as dependent and noncontributory and reflected in the referent of PLwD as a “care recipient”, to an understanding that care relationships reflect interdependence and reciprocity. More specifically, “care partner” is emerging as the preferred referent among PLwD and family members of individuals at an early disease stage and/or for individuals living alone in which some support may be necessary but for which hands-on care is not yet necessary. Thus, “partner” may more accurately reflect the role of a family member or paid individual than the term “caregiver.”<sup>3</sup> Similarly, some family caregivers reject the label “informal caregiver” and view the term as diminishing their central role in the daily life of a person living with dementia and the extraordinary level of care provided (e.g., “there is nothing informal about the care I provide.”). The term “informal caregivers” has been used to contrast with “formal caregivers” who are typically defined as paid providers of care. This distinction is not accurate as many families establish a division of labor with some members paying for others to provide intense dementia care. Additionally, some service programs compensate family members for providing care.

---

<sup>3</sup> The term “care partner” has been expressed as a preferred referent point in various recent national convenings, although an evidence base for the acceptability of the term to diverse caregivers has not been established. Similarly, the rejection of the use of the term “informal caregiving” has been observed in various caregiver conferences but the evidence is not clear as to the level of acceptability of these terms.

Finally, we find that families may not self-identify as a “caregiver”, viewing their activities as constituting or residing in the boundaries of normal familial and societal expectations. This is a challenge for identifying and determining their eligibility for participation in existing services or clinical trials.

[Table 2]

The preferred terminology among individuals providing extraordinary care who are from different race, cultural, ethnic and socioeconomic backgrounds is unclear. Research into the attributions and meanings of nomenclature is included as a research recommendation as it would provide important foundational knowledge from which to develop and refine caregiver interventions and also inform outreach for recruitment in trials and dissemination efforts.

In sum, the term “caregiver” itself reflects an evolving science of the care context and the shifting preferred language of different stakeholder groups including families themselves, PLwD, health providers and others. Nevertheless, from a practical stance, to discuss intervention research for family members and health care providers, a term must be applied. Thus, for the purpose of this paper, we use the term “family caregiver” and adopt the definition employed by

**Box 2. Definition of Family Caregiver**

“Family caregivers are relatives, partners, friends, or neighbors who assist an older adult (referred to in this report as a care recipient) who needs help due to physical, mental, cognitive, or functional limitations. The caregiver’s involvement is driven primarily by a personal relationship rather than by financial remuneration. Family caregivers may live with, or apart from, the person receiving care. Care may be episodic, or of short or long duration.” (Schulz and Eden, 2016).

the National Academy of Science, Engineering and Medicine Report, *Families Caring for an Aging Society* (see Box 2).

Noteworthy is that while the term family caregiver refers to an individual with a personal connection, it is not restrictive to blood relatives. We also however, intermittently apply the term “care partner” in recognition of the role family members may assume in early disease stages (pre and post-diagnostically). By using this term, we also seek to signal the need for a different orientation in intervention research; one that is sensitive to the significance of nomenclature and disease stage in the design of caregiver interventions, and that accounts for the different roles and needs families have along the disease trajectory. We use the term “diversity” in the broadest sense to refer to families of different race, ethnic, socioeconomic and/or geographic backgrounds. Finally, we use the term “formal caregiver” to refer to individuals who are not related to an individual living with dementia, who do not provide care due to a personal relationship, and who are paid for their provision of care in a care setting (nursing home, assisted living, adult day, home).

What is an “intervention”?

The research terminology to describe the scientific body of intervention research is similarly challenging. While common research parlance uses “intervention,” this term can imply a set of invasive procedures and may not be well received or understood among diverse family caregivers. An “intervention” can refer to either strategies, programs, services, a protocol or an action or process to improve a situation. We use the term “intervention” although recognize that when implemented in a real world setting, this may not be appropriate and need adjustment to reflect the preferences and understandings of particular community and stakeholder groups.

An equal challenge is characterizing “interventions.” Interventions have been broadly defined as either pharmacological or nonpharmacological and within the latter, various

classifications have been proposed with little to no consensus making it rather challenging to synthesize and evaluate the evidence. A review of 23 meta-analyses and systematic reviews for example demonstrated vast differences and inconsistencies in terminology applied to similar intervention content; thus, thwarting cross study comparisons and understanding which interventions may be most effective for specified desired outcomes and for which groups (Gaugler et al., 2017).

### History of Caregiver Intervention Research

Caregiver intervention research has a long and impressive history that summarized in terms of three co-occurring phases building on each other over the past 50+ years (Pruchno & Gitlin, 2012; Callahan et al., 2013). The first phase of interventions were dominated by use of stress process frameworks and a psychological orientations emphasizing symptom reduction such as caregiver burden and depression as a way to avoid PLwD residential placement. Interventions provided education, social support, counseling and referrals and also sought to evaluate respite opportunities and care management. A slew of caregiver interventions were developed and tested, each with a different approach that was not well documented. Results were largely inconsistent with only a few showing statistical significance with small effect sizes for reducing depression and burden. These studies were methodologically flawed and lacked adequate documentation of intervention processes, an inattention to fidelity, and enrollment of caregivers who were not diverse nor may not have experienced the outcomes of interest (e.g., non-depressed caregivers in which main outcome was depression). Nevertheless, an emerging theme from these initial trials was that individualized, high intensity interventions targeting

primary caregivers appeared to result in better outcomes (mood, burden, wellbeing) than group supportive approaches.

A second discernable phase in caregiver intervention research was marked by more methodologically sophisticated clinical trials (1990s) such as the seminal study by Mittelman and colleagues (1993) to determine the long-term effectiveness of comprehensive support for spouse-caregivers and their relatives for the purposes of postponing nursing home placement. After 8 months, caregivers in the intervention group were significantly less depressed than controls, and nursing home placement was delayed by 1.5 years. No other studies at that time achieved this result, although the trial had methodological flaws (e.g., interventionists collected outcome data). Noteworthy is that the intervention has been replicated with positive results for some but not all caregivers (Gaugler et al., 2018; Sperling et al., 2019).

Yet a third discernable historical phase in caregiver intervention research consisted of the conduct of more robust and methodologically sound clinical trials although stress process frameworks and focus on symptom reduction outcomes persisted, the exemplar being the NIA/NINR REACH Resources for Enhancing Alzheimer's Caregiver Health initiatives (Phase I and II). REACH I involved testing six different interventions (psycho-educational group counseling, individual counseling, skills training, problem solving, technology-based education and supportive programs) which shared a common data set in order to compare outcomes across different approaches. Each intervention tested included more rigorous methodologies than previously, minimal control groups and inclusion of racially, ethnically (Caucasian, African American and Latino) diverse caregivers. Using a common set of measures as well as site specific measures, improvements were found for some but not all interventions resulting in reduction of burden across interventions and reduction of caregiver depression by only a few

(Gitlin et al., 2003; see also *The Gerontologist* 2003 for publications of each REACH I intervention trial). REACH II tested a multi-component intervention developed from the common and active elements of each of the REACH I interventions. Five sites tested the same intervention and found positive outcomes for caregiver upset particularly for Latino and White caregivers, and spousal African Americans (Belle et al., 2006).

Significantly, both REACH I and REACH II initiatives ushered in a new scientific era setting a rigorous bar for the conduct of caregiver intervention trials. For example, these initiatives were the first to attend to fidelity, evaluate use of technology for treatment delivery, consider dose-response, standardize treatments with manuals and documented intervention trainings, and identify, label and evaluate treatment components. One could argue that the clinical trial standards (e.g., blinding to treatment allocation, methods to enhance and track fidelity among others) developed and applied in the REACH initiatives have yet to be uniformly adopted as normative clinical trial practice in caregiver intervention research. REACH II also demonstrated that active components of effective interventions appear to include tailoring to unique and specific family concerns; providing skill building and involving the caregiver actively in the treatment process is more effective than didactic, prescriptive approaches; and the importance of assessing for caregiver needs and risks from which to prioritize and tailor information and skill building.

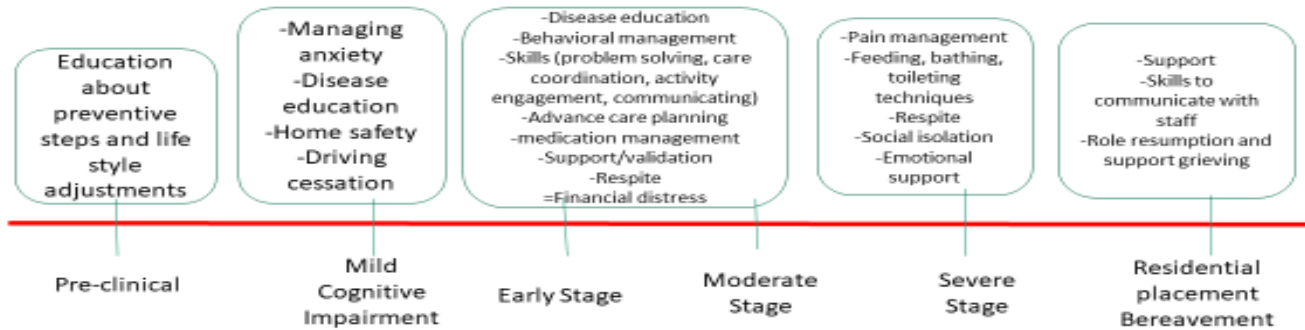
This brief historical sketch serves as a backdrop for examining intervention research that has been conducted over the past two decades, which is the main focus of this paper.

Conceptual Frameworks for Understanding Caregiver Intervention Research



To understand the state-of-the science of caregiver intervention research including gaps and need for future directions, we draw upon several conceptual frameworks.

Figure 1 Documented Caregiver Needs by Disease Stage (adapted from Gitlin & Hodgson, 2018)



The first model we draw upon as shown in Figure 1, is a basic disease trajectory reflecting the journey from pre-clinical to end-of-life of a PLWD. Listed for each disease stage, are key known needs of family caregivers documented in previous research (Gitlin & Hodgson, 2018). Using this model, we can align existing interventions with family caregiver needs and disease stages in order to discern what needs are addressed at each disease stage.

We also draw upon the NIA Behavioral Intervention Stage model to evaluate the stage of <https://www.nia.nih.gov/research/dbsr/nih-stage-model-behavioral-intervention-development> development of published intervention studies from its phase of development/discovery, to its testing in efficacy trials, to its evaluation of effectiveness, dissemination and implementation (Onken et al., 2014). We seek to appraise the field as a whole in terms of where along this stage model intervention studies reside in their developmental life cycle.

## REVIEW AND SYNTHESIS

### Methodological Approach

Given the magnitude of published intervention studies, we conducted a review of reviews of intervention research for caregivers (family and formal providers). Four different reviews and sources of data as summarized in Box 3 were pursued. For each review, we followed various approaches involving search of different databases and use of key words described below for

<b><u>Box 3– Summary of Types of Literature Reviewed</u></b>	
<b>Family Caregivers</b>	
1. Scoping, meta analyses, and systematic reviews:	
a) nonpharmacological interventions;	
b) translational studies of proven programs;	
c) pharmacological interventions of dementia drugs	
d) select global trial activity	
2. Cochrane reviews and select reports	
3. Recent individual studies including pragmatic trials and published protocols	
<b>Formal Caregivers</b>	
4. Reviews and individuals studies of interventions with outcomes related to formal caregivers	

each search.  
Our search  
identified  
reviews of  
clinical trials  
as well as non-  
RCTs testing

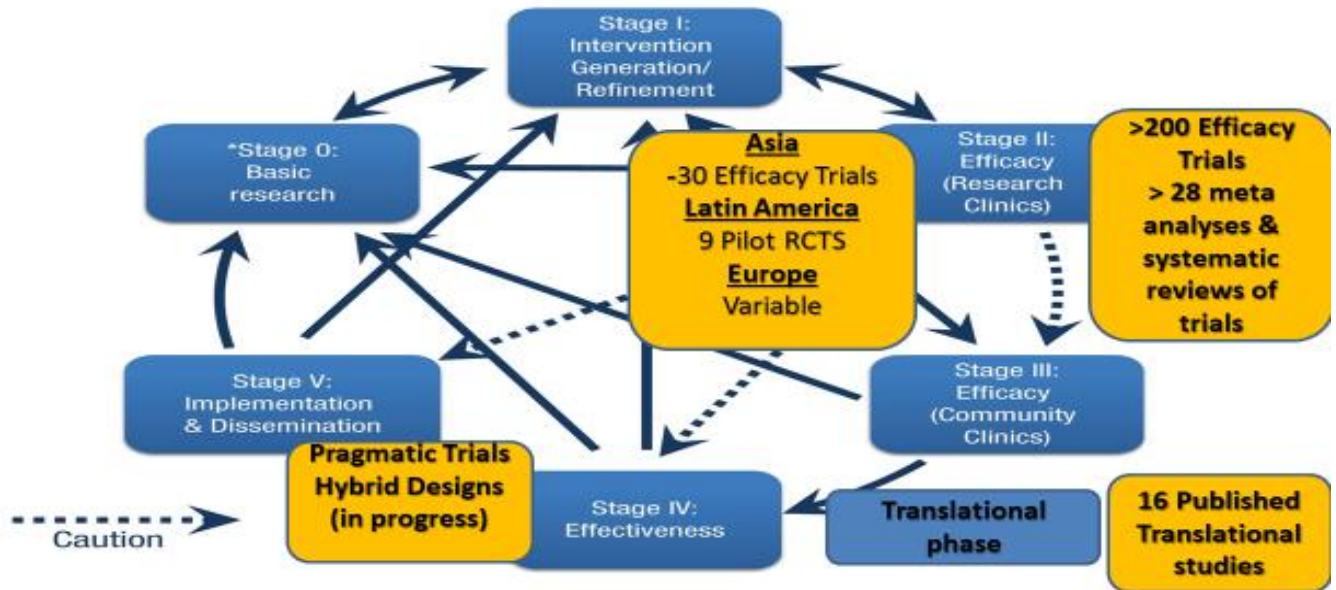
nonpharmacological approaches as well as pharmacological approaches for PLwD that report outcomes for family caregivers. We also searched for relevant Cochrane reviews and reviewed relevant reports from National Research Summits on dementia including recommendations from the Advisory Council for the National Alzheimer’s Plan Act. Finally, we considered review of studies and individual studies of interventions that target formal providers and reported outcomes for this group. In summarizing these reviews, consideration was given to the settings of studies, disease stage targeted, intervention types, if targeting and tailoring factors were identified, the outcomes measured and their key results.

## Results

Our review of reviews uncovered an enormous number of intervention studies with well over 200 unique interventions tested for family caregivers (Gitlin & Hodgson, 2015). Using the

NIA Stage Model for Behavioral Interventions (Figure 2) to locate existing caregiver

**Figure 2. Non-pharmacological Interventions for Family Caregivers along the NIA Stage Model**



interventions along their developmental pathway, we find that most interventions for family caregivers (>200) have been tested primarily at the efficacy stage (stage II and III) with very few subsequently tested in effectiveness, pragmatic or translation studies to evaluate their delivery in care settings (stage IV and V). For formal caregivers, studies are primarily efficacy trials (stage 3) but are formative with no data concerning long-term effects and whether tested programs become fully integrated and sustained into workflows. In other words, most published studies focus on proving efficacy with few interventions having been tested in real world contexts for their effectiveness and implementation processes, and none documenting scalability, dissemination and sustainability (stage V). This is the case for interventions tested in the United States and those conducted in other parts of the world.

*Meta Analyses and Systematic Reviews of Family Caregiver Interventions*

To examine efficacy of nonpharmacological interventions for family caregivers, we conducted an extensive review of published reviews published between 2000-2019 that reported the effects of nonpharmacologic interventions on any outcome related to PLwD (reported in the Gaugler et al., Decadal paper), their family/friend caregivers, and/or clinical staff (reported in this paper). We included reviews that had a clearly formulated research question and applied a methodological framework to identify, select, and analyze primary research. We conducted our search in Medline and identified 4,112 articles of which 257 met inclusion criteria. Review articles were grouped into three categories: 1) primary outcome(s) focused on PLwD (n=203) and summarized in Dr. Gaugler et al's Decadal paper, 2) primary outcome(s) focused on family caregivers (n=26), and 3) primary outcome was not specific to PLwD or family caregiver (n=28).<sup>4</sup> This search yielded an enormous body of research although findings tend to be consistent across reviews. Table 3 presents a summary of the 28 reviews with key conclusions presented in Box 4.

[Table 3]

---

<sup>4</sup> Key words include: "dementia"[Mesh] OR "alzheimer disease"[Mesh] OR "alzheimer disease/psychology"[Mesh] OR "Dementia/therapy"[Mesh] OR dementia OR Alzheimer") AND (intervent\* OR treat\* OR therapy OR "behavior therapy" OR program OR "combined modality therapy"[Mesh] psychotherapy OR "psychotherapy, group" OR "Patient education as topic"[Mesh] OR "psychomotor agitation/therapy"[Mesh] OR "music therapy" OR "art therapy" OR "group therapy" OR nonpharmacological OR nondrug OR non-drug OR non pharmacological OR non-pharmacologic OR "physical therapy" OR "tailored activities" OR "visual art" OR "fine art" OR "mindfulness" OR "mindfulness based" OR "telephone-based" OR "mobile app" OR Psychotherapy, Group\*

## **Box 4. Key Conclusions from Review of Reviews of Family Caregiver Interventions**

### **Strengths**

- Many different interventions support family caregivers (e.g., psychoeducation, counseling, problem-solving, skill building, social support, respite)
- Most interventions afford benefits on important outcomes (e.g., health behaviors, depressive symptoms, burden, confidence, wellbeing)
- Effective programs individualize to unmet needs, are multicomponent reflecting some combination of counselling, support, education, stress, mood management, skill-building (versus education alone)
- Effective programs include a needs assessment from which information, skills and strategies are tailored
- No one program is effective for all desired outcomes nor address all unmet needs
- Caregivers appear to have preferences as to how they wish to receive support (one size does not fit all)
- Delivery of interventions through technology has promise but evidence is inconsistent

### **Limitations**

- Small effect sizes, unclear as to clinical significance, with much room for improving impacts
- Inconsistent labeling of interventions and their components making it difficult to compare across studies
- Mechanisms by which (or why) interventions are effective not examined as well as moderation effects (which interventions work best for whom)
- Overreliance on stress process theoretical frameworks and orientation towards deficit reduction
- Samples not well characterized with some reports lacking basic details of caregiver characteristics
- There was a lack of interventions at pre-clinical, mild and late stages including bereavement. Most studies address caregiver needs at moderate disease stage.
- No interventions addressed financial distress, physical burdens, social isolation, (See Figure 1)
- Limited cost data and understanding of cost effectiveness
- Singular focus on “primary” caregiver vs family network
- Usual care typically used as control group condition; no control of attention afforded treatment groups
- Most studies examined immediate treatment effects with long term effects (>18 months) not well understood
- Fidelity rarely discussed nor accounted for analytically
- Dose-response relationships not explored
- Single versus double blind trial designs may introduce sources of bias

### *Translational Trials to Evaluate Family Caregiver Interventions in Real Settings*

We also conducted a search to identify studies that translated a proven family caregiver programs in dementia for delivery in a community or health care system (Hodgson & Gitlin, in press) published in English since 2005. We identified studies that explicitly tested the implementation of a caregiver support program previously shown to be efficacious in a randomized clinical trial. Four electronic databases were searched, SCOPUS, Medline, EMBASE, and Google Scholar using the following terms: ‘dementia caregivers’ AND ‘intervention’ plus a combination of either ‘implementation’, ‘translation’ OR ‘sustainability. Also, reference lists of publications were scanned for additional published papers for possible inclusion in the review. Studies were included in the review which met four criteria: 1) participants were family caregivers who had an active role in the provision of care for an adult with dementia; 2) interventions were directed towards supporting a primary caregiver to improve their own functioning/well-being or assist them in providing support to the person with dementia; 3) interventions had demonstrated efficacy or effectiveness with one or more caregiver-related outcomes in previous publications; and 4) programs had one or more prior publications of the original study design that included at least two conditions (eg, randomized controlled trials and quasi-experimental studies), one of which must have been a control condition (e.g., active controls, waiting list controls, or treatment as usual controls).

The search initially yielded 1,130 articles. Of these, 136 titles were identified as having some relevance and their titles and abstracts were reviewed. From this set, 41 full text articles were retrieved, and 28 were determined to meet study inclusion criteria. Table 4 (from Hodgson & Gitlin) presents the characteristics of these studies including the tested intervention,

setting/sample, primary outcomes, study design, implementation framework identified, and implementation strategies utilized.

[Table 4]

As shown, studies mostly deployed a pre-post or descriptive study design. Of the 28 studies, the Resources for Enhancing Alzheimer's Caregivers Health (REACH) program was the leading family care intervention implemented (n=9, 32%), followed by the Reducing Disability in Alzheimer's Disease (RDAD) intervention (n=4, 14% ) and the Savvy Caregiver Program (SCP) (n=3, 11%). Two studies evaluated the implementation of the Staff Training in Assisted-living Residences—Care (STAR-C) intervention and two studied the New York University intervention (NYUCI). The nine remaining studies evaluated other evidence-based family care programs.

Of programs most frequently translated, there were similarities in protocols but also clear differences. The REACH program instructs family caregivers in behavioral skills (problem solving, stress management, mood management) in order to manage ongoing and evolving behavioral problems, in addition to managing the caregivers' own physical and emotional health (Belle, Burgio, Burns et al., 2008). The RDAD program provides family caregivers and persons with dementia physical and behavioral education in the home including endurance, strength, and balance/flexibility exercises, dementia education, training to increase pleasant events, and activator-behavior-consequence problem-solving approaches (Logsdon, McCurry, Teri, 2005). SCP includes a psychoeducational program delivered in a group format to improve caregiver knowledge, confidence and skills in managing caregiving tasks, and carrying out the caregiving role effectively (Hepburn, Lewis, Sherman, Tornatore, 2003). STAR-C is a counseling program that teaches family members a systematic behavioral approach for reducing mood and behavior problems in through education, support, and skills training (Teri, McCurry, Logsdon, Gibbons,

2005; Teri et al., 2018). The NYUCI program offers individual and family counseling, support groups, and phone consultation to manage stress and improve problem-solving, manage problem behaviors and promote communication and support among family members (Mittelman, Roth, Haley, Zarit, 2004). Interventions were implemented in community agencies (including Area Agencies on Aging), home settings, or health care systems. Box 5 summarizes the key conclusions from a review of these translational studies.

#### **Box 5. Key Conclusions from Reviews of Translational Studies**

- Interventions were effectively implemented in settings and found to be effective on select outcomes using pre-post study designs
- A range of implementation strategies were used including adapting proven programs to context, engagement of stakeholders, coaching of staff interventionists
- Few studies used a theoretical framework to understand translational processes
- Translation appears to be an important stage in the life cycle of an intervention that involves adapting the program to fit local contexts, identifying stakeholders and what they value, training staff and integrating programs into daily workflows
- It is unclear if programs were sustained following conclusion of these studies and if they became part of workflow of a setting

#### *Meta-analyses of Pharmacological Studies for PLwD Reporting Family Caregiver Outcomes*

We identified published systematic reviews and meta-analysis published between 2004-2019 that reported the effects of pharmacological interventions for PLwD on caregiver-specific outcomes. We used Ovid Medline (R) [1996 to October Week 2 2019] and identified 438 articles of which only three met the following inclusion criteria: 1) study tested a particular drug



treatment for PLwD and reported outcomes for family caregivers; and 2) published in English.<sup>5</sup> Publications were first reviewed by title and abstract content for appropriateness of inclusion in the review followed by full-text review of selected articles. Reviews were excluded if they only reported effects of pharmacological interventions on outcomes related to PLwD.

As shown in Table 5, three studies were identified and subsequently included in this review. In summary, positive benefits were found for family caregivers for a range of pharmacological treatments used in dementia care; antipsychotic medications and cholinesterase inhibitors for PLwD had a beneficial effect on caregiver burden, time use and time caregivers spent caregiving. However, no effects on psychological well-being, caregiver stress, health costs or satisfaction were found. Among the beneficial pharmacological treatments reported for caregivers included Donepezil, Rivastigmine and Zonisamide for cognitive, neuropsychiatric and functioning outcomes respectively for PLwD. Additionally, trials of Zonisamide, Ramelteon (in mild dementia) and Memantine reported some benefit for caregiver burden. Taken as a whole, these studies suggest that addressing clinical symptoms of dementia may improve caregiver wellbeing but more research appears to be warranted. Future pharmacological trials should examine outcomes for family caregivers as part of standard clinical trial practice.

[Table 5]

### *Global Activity*

We conducted scoping reviews of caregiver intervention trials tested in different regions of the world to determine if approaches, outcomes and findings were similar to the United States trial experience.

---

<sup>5</sup> Key terms for the search included: Pharmacology; Pharmacological; Medication; Drugs; Dementia; Dementia caregiver; Caregivers; Caregiver Burden; Caregiver outcomes; Caregiver Distress.

Asia: A scoping review of trials conducted in Asia yielded 30 single intervention trials with all reporting statistically significant ( $p < .05$ ) benefits for family caregivers. Outcomes were primarily for depression, burden, quality of life and self-efficacy (Hinton et al., 2019). Seven of the 30 studies (23%) examined outcomes of interventions that were originally developed in the United States. Although outcomes of these 30 trials are similar to those found in USA trials, several limitations are noted: studies were tested primarily in high-income Asian countries making it difficult to generalize their benefits to caregivers in low-income Asian countries where the number of PLwD will increase dramatically, studies lacked detail concerning necessary cultural adaptations; similar to the USA trials, studies target a single self-identified primary caregiver and focus on a limited set of psychosocial outcomes drawing principally on stress process theories to framework interventions and outcomes.

Latin America: In a scoping review of trials conducted in Latin America, 9 intervention studies were identified with 6 (67%) conducted in Brazil, and 1 each in Mexico, Colombia and Peru. These studies were pilot randomized trials ( $n < 50$ ; NIA Stage Model 1, 2) and focused on outcomes for both PLwD and caregivers. Similar to studies conducted in Asia and the United States, interventions focused primarily on symptom reduction (decrease depression, anxiety and/or burden in family caregivers), with most studies (but not all) reporting benefits on these outcomes. Studies did not examine if improvements in PLwD mediated changes observed in caregivers, representing a missed opportunity to evaluate direct and indirect treatment effects for caregivers (Garjardo et al., manuscript in process).

Europe/USA: A recent meta-analysis of trials examining occupational therapy delivered home-based caregiver support interventions identified 16 randomized controlled trials tested in different countries (Bennet et al., 2019). Of these, 10 (63%) were conducted in the United

States, with other included interventions tested in Germany, Netherlands, Hong Kong, Wales, Australia, and Brazil. A total of 2,423 dyads (PLwD and caregivers) were included and all but two trials compared an intervention arm to usual care, whereas two involved a control group receiving an alternative treatment. Interventions were designed to optimize daily function of the PLwD and also included caregiver outcomes. For caregiver depression, two of six studies that included this outcome showed statistically significant benefit. Four studies examined caregiver burden with none reporting statistically significant between group differences following intervention. Three studies examining hours caregivers spent doing things for PLwD all showed declines. For the six studies examining caregiver upset with behavioural symptoms, all reported small but statistically significant benefits for the intervention groups. As to quality of life, two of three studies examining this outcome reported large, significantly significant between group differences after intervention. Most studies had moderate to high risk of bias. However, taken as a whole, this group of studies demonstrates that modifying clinical symptoms of dementia have positive effects on select caregiver outcomes. Yet, more research in this area is needed to understand mechanisms, variations in outcomes for different samples and the relationship of the magnitude of change in PLwD to caregiver benefits.

Another systematic review of trials in Europe identified four psychosocial interventions for caregivers who had placed their relatives with dementia in residential care settings (Brooks, et al., 2018). Two studies tested individualized multicomponent interventions, and two involved cluster RCTs of group multicomponent interventions with a total of 302 caregivers involved. Significant improvements were reported for caregiver feelings of guilt, role overload, and distress, but no significant effects were found for satisfaction with the residential care facility. Meta-analyses indicated there was no overall treatment effects at three to four months post-

intervention on caregiver burden and depression. For group interventions, no significant effects on distress were found yet there was improvement in guilt and sense of sadness. The authors concluded that although these studies had high risk of bias, it appears that individualized multi-component psychosocial interventions following residential care placement address role overload, distress and guilt; yet there is insufficient evidence that individualized or group interventions improve depression, burden or satisfaction.

Still, another meta-analysis of trials conducted in Western and Southern Europe and which included some trials tested in the United States, evaluated the efficacy of psychoeducational programs and psychotherapeutic interventions on depression, anxiety, burden and quality of life (Kishita et al., 2018). Authors found that psychoeducation-skill building interventions delivered face-to-face impacted burden; whereas psychotherapeutic interventions (using Cognitive Behavior Therapy) appeared to impact anxiety and depression regardless of mode of delivery (face-to-face vs. technology).

In summary, these reviews reveal a similar pattern globally. First, multi-component interventions targeting family caregivers have small but meaningful effects on important but select psychosocial and wellbeing outcomes. Second, not every intervention yields the same positive benefits, and effect sizes are small. Third, studies are primarily at the pilot (NIA Stage 1) or efficacy (NIA Stage 2, 3) stage of testing with no to few trials that are translational and pragmatic trials. Furthermore, there is an underreporting of fidelity, implementation processes, and adverse events, an overreliance on targeting primary caregivers (vs. family network), use of stress-process and psychological theories/frameworks and under-enrollment of diverse caregivers. Furthermore, due to the substantial heterogeneity of studies and methodological

flaws with high risk of bias noted in most meta-analyses, the grade of evidence across studies overall tends to be low.

### *Cochrane Reviews*

We identified three relevant Cochrane Reviews synthesizing dementia family caregiver interventions conducted between 2014 to present. Lins et al. (2014) review examined whether telephone counselling was effective in reducing symptoms of depression and other stresses in family caregivers. Nine studies were identified that investigated efficacy of telephone counselling and two studies that examined the quality of the experience. The efficacy studies investigated three types of telephone counselling: telephone counselling only (six studies); telephone counselling plus video sessions (one study); and telephone counselling plus video sessions and a workbook (two studies). The review found some evidence that telephone counselling was effective for reducing depressive symptoms in caregivers of people with dementia (three studies), but no clear positive effects were found for any other outcomes such as stress or anxiety. The studies that investigated the experiential aspects of telephone counselling revealed a range of caregiver needs that remain unmet by telephone counseling and factors that serve as barriers and drivers of implementation of this type of intervention. All studies were of moderate quality. The authors concluded that there is some evidence that telephone counseling can reduce depressive symptoms for caregivers of people with dementia and that telephone counselling meets important needs of the caregiver. Authors also indicated that the results of this review should be interpreted with caution due to the small number of included studies and their moderate quality.

Maayan, Soares-Weiser and Lee (2014) reviewed four studies with a total of 753 participants which assessed the benefits and harms of respite care for people with dementia and

their family caregivers, and, in particular, the effect of respite on institutionalization; three studies compared respite to no respite care and one compared respite care to polarity therapy, a type of touch therapy for persons living with dementia. The three studies comparing respite to no respite care found no evidence of benefit of respite for caregivers on any outcomes including rates of institutionalization and caregiver burden. The study comparing respite care to polarity therapy found that polarity therapy decreased caregiver perceived stress but there were no differences between polarity therapy and respite care for other measures of psychological health. Authors concluded that current evidence does not demonstrate benefits (or adverse effects) from respite care for caregivers and that no meaningful conclusions for practice can be drawn from the available evidence.

The most recent review by Liu, Sun and Zhong (2018)<sup>6</sup> examined efficacy of Mindfulness-based stress reduction (MBSR) for reducing stress of family caregivers. Data from five randomized controlled trials involving a total of 201 caregivers were analyzed. Findings from three studies (N= 135 caregivers) showed that those receiving MBSR appeared to have a lower level of depressive symptoms following intervention compared to those receiving an active control treatment condition. However, there was no clear evidence of any effect on depression when MBSR was compared with an inactive control treatment. Mindfulness-based stress reduction may also lead to a reduction in caregivers' anxiety symptoms; yet this intervention may slightly increase feelings of burden. Authors indicated that the results on anxiety and burden were unclear and they were unable to draw conclusions about caregivers' coping strategies and the risk of dropping out of treatment due to the very low quality of the evidence. In addition, authors indicated that none of the studies measured quality of life of caregivers or people with dementia, or

---

<sup>6</sup> This review is also included on Table 3.

the rate of admission of people with dementia to care homes or hospitals. Only one study reported on adverse events, noting one minor adverse event (neck strain in one participant practicing yoga at home). This review provides preliminary evidence on the effect of MBSR in treating some stress-related problems of family caregivers of people with dementia. The authors conclude that higher quality studies are needed to confirm whether MBSR is beneficial for family caregivers.

Finally, of interest is a Cochrane review of 21 studies that tested telephone support compared to usual care for caregivers of individuals with serious illness but not necessarily dementia. Given the importance of using technologies for scaling supportive interventions and enhancing cost efficiencies in delivery, findings from this review provide insight into potential research directions. Unfortunately, authors found that studies overall had little to no difference between telephone support and usual care for caregiver quality of life, burden and depression. However, there was high satisfaction with the interventions and no adverse events and some indication that these approaches result in a reduction of caregiver anxiety and improvement in preparedness to care. There were little to no differences between telephone support and usual care for outcomes other outcomes such as problem-solving, social activity, competence, coping, stress, knowledge, physical health, self-efficacy, family functioning, and satisfaction with supports. The quality of trials was low with overall high risk of bias and small sample sizes suggesting that this approach warrants more methodologically sound research (Corry et al., 2019). Telephone support has been shown to be variably effective, yet a recent pragmatic trial (Possin et al., 2019, discussed below) shows that this approach can have important benefits.

*Pragmatic Trials for Family Caregivers*

Pragmatic trials using cluster randomization and/or hybrid designs that evaluate effectiveness and implementation processes are relatively new to the field of family caregiver intervention research and hence there are single trials being reported but no systematic or meta-analytic reviews available to date. There are numerous comprehensive collaborative care models for example tested in health systems that have been shown to have positive effects for caregivers (Heintz et al., in press) along psychosocial outcomes. Similarly, a trial of the COPE program in Community based Medicaid Waiver programs in Connecticut is very promising, showing improvement in caregiver wellbeing (Fortinsky et al., 2016). Also, a pilot study of the ADS Plus program (Adult Day Service Plus) that augments caregiver support for family caregivers utilizing adult day services for the PLwD resulted in reduced depression and burden and improved confidence and more days using adult day services (Gitlin et al., 2008). A NIA funded trial involving 57 adult day sites to test this program is now in progress (Gitlin et al., 2018).

Finally, the results of a recent trial testing the Care Ecosystem in three states showed benefits for family caregivers at 6 and 12 months (Possin et al., 2019). The collaborative dementia care management approach delivered via telephone and involving clinical teams via the internet, compared with usual care, decreased caregiver depression and burden and improved self-efficacy at 6 months with depression and burden reductions continuing up to 12 months. Positive benefits for PLwD were also found.

These studies suggest that it is possible to integrate evidence-based approaches into different care settings and that pragmatic trials represent a promising development in caregiver intervention research which will yield important knowledge regarding how to bring evidence to community-based and health care settings.



### *Meta-analyses of Non-Pharmacological Studies Reporting Outcomes for Formal Providers*

A scoping review of review of reviews of interventions designed to aid formal dementia caregivers in any professional setting (through education, skills training, therapeutic practice, etc.) was performed for published trials from 2009 to 2019. We also searched for individual trials that reported on interventions for formal caregivers working in a formal setting that clearly described an intervention protocol and presented quantitative outcomes. The primary search was conducted in SCOPUS and was supported by manual examination of references where relevant as well as use of Google Scholar's 'Cited By' and 'Related Articles' tools. An initial narrow search yielded 8 reviews and 17 articles of individual trials. As to the latter, 11 were reviewed and five included for further review. From this initial five, the Google Scholar 'Cited By' tool listed 105 additional articles of which 19 were reviewed and 17 included. Finally, a broader search was done in SCOPUS that yielded 180 articles of which 47 were reviewed and 37 selected for final review. During final review, 8 articles were systematically reviewed, 4 were non-dementia trials, and an additional 18 articles were evaluation, implementation papers or study protocols. Thus, 29 individual articles met inclusion criteria for this report (table summarizing these articles available upon request). We report in Table 6 a summary of the review of reviews.

[Table 6]

This review of reviews revealed that various interventions have been tested with most seeking to improve knowledge, comfort with and/or confidence in managing care challenges. Training time was highly variable from a few hours to a few months. Most studies reported benefits (e.g., improved confidence) from education, experiential trainings and workshops. Studies sought to test novel training strategies and go beyond prescriptive education sessions (although education was an important component for all interventions) to offer skills regarding

patient assessment and communication, techniques for modifying staff practices and interacting with patients/residents. These include training in dementia care mapping (DCM), acupuncture, and/or use of multi-sensory environments. Few examined online training delivery. Most studies found benefits which included; improved attitudes towards dementia, increased staff knowledge about the disease and self-efficacy, better communication with patients, and improved staff stress and related outcomes. Findings for residents included less use of physical restraint, improved quality of life, reduced behavioral symptoms, and in one case a reduction in the use of antipsychotic prescription, though this was not replicated in one other trial that assessed prescription usage. Unclear are long term effects on retention of trained staff, delivery of quality care and resident outcomes as well as whether interventions are sustained following study conclusion. More attention to workforce preparation and at earlier stages in professional education are warranted. Also, recent research demonstrates that formal caregivers who care for a resident and an older adult or who care for a resident, an older adult and children are at higher risk for greater burden and depression (double and triple jeopardy) than their counterparts (DePasquale et al., 2016). This group in particular merits supportive interventions that address their unique caregiving roles.

#### NOW AND INTO THE FUTURE

This review of reviews on the whole yields a compelling picture and a central duality that can be characterized as the “glass is half full,” and the “glass is half empty.” The “half full” picture shows an impressive array of interventions that can improve psychosocial well-being in the United States and globally. These interventions address many (but not all) needs of family caregivers, and as it concerns disease education, strategies for positive coping and managing behavioral symptoms, problem solving, and counseling, that emerge primarily at the moderate

disease stage of caregiving. Regardless of noted limitations (Box 4 and 5), as a whole, the evidence is overwhelmingly positive with regard to psychosocial outcomes and demonstrates that we can make a real difference in family caregiver wellbeing. A few trials have also demonstrated health benefits and reduction in health care utilization. The evidence is strong enough across various studies and reviews to suggest that many of these interventions should be deployed now and fully integrated into community-based and health care settings.

Regardless of this evidence, the glass is also half-empty with more and better caregiver intervention research required to make a real difference in the lives of caregivers (family and formal). First, effect sizes in studies tend to be small, suggesting that there is much room for improvement. Second, interventions tend to address caregiver concerns and needs that manifest at the moderate disease stage suggesting that intervention development to address caregiver support at other disease stages would be important. Third, most trials lack diverse samples such that it is unclear if existing interventions are relevant to racially/ethnically diverse family members. Unclear are the adaptations needed to existing proven interventions for diverse populations, whether new interventions are needed, and how race, ethnicity, culture, geographic location, socioeconomic and health literacy and their intersectionality influence access, needs, values, care approaches, treatment preferences, and readiness to engage in interventions. Fourth, outcomes tend to focus on symptom reduction and address a limited set of psychosocial outcomes. A broader swath of outcomes that matter to different stakeholder groups would be important to test and adoption of strength-based approaches with their associated outcomes (e.g., improving resilience, relationship quality and positive affect) is needed. Fifth, proven interventions have not been fully integrated into routine community-based and health care systems. Interventions are also not well-characterized making replication and adaptation

challenging. Sixth, the mechanisms of action, or why interventions work is unclear. Even for well-established interventions such as REACH, SAVVY, or RDAD that have been replicated, it is not clear as to the particular pathways by which these approaches reduce distress, impact caregiver health, or reduce depression. Seventh, with few exceptions (Jutkowitz et al., 2019; Gitlin et al., 2010; Nichols et al., 2007), cost data are limited as well as tested payment models including caregivers willingness to pay for proven interventions. A similar scenario emerges for formal caregivers and the above points apply to this body of research as well. There are other important missing evidentiary qualities. Interventions to date have not:

- Addressed the shrinking number of available caregivers, long distance caregivers, and culturally diverse caregivers;
- Included the family as a unit, family networks and division of labor nor considered outcomes related to family functioning;
- Examined specific needs and supportive approaches by stage of dementia and life course of caregivers. For example, a spouse or older caregiver may have significant medical/physical impairments and related needs in addition to their caregiving responsibilities. A younger caregiver (adult child) may be juggling work and/or care responsibilities of others in a household including children. A caregiver who works may depend upon employer health insurance and may be challenged balancing work and caregiving tasks.
- Considered formal caregivers who may be at “double jeopardy” (caring at work and caring for a person at home) or “triple jeopardy” (caring at work, caring for children and caring for an older adult at home) and experience more distress than their counterparts (DePasquale et al., 2016).

- Examined objective (physiological) outcomes and relationship to subjective measures.
- Established who needs minimal support and who needs more high touch or intense support (who to target and for what).

## Research Recommendations

In response to this state-of-the-science, we offer three broad recommendations to advance this area of inquiry and that can build a strong body of evidence with potential to make a real impact in the lives of family and formal caregivers. These broad areas include: conducting caregiver intervention research differently; engaging in implementation research to bring the evidence to real settings; and developing new interventions that address unmet needs of diverse caregivers and across the disease trajectory. For each of these areas, we provide multiple and specific research suggestions. For our first area, we identify 8 domains with specific recommendations for each that would enhance the science and hence evidence base for caregiver

<b>Recommendation 1. Conduct Caregiver Intervention Research Differently</b>	
<b>Domain</b>	<b>Specific Recommendations</b>
Improve clinical relevance of ongoing trials	<ul style="list-style-type: none"> <li>• Evaluate dose-response relationships, determine minimum treatment exposure for benefit</li> <li>• Evaluate long term effects and if/when booster sessions needed</li> <li>• Link interventions to disease stage of PLwD and life course of caregiver</li> <li>• Determine and report clinical significance of outcome measures</li> <li>• Include more diverse caregivers and better characterize samples (sex, race/ ethnicity, financial strain, age, other care responsibilities)</li> <li>• Establish clinically meaningful cutoff values for key caregiver outcomes (e.g., burden, upset)</li> <li>• Report adverse events to monitor tolerability of interventions</li> </ul>
Adequately describe interventions to enable reproducibility, replication, adaptation, widespread adoption and scalability	<ul style="list-style-type: none"> <li>• Identify theory base(s) guiding intervention and use a theory based approach to classify intervention components</li> <li>• Adequately describe intervention components and consider dosing of components</li> <li>• Describe interventionist characteristics and training requirements</li> <li>• Detail dose and intensity (number of sessions, duration) of intervention</li> <li>• Describe treatment fidelity plan, fidelity outcomes and relationship of adherence to outcomes</li> <li>• Describe type of blinding applied to trials</li> </ul>
Examine mediation and moderation effects	<ul style="list-style-type: none"> <li>• Examine theoretically identified mediation effects to understand pathways by which benefits are achieved in interventions</li> <li>• Identify direct and indirect treatment effects (e.g., which benefits are linked to PLwD changes)</li> <li>• Examine moderation effects to determine who benefits most and from which interventions</li> </ul>
Derive consensus as to naming and framing interventions and their components	<ul style="list-style-type: none"> <li>• Hold consensus conference to identify interventions and treatment components and derive agreement as to their naming and framing</li> <li>• Consistently report intervention components and naming and framing in publications to enable cross study comparisons</li> </ul>

interventions. The 8 domains are to: improve clinical relevance, adequately describe

interventions, examine mediation and moderation effects, derive consensus as to terminology for

<b>Recommendation 1 (continued). Conduct Caregiver Intervention Research Differently</b>	
<b>Domain</b>	<b>Specific Recommendations</b>
<b>Enhance study designs</b>	<ul style="list-style-type: none"> <li>• Locate designs along NIA stage model to understand their stage of development</li> <li>• Use different designs (pragmatic, stepped wedge, hybrid, mixed methods) to address multiple questions (effectiveness and implementation)</li> <li>• Use attention control groups that control for attention</li> <li>• Compare treatments with similar outcomes to determine which one works best and for whom</li> <li>• Examine treatment effects over longer time frames and identify if and when boosters are needed</li> <li>• Follow and report adverse events</li> <li>• Use simulation modeling to identify factors for targeting and tailoring and make cost projections</li> </ul>
<b>Engage stakeholders</b>	<ul style="list-style-type: none"> <li>• Identify and include measures that reflect what matters most to family caregivers and/or other stakeholders</li> <li>• Address unmet needs that have not yet been examined (e.g., financial strain) and for different stages</li> <li>• Examine dyadic relationships and which types of interventions impact caregiver and person;</li> <li>• Examine informal networks, family decision-making and use a family centric approach</li> </ul>
<b>Include diverse study samples and better characterize caregivers</b>	<ul style="list-style-type: none"> <li>• Examine disparities in access to caregiver support programs</li> <li>• Identify recruitment strategies for involving diverse study samples</li> <li>• Identify adaptations to interventions for different cultural groups</li> <li>• Adequately describe caregiver samples (age, race, ethnicity, stage in life course, other care responsibilities, length of time caregiving)</li> </ul>
<b>Evaluate cost, cost effectiveness and cost benefits</b>	<ul style="list-style-type: none"> <li>• Evaluate costs, cost effectiveness, added value of interventions</li> <li>• Develop and test payment models</li> <li>• Conduct sensitivity analyses to determine ways to streamline interventions (e.g., reduce number of sessions, integrate technologies such as telehealth to offset travel and face time costs)</li> </ul>

labeling interventions and their components, enhance study designs, engage stakeholders up

front in study designs, include more diverse samples, and evaluate cost and cost effectiveness.

Our second area for recommendations concerns engaging in implementation research to translate, scale up, disseminate and implement existing, proven programs/interventions into health care contexts and purposively address health disparities in access to and involvement in caregiver programs (NIA Stage IV and V). While there are many proven caregiver support interventions, very few move beyond the efficacy stage. Furthermore, there are no agreed upon criteria for identifying which interventions should move forward and translational efforts are typically dependent upon the interest in and involvement of the original developers.

This area consists of 5 domains with specific recommendations for each. The 5 domains include to: identify and test specific implementation strategies that are effective for different care

<b>Recommendation 2. Implement Proven Interventions in Health Care Settings</b>	
<b>Domain</b>	<b>Specific Recommendations</b>
Test different strategies for implementing proven interventions in different care settings	<ul style="list-style-type: none"> <li>• Use proven implementation strategies (ERIC framework) to identify and test strategies for implementing proven interventions</li> <li>• Identify, expand upon, adapt or develop implementation theories to guide implementation processes in different care settings</li> </ul>
Examine payment models for different care settings	<ul style="list-style-type: none"> <li>• Identify and test payment models for different care settings</li> <li>• Determine cost for training, cost for delivery, ways to minimize costs</li> </ul>
Develop and examine outcomes of relevance to different stakeholders and care contexts	<ul style="list-style-type: none"> <li>• Identify value propositions, cost propositions, infrastructure needs of different organizational contexts for embedding proven caregiver programs</li> <li>• Develop and test measures related to context and readiness of settings to use evidence</li> <li>• Assess contextual factors that support or deter implementation</li> </ul>
Use different study designs specific for implementation and to evaluate effectiveness, fidelity, implementation, sustainability	<ul style="list-style-type: none"> <li>• Use pragmatic, hybrid, stepped wedge, mixed methods and other designs to evaluate effectiveness and implementation processes in health settings</li> <li>• Identify efficient strategies to support fidelity</li> <li>• Identify and test strategies that promote wide scale implementation</li> <li>• Identify and test strategies that sustain interventions in specific settings</li> </ul>
Use theory bases to examine and understand translational and implementation processes	<ul style="list-style-type: none"> <li>• Develop, adapt and/or use existing theoretical frameworks to understand implementation processes</li> <li>• Identify and test ways to scale evidence to different practice settings</li> </ul>

settings and types of interventions; evaluate different payment models; develop and evaluate outcomes that matter to different stakeholder groups; use different study designs to evaluate effectiveness, fidelity, implementation and sustainability, and use theory to examine and understand implementation processes including dissemination and scaling up.

Our third area for recommendations addresses the need for foundational research from which to develop new interventions (NIA Stage 0 and I1). We suggest 8 domains with each having specific recommendations. These domains include to: understand nomenclature; develop new measures, identify recruitment strategies to engage diverse family caregivers, understand the lived experience, develop new interventions or adapt proven interventions for diverse family

caregivers, identify factors for targeting caregivers at risk, strategies for engaging a family unit and strategies for tailoring interventions to caregiver characteristics.

<b>Recommendation 3. Develop New Interventions</b>	
<b>Domains</b>	<b>Specific Recommendations</b>
Nomenclature	<ul style="list-style-type: none"> <li>Identify how family members from different backgrounds (race/ethnic, linguistic groups) self-identify and their preferred terminologies for “caregiver” “intervention” and other associated terms</li> </ul>
Measurement development	<ul style="list-style-type: none"> <li>Develop new measures to address strengths (e.g., adaptive processes, resilience, preserved abilities) and deficits (e.g., risks, symptomatology), that are culturally relevant</li> <li>Identify and assess what matters most to individuals and care partners, and what constitutes meaningful change</li> <li>Develop measures capturing family dynamics, division of labor, role differentiation and family wellbeing</li> <li>Determine short and long term effects of interventions on different outcomes</li> </ul>
Recruitment	<ul style="list-style-type: none"> <li>Identify strategies for recruiting and enrolling diverse family caregivers</li> <li>Identify best practices for retaining diverse family caregivers in trials</li> </ul>
Understand lived experiences from which to develop intervention strategies that support what matters most	<ul style="list-style-type: none"> <li>Understand what caregivers (formal and family) do, how crises are prevented and/or managed/resolved, strategies deployed (e.g., negative communications, problem-solving)</li> <li>Understand adaptive mechanisms, forms of resilience</li> <li>Understand caregiver “styles”, preferences, readiness to adapt and use new strategies</li> </ul>

<b>Recommendation 3(continued). Develop New Interventions</b>	
<b>Domains</b>	<b>Specific Recommendations</b>
Develop new interventions or adapt proven programs for under-represented populations	<ul style="list-style-type: none"> <li>Identify unmet needs by disease stage and for different groups and whether existing or new interventions are needed</li> <li>Understand unmet needs by disease stage and caregiver’s stage in their own life course and for different race/ethnic groups</li> <li>Identify strategies for adapting interventions</li> <li>Develop interventions that address preferences of diverse caregivers and how they wish to receive intervention (through technology, telehealth, group, in person, web)</li> </ul>
Identify factors that place caregivers at risk and develop intervention strategies for these groups)	<ul style="list-style-type: none"> <li>Identify approaches, develop measures to identify at risk caregivers (Candidate factors may include but not limited to: number of hours caregiving; care management style; communication patterns; double and triple jeopardy formal caregivers, health profile, financial resources)</li> <li>Develop risk screening tools to identify at risk groups</li> </ul>
Develop interventions that target the family unit (versus primary caregiver)	<ul style="list-style-type: none"> <li>Develop interventions that support families (versus single primary caregivers)</li> <li>Develop new measures to assess changes in family network, strengthen division of labor and how families work collaboratively</li> </ul>
Identify and test strategies for tailoring interventions	<ul style="list-style-type: none"> <li>Develop strategies for tailoring interventions for diverse caregivers. Candidate tailoring factors might include: needs, education level, readiness, cultural preferences, styles</li> </ul>



## **Conclusion**

In summation, our extensive review of multiple reviews reveals the existence of an enormous body of research, evidence that most interventions can support caregiver psychosocial wellbeing and that there is room for much improvement. The methodological sophistication of clinical trials in this area has steadily improved but remains still uneven with most reviews suggesting risk of biases. This state-of-the-science indicates great progress but that nevertheless more work is in order including changing the methodologies and paradigms by which interventions are advanced and tested. In question is the theory-base of most interventions and their overreliance on stress-process frameworks and consequently their pursuit of impacting a narrow set of outcomes measuring symptom reduction (e.g., burden, depression, upset). This is in contrast to assuming a strength-based approach with outcomes focusing on strengthening resilience, family functioning, and adaptation. Moreover, existing proven programs are not yet integrated in health and community-based care settings, few reach diverse caregivers, nor are they known and available to health providers or families as in the case of the Smiths. Additionally, existing interventions do not address all of Mrs. Smith's unmet needs (e.g., physical and financial stressors), and any one proven intervention may address some areas but not all.

Echoed throughout the long history of caregiver intervention research up to the present are these three themes: there is evidence, the evidence is not integrated in real world settings, and more intervention research is needed using different methodologies and paradigms. This reflects the experience both within the United States and worldwide and applies to interventions for both family caregivers and formal providers.

Overall, caregiver (family and formal) intervention research is critical to the advancement of comprehensive dementia care. This is a highly promising area of investigation that has potential to improve quality of life, alleviate the burdens of dementia and strengthen the abilities of caregivers to provide dementia care. In order to realize the potential of this area of inquiry, multiple research fronts must be pursued and new frameworks and methodologies are necessary.

## References

- Alzheimer's Association. (2012). *2012 Alzheimer's disease facts & figures*. Chicago: Alzheimer's Association. Retrieved from [https://www.alz.org/downloads/facts\\_figures\\_2012.pdf](https://www.alz.org/downloads/facts_figures_2012.pdf)
- Alzheimer's Association. (2019). *2019 Alzheimer's disease facts & figures*. Chicago: Alzheimer's Association. Retrieved from <https://www.alz.org/media/documents/alzheimers-facts-and-figures-2019-r.pdf>
- Belle, S. H. (2006). Enhancing the quality of life of dementia caregivers from different ethnic or racial groups. *Annals of Internal Medicine*, *145*(10), 727. <https://doi.org/10.7326/0003-4819-145-10-200611210-00005>
- Bennett, S., Laver, K., Voigt-Radloff, S., Letts, L., Clemson, L., Graff, M., ... Gitlin, L. (2019). Occupational therapy for people with dementia and their family carers provided at home: a systematic review and meta-analysis. *BMJ Open*, *9*(11), e026308. <https://doi.org/10.1136/bmjopen-2018-026308>
- Brooks, D., Fielding, E., Beattie, E., Edwards, H., & Hines, S. (2018). Effectiveness of psychosocial interventions on the psychological health and emotional well-being of family carers of people with dementia following residential care placement. *JBISRIR Database of Systematic Reviews and Implementation Reports*, *16*(5), 1240–1268. <https://doi.org/10.11124/JBISRIR-2017-003634>
- Burton, L. C., Zdaniuk, B., Schulz, R., Jackson, S., & Hirsch, C. (2003). Transitions in spousal caregiving. *The Gerontologist*, *43*(2), 230–241. <https://doi.org/10.1093/geront/43.2.230>
- Callahan, C. M., Kales, H. C., Gitlin, L. N., & Lyketsos, C. G. (2013). The historical development and state of the art approach to design and delivery of dementia care services. In

*Designing and Delivering Dementia Services* (pp. 17–30). Oxford, UK: John Wiley & Sons, Ltd.  
<https://doi.org/10.1002/9781118378663.ch2>

Corry, M., Neenan, K., Brabyn, S., Sheaf, G., & Smith, V. (2019). Telephone interventions, delivered by healthcare professionals, for providing education and psychosocial support for informal caregivers of adults with diagnosed illnesses. *Cochrane Database of Systematic Reviews*. <https://doi.org/10.1002/14651858.CD012533.pub2>

DePasquale, N., Davis, K. D., Zarit, S. H., Moen, P., Hammer, L. B., & Almeida, D. M. (2016). Combining formal and informal caregiving roles: The psychosocial implications of double- and triple-duty care. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, *71*(2), 201–211. <https://doi.org/10.1093/geronb/gbu139>

Fortinsky, R. H., Gitlin, L. N., Pizzi, L. T., Piersol, C. V., Grady, J., Robison, J. T., & Molony, S. (2016). Translation of the Care of Persons with Dementia in their Environments (COPE) intervention in a publicly-funded home care context: Rationale and research design. *Contemporary Clinical Trials*, *49*, 155–165. <https://doi.org/10.1016/j.cct.2016.07.006>

Gaugler, J., & Kane, R. (Eds.). (2015). *Family Caregiving in the New Normal* (1st Editio). Elsevier. <https://doi.org/10.1016/C2013-0-04745-7>

Gaugler, J. E., Jutkowitz, E., Shippee, T. P., & Brasure, M. (2017). Consistency of dementia caregiver intervention classification: an evidence-based synthesis. *International Psychogeriatrics*, *29*(1), 19–30. <https://doi.org/10.1017/S1041610216001514>

Gaugler, J. E., Reese, M., & Mittelman, M. S. (2018). The effects of a comprehensive psychosocial intervention on secondary stressors and social support for adult child caregivers of persons with dementia. *Innovation in Aging*, *2*(2). <https://doi.org/10.1093/geroni/igy015>

Gitlin, L. N., Belle, S. H., Burgio, L. D., Czaja, S. J., Mahoney, D., Gallagher-Thompson, D., ... Ory, M. G. (2003). Effect of multicomponent interventions on caregiver burden and depression: The REACH multisite initiative at 6-month follow-up. *Psychology and Aging, 18*(3), 361–374. <https://doi.org/10.1037/0882-7974.18.3.361>

Gitlin, L. N., Reeve, K., Dennis, M. P., Mathieu, E., & Hauck, W. W. (2006). Enhancing quality of life of families who use adult day services: Short- and long-term effects of the adult day services plus program. *The Gerontologist, 46*(5), 630–639. <https://doi.org/10.1093/geront/46.5.630>

Gitlin, L. N., Hodgson, N., Jutkowitz, E., & Pizzi, L. (2010). The cost-effectiveness of a nonpharmacologic intervention for individuals with dementia and family caregivers: The Tailored Activity Program. *The American Journal of Geriatric Psychiatry, 18*(6), 510–519. <https://doi.org/10.1097/JGP.0b013e3181c37d13>

Gitlin, L. N., & Schulz, R. (2012). Family caregiving of older adults. In T. R. Prohaska, L. A. Anderson, & R. H. Binstock (Eds.), *Public Health for an Aging Society* (pp. 181-204). Baltimore, MD: Johns Hopkins University Press.

Gitlin, L. N., Hodgson, N. (2015). Caregivers as therapeutic agents in dementia care: The evidence-base for interventions supporting their role. In J. Gaugler and R. Kane, (eds), *Family Caregiving in the New Normal* (pp. 305-353). Boston, MA: Elsevier.

Gitlin, L., & Hodgson, N. (2018). *Better Living with Dementia* (1st Edition). Academic Press. <https://doi.org/10.1016/C2016-0-01912-5>

Gitlin, L., Maslow, K., & Khillan, R. (2018). *National Research Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers: Report to the National*

*Advisory Council on Alzheimer's Research, Care, and Services*. Retrieved from <https://aspe.hhs.gov/system/files/pdf/259156/FinalReport.pdf>

Gitlin, L. N. (2019). Whose responsibility is it? Balancing individual, family, and societal needs for supporting seriously ill older adults. *Journal of the American Geriatrics Society*, 67(S2), S457–S460. <https://doi.org/10.1111/jgs.15819>

Gitlin, L. N., Marx, K., Scerpella, D., Dabelko-Schoeny, H., Anderson, K. A., Huang, J., ... Gaugler, J. E. (2019). Embedding caregiver support in community-based services for older adults: A multi-site randomized trial to test the Adult Day Service Plus Program (ADS Plus). *Contemporary Clinical Trials*, 83, 97–108. <https://doi.org/10.1016/j.cct.2019.06.010>

Hodgson, N., & Gitlin, L. (In press). Implementing and sustaining family care programs in real world settings: barriers and facilitators. In J. Gaugler, *Bridging the Family Care Gap*. Elsevier Publishing.

Heintz, H., Monette, P., Epstein-Lubow, G., Smith, L., Rowlett, S., & Forester, B. P. (2019). Emerging collaborative care models for dementia care in the primary care setting: A narrative review. *The American Journal of Geriatric Psychiatry*. <https://doi.org/10.1016/j.jagp.2019.07.015>

Hepburn, K. W., Lewis, M., Sherman, C. W., & Tornatore, J. (2003). The Savvy Caregiver Program: Developing and testing a transportable dementia family caregiver training program. *The Gerontologist*, 43(6), 908–915. <https://doi.org/10.1093/geront/43.6.908>

Hinton, L., Tran, D., Nguyen, T.-N., Ho, J., & Gitlin, L. (2019). Interventions to support family caregivers of people living with dementia in high, middle and low-income countries in Asia: a scoping review. *BMJ Global Health*, 4(6), e001830. <https://doi.org/10.1136/bmjgh-2019-001830>

Jutkowitz, E., Kuntz, K. M., Dowd, B., Gaugler, J. E., MacLehose, R. F., & Kane, R. L. (2017). Effects of cognition, function, and behavioral and psychological symptoms on out-of-pocket medical and nursing home expenditures and time spent caregiving for persons with dementia. *Alzheimer's & Dementia*, 13(7), 801–809. <https://doi.org/10.1016/j.jalz.2016.12.011>

Jutkowitz, E., Scerpella, D., Pizzi, L. T., Marx, K., Samus, Q., Piersol, C. V., & Gitlin, L. N. (2019). Dementia family caregivers' willingness to pay for an in-home program to reduce behavioral symptoms and caregiver stress. *Pharmacoeconomics*, 37(4), 563–572. <https://doi.org/10.1007/s40273-019-00785-6>

Jutkowitz, E., Gaugler, J., Trivedi, A., Mitchell, L., & Gozalo, P. (In press) Family caregiving in the community up to 8-years after onset of dementia.

Kishita, N., Hammond, L., Dietrich, C. M., & Mioshi, E. (2018). Which interventions work for dementia family carers?: An updated systematic review of randomized controlled trials of carer interventions. *International Psychogeriatrics*, 30(11), 1679–1696. <https://doi.org/10.1017/S1041610218000947>

Lins, S., Hayder-Beichel, D., Rücker, G., Motschall, E., Antes, G., Meyer, G., & Langer, G. (2014). Efficacy and experiences of telephone counselling for informal carers of people with dementia. *Cochrane Database of Systematic Reviews*. <https://doi.org/10.1002/14651858.CD009126.pub2>

Liu, Z., Sun, Y.-Y., & Zhong, B. (2018). Mindfulness-based stress reduction for family carers of people with dementia. *Cochrane Database of Systematic Reviews*. <https://doi.org/10.1002/14651858.CD012791.pub2>

Logsdon, R. G., McCurry, S. M., & Teri, L. (2005). A home health care approach to exercise for persons with Alzheimer's disease. *Care Management Journals*, 6(2), 90–97.

<https://doi.org/10.1891/152109805780650689>

Maayan, N., Soares-Weiser, K., & Lee, H. (2014). Respite care for people with dementia and their carers. *Cochrane Database of Systematic Reviews*.

<https://doi.org/10.1002/14651858.CD004396.pub3>

Marx, K. A., Stanley, I. H., Van Haitsma, K., Moody, J., Alonzi, D., Hansen, B. R., & Gitlin, L. N. (2014). Knowing versus doing: education and training needs of staff in a chronic care hospital unit for individuals with dementia. *Journal of Gerontological Nursing*, 40(12), 26–

34. <https://doi.org/10.3928/00989134-20140905-01>

MetLife Mature Market Institute. (2011). *The MetLife study of caregiving costs to working caregivers: Double jeopardy for baby boomers caring for their parents*. MetLife Insurance Company. Retrieved from <http://www.caregiving.org/wp-content/uploads/2011/06/mmi-caregiving-costs-working-caregivers.pdf>

Mittelman, M. S., Ferris, S. H., Steinberg, G., Shulman, E., Mackell, J. A., Ambinder, A., & Cohen, J. (1993). An intervention that delays institutionalization of Alzheimer's disease patients: Treatment of spouse-caregivers. *The Gerontologist*, 33(6), 730–740.

<https://doi.org/10.1093/geront/33.6.730>

Mittelman, M. S., Roth, D. L., Haley, W. E., & Zarit, S. H. (2004). Effects of a caregiver intervention on negative caregiver appraisals of behavior problems in patients with Alzheimer's disease: Results of a randomized trial. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 59(1), P27–P34. <https://doi.org/10.1093/geronb/59.1.P27>



Nichols, L. O., Chang, C., Lummus, A., Burns, R., Martindale-Adams, J., Graney, M. J., ... Czaja, S. (2008). The cost-effectiveness of a behavior intervention with caregivers of patients with Alzheimer's disease. *Journal of the American Geriatrics Society*, 56(3), 413–420.  
<https://doi.org/10.1111/j.1532-5415.2007.01569.x>

Onken, L. S., Carroll, K. M., Shoham, V., Cuthbert, B. N., & Riddle, M. (2014). Reenvisioning Clinical Science. *Clinical Psychological Science*, 2(1), 22–34.  
<https://doi.org/10.1177/2167702613497932>

O'Shaughnessy, C. (2014). *National spending for long-term services and supports (LTSS), 2012*. National Health Policy Forum. Retrieved from  
[https://hsrc.himmelfarb.gwu.edu/sphhs\\_centers\\_nhpf/284](https://hsrc.himmelfarb.gwu.edu/sphhs_centers_nhpf/284)

Pinquart, M., & Sörensen, S. (2003). Associations of stressors and uplifts of caregiving with caregiver burden and depressive mood: A meta-analysis. *The Journals of Gerontology: Series B*, 58(2), P112–P128. <https://doi.org/10.1093/geronb/58.2.P112>

Possin, K. L., Merrilees, J. J., Dulaney, S., Bonasera, S.J., Chiong, W., ... Miller, B. L. (2019). Effect of collaborative dementia care via telephone and Internet on quality of Life, caregiver well-being, and health care use: The Care Ecosystem randomized clinical trial. *JAMA Internal Medicine*. doi:10.1001/jamainternmed.2019.4101

Pruchno, R., & Gitlin, L. (2012). Family caregiving in late life: Shifting paradigms. In R. Blieszner & V. Bedford, *Handbook of families and aging* (pp. 515-541). Santa Barbara, CA: Praeger Publishers.

Riffin, C., Van Ness, P. H., Wolff, J. L., & Fried, T. (2017). Family and other unpaid caregivers and older adults with and without dementia and disability. *Journal of the American Geriatrics Society*, 65(8), 1821–1828. <https://doi.org/10.1111/jgs.14910>

Schulz, R., & Eden, J. (Eds.). (2016). *Families caring for an aging america*. National Academies Press. <https://doi.org/10.17226/23606>

Shahly, V., Chatterji, S., Gruber, M. J., Al-Hamzawi, A., Alonso, J., Andrade, L. H., ... Kessler, R. C. (2013). Cross-national differences in the prevalence and correlates of burden among older family caregivers in the World Health Organization World Mental Health (WMH) Surveys. *Psychological Medicine*, *43*(4), 865–879. <https://doi.org/10.1017/S0033291712001468>

Sperling, S. A., Brown, D. S., Jensen, C., Inker, J., Mittelman, M. S., & Manning, C. A. (2019). FAMILIES: an effective healthcare intervention for caregivers of community dwelling people living with dementia. *Aging & Mental Health*, 1–9. <https://doi.org/10.1080/13607863.2019.1647141>

Teri, L., Logsdon, R. G., McCurry, S. M., Pike, K. C., & McGough, E. L. (2018). Translating an evidence-based multicomponent intervention for older adults with dementia and caregivers. *The Gerontologist*. <https://doi.org/10.1093/geront/gny122>

Teri, L., McCurry, S. M., Logsdon, R., & Gibbons, L. E. (2005). Training community consultants to help family members improve dementia care: A randomized controlled trial. *The Gerontologist*, *45*(6), 802–811. <https://doi.org/10.1093/geront/45.6.802>

World Health Organization. (2012). *Dementia: A public health priority*. Geneva, Switzerland: WHO Press. Retrieved from <https://extranet.who.int/agefriendlyworld/wp-content/uploads/2014/06/WHO-Dementia-English.pdf>

Winter, L., & Parks, S. M. (2008). Family discord and proxy decision makers' end-of-life treatment decisions. *Journal of Palliative Medicine*, *11*(8), 1109–1114. <https://doi.org/10.1089/jpm.2008.0039>

Wolff, J. L. (2008). Hidden in plain sight: Medical visit companions as a resource for vulnerable older adults. *Archives of Internal Medicine*, 168(13), 1409.

<https://doi.org/10.1001/archinte.168.13.1409>

Wolff, J. L., Roter, D. L., Boyd, C. M., Roth, D. L., Echavarría, D. M., Aufill, J., ... Gitlin, L. N. (2018). Patient–family agenda setting for primary care patients with cognitive impairment: the SAME page trial. *Journal of General Internal Medicine*, 33(9), 1478–1486.

<https://doi.org/10.1007/s11606-018-4563-y>

<b>Table 1 Terms Referring to Family Members of Older Adults in Health Care Encounters</b>	
<b>Context</b>	<b>Term/Citation</b>
Families who attend medical appointments	Medical visit companions or companions (Wolff & Roter, 2008)
Families involved in helping older adults transition from hospital to home	Informal caregivers (Burton, Zdaniuk, Schulz, Jackson, & Hirsch, 2003;
Families who provide medical information for older relatives with cognitive impairments	Key informants (various citations in medical studies)
Families involved in end-of -life care or with incapacitated individuals	Proxy decision-makers (Winter & Parks, 2008).

**Table 2 Definition of a Family Caregiver in Key Legislation and Advocacy Groups**

Legislation/ Organization	Source	Definition of Caregiver
National Alliance of Caregiving	Family Caregiver Alliance: <a href="https://www.caregiver.org/definitions-0">https://www.caregiver.org/definitions-0</a>	<b>Informal Caregiver:</b> “Any relative, partner, friend or neighbor who has a significant, personal relationships with, and provides a broad range of assistance for an older person or an adult with a chronic or disabling condition. These individuals may be primary or secondary caregivers and live with, or separately from, the person receiving care”
RAISE	RAISE Family Caregiving Act: <a href="https://acl.gov/sites/default/files/about-acl/2018-10/PLAW-115publ119%20-%20RAISE.pdf">https://acl.gov/sites/default/files/about-acl/2018-10/PLAW-115publ119%20-%20RAISE.pdf</a>	<b>Family Caregiver:</b> “The term “family caregiver” means an adult family member or other individual who has a significant relationship with, and who provides a broad range of assistance to, an individual with a chronic or other health condition, disability, or functional limitation.”
National Academy of Science Engineering and Medicine	Families Caring for an Aging America Report: <a href="https://www.johnahartford.org/images/uploads/reports/Family_Caregiving_Report_National_Academy_of_Medicine_IOM.pdf">https://www.johnahartford.org/images/uploads/reports/Family_Caregiving_Report_National_Academy_of_Medicine_IOM.pdf</a>	<b>Family Caregiver:</b> “Family caregivers are relatives, partners, friends, or neighbors who assist an older adult (referred to in this report as a care recipient) who needs help due to physical, mental, cognitive, or functional limitations. The caregiver’s involvement is driven primarily by a personal relationship rather than by financial remuneration. Family caregivers may live with, or apart from, the person receiving care. Care may be episodic, or of short or long duration.”
Caregiver Advise, Record, Enable (CARE) ACT	PA Legislature: <a href="https://www.legis.state.pa.us/CFDOCS/Legis/PN/Public/btCheck.cfm?txtType=HTM&amp;sessYr=2015&amp;sessInd=0&amp;billBody=H&amp;billTyp=B&amp;billNr=1329&amp;pn=2973">https://www.legis.state.pa.us/CFDOCS/Legis/PN/Public/btCheck.cfm?txtType=HTM&amp;sessYr=2015&amp;sessInd=0&amp;billBody=H&amp;billTyp=B&amp;billNr=1329&amp;pn=2973</a>	In total, 39 states, the District of Columbia, Puerto Rico, and U.S. Virgin Islands have enacted or are in the process of enacting some version of the AARP CARE Act. Each state’s legislative language definition language differs. For PA, the following definition is provided... <b>Lay Caregiver:</b> “Lay Caregiver-An individual with a significant relationship to a patient and who: (1) is designed and accepts the role as a lay caregiver by the

		patient pursuant to this act; and (2) provides after-care assistance to the patient living in the patient’s residence”
VA Caregiver Initiative	<a href="#">38 USC § 1720G(d)(1)</a> *Turns out all VA definitions connect to this definition in the U.S. Code	U.S. Code § 1720G.Assistance and support services for caregivers <b>Caregiver:</b> “The term “caregiver”, with respect to an eligible veteran under subsection (a) or a covered veteran under subsection (b), means an individual who provides personal care services to the veteran.”
CDC Behavior Risk Factor Surveillance System (BRFSS)	BRFSS Questionnaire 2018 (page 65) <a href="https://www.cdc.gov/brfss/questionnaires/pdf-ques/2018_BRFSS_English_Questionnaire.pdf">https://www.cdc.gov/brfss/questionnaires/pdf-ques/2018_BRFSS_English_Questionnaire.pdf</a>	CDC identifies caregivers in their annual BRFSS questionnaire with the following question: “During the past 30 days, did you provide regular care or assistance to a friend or family member who has a health problem or disability?”

**Table 3 Summary of Scoping, Systematic and Meta-analytic Reviews of Nonpharmacologic Interventions for Family Caregivers**

Citation/ Method	Date of Reviews/ Population	# of Studies Included/  Study Designs Included	Types of Interventions	Caregiver Outcomes	Key Findings
<p>Abrahams, R., Liu, K. P. Y., Bissett, M., Fahey, P., Cheung, K. S. L., Bye, R., ... Chu, L.-W. (2018). Effectiveness of interventions for co-residing family caregivers of people with dementia: Systematic review and meta-analysis. <i>Australian Occupational Therapy Journal</i>, 65(3), 208–224. <a href="https://doi.org/10.1111/1440-1630.12464">https://doi.org/10.1111/1440-1630.12464</a></p> <p>Systematic review and meta-analysis</p>	<p>Up to 2015</p> <p>Family caregivers of persons with any type of dementia.</p>	<p>22</p> <p>Randomized controlled trial</p>	<p>Multicomponent interventions</p>	<p>Burden Depression Health Social supports</p>	<ul style="list-style-type: none"> <li>• Multicomponent interventions decreased burden and, depression, and improved health, and social support; approaches had benefits on some but not all outcomes</li> <li>• Interventions involving counselling, support groups, education, stress/mood management, were key components.</li> </ul>
<p>Acton GJ, Kang J. Interventions to reduce the burden of caregiving for an adult with dementia: a meta-analysis. <i>Research in nursing &amp; health</i>. 2001;24 (5):349-360.</p>	<p>1966-1999</p> <p>Family caregivers of persons with dementia.</p>	<p>24</p> <p>Randomized controlled trial</p> <p>Quasi-experimental</p>	<p>Support groups Education Psychoeducation Counseling Respite care Multicomponent</p>	<p>Burden</p>	<ul style="list-style-type: none"> <li>• Multicomponent interventions significantly reduced caregiver burden.</li> <li>• Other interventions did not significantly reduce caregiver burden.</li> </ul>

Systematic review and meta-analysis		Interventions compared to usual care; control groups not well described			
Boots LM, de Vugt, ME, van Knippenberg RJ, Kempen GI, Verhey FR. A. (2014). Systematic review of Internet-based Supportive interventions for caregivers of patients with dementia. <i>International journal of geriatric psychiatry</i> , 29(4):331-344.  Systematic review	1995 – 2013  Informal caregivers of persons with mild cognitive impairment or dementia.	12 studies  Randomized controlled trial  Quasi-experimental  Interventions compared primarily to usual care	Internet support interventions for caregivers	Caregiver functioning  Caregivers' well-being (depression, sense of competence, decision-making confidence, self-efficacy, burden, etc.)	<ul style="list-style-type: none"> <li>• Studies varied in quality and overall evidence was low.</li> <li>• Some evidence indicates interventions can improve aspects of caregiver well-being.</li> </ul>
Cooper C, Balamurali TB, Selwood A, Livingston G. (2007). A systematic review of intervention studies about anxiety in caregivers of people with dementia. <i>International journal of geriatric psychiatry</i> . 22(3):181-188.	1981 – 2004  Informal caregivers of persons with dementia.	24  Randomized controlled trial  Quasi-experimental  Interventions compared to usual care, local support groups, information	Cognitive behavioral therapy (CBT) Behavioral management techniques (BMT) p/- Cognitive therapy techniques  IT support for caregivers  Professional support for caregivers	Anxiety	<ul style="list-style-type: none"> <li>• Preliminary evidence that caregiver groups and relaxation strategies improve anxiety, but overall studies varied in quality and there was limited efficacy evidence.</li> </ul>



Systematic review		workshops and/or phone support	Groups involving relaxation/yoga  Exercise  Services for CR  Respite		
Dam AE, de Vugt ME, Klinkenberg IP, Verhey FR, van Boxtel MP. A systematic review of social support interventions for caregivers of people with dementia: Are they doing what they promise? <i>Maturitas</i> . 2016;85:117-130.  Systematic review	1987 - 2014  Informal caregivers of community-dwelling persons with dementia.	39  Randomized controlled trial  Quasi-experimental  Interventions compared to usual, education, telephone calls	Social support:  Befriending and peer support interventions  Family support and social network interventions  Support groups interventions  Remote interventions using the internet or telephone	Well-being (e.g., depression, burden, and quality of life)  Social support	<ul style="list-style-type: none"> <li>Results were inconsistent, but there was some evidence that multi-component interventions are most effective on improving measures of caregiver well-being.</li> </ul>
Gallagher-Thompson D, Coon DW. Evidence-based psychological treatments for distress in family caregivers of older adults. <i>Psychology and aging</i> . 2007;22(1):37-51.  Systematic review	1989 - 2004  Family members caring for a person with cognitive and/or physical impairment.	19  Specific study designs not reported  Interventions compared to usual care, workshops, comparative effectiveness	Evidence-based psychological treatments:  Psychoeducational programs  Psychotherapy  Multicomponent interventions	Distress (e.g., anger, anxiety, burden, coping, depression, distress, life satisfaction, mood, and social support)	<ul style="list-style-type: none"> <li>Psychoeducational skills building interventions were effective in reducing caregiver distress, improving coping, and self-efficacy.</li> <li>Psychotherapy was effective in reducing depressive symptoms.</li> </ul>

<p>Hurley RV, Patterson TG, Cooley SJ. Meditation-based interventions for family caregivers of people with dementia: a review of the empirical literature. <i>Aging &amp; mental health</i>. 2014;18(3):281-288.</p> <p>Systematic review</p>	<p>2004 – 2012</p> <p>Family caregiver of a person with dementia.</p>	<p>8</p> <p>Randomized controlled trial</p> <p>Case series</p> <p>Interventions compared to usual care, passive relaxation, music, education or respite</p>	<p>Meditation-based interventions</p>	<p>Depression</p> <p>Burden</p>	<ul style="list-style-type: none"> <li>• Low quality evidence indicates meditation-based interventions may have beneficial results for caregivers.</li> <li>• Interventions had low attrition and were feasible and acceptable.</li> </ul>
<p>Jackson, D., Roberts, G., Wu, M. L., Ford, R., &amp; Doyle, C. (2016). A systematic review of the effect of telephone, internet or combined support for carers of people living with Alzheimer's, vascular or mixed dementia in the community. <i>Archives of Gerontology and Geriatrics</i>, 66, 218–236. <a href="https://doi.org/10.1016/j.archger.2016.06.013">https://doi.org/10.1016/j.archger.2016.06.013</a></p> <p>Systematic review</p>	<p>Up to 2015</p> <p>Caregivers of persons living with dementia.</p>	<p>22</p> <p>Randomized controlled trial</p> <p>Quasi-experimental</p> <p>Interventions compared to usual care, attention control, active comparisons</p>	<p>Telephone, internet, or combination of telephone internet</p>	<p>Burden</p> <p>Distress</p> <p>Stress</p> <p>Depression</p> <p>Anxiety</p> <p>Self-efficacy</p> <p>Quality of life</p> <p>Overall health</p> <p>Coping</p>	<ul style="list-style-type: none"> <li>• Combined telephone and internet interventions significantly reduced depression, burden, and increased self-efficacy.</li> </ul>

<p>Jaffray L, Bridgman H, Stephens M, Skinner T. Evaluating the effects of mindfulness-based interventions for informal palliative caregivers: A systematic literature review. <i>Palliative medicine</i>. 2016;30(2):117-131.</p> <p>Systematic review</p>	<p>2010 – 2014</p> <p>Informal palliative caregivers.</p>	<p>10 (7 focused on dementia caregivers)</p> <p>Randomized controlled trial</p> <p>Quasi-experimental</p> <p>Interventions compared to usual care, respite</p>	<p>Mindfulness-based interventions</p>	<p>Depression Quality of life Caregiver burden Anxiety Stress</p>	<ul style="list-style-type: none"> <li>• Mindfulness-based interventions may reduce caregiver burden and depression.</li> <li>• Interventions were feasible and acceptable.</li> </ul>
<p>Jones C, Edwards RT, Hounsom B. A systematic review of the cost-effectiveness of interventions for supporting informal caregivers of people with dementia residing in the community. <i>International psychogeriatrics</i>. 2012;24(1):6-18.</p> <p>Systematic review</p>	<p>1991 – 2010</p> <p>Informal caregivers of persons with dementia.</p>	<p>12</p> <p>Randomized controlled trial</p> <p>Simulation</p> <p>Quasi-experimental</p> <p>Control conditions not clearly reported but appear to be usual care</p>	<p>Pharmacological Psychosocial Service delivery</p>	<p>Cost-effectiveness Stress/Strain Quality of Life Anxiety Depression Coping Burden</p>	<ul style="list-style-type: none"> <li>• There are limited data on the cost-effectiveness of interventions that support caregivers.</li> <li>• Pharmacologic interventions for persons with dementia had no effects on caregivers.</li> <li>• Psychosocial interventions had missed effects for caregivers.</li> </ul>
<p>Jutten LH, Mark RE, Wicherts JM, Sitskoorn MM. The effectiveness of psychosocial and behavioral interventions for informal dementia</p>	<p>2002 – 2016</p> <p>Informal caregivers of persons with dementia.</p>	<p>60</p> <p>Controlled trials</p>	<p>Psychosocial Psychobehavioral Psychoeducational</p>	<p>Caregiver burden Depression Anxiety Quality of Life Stress</p>	<ul style="list-style-type: none"> <li>• For all outcomes except anxiety interventions were associated with significant but small improvements.</li> </ul>

<p>caregivers: Meta-analyses and meta-regressions. <i>Journal of Alzheimer's disease</i> : JAD. 2018;66(1):149-172.</p> <p>Systematic review, meta-analyses, and meta-regressions</p>		<p>Interventions compared to usual care control groups</p>		<p>Sense of competence</p>	<ul style="list-style-type: none"> <li>The method of delivering the intervention was not associated with outcomes.</li> </ul>
<p>Kishita N, Hammond L, Dietrich CM, Mioshi E. Which interventions work for dementia family carers?: an updated systematic review of randomized controlled trials of carer interventions. <i>International psychogeriatrics</i>. 2018;30(11):1679-1696.</p> <p>Systematic review and meta-analyses</p>	<p>2006 – 2016</p> <p>Family caregivers of persons with dementia.</p>	<p>30</p> <p>Randomized controlled trials</p> <p>Interventions compared to usual care</p>	<p>Psychoeducation-skill building interventions</p> <p>Cognitive based therapy/ psychotherapeutic interventions</p>	<p>Depression</p> <p>Anxiety</p> <p>Burden</p> <p>Quality of life</p>	<ul style="list-style-type: none"> <li>Psychoeducation skills building interventions, especially when delivered face-to-face, were effective in reducing caregiver burden.</li> <li>Psychotherapeutic interventions effectively reduced anxiety and depression.</li> </ul>
<p>Leung P, Orgeta V, Orrell M. The effects on carer well-being of carer involvement in cognition-based interventions for people with dementia: a</p>	<p>2000 – 2015</p> <p>Caregivers of persons with dementia.</p>	<p>8 (7 studies included in meta-analysis)</p> <p>Randomized controlled trials</p>	<p>Caregiver involvement in cognition-based interventions for persons with dementia:</p> <p>Cognitive stimulation</p> <p>Cognitive rehabilitation</p>	<p>Wellbeing (quality of life, mood, physical and mental health).</p> <p>Caregiving relationship and</p>	<ul style="list-style-type: none"> <li>Caregiver engagement in cognitive-based interventions for persons with dementia significantly improved caregiver quality of life and reduced caregiver depression.</li> </ul>

<p>systematic review and meta-analysis. <i>International journal of geriatric psychiatry.</i> 2017;32(4):372-385.</p> <p>Systematic review and meta-analysis</p>		<p>Interventions compared to usual care</p>	<p>Cognitive training</p>	<p>Caregiver burden</p>	
<p>Li R, Cooper C, Austin A, Livingston G. Do changes in coping style explain the effectiveness of interventions for psychological morbidity in family carers of people with dementia? A systematic review and meta-analysis. <i>International psychogeriatrics.</i> 2013;25(2):204-214.</p> <p>Systematic review and meta-analysis</p>	<p>1996 – 2010</p> <p>Caregivers of persons with dementia.</p>	<p>8</p> <p>Randomized controlled trials</p> <p>Intervention groups compared to usual care, minimal telephone support, information</p>	<p>Group coping skills</p> <p>Group coping skills with behavioral activation</p> <p>Anger Management</p> <p>Depression Management</p> <p>Remotely delivered (web-viewable or home videos with weekly phone calls)</p> <p>Dyadic counseling</p> <p>Cognitive stimulation therapy</p> <p>Individual behavioral management</p>	<p>Anxiety</p> <p>Depression</p> <p>Coping</p>	<ul style="list-style-type: none"> <li>Group coping alone and with behavioral activation had mixed effects on dysfunctional/positive coping, but these interventions significantly reduced depressive symptoms.</li> </ul>
<p>Lins S, Hayder-Beichel D, Rucker G, et al. Efficacy and experiences of telephone counselling for informal carers of people with</p>	<p>1999 - 2008</p> <p>Family caregivers of persons with dementia.</p>	<p>11</p> <p>Randomized controlled trials</p> <p>Qualitative studies</p>	<p>Telephone counselling</p>	<p>Depressive symptoms</p> <p>Burden</p> <p>Distress</p> <p>Anxiety</p> <p>Quality of life</p>	<ul style="list-style-type: none"> <li>Telephone counselling resulted in a reduction in depressive symptoms for caregivers of persons with dementia.</li> </ul>

dementia. <i>The Cochrane database of systematic reviews</i> . 2014(9):Cd009126.  Systematic review		Interventions compared to usual care, friendly calls		Self-efficacy Satisfaction Social support	<ul style="list-style-type: none"> <li>• Effects of telephone counselling on other outcomes were uncertain.</li> </ul>
Liu Z, Chen QL, Sun YY. Mindfulness training for psychological stress in family caregivers of persons with dementia: a systematic review and meta-analysis of randomized controlled trials. <i>Clinical interventions in aging</i> . 2017;12:1521-1529.  Systematic review and meta-analysis	2010 - 2017  Family caregivers of persons with dementia.	7  Randomized controlled trials  Interventions compared to active control or usual care	Mindfulness training	Depression  Anxiety  Perceived stress  Burden  Mental health-related quality of life	<ul style="list-style-type: none"> <li>• Mindfulness training significantly improved caregiver depression, stress, and mental health-related quality of life.</li> <li>• Intervention was not associated with improvements in caregiver burden or anxiety.</li> </ul>
Liu Z, Sun YY, Zhong BL. Mindfulness-based stress reduction for family carers of people with dementia. <i>The Cochrane database of systematic reviews</i> . 2018;8:Cd012791.  Systematic review and meta-analysis	2010 – 2016  Family caregivers of persons with dementia.	5  Randomized controlled trial  Interventions compared to attention control groups or usual care	Mindfulness-based stress reduction	Depression  Anxiety  Burden  Coping style	<ul style="list-style-type: none"> <li>• Mindfulness-based stress reduction decreased caregiver anxiety.</li> <li>• The effect of the intervention on burden, depression, and coping style was unclear.</li> </ul>

<p>Marim CM, Silva V, Taminato M, Barbosa DA. Effectiveness of educational programs on reducing the burden of caregivers of elderly individuals with dementia: a systematic review. <i>Revista latino-americana de enfermagem</i>. 2013;21 Spec No:267-275.</p> <p>Systematic review and meta-analysis</p>	<p>1994 – 2011</p> <p>Caregivers of persons with dementia.</p>	<p>7 (4 studies included in meta-analysis)</p> <p>Randomized controlled trials</p> <p>Interventions compared to usual care</p>	<p>educational and support programs</p>	<p>Burden</p>	<ul style="list-style-type: none"> <li>Education and support interventions significantly reduced caregiver burden.</li> </ul>
<p>Peacock SC, Forbes DA. Interventions for caregivers of persons with dementia: a systematic review. <i>The Canadian journal of nursing research = Revue canadienne de recherche en sciences infirmieres</i>. 2003;35(4):88-107.</p> <p>Systematic review</p>	<p>1993-2001</p> <p>Family caregivers of persons with dementia.</p>	<p>11</p> <p>Randomized controlled trial</p>	<p>Interventions designed to enhance caregiver well-being:</p> <p>Education</p> <p>Case management</p> <p>Psychotherapy</p> <p>Computer networking</p>	<p>Depression</p> <p>Strain</p> <p>Stress</p> <p>Behavior</p> <p>Institutionalization</p>	<ul style="list-style-type: none"> <li>Caregiver interventions were associated with mixed effects.</li> </ul>
<p>Pinquart M, Sorensen S. Helping caregivers of persons with dementia: which interventions</p>	<p>1982 – 2005</p>	<p>127 (29 studies focused on caregivers of</p>	<p>Psychoeducational interventions</p> <p>Cognitive-behavioral therapy</p>	<p>Caregiver burden</p> <p>Depressive symptoms</p>	<ul style="list-style-type: none"> <li>Interventions resulted in small but statistically significant improvements</li> </ul>

<p>work and how large are their effects? <i>International psychogeriatrics.</i> 2006;18(4):577-595.</p> <p>Systematic review and meta-analysis</p>	<p>Caregivers of persons with dementia.</p>	<p>patients with Alzheimer's disease</p> <p>1 study on caregivers for presenile dementia</p> <p>97 on caregivers for dementia in general)</p> <p>Specific study designs not reported, but studies had to have a usual care control condition</p>	<p>Counseling/case management</p> <p>General support</p> <p>Respite</p> <p>Training of the person with dementia</p> <p>Multicomponent interventions</p> <p>Miscellaneous interventions</p>	<p>Subjective well-being</p> <p>Ability/knowledge</p> <p>Self-efficacy</p> <p>Knowledge about dementia and available services</p> <p>Institutionalizing</p>	<p>in caregiver burden, depression, and well-being.</p> <ul style="list-style-type: none"> <li>• Multicomponent interventions significantly reduced the risk of initialization.</li> </ul>
<p>Scott JL, Dawkins S, Quinn MG, et al. Caring for the carer: a systematic review of pure technology-based cognitive behavioral therapy (TB-CBT) interventions for dementia carers. <i>Aging &amp; mental health.</i> 2016;20(8):793-803.</p> <p>Systematic review and meta-analysis</p>	<p>2002 – 2013</p> <p>Caregivers of persons with dementia.</p>	<p>4</p> <p>Randomized controlled trial</p> <p>Interventions compared to usual care or minimal intervention</p>	<p>Technology-based cognitive behavioral therapy</p>	<p>Depression</p>	<ul style="list-style-type: none"> <li>• Technology-based cognitive behavioral therapy resulted in a small improvement in depressive symptoms for dementia caregivers.</li> <li>• There was no evidence on the long-term effect of the intervention.</li> </ul>
<p>Selwood A, Johnston K, Katona C, Lyketsos C,</p>	<p>1981 – 2004</p>	<p>62</p>	<p>Psychological based interventions:</p>	<p>Burden</p> <p>Stress</p>	<ul style="list-style-type: none"> <li>• Individual behavioral management therapy with</li> </ul>



<p>Livingston G. Systematic review of the effect of psychological interventions on family caregivers of people with dementia. <i>Journal of affective disorders.</i> 2007;101(1-3):75-89.</p> <p>Systematic review</p>	<p>Family caregivers of persons with dementia.</p>	<p>Specific study designs not reported</p> <p>Interventions compared to active control, comparative effectiveness</p>	<p>Educational interventions</p> <p>Dementia specific therapies targeted at the patient</p> <p>Group/individual caregiving coping strategies</p> <p>Individual behavioral management techniques &lt;6 sessions</p> <p>Individual behavioral management techniques ≥6 sessions</p> <p>Supportive therapy</p>	<p>Depression Anxiety Mood Perceived strain Anger Well-being Distress Quality of life Psychological health Life satisfaction</p>	<p>≥6 sessions reduced caregiver symptoms.</p> <ul style="list-style-type: none"> <li>Interventions teaching caregivers coping strategies improved caregiver psychological health.</li> </ul>
<p>Tang WK, Chan CY. Effects of psychosocial interventions on self-efficacy of dementia caregivers: a literature review. <i>International journal of geriatric psychiatry.</i> 2016;31(5):475-493.</p> <p>Systematic review</p>	<p>2001 – 2014</p> <p>Caregivers of persons with dementia.</p>	<p>14</p> <p>Randomized controlled trial</p> <p>Quasi-experimental</p> <p>Interventions compared to usual care, and different treatments (brief information, support, education, telephone calls)</p>	<p>Psychosocial interventions:</p> <p>Cognitive behavior psychoeducational intervention</p> <p>Leisure intervention</p> <p>Psychoeducational and skill-training</p> <p>Learning to become a family caregiver program</p> <p>Dementia care consultation intervention</p>	<p>Self-efficacy Burden</p>	<ul style="list-style-type: none"> <li>Psychosocial interventions improved caregivers' self-efficacy.</li> </ul>

			<p>Video/workbook/telephone coaching</p> <p>Home-based caregiver training program</p> <p>The Savvy program: a transportable psychoeducation program</p> <p>In-home caregiver psychoeducational training program</p> <p>Mindfulness meditation</p> <p>Manualized yoga meditation program</p>		
<p>Thinnes A, Padilla R. Effect of educational and supportive strategies on the ability of caregivers of people with dementia to maintain participation in that role. <i>The American journal of occupational therapy : official publication of the American Occupational Therapy Association.</i> 2011;65(5):541-549.</p>	<p>2001 – 2009</p> <p>Caregivers of persons with dementia.</p>	<p>43</p> <p>Meta-analyses</p> <p>Randomized controlled trials</p> <p>Quasi-experimental</p> <p>Control conditions unclear</p>	<p>Educational and supportive strategies:</p> <p>Occupational therapy</p> <p>Caregiver education</p> <p>Interventions with caregivers and patients</p> <p>Caregiver counseling which involves the whole family</p>	<p>Burden</p> <p>Quality of life</p> <p>Depression</p> <p>Self-care</p> <p>Social support</p> <p>Satisfaction</p> <p>Coping</p> <p>Time caregiving</p> <p>Institutionalization</p> <p>Behaviors</p>	<ul style="list-style-type: none"> <li>• Interventions that engaged dyads in the home were the most successful.</li> <li>• Combined tailored supportive and educational strategies appeared to be most useful to caregivers.</li> </ul>

Systematic review			<p>Combination of tailored supportive and educational strategies</p> <p>Dydic interventions conducted in the home</p> <p>Technology-mediated interventions</p> <p>Respite care</p>		
<p>Vernooij-Dassen M, Draskovic I, McCleery J, Downs M. Cognitive reframing for carers of people with dementia. <i>The Cochrane database of systematic reviews</i>. 2011(11):Cd005318.</p> <p>Systematic review and meta-analysis</p>	<p>1987 – 2007</p> <p>Family caregivers of persons with dementia.</p>	<p>11</p> <p>Randomized controlled trials</p> <p>Interventions compared to usual care, telephone calls</p>	Cognitive reframing	<p>Anxiety</p> <p>Depression</p> <p>Stress</p> <p>Burden</p> <p>Coping or self-efficacy</p> <p>Memory and Behavior</p> <p>Quality of life</p>	<ul style="list-style-type: none"> <li>• Cognitive reframing improved caregiver anxiety, depression, and subjective stress.</li> <li>• The intervention was not found to have an effect on caregiver coping, burden, the person with dementia's behavior or institutionalization.</li> </ul>
<p>Waller A, Dilworth S, Mansfield E, Sanson-Fisher R. Computer and telephone delivered interventions to support caregivers of people with dementia: a</p>	<p>1990 – 2016</p> <p>Caregivers of persons with dementia.</p>	<p>34</p> <p>Randomized controlled trial</p> <p>Quasi-experimental</p>	Telephone- and computer-delivered interventions	<p>Burden</p> <p>Self-efficacy</p> <p>Depression</p> <p>Social support</p> <p>Treatment satisfaction</p> <p>Well being</p>	<ul style="list-style-type: none"> <li>• Study quality was low but telephone and computer interventions which were based on psychoeducation, peer support, or skills training were associated with improvements in</li> </ul>

<p>systematic review of research output and quality. <i>BMC geriatrics</i>. 2017;17(1):265.</p> <p>Systematic review</p>		<p>Interventions compared to a variety of control group conditions including usual care and attention, respite, education</p>		<p>Knowledge Quality of life Behaviors Anxiety Strain</p>	<p>measures of caregiver wellbeing.</p>
<p>Walter, E., &amp; Pinquart, M. (2019). How Effective Are Dementia Caregiver Interventions? An Updated Comprehensive Meta-Analysis. <i>The Gerontologist</i>, XX(XX), 1–11. <a href="https://doi.org/10.1093/geront/gnz118">https://doi.org/10.1093/geront/gnz118</a></p> <p>Systematic review and meta-analysis</p>	<p>2016-2019</p> <p>Family caregivers of persons with dementia.</p>	<p>280</p> <p>Randomized controlled trial</p> <p>Quasi-experimental</p> <p>Interventions compared to usual care or minimal attention</p>	<p>Psychosocial interventions which target the experience/behavior of the caregiver</p>	<p>Burden Depression Anxiety Well-being Ability/knowledge</p>	<ul style="list-style-type: none"> <li>• Interventions result in small-to-moderate improvements in ability/knowledge well-being, burden, depression, and anxiety.</li> <li>• Psychoeducation and multicomponent interventions affected most outcomes.</li> </ul>
<p>Wilson, S., Toye, C., Aoun, S., Slatyer, S., Moyle, W., &amp; Beattie, E. (2017). Effectiveness of psychosocial interventions in reducing grief experienced by family carers of people with dementia. <i>JBIC Database of Systematic Reviews</i></p>	<p>1995 – 2016</p> <p>Family caregivers of persons living with dementia.</p>	<p>3</p> <p>Randomized controlled trial</p> <p>Quasi-experimental</p> <p>Interventions compared to usual care or minimal support</p>	<p>Psychosocial interventions</p>	<p>Grief</p>	<ul style="list-style-type: none"> <li>• There is limited evidence on the effect of psychosocial interventions on reducing caregiver grief.</li> </ul>

<p><i>and Implementation Reports, 15(3), 809–839.</i> <a href="https://doi.org/10.11124/JBISRIR-2016-003017">https://doi.org/10.11124/JBISRIR-2016-003017</a></p> <p>Systematic review</p>					
--	--	--	--	--	--

**Table 4. Summary of Translational Studies (n=28) and their Implementation Strategies\***

Study Description				Implementation Phase			Framework
Author	Intervention	Sample/ Setting	Major Outcomes	Pre- implementatio n	Implementatio n	Sustainabilit y	Study Design; Framework
Altpeter et al., 2015	REACH II	15 REACH II family consultants and coaches; North Carolina organizations (Dept of Social Services; AAA; hospital)	Mid-course assessment: Review implementation process, build on demonstrated strengths, identify problem areas and needs for adaptation to better fit service delivery, and modify operations	<ul style="list-style-type: none"> <li>• Needs assessment</li> <li>• Assessment of readiness</li> <li>• Feedback process</li> <li>• Quality monitoring tools</li> </ul>	<ul style="list-style-type: none"> <li>• Presence of supervision</li> <li>• Progress monitoring</li> <li>• Supportive facilitation</li> <li>• Fidelity monitoring</li> <li>• Adaptability</li> </ul>	Financing status	Pre-test post test of mid-course process; RE-AIM
Antonio et al., 2017	PACCS	Number of caregivers not specified; Home	Using behavioral change technique to translate a “live” intervention to an information technology-delivered modality	None	<ul style="list-style-type: none"> <li>• Adaptability</li> </ul>	Not specifically addressed	Descriptive; Behavioral Change Technique Taxonomy
Aoun et al., 2018	FECH	64 dyads contacted by telephone following discharge from a hospital setting	Describe implementation process; Highlight barriers and facilitators of implementation; Feasibility of translation into clinical practice	<ul style="list-style-type: none"> <li>• Feedback process</li> <li>• Needs assessment</li> </ul>	<ul style="list-style-type: none"> <li>• Supportive facilitation</li> <li>• Consumer feedback</li> <li>• Presence of supervision</li> <li>• Adaptability</li> </ul>	Infrastructure changes	Pretest-Posttest; None specified
Burgio et al., 2009	REACH OUT	272 dementia caregivers at home	Care recipient risk, mood, memory, and behavior problems; caregiver stress and emotional well-being; caregiver health; and program satisfaction.	<ul style="list-style-type: none"> <li>• Needs assessment</li> <li>• Formal commitment</li> </ul>	<ul style="list-style-type: none"> <li>• Adaptability</li> <li>• Presence of supervision</li> </ul>	Not specifically addressed	Pretest-Posttest; None specified

					<ul style="list-style-type: none"> <li>• Ongoing training/consultation</li> <li>• Consumer feedback</li> </ul>		
Cheung et al., 2014	REACH HK	201 dementia family dyads at home	Depression; Burden; positive aspects of caregiving; memory and behavioral checklist	<ul style="list-style-type: none"> <li>• Formal commitment</li> </ul>	<ul style="list-style-type: none"> <li>• Adaptability</li> <li>• Consumer feedback</li> </ul>	Not specifically addressed	Pretest-Posttest; RE-AIM
Dekker-van Weering et al., 2019	PERSSILA A project	57 older adults and 8 formal caregivers in the home setting	Evaluation of implementation strategy, actual use, and user experience	<ul style="list-style-type: none"> <li>• Feedback process</li> <li>• Needs assessment</li> </ul>	<ul style="list-style-type: none"> <li>• Consumer feedback</li> <li>• Progress monitoring</li> <li>• Stakeholder education meeting</li> <li>• Supportive facilitation</li> </ul>	Not specifically addressed	Qualitative descriptive; none specified
Dopp et al., 2015	COTiD	71 dyads and 45 service units in the community and clinic setting	Intended adherence of therapists to the COTiD program	<ul style="list-style-type: none"> <li>• (Inferred) Formal commitment</li> </ul>	<ul style="list-style-type: none"> <li>• Stakeholder education meeting</li> <li>• Presence of supervision</li> <li>• (Optional) Progress monitoring</li> <li>• Ongoing training/consultation</li> <li>• Fidelity monitoring</li> </ul>	Not specifically addressed	Randomized Control Trial; Various frameworks

Easom et al., 2013	GA REACH	85 family caregivers in community setting	Burden, depression, health and healthy behaviors, caregiving frustrations, social support, dementia-related behaviors, and plans for institutionalization	<ul style="list-style-type: none"> <li>• Formal commitment</li> </ul>	<ul style="list-style-type: none"> <li>• Ongoing training/consultation</li> <li>• Supportive facilitation</li> <li>• Consumer feedback</li> <li>• Progress monitoring</li> <li>• Fidelity monitoring</li> </ul>	Financing status	Pretest-Posttest; None specified
Gaugler et al., 2018	NYUCI-AC	54 adult child caregivers in the 7-county Minneapolis/St. Paul region	Conduct a process evaluation of the NYUCI-AC to help inform potential implementation efforts in practice contexts	<ul style="list-style-type: none"> <li>• None (evaluation was performed post hoc)</li> </ul>	<ul style="list-style-type: none"> <li>• Fidelity monitoring</li> <li>• Consumer feedback</li> <li>• Progress monitoring</li> </ul>	Not specifically addressed	Mixed methods design; MRC framework (post hoc)
Gitlin et al., 2010	ESP	41 dementia caregivers	Therapist delivery, caregiver receipt, and enactment	<ul style="list-style-type: none"> <li>• Feedback process</li> <li>• Needs assessment</li> <li>• Quality monitoring tools</li> </ul>	<ul style="list-style-type: none"> <li>• Progress monitoring</li> <li>• Supportive facilitation</li> <li>• Ongoing training/consultation</li> <li>• Adaptability</li> <li>• Fidelity monitoring</li> </ul>	Financing status Infrastructure changes	Descriptive; RE-AIM
Griffiths et al., 2016	Tele-Savvy	30 dementia caregivers from the Atlanta VA	Process of transforming in-person into internet-based program; Results of initial implementation	<ul style="list-style-type: none"> <li>• Feedback process</li> </ul>	<ul style="list-style-type: none"> <li>• Stakeholder education meeting</li> <li>• Fidelity monitoring</li> </ul>	Not specifically addressed	Pretest-Posttest; Quality Improvement framework



					<ul style="list-style-type: none"> <li>• Consumer feedback</li> <li>• Supportive facilitation</li> </ul>		
Klug et al., 2014	North Dakota Dementia Care Services Program	1,750 caregivers of 951 persons with dementia in Home setting	Reduction in potentially avoidable health care use and costs; Delay in long-term care placement; Improved behavioral health and empowerment of the caregiver	<ul style="list-style-type: none"> <li>• Quality monitoring tools</li> <li>• Needs assessment</li> </ul>	<ul style="list-style-type: none"> <li>• Fidelity monitoring</li> <li>• Adaptability</li> <li>• Stakeholder education meeting</li> </ul>	Not specifically addressed	Quasi-experimental ; None specified
Lindauer et al., 2019	Tele-STAR	13 family caregivers in the local community	Explore the preliminary efficacy of Tele-STAR; assess the fidelity of Tele-STAR to the original STAR-C	<ul style="list-style-type: none"> <li>• Feedback process</li> <li>• Quality monitoring tools</li> </ul>	<ul style="list-style-type: none"> <li>• Consumer feedback</li> <li>• Fidelity monitoring</li> <li>• Progress monitoring</li> <li>• Presence of supervision</li> <li>• Ongoing training/consultation</li> <li>• Stakeholder education meeting</li> <li>• Locally tailored strategies</li> </ul>	Financing status	Pretest-Posttest; None specified
Lykens et al., 2014	REACH II	494 families home/community setting	Depression, caregiver burden, self-care, and social support	<ul style="list-style-type: none"> <li>• Formal commitment</li> <li>• Needs assessment</li> </ul>	<ul style="list-style-type: none"> <li>• Ongoing training/consultation</li> <li>• Adaptability</li> </ul>	Financing status	Pretest-Posttest; None specified

Martinda le-Adams et al., 2017	REACH into Indian Country	Number of caregivers not specified; Home/community setting	Describe implementation activities employed in a American Indian and Alaskan Native community setting	<ul style="list-style-type: none"> <li>• Needs assessment</li> <li>• Feedback process</li> <li>• Formal commitment</li> <li>• Implementation blueprint</li> </ul>	<ul style="list-style-type: none"> <li>• Adaptability</li> <li>• Staged implementation</li> <li>• Consumer feedback</li> <li>• Ongoing training/consultation</li> <li>• Locally tailored strategies</li> <li>• Stakeholder education meetings</li> </ul>	Not undergone at time of publication	Descriptive; Fixsen and Blasé
McCarroll et al., 2019	Care to Plan	22 community advisory board members (professionals, community advocates, family CGs)	Describing the construction of a CAB in order to serve as a guide for future translation; presenting evidence supporting the effectiveness of incorporating a CAB in the development of a dementia caregiver intervention	<ul style="list-style-type: none"> <li>• Needs assessment</li> <li>• Feedback process</li> <li>• Local champion</li> </ul>	<ul style="list-style-type: none"> <li>• Stakeholder education meeting</li> <li>• Consumer feedback</li> </ul>	Not specifically addressed	Case study; None specified
McCurry et al., 2017	STAR-C	158 dyads served by Oregon AAAs	Feasibility of implementation Efficacy Fidelity	<ul style="list-style-type: none"> <li>• Unclear (inferred formal commitment)</li> </ul>	<ul style="list-style-type: none"> <li>• Education</li> <li>• Fidelity monitoring</li> <li>• Consumer feedback</li> </ul>	Not specifically addressed	Pretest-Posttest; None specified
McCurry et al., 2018	RDAD	255 dyads served by Washington/Oregon AAAs	Describe program implementation, challenges faced	<ul style="list-style-type: none"> <li>• Unclear (inferred formal commitment)</li> </ul>	<ul style="list-style-type: none"> <li>• Presence of supervision</li> <li>• Adaptability</li> <li>• Education</li> </ul>	Not specifically addressed	Case series; non specified

Menne et al., 2014	RDAD	219 dementia caregivers	Caregiver reported strain; Relationship strain; Unmet needs; Use of RDAD components	<ul style="list-style-type: none"> <li>• Formal commitment</li> <li>• Quality monitoring tools</li> </ul>	<ul style="list-style-type: none"> <li>• Adaptability</li> <li>• Progress monitoring</li> </ul>	Not specifically addressed	Pretest-Posttest; None specified
Meyer et al., 2019	Fall Prevention Knowledge	25 dyads in the community setting	Utilization of the KTA framework to support adoption and knowledge of falls prevention	<ul style="list-style-type: none"> <li>• Assessment of readiness</li> <li>• Local champion</li> <li>• Needs assessment</li> </ul>	<ul style="list-style-type: none"> <li>• Adaptability</li> <li>• Locally tailored strategies</li> <li>• Progress monitoring</li> <li>• Supportive facilitation</li> <li>• Consumer feedback</li> <li>• Staged implementation</li> </ul>	Not specifically addressed	Mixed methods; Knowledge to Action framework
Nichols et al., 2016	REACH VA	125 caregivers VA community based setting	Describe the trajectory of REACH VA from national randomized clinical trial through translation to national implementation	<ul style="list-style-type: none"> <li>• Needs assessment</li> <li>• Formal commitment</li> <li>• Implementation blueprint</li> </ul>	<ul style="list-style-type: none"> <li>• Progress monitoring</li> <li>• Staged implementation</li> <li>• Consumer feedback</li> <li>• Adaptability</li> <li>• Ongoing training/consultation</li> <li>• Fidelity monitoring</li> </ul>	Infrastructure changes Resource sharing	Pretest-Posttest; Fixsen and Blasé

Paone - 2014	NYUCI	14 program sites (number of caregivers not specified) Community based agencies	How intervention sites were able to follow intervention; How intervention was being embedded at program sites; Cost to produce intervention at sites; Perceived value and satisfaction of caregivers	<ul style="list-style-type: none"> <li>• Assessment of readiness</li> <li>• Formal commitment</li> <li>• Quality monitoring tools</li> </ul>	<ul style="list-style-type: none"> <li>• Supportive facilitation</li> <li>• Adaptability</li> <li>• Progress monitoring</li> <li>• Consumer feedback</li> <li>• Presence of supervision</li> <li>• Ongoing training/consultation</li> </ul>	Financing status Infrastructure changes	Mixed methods; RE-AIM
Primetic a et al., 2015	RDAD	Number of caregivers not specified; Community based agencies	Reviews the implementation tasks necessary for agencies to implement the RDAD intervention	<ul style="list-style-type: none"> <li>• Implementation blueprint</li> <li>• Assessment of readiness</li> <li>• Formal commitment</li> <li>• Needs assessment</li> <li>• Local champion</li> </ul>	<ul style="list-style-type: none"> <li>• Education</li> <li>• Ongoing training/consultation</li> <li>• Fidelity monitoring</li> <li>• Locally tailored strategies</li> <li>• Consumer feedback</li> <li>• Progress monitoring</li> <li>• Presence of supervision</li> </ul>	Financing status Infrastructure changes	Descriptive; RE-AIM
Samia et al., 2014	Maine Savvy Caregiver Project	676 caregivers at home	Formative evaluation of reach, adoption, implementation and maintenance	<ul style="list-style-type: none"> <li>• Assessment of readiness</li> <li>• Implementation blueprint</li> </ul>	<ul style="list-style-type: none"> <li>• Adaptability</li> <li>• Fidelity monitoring</li> <li>• Progress monitoring</li> </ul>	Infrastructure changes	Quasi-experimental mixed method; RE-AIM

				<ul style="list-style-type: none"> <li>• Quality monitoring tools</li> <li>• Formal commitment</li> </ul>	<ul style="list-style-type: none"> <li>• Ongoing training/consultation</li> <li>• Education</li> </ul>		
Smith & Bell, 2005	Savvy Caregiving Program	54 urban and 42 rural caregivers at home	Caregiver depression; Effectiveness of SCP training; Usage of intervention materials	<ul style="list-style-type: none"> <li>• Formal commitment</li> <li>• Assessment of readiness</li> <li>• Quality monitoring tools</li> </ul>	<ul style="list-style-type: none"> <li>• Ongoing training/consultation</li> <li>• Supportive facilitation</li> <li>• Adaptability</li> <li>• Progress monitoring</li> </ul>	Not specifically addressed	Pretest-Posttest; None specified
Stevens et al., 2012	FCP	164 enrolled caregiving dyads at home	Outcomes of the RE-AIM framework: reach, efficacy, adoption, integration, and maintenance	<ul style="list-style-type: none"> <li>• Assessment of readiness</li> <li>• Quality monitoring tools</li> <li>• Formal commitment</li> </ul>	<ul style="list-style-type: none"> <li>• Progress monitoring</li> <li>• Supportive facilitation</li> <li>• Ongoing training/consultation</li> </ul>	Financing status	Descriptive; RE-AIM
Teri et al., 2012	RDAD and STAR-C	Number of caregivers not specified; Community program setting	Focuses on strategies that were incorporated throughout development of the interventions to facilitate community-based translation and elucidates the challenges and opportunities faced	<ul style="list-style-type: none"> <li>• Formal commitment</li> <li>• Needs assessment</li> <li>• Quality monitoring tools</li> </ul>	<ul style="list-style-type: none"> <li>• Ongoing training/consultation</li> <li>• Consumer feedback</li> <li>• Supportive facilitation</li> <li>• Adaptability</li> <li>• Presence of supervision</li> <li>• Progress monitoring</li> </ul>	Financing status	Descriptive; None specified

Teri et al., 2018	RDAD-NW	10 AAAs, 225 community dyads	Evaluate the implementation of RDAD-NW and the effectiveness of the translation on outcomes of activity, mood, and QoL	<ul style="list-style-type: none"> <li>• Formal commitment</li> </ul>	<ul style="list-style-type: none"> <li>• Fidelity monitoring</li> <li>• Staged implementation</li> <li>• Consumer feedback</li> <li>• Adaptability</li> <li>• Ongoing consultation</li> </ul>	Financing status	Pretest-Posttest; None identified
-------------------	---------	------------------------------	--	---	---	------------------	-----------------------------------

\*Note: From Hodgson and Gitlin, in press, Gaugler, Bridging the Gap in Family Care, Elsevier Publ.

**Table 5 Summary of Meta-analyses of Pharmacological Treatments for Persons Living with Dementia that Report Outcomes for Family Caregivers**

<b>Full citation</b>	<b>Number of studies included</b>	<b>Date review was conducted</b>	<b>Total number of participants in the study</b>	<b>Drugs tested</b>	<b>Outcome measures</b>	<b>Results</b>
Lingler, J. H., Martire, L. M., & Schulz, R. (2005). Caregiver-Specific outcomes in antedementia clinical drug trials: A systematic review and Meta-Analysis. <i>Journal of the American Geriatrics Society</i> , 53(6), 983-990. doi:10.1111/j.1532-5415.2005.53313.x	17	1990- 2004	4744	Donepezil Velnacrine Galantamine Rivastigmine Metrifonate Memantine	Psychological well-being Time use Behavior-related burden Burden Time use Ease of use / satisfaction Health costs	<u>Burden:</u> Four trials (N=1,594) met criteria for inclusion. Individual effect sizes ranged from 0 to 0.39, with metaanalysis showing treatment to have a small yet statistically significant effect for burden. <u>Time Use:</u> For six trials (N =2,286) in the metaanalysis, individual effect sizes ranged from 0 to 0.21, and metaanalysis resulted in a weighted average effect size of $d = 0.15$ (95% CI = 0.07–0.24). <u>Other Caregiver-Specific Variables:</u> A few studies provided reports on other endpoints (psychological well-being ( $k = 1$ ), healthcare costs ( $k = 2$ ), satisfaction with treatment ( $k = 2$ ). Reporting of caregivers' baseline characteristics was sporadic in the identified trials. (p. 985).

<p>Schoenmakers, B., Buntinx, F., &amp; De Lepeleire, J. (2009). Can pharmacological treatment of behavioural disturbances in elderly patients with dementia lower the burden of their family caregiver? <i>Family Practice</i>, 26(4), 279.</p>	8	1995-2004	3972	<p>Donepezil Velnacrine Haloperidol Trazodone Metformin Galantamine</p>	<p>Caregiver time Caregiver stress Burden Health status Caregiver distress Allocation of caregiver time</p>	<p><u>Effect on burden:</u> Meta-analysis showed a small but significant beneficial effect with a mean difference of 0.27 (95% CI 0.13–0.41, chi-square 2.98, I<sup>2</sup> = 0%) of antipsychotic drug treatment on behavioural disturbances and caregiver burden. The effect of cholinesterase inhibitors in behaviourally disturbed demented on caregiver burden shows a mean difference of 0.23 (95% CI 0.08–0.33). <u>Caregiver time spent:</u> Meta-analysis of time in minutes spent by family caregiver favours treatment arm (mean difference 41.65 minutes/day, 95% CI 25.29–58.02, chi-square 3.73, I<sup>2</sup> = 0%). Findings suggest that pharmacological treatment of people with dementia lower caregiver burden and time spent caregiving.</p>
--	---	-----------	------	---	---	---



**Table 6. Summary of Reviews of Interventions for Formal Caregivers Providing Dementia Care**

Full Citation	Sample [size]	Setting	Intervention Type	Main Outcomes
Barbosa, Ana, Liliana Sousa, Mike Nolan, and Daniela Figueiredo. (2015). “Effects of Person-Centered Care Approaches to Dementia Care on Staff.” <i>American Journal of Alzheimer’s Disease &amp; Other Dementias</i> 30(8): 713–22.	7 studies included	Residential aged care facilities	Person-centered care approaches on stress, burnout, and job dissatisfaction	<ul style="list-style-type: none"> <li>- 5 of 7 studies reported benefits for direct care workers suggesting potential effectiveness of person-centered care on staff outcomes</li> <li>- Methodological weakness and study heterogeneity make it difficult to draw firm conclusions</li> </ul>
Bird, Mike, Katrina Anderson, Sarah MacPherson, and Annaliese Blair.( 2016). “Do Interventions with Staff in Long-Term Residential Facilities Improve Quality of Care or Quality for Life People with Dementia? A Systematic Review of the Evidence.” <i>International Psychogeriatrics</i> 28(12): 1937–63.	46 studies included	Long-term residential care facilities	Staff development of capacity to provide superior care and quality of life for residents with dementia	<ul style="list-style-type: none"> <li>- Studies demonstrated change over 3 months or greater, including for reduction in challenging behaviors and restraint use</li> <li>- Methodological weakness – not all studies reported on resident outcomes</li> <li>- A number of studies failed to report on quality of care</li> </ul>
Eggenberger, Eva, Katharina Heimerl, and Michael I. Bennett.( 2013). “Communication Skills Training in Dementia Care: A Systematic Review of Effectiveness, Training Content, and Didactic Methods in Different Care Settings.” <i>International Psychogeriatrics</i> 25(3): 345–58.	12 studies included	Various care settings	Enhancement interventions for communication in dementia care	<ul style="list-style-type: none"> <li>- Communication skills greatly improve well-being and quality of life for people with dementia</li> <li>- Communication training shows impact on professional and informal caregivers communication skills, competency, and knowledge.</li> </ul>
Forsetlund, Louise, Morten C Eike, Elisabeth Gjerberg, and Gunn E Vist. (2011). “Effect of Interventions to Reduce Potentially Inappropriate Use of Drugs in Nursing Homes: A Systematic	20 studies included	Nursing home	Reducing inappropriate use or over-prescription of drugs	<ul style="list-style-type: none"> <li>- Educational initiatives had a significant effect on drug usage, though this was reflected by 5 of 10 studies</li> </ul>

Review of Randomised Controlled Trials.” BMC Geriatrics 11(1): 16.				<ul style="list-style-type: none"> <li>- Medication review initiatives had significant effect on at least one measure of drug usage, though this was only in 4 of 7 studies</li> <li>- All interventions are context dependent and only 5 of 20 studies gave information as to the extent of implementation</li> </ul>
Moyle, Wendy, Mei Chi Hsu, Susan Lief, and Myrra Vernooij-Dassen. (2010). “Recommendations for Staff Education and Training for Older People with Mental Illness in Long-Term Aged Care.” International Psychogeriatrics 22(7): 1097–1106.	17 studies included	Long-term aged care	Geriatric mental health education and staff training	<ul style="list-style-type: none"> <li>- Majority of studies focus on behavioral management as opposed to mental health needs of older adults in LTCs.</li> <li>- Data supports education and training in a number of conditions</li> <li>- Of vital importance for intervention effectiveness is the need for organizational leaders to support training</li> <li>- Ongoing training required to sustain change</li> </ul>
Spector, Aimee, Catherine Revolta, and Martin Orrell. (2016). “The Impact of Staff Training on Staff Outcomes in Dementia Care: A Systematic Review.” International Journal of Geriatric Psychiatry 31(11): 1172–87.	19 studies included	Various care settings	Staff training for improved staff outcomes	<ul style="list-style-type: none"> <li>- 16 studies found significant change following training in at least one staff domain, with knowledge improving most frequently</li> <li>- The most effective approaches were those focused on managing behavioral symptoms of dementia</li> </ul>
Terkelsen, Anne Seneca, Jacob Vorup Petersen, and Hanne Kaae Kristensen. (2019). “Mapping Empirical Experiences of Tom Kitwood’s Framework of Person-centred Care for Persons with Dementia in Institutional Settings. A Scoping	19 studies included	Various (“institutional”) care settings	Mapping of empirical experiences in clinical practice using Kitwood’s theoretical framework	<ul style="list-style-type: none"> <li>- Tendency towards positive experiences as a result of person-centered approaches in clinical practice</li> <li>- Kitwood’s framework found to be beneficial and useful in practice</li> </ul>

Review.” Scandinavian Journal of Caring Sciences (6): scs.12709.				
Westermann, Claudia, Agnessa Kozak, Melanie Harling, and Albert Nienhaus. (2014). “Burnout Intervention Studies for Inpatient Elderly Care Nursing Staff: Systematic Literature Review.” International Journal of Nursing Studies 51(1): 63–71.	16 studies included	Inpatient elderly and geriatric long-term care	Burnout intervention studies	<ul style="list-style-type: none"> <li>- Interventions classified as work-directed, person-directed, and combined approach of both</li> <li>- 7 of 16 reported reduction in staff burnout (2 work-directed, 2 person-directed, and 3 combined)</li> <li>- Person-directed interventions reduced burnout in the shorter term (1 month) while work-directed interventions retained effects of burnout reduction for more than 1 year</li> </ul>