Non-Pharmacological Interventions for Persons Living with Alzheimer's Disease: Decadal Review and Recommendations

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EXECUTIVE SUMMARY

This National Academies of Science, Engineering, and Medicine decadal paper generates recommendations to advance the science of non-pharmacological interventions for persons living with AD. In addition to a brief synthesis of scientific evidence identifying potentially effective approaches, we aim to summarize and integrate the results to offer a roadmap of sorts to advance future scientific inquiry in this area.

We conducted a scoping review of systematic reviews published between 2016-2019 that reported the effects of non-pharmacological interventions on any outcome related to persons with dementia, their family/friend caregivers, and/or clinical staff. We found 49 systematic reviews and meta-analyses of RCTs for non-pharmacological interventions for persons with AD in the prior three years alone. Foundational evidence and "signals" apparent in this recent intervention literature suggests that certain intervention approaches are potentially effective (particularly studies that feature protocols with stronger, more transparent reporting strategies and rigorous designs). However, conclusions as to efficacy or effectiveness are challenging if not impossible due to how control groups are defined, incomplete reporting of protocols and key intervention characteristics, heterogeneous outcome measures, and lack of clarity related to effect sizes or, perhaps more importantly, the clinical relevance of reported effects. Such challenges make any conclusions drawn by even highly rigorous systematic reviews or meta-analyses suspect.

For persons living with AD, their care providers, and researchers, the lack of consistent or interpretable evidence supporting the efficacy of non-pharmacological interventions for persons with AD is a source of frustration. In response, we offer recommendations to advance this area of science and to build upon a body of evidence that is less than convincing regarding the potential of non-pharmacological interventions for persons with AD. If intervention research continues to largely consider negative outcomes, then providers of dementia care will also continue to orient their services and supports through the lens of inexorable decline. Incorporating a more holistic perspective in the science of interventions for persons with dementia may very well redirect dementia care to emphasize not only what someone can no longer do, but also what someone can *still* do (e.g., strength-based interventions). An *a priori* focus on implementation could avoid the current state of affairs where an intervention is designed, tested, and shown as efficacious but is too complex, requires too much training to deliver, and focuses on outcomes that have little to no meaning to end users. Incorporating stakeholders throughout the scientific process could also help to avoid this common scenario. Non-pharmacological interventions for people living with AD should consider incorporating measures that better align with achievable goals in dementia care and perhaps stimulate providers themselves to begin incorporating these key domains in their day-to-day service delivery. More routine dissemination of process evaluations would help providers identify program elements that are amenable to implementation and result in an improved understanding of how and why interventions work. To date, non-pharmacological interventions of persons living with AD have not adopted rigorous reporting frameworks formally or consistently, but doing so would overcome a significant challenge when interpreting and implementing strategies to benefit persons with AD. The dementia capable/dementia friendly grassroots movement has led to exciting innovation that may lead to new community-level delivery approaches. Greater alignment between dementia friendly efforts and scientific research may be beneficial. A range of additional recommendations emerging from the 2017 *Research Summit on Dementia Care: Building Evidence for Services and Supports* should also guide future evaluations of non-pharmacological interventions for persons with Alzheimer's disease, including increased understanding related to the experience of AD among diverse, underrepresented families, comprehensive care models, and technological innovations.

The National Alzheimer's Project Act has spurred increased research activity and excitement among scientists as well as the AD community at-large. There is new energy in the development, design, and evaluation of non-pharmacological interventions for persons with AD. However, there are significant challenges to conducting rigorous research in this area. Questions remain about how positive results and interventions can benefit *all* persons living with AD. Reframing the dementia experience as one that encapsulates resilience as well as decline is a rallying point for researchers and can improve the design, measurement, and implementation potential of non-pharmacological interventions for persons living with AD.

INTRODUCTION

The unprecedented aging of U.S. society combined with the increasing number of people living with Alzheimer's disease (AD) has created a stark public health concern. There is little doubt that AD drives healthcare costs to a greater extent than most other chronic conditions among older persons (The Alzheimer's Association, 2019). The presence of AD is routinely associated with greater mortality and morbidity risk than among age-matched controls. In addition, the co-occurrence of AD with other chronic conditions among older persons greatly complicates, if not overwhelms, standard healthcare practice in many provider systems (Atri, 2019; Borson & Chodosh, 2014). An additional concern is the extent to which families serve as the primary source of at-home care for older persons with AD, often at great cost to themselves and their employers (National Academies of Sciences, Engineering, and Medicine, 2016; Gaugler, Jutkowitz, & Peterson, 2017; Gaugler, Pestka, et al., 2018; L. N. Gitlin & Schulz, 2012; Spillman, Wolff, Freedman, & Kasper, 2014).

Most resources and efforts to cure, prevent, and even treat/manage AD have focused on pharmacological solutions. The modest (at best) benefits of pharmacotherapy for persons with AD, along with the considerable challenge of effective medication management in dementia, have led to the exploration of a wide array of non-pharmacological treatments to prevent and more effectively manage AD. The extensive heterogeneity in content, duration, frequency, and delivery of these interventions have made it difficult for researchers to determine whether and how these strategies are beneficial to persons with AD (Brasure et al., 2018; Brasure et al., 2016; Jutkowitz et al., 2016; Kane et al., 2017). However, the rapidly emerging research base documenting non-pharmacological interventions' potential to treat, manage, or prevent AD have begun to provide researchers, clinicians, families, and persons with AD with an emerging picture of optimal AD care.

This National Academies of Science, Engineering, and Medicine decadal paper generates recommendations to advance the science of non-pharmacological interventions for persons living with AD. In addition to a brief synthesis of scientific evidence identifying potentially effective approaches, we aim to summarize and integrate the results to offer a roadmap of sorts to advance future scientific inquiry in this area.

SYNTHESIS OF EVIDENCE

With the updated 2011 diagnostic guidelines for AD, a framework emerged to guide clinicians when identifying individuals in the mild cognitive impairment as well as the "pre-clinical" stages of the disease. The preclinical stage includes those who are asymptomatic or demonstrate early symptoms but do not exhibit the changes in cognition and thinking that reflect mild cognitive impairment nor require extensive help with activities of daily living (Atri, 2019; Jack et al., 2018; Mast, 2018; Sperling et al., 2011). This new framework provides clinicians, researchers, and others a structure to identify individuals much earlier in the disease process, where it is hypothesized that treatments or preventive efforts of the future may better exert positive benefits for persons at-risk for AD prior to symptom manifestation (Atri, 2019; Jack et al., 2018).

Non-pharmacological interventions will likely have a central place in any potential AD prevention effort (Livingston et al., 2017; Rosenberg et al., 2018). However, there is no prevention or treatment strategy on the horizon that will divert individuals entirely from the later stages of AD (called "AD Dementia" in the 2011 diagnostic criteria update). Cognitive impairment across multiple domains, behavioral challenges, and functional decline throughout the middle and later stages of AD will still require effective non-pharmacological management strategies (indeed, such approaches are often the interventions of choice in these stages of AD) (Gaugler, Yu, Wood, & Shippee, 2014; Odenheimer et al., 2013).

Appraising the Findings: What Non-Pharmacological Interventions Work for Persons with AD?

Method

We conducted a scoping review of systematic reviews published between 2016-2019 that reported the effects of non-pharmacological interventions on any outcome related to persons with dementia, their family/friend caregivers, and/or clinical staff. We included reviews that had a clearly formulated research question and applied a methodological framework to identify, select, and analyze primary research. Reviews were excluded if they only reported effects of a pharmacologic intervention. We conducted our search in Medline (see Appendix for strategy) and identified 4,112 articles of which 49 met our inclusion criteria.

As Table x-1 suggests, there exists a remarkably heterogeneous base of non-pharmacological interventions evaluated within randomized controlled trial (RCT) designs. Recent syntheses and reviews of interventions indicate important weaknesses in the scientific rigor of existing studies related to design, sample sizes, measurement, and complexity of interventions evaluated (thus making it difficult to combine single studies into intervention categories) (Gaugler Jutkowitz, Shippee, & Brasure, 2017). However, several individual studies and programs have demonstrated important benefits for persons with AD. To this end, it is important that clinical providers as well as people with AD and their families realize that there *are* single interventions that have potential to improve outcomes.

We found 49 systematic reviews and meta-analyses of RCTs for non-pharmacological interventions for persons with AD in the prior three years alone. Foundational evidence and “signals” apparent in this recent intervention literature suggests that certain intervention approaches are potentially effective (particularly studies that feature protocols with stronger, more transparent reporting strategies and rigorous designs) (Jiska Cohen-Mansfield, 2001; Gitlin & Hodgson, 2015; Gitlin, Kales, & Lykestos, 2012; Gitlin, Marx, Stanley, & Hodgson, 2015; Gitlin, Hodgson, Choi, & Marx, 2015).

Notwithstanding the growing number of individual evaluations and systematic reviews of non-pharmacological interventions for persons with AD, this literature is still nascent in its development and rigor when compared to pharmacological interventions for AD. Conclusions as to efficacy or effectiveness are challenging if not impossible due to how control groups are defined, incomplete reporting of protocols and key intervention characteristics, heterogeneous outcome measures, and lack of clarity related to effect sizes or, perhaps more importantly, the clinical relevance of reported effects. Such challenges make any conclusions drawn by even highly rigorous systematic reviews or meta-analyses suspect. Indeed, of the 49 recent systematic reviews included in Table x-1, 25 have concluded that evidence is insufficient or lacking the rigor necessary to draw strong conclusions as to the efficacy of a range of intervention strategies.

Below we summarize the effects of non-pharmacological interventions for several key dementia symptom domains.

Cognitive Decline

Several strategies, some of them difficult to distinguish from each other, have attempted to alleviate cognitive decline in persons living with AD. For example, cognitive training includes guided tasks that are performed in various modalities with the goal of improving memory and thinking. Cognitive training tends to improve domain specific areas of cognition that are targeted in studies (e.g., speed of processing, attention). Cognitive rehabilitation, which has as its goal to enhance daily living for persons with AD through the inclusion of memory activities and memory-boosting approaches, has shown limited benefit particularly when compared to other strategies designed to maintain or improve cognition for persons living with dementia (Bahar-Fuchs, Clare, & Woods, 2013; Bahar-Fuchs, Martyr, Goh, Sabates, & Clare, 2019; Huntley, Gould, Liu, Smith, & Howard, 2015). In general, cognitive interventions (e.g., reminiscence therapy, cognitive training, cognitive rehabilitation, cognitive stimulation) appear to exert moderate benefits for cognition (Folkerts, Roheger, Franklin, Middelstadt, & Kalbe, 2017; Garcia-Casal et al., 2017).

One strategy that has generated more positive effects in reducing cognitive decline is Cognitive Stimulation Training (CST). Cognitive Stimulation Training is the only non-pharmacological therapy recommended for the treatment of AD by the National Institute for Health and Clinical Excellence in the United Kingdom. Cognitive Stimulation Therapy is often delivered in a group format with the goal of enhancing cognitive and social function through various approaches, such as reminiscence and reality orientation (orienting individuals to the day, date, and weather to place persons in “reality”). Systematic reviews have found that CST can help improve cognition and memory, usually for persons with less severe dementia symptomatology (Aguirre, Woods, Spector, & Orrell, 2013; Bahar-Fuchs et al., 2019; Woods et al., 2012). Important caveats are the need to determine whether CST is as effective in community-based settings (to date most high-quality CST evaluations have taken place in congregate, residential environments). Moreover, CST appears to have short-term benefits (Bahar-Fuchs et al., 2019) and does not appear to consistently improve other important domains in AD such as mood, behavioral symptoms, or daily function.

Physical activity has also attracted attention for its potential to maintain or enhance cognitive function for persons with AD. Aerobic and non-aerobic exercise have shown positive effects on cognitive function for persons living with dementia and may also slow cognitive decline (Duan et al., 2018; Farina, Rusted, & Tabet, 2014; Groot et al., 2016; Karssemeijer et al., 2017; Liang et al., 2018; Lim, Pysklywec, Plante, & Demers, 2019). Reality orientation also appears to exert moderate benefits on cognition for persons living with dementia (Chiu, Chen, Chen, & Huang, 2018).

It is important to emphasize that current research does not provide a clear picture as to which interventions are most consistently efficacious when preventing cognitive decline (Oh & Rabins, 2019). For example, a rigorous 2017 systematic review commissioned by the National Institute on Aging and conducted by the Agency of Healthcare Research and Quality (via the University of Minnesota's Evidence-Based Practice Center) found that, overall, the rigor of available research remains less than optimal (Kane et al., 2017; Oh & Rabins, 2019; see also Oltra-Cucarella et al., 2018). Patterns or "signals" of effectiveness are emerging for different types of physical activities (e.g., aerobic exercise, resistance training). Given that one comprehensive report estimated that up to 35% of dementia risk is potentially attributable to preventable domains across the life course such as less early-life education, mid-life hearing loss, mid- and later-life cardiovascular risk factors, and later life social isolation and depression (Livingston et al., 2017), recent individual interventions have adopted a multi-component approach to target several of these risk factors simultaneously. The FINGER study (the Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability) attempts to modify nutrition, exercise, cognitive training and social activity among older adults and has demonstrated positive benefits in maintaining or even enhancing cognition (Ngandu et al., 2015;

Oh & Rabins, 2019; Rosenberg et al., 2018). Programs that de-prescribe multiple medications also hold considerable potential in this area, as certain types of medications that older persons may use (e.g., benzodiazepines) as well as the use of multiple medications may exacerbate cognitive issues in older persons (Oh & Rabins, 2019).

Functional Decline

Functional dependence is a core symptom of dementia and is directly linked to several potentially adverse events for individuals living with AD such as falls and greater dependence on help from others. Functional dependence is not only due to neuropathological decline that occurs during the course of dementia, but also results from contextual factors that are inappropriately designed or delivered to meet the needs of the person living with AD (Gitlin, Hodgson, Choi, & Marx, in press). Contextual factors that may contribute to cognitive decline include complications with medication management; cluttered, loud, or poorly lighted environments; information that is ineffectively communicated; and overly complex tasks that do not recognize what the person with AD can still complete. However, these factors are modifiable.

Scientific evidence suggests that several classes of interventions for persons with AD are modestly beneficial in reducing functional decline. Occupation-based and cognitive interventions have demonstrated effectiveness in reducing functional decline for persons with AD as reported in systematic reviews (Smallfield & Heckenlaible, 2017). Promoting and/or improving physical activity for persons with AD is also potentially beneficial; this may occur through routine care interactions in formal care settings (e.g., Function Focused Care) (Galik, Resnick, Hammersla, & Brightwater, 2014; Resnick & Galik, 2013) along with other physical activity programs that feature aerobic exercise, resistance training, flexibility, or activities that combine all three (Gitlin, Choi, et al., in press; Henwood, Neville, Baguley, Clifton, & Beattie, 2015; Karssemeijer et al., 2017; Lewis, Peiris, & Shields, 2017; McCaffrey, Park, Newman, & Hagen, 2014; Potter, Ellard, Rees, & Thorogood, 2011; Vreugdenhil, Cannell, Davies, & Razay, 2012). In-home modification and family caregiver skills training programs have also demonstrated some ability to slow functional decline among persons living with AD (Gitlin, Winter, Dennis, Hodgson, & Hauck, 2010; Graff et al., 2006). Specifically, approaches that provide education and strategies to the caregiver to manage behavioral challenges, offer physical activity for the person living with AD, and home modification may help to stem functional decline (Gitlin, Choi, et al., in press).

Behavioral and Psychological Symptoms

Behavioral and psychological symptoms are among the most challenging for persons living with AD to experience and for their care providers to manage. Behavioral and psychological symptoms often drive the residential care admission process for persons with AD (Gaugler, Yu, Krichbaum, & Wyman, 2009) and thus are a prime target for non-pharmacological interventions. Tailoring activities to interests of persons living with AD has generated quality evidence in reducing behavioral challenges (Gitlin et al., 2009, 2016, 2018). In addition, combining skills building for caregivers along with education and support has shown promise in reducing behavioral and psychological symptoms for persons with AD (Belle et al., 2006; Brodaty & Arasaratnam, 2012). A recent meta-analysis has suggested that multidisciplinary care, massage and touch therapy, and music combined with massage and touch therapy showed clinical efficacy in reducing aggression and agitated behaviors for individuals living with dementia, and that such approaches appear more beneficial than pharmacological approaches in managing behavioral and psychological symptoms (Watt et al., 2019). It is important to note that close to half of the studies included were of lower scientific quality in the Watt et al. meta-analysis. A 2019 “review of reviews” as well as other recent systematic reviews have found that cognitive and sensory stimulation, music therapy, animal therapy, and psychotherapeutic approaches (e.g., cognitive behavioral therapy) hold potential for reducing depressive symptoms and anxiety as well as enhancing overall quality of life and mood (Kishita, Backhouse, & Mioshi, 2020; see also Hu, Zhang, Leng, Li, & Chen, 2018; Liang et al., 2018; Lorusso & Bosch, 2018; Peluso et al., 2018; Tay, Subramaniam, & Oei, 2019; van der Steen et al., 2018; Wood, Fields, Rose, & McLure, 2017; Yen & Lin, 2018; Zhang et al., 2017). Cognitive stimulation and training, as described above, also appears to have some promise in improving well-being and reducing depression among persons living with dementia in addition to its benefits for cognitive function (Aguirre et al., 2013; Fukushima et al., 2016; Garcia-Casal et al., 2017).

DRIVING THE SCIENCE OF NON-PHARMACOLOGICAL INTERVENTIONS FORWARD

For persons living with AD, their care providers, and researchers, the lack of consistent or interpretable evidence supporting the efficacy of non-pharmacological interventions for persons with AD is a source of frustration. Perhaps the collective findings suggest that in fact many non-pharmacological approaches are non-effective. Alternatively, the results of systematic reviews may emphasize a need to reframe how we design, evaluate, and implement interventions for persons with AD, their families, and care providers. In response to the latter point we offer recommendations to advance this area of science and to build upon a body of evidence that is less than convincing regarding the potential of non-pharmacological interventions for persons with AD.

What is Our Philosophy?

Alzheimer's disease is precisely that: a disease, and one that is chronic and progressive. However, the characterization of AD as a disease of unavoidable decline has also led to discounting of personhood (Ballenger, 2017) and an unwillingness to consider the care preferences of people living with dementia. In other words, the "disease" in Alzheimer's has progressed beyond studies of biological processes and has influenced how we view and care for people living with dementia in ways for which they are voicing considerable dissatisfaction (Camp, 2019).

People living with dementia are explicit in their desires to remain involved in the community (Heid, Bangerter, Abbott, & Van Haitsma, 2017; Reamy, Kim, Zarit, & Whitlatch, 2011), but are at risk for social isolation due to stigmatization, functional challenges, depression, or other issues. In response to calls from family members and persons living with dementia to redefine AD, researchers in Europe have begun to consider AD as an experience that is simultaneously influenced by cellular or biological changes as well as cultural attitudes and sociocultural factors (e.g., the inclusion of persons living with dementia in valued social roles and relationships) (Gaugler, Bain, et al., 2019; Sabat, Napolitano, & Fath, 2004). A major consequence of viewing AD as a social process is that the focus of care, interventions, or scientific study of AD is reframed away from the sole focus on decline and instead towards structural limitations and environmental factors that may explain why persons with AD are not fully engaging with or maximizing their existing cognitive and functional abilities (Cohen-Mansfield, Golander, & Arnheim, 2000; Gaugler, Bain, et al., 2019; Groen-van de Ven et al., 2017).

The INTERDEM Social Health Taskforce, a consortium of primarily European researchers, has offered a new definition of health that reflects the experiences of people living with AD (Dröes et al., 2017). Although many persons with dementia struggle with changes in memory, cognitive, function, and behavior daily, some people living with AD continue to remain engaged in life activities that maintain personhood. For this reason, the INTERDEM Social Health Taskforce has recommended an emphasis on *social health*, or the extent a person with AD is able to participate in social life. Specifically, social health refers to: 1) functioning to maximize the person with AD's abilities; 2) maintaining autonomy and coping effectively with the challenges of AD; and 3) engaging in social activities and relationships in meaningful ways.

Such a philosophical and theoretical approach has appeal in that it better reflects the true experience of family caregivers and persons living with AD. The social health model also has profound ramifications for the methodology of non-pharmacological interventions for persons with AD. Inherent in the social health model is the incorporation of standard measures that capture not only the decline that occurs during the course of AD, but also domains that reflect resilience and positive affect. To help facilitate how we understand and approach the study of non-pharmacological interventions for persons living with AD, steps such as relabeling existing measures, incorporating alternative approaches to interpret findings (e.g., understanding how/why persons with AD are resilient in the face of cognitive or functional challenges; Gaugler, Bain, et al., 2019), and adopting conceptual/theoretical frameworks ranging from positive aging to person-centered dementia care models are recommended.

One example of a conceptual model that reframes AD in ways that capture the range of potential outcomes of non-pharmacological interventions for persons living with AD is Gitlin and Hodgson's modification of Powell Lawton's "Good Life" model (Gitlin & Hodgson, 2018;

Lawton, 1983). The model includes four domains that contribute to a "good life:" behavioral competencies (e.g., physical function, activities, behavior); psychological well-being (positive or negative effect); appraisal of life (a sense of meaning and personal valuation of life); and objective environment (the physical and social environment surrounding a person). In the context of AD, the model offers a conceptual framewor0k in which to study resources and strengths as well as needs for persons living with dementia (see Figure x-1).

The addition of new, more integrated/holistic conceptual models can also drive the selection and development of appropriate outcome measures. The Alzheimer's Association has created new dementia care practice recommendations (DCPR) that require measures to determine whether these recommendations are achieved (see Figure x-2) (Fazio, Pace, Maslow, Zimmerman, & Kallmyer, 2018). This has led to the formation of the Alzheimer's Association Psychosocial Measurement Workgroup, which is reviewing existing methodologies with the goal of reorienting how researchers approach and measure life with AD to highlight not only decline, but also resilience and adaptability.

If intervention research continues to largely consider negative outcomes, then providers of dementia care will also continue to orient their services and supports through the lens of inexorable decline. Incorporating a more holistic perspective in the science of interventions for persons with dementia may very well redirect dementia care to emphasize not only what someone can no longer do, but also what someone can *still* do (e.g., strength-based interventions). Health care will require substantial transformation in order to deliver optimal dementia care in this manner, however (Gitlin, 2019). Dementia progresses in a "living context," and even small changes to the person's environment or care can result in significant improvements (Gitlin, 2019). Enhancement of professional training across key healthcare disciplines (nurses, social workers, occupational and physical therapists) so that these providers better understand how positive differences are possible in the lives of people living with AD is an important first step towards accomplishing a shift to a “dementia capable” paradigm (Borson & Chodosh, 2014). Similar to how the disability movement has reoriented how we label, think, and deliver care to individuals living with disabilities (Gaugler, 2016), the care philosophy for persons living with AD requires a fundamental, paradigmatic shift to enhance the well-being and social health of individuals with dementia and their families. This transformation will also offer more fertile ground for the successful implementation of evidence-based, strengths-based, non-pharmacological interventions so that they can reach those who could benefit the most from such programs.

Advancing Implementation Science

Systematic reviews and meta-analyses suggest that various non-pharmacological treatments for persons living with AD may hold promise in reducing cognitive decline, maintaining or sometimes even improving function, and managing behavioral concerns. Moving beyond such reviews (which, as noted above, are hindered by attempts to synthesize a complex and highly variable literature), several single intervention programs have demonstrated significant benefits for people with dementia. However, it is unclear how many of these promising interventions are readily available for people living with AD or their families.

There are multiple challenges to ensuring that persons with dementia and their families receive evidence-based programs and services (Gitlin, Choi, & Marx, in press). For example, many providers themselves are unaware of the various evidence-based practices that exist for dementia care, particularly if this evidence is largely disseminated in academic journals. Many healthcare professions that serve older persons and their families do not receive adequate training in dementia care. Researchers themselves are not necessarily rewarded for advancing their research beyond the scientific evaluation stage; thus, many promising practices that could benefit people living with AD and their families remain "on the shelf" in scientific journals that very few in clinical or community-based care settings read.

Researchers must continue to disseminate evidence-based dementia care programs to reach stakeholders (and academic institutions should reward such endeavors). Viewing implementation as important at the *outset* of intervention design would help researchers craft programs that are most immediately relevant to persons living with AD and their families. An *a priori* focus on implementation could avoid the current state of affairs where an intervention is designed, tested, and shown as efficacious but is too complex, requires too much training to deliver, and focuses on outcomes that have little to no meaning to end users. Incorporating stakeholders throughout the scientific process could also help to avoid this common scenario (Gitlin & Czaja, 2015; Gitlin, 2019; Wethington & Burgio, 2015).

Researchers should consider multiple factors that can facilitate or hinder implementation success. The context of where an intervention is to be delivered and for whom is critical. The feasibility and acceptability of delivering a given intervention in a home, clinic, or community-based environment are all issues that researchers must address early in intervention development and evaluation. Whether people with AD and their family caregivers are actually *ready* to receive a given intervention, willing to pay to receive a particular intervention, or perceive the intervention as something that can save time are all important evaluation components that to-date are rarely incorporated in RCTs (Gitlin & Rose, 2016Jutkowitz, Gitlin, & Pizzi, 2010). A factor that often hinders implementation potential of non-pharmacological interventions for persons with AD is the extent to which healthcare providers must obtain formal training in order to deliver a given program. If training is time-intensive and there is little likelihood for staff reimbursement for either training or intervention delivery, healthcare systems are unlikely to adopt an evidence-based intervention into their routine practice schedule. Adopting optimization approaches that identify elements of complex interventions that are most effective and amenable to translation in real-world settings (the Multiphase Optimization Strategy; see (Collins, Murphy, & Strecher, 2007) and "pragmatic" trials where interventions are tested in real-world healthcare settings (Baier, Jutkowitz, Mitchell, McCreedy, & Mor, 2019; Baier, Mitchell, Jutkowitz, & Mor, 2018) are additional strategies that can enhance the implementation potential of interventions.

Easy-to-use decision-making tools to more effectively connect providers with available non-pharmacological interventions that are ready for implementation could also address the dissemination gap. The Benjamin Rose Institute has developed a tool that includes relevant information for providers to utilize when considering implementation of evidence-informed dementia caregiver interventions in their organizations or healthcare settings (The Family Caregiver Alliance, 2019). Creating a similar tool that includes evidence-based, non-pharmacological interventions for persons living with AD may further expedite the timeline between scientific evaluation and the actual delivery of promising approaches to people who need them.

Engagement of Persons Living with AD and their Family Caregivers

An important element of "reframing" non-pharmacological interventions for persons living with AD is involving them in all stages of the research process. In the U.K., "patient and public involvement" (PPI) is an essential facet of AD research infrastructure (Gaugler, Bain, et al., 2019; Gove et al., 2018). In PPI, people living with AD and their caregivers offer critical input as well as approval of research ideas that involve persons living with dementia and their care providers. The PPI engagement process has helped to refine as well as develop new measures that capture the wider experience of living with AD (Oksnebjerg et al., 2018). Over the past decade, over 50 articles have examined various facets of engaging persons living with AD in the research process (Bethell et al., 2018). Although most efforts feature persons living with AD and their caregivers in an advisory capacity during the conduct of various research studies, others have utilized engagement to inform study preparation or dissemination activities. It remains largely unknown how PPI-inspired strategies influence research rigor, performance, or intervention outcomes. In one exception, use of focus groups helped enhance recruitment success (Iliffe, McGrath, & Mitchell, 2013). More inquiry is needed to refine how persons living with AD and their family caregivers are involved in research, and perhaps more importantly, how these integral stakeholders improve the evaluation and eventual outcomes of non-pharmacological interventions for persons living with AD.

Aligning Measures with Treatment (and Personal) Goals

Although validated measures of cognitive decline are used in healthcare encounters for persons living with AD, such assessments do not capture the breadth of experience during dementia nor do they fully describe the function, capacity, and indeed *social* health of the individual. Unfortunately, measures linked to domains of optimal dementia care (see Sanders et al., 2017 and https://www.ichom.org/portfolio/dementia/12298/) are not regularly obtained in healthcare settings. This is likely due to unfamiliarity with available measures, a healthcare workforce that as of yet is not “dementia friendly” about assessment procedures, and similar challenges (Gitlin & Hodgson, 2018).

Including measures in non-pharmacological interventions that align with the goals of dementia care treatment as outlined by the American Academy of Neurology (Sanders et al., 2017) or similar organizations would advance the state of the science considerably. Gitlin and Hodgson have aligned their “Good Life” model with domains and respective measures that effectively integrate the full experience of persons with AD and, based on available evidence, are potentially “achievable” via available interventions. These measures and goals reflect those that are important to persons with AD, their family caregivers, and other important stakeholders and are core to what we currently understand as optimal dementia care. Non-pharmacological interventions for people living with AD should consider incorporating measures that better align with achievable goals in dementia care and perhaps stimulate providers themselves to begin incorporating these key domains in their day-to-day service delivery (Gitlin & Hodgson, 2018).

Another facet of measurement development that has gained attention in the past decade is the development and use of measures that matter to persons with AD and their family caregivers (Tochel et al., 2019). In most instances, measures incorporated in non-pharmacological interventions for persons living with AD are valued for their scientific/psychometric properties alone. In addition to the use of robust engagement techniques to refine and develop new measures relevant to the dementia experience, classic techniques such as goal attainment scaling (where personalized goals are identified and measured as a central outcome of an intervention) could help researchers report benefits that are of the greatest value to persons living with AD. Such efforts may also improve clinical care as providers become more aware of issues and goals of central importance to the people and families they serve (Jennings, Ramirez, Hays, Wenger, & Reuben, 2018).

Achieving Greater Understanding of Intervention Benefits and Mechanisms

Some complex, multicomponent interventions may exert positive benefits for persons living with AD, including helping those living with dementia to remain at home. A gap in the current state of the science is an absence of clarity about how and why certain components in complex interventions are more beneficial than others (Gaugler, Reese, & Mittelman, 2018; Gitlin & Hodgson, 2015; Wethington & Burgio, 2015). Few efforts have attempted to "decompose" complex interventions to ascertain whether specific components contribute more to positive outcomes than do other components (for an exception, see Czaja, Schulz, Lee, Belle, & Investigators, 2003).

In addition to the innovative optimization methods mentioned above (e.g., the Multiphase Optimization Strategy; see Collins et al., 2007), there is a need for "process" evaluations of non-pharmacological interventions for persons with AD. Although RCTs continue as the gold standard for establishing evidence, if no information is offered as to why a given intervention is efficacious practitioners are deprived of important information about how to replicate or implement that intervention into practice (Moore et al., 2015; Oakley et al., 2006). The 2015 Medical Research Council's (MRC) framework is useful when guiding process evaluations (Moore et al., 2015). The framework includes a *description* of the intervention and its causal/theoretical pathways. The *implementation process* refers to measurements of how delivery of the intervention is accomplished as well as a description of what is delivered as part of the intervention (note that the term implementation here differs from how we describe implementation earlier; the latter refers to the study of adopting evidence-based interventions into real-world contexts). *Impact* represents participant responses to an intervention, as well as unexpected consequences or pathways to intervention benefit. The framework also emphasizes the intervention *context* as integral to how context influences implementation and mechanisms of impact, and vice versa (Moore et al., 2015). Frameworks such as those developed by the Medical Research Council can help scientists and key stakeholders disentangle how or why such interventions are successful or not. More routine dissemination of process evaluations would help providers identify program elements that are amenable to implementation and result in an improved understanding of how and why interventions work.

Process evaluations also provide clues as to whether adherence to a given intervention protocol (or lack thereof) is driving outcome findings in RCTs. An accepted design characteristic of RCTs is intention to treat principle: investigators collect outcome information for participants who are randomly assigned to receive an intervention treatment regardless of whether they adhere to/use the treatment as intended. If participants' adherence to interventions deviates from what is expected, investigators cannot be certain whether the findings are due to such deviations or lack of efficacy/effectiveness of the intervention. Greater methodological attention to how interventions for persons with AD are used following randomization would yield improved scientific and clinical findings, as such information would indicate whether an intervention is potentially beneficial if used as intended (Hernan & Robins, 2017).

Advancing Pragmatic Trials in Dementia Care Interventions: The NIA IMPACT Collaboratory

The National Institute on Aging has made considerable, recent investments in research infrastructure to advance dementia care interventions and to begin to understand how evidence-based interventions work in real-world healthcare settings. The goal of the NIA IMPACT (Imbedded Pragmatic AD/ADRD Clinical Trials) Collaboratory is to support and facilitate the integration of embedded pragmatic clinical trials (ePCTs) in healthcare systems that provide care to persons living with AD and their family caregivers.

The NIA IMPACT Collaboratory includes experts in research, practice, and community engagement in dementia care from throughout the U.S. Through its various “Cores,” or committees of experts designed to provide consultation to researchers and advance the science of pragmatic trials in dementia care, the NIA IMPACT Collaboratory is a national resource for all U.S. researchers to ascertain if evidence-based, non-pharmacological interventions can effectively operate in the healthcare settings where persons with AD receive their care. The NIA IMPACT Collaboratory was funded in the fall of 2019 for a 5-year period and will support approximately 40 or more 1-year ePCT pilot studies. In addition to directly supporting pragmatic research to enhance dementia care, the Collaboratory will create and provide technical assistance to guide the conduct of ePCTs in concert with healthcare systems to enhance care provided to persons living with AD and their family caregivers. A key objective of the Collaboratory is robust engagement with stakeholders (including healthcare systems) to ensure that ePCT-derived knowledge is disseminated in ways that are useful and effective when advancing dementia care (https://impactcollaboratory.org/).

Reporting

Inadequate reporting has hindered our understanding of which types of non-pharmacological interventions are most beneficial for persons with AD. Key intervention characteristics such as content of the intervention; delivery method; source of delivery; standardized vs. tailored content; structure/type; intensity; and intended audience are reported inconsistently or not at all. This has led to systematic reviews and meta-analyses inconsistently classifying intervention types (i.e., an intervention is labeled as a certain type in one review and then another in a different review), making it extremely difficult to draw conclusions about which classes of interventions are most effective (Gaugler et al., 2017). Several recommendations could address this issue, some of which are currently mandated by major funders such as the National Institutes of Health (NIH). For example, randomized controlled evaluations of non-pharmacological interventions funded by the NIH must register their study on ClinicalTrials.gov, which can help facilitate reporting transparency. Although not mandated, a best practice that is becoming more common is publishing full intervention protocols in the literature that describe, in detail, how the non-pharmacological intervention is designed and delivered (Gitlin & Czaja, 2015; Gitlin et al., 2019). Publishing protocols provides scientists and other stakeholders with more detailed information about a project's full/*a priori* aims, study procedures, analysis plans, measures, and intervention content than is possible in studies that report outcome results only. As methods for reproducibility become more common and accepted (e.g., providing publicly accessible data along with syntax libraries documenting how and why certain analytic decisions were made), it is likely the field's ability to synthesize findings across evaluations will improve.

Recommendations exist that could further enhance the reporting of non-pharmacological interventions for persons with AD. For example, the Intervention Taxonomy framework, or ITAX (Schulz, Czaja, McKay, Ory, & Belle, 2010) recommends that protocol papers or other intervention dissemination efforts report the following delivery characteristics: method of contact between intervention provider and recipient; materials used in the delivery of the intervention; location of intervention delivery; duration and intensity; extent of intervention "scripting;" sensitivity of intervention to participant background, skills, and abilities; interventionist training; adaptability; and treatment implementation. The content and goals of the intervention along with mechanisms thought to influence outcomes are additional reporting components of iTAX. To date, non-pharmacological interventions of persons living with AD have yet to adopt such rigorous reporting frameworks formally or consistently, but doing so would overcome a significant challenge when interpreting and implementing strategies to benefit persons with AD (Gaugler et al., 2017).

Adverse event reporting is routinely mandated as part of the human subjects regulatory process. Adverse events may also be relevant when evaluating non-pharmacological interventions for persons living with AD, but adverse events are rarely reported in outcome analyses when compared to pharmacological studies (for examples in other disease contexts see Meister et al., 2016; Vaughan, Goldstein, Alikakos, Cohen, & Serby, 2014). Adverse events are important to various stakeholders (payers, people living with dementia, family caregivers), and reporting on differential rates of adverse events across treatment and control conditions would improve the overall quality of intervention reporting.

Creating Stronger Control Groups

The gold standard of evidence-based interventions remains the double-blinded, RCT research design. However, in non-pharmacological intervention evaluations for persons living with AD it is often difficult to "blind," or keep participants unaware, of whether they are receiving an intervention or are assigned to a control group. A variety of control group types exist (Rebok, 2016). Evaluators of many non-pharmacological interventions often choose to compare an intervention to a "usual" or no-care control group. In other instances, investigators create an "attention" control group that offers the same frequency of social contact that participants in a treatment group receive in order to adjust for the possibility that simple social contact is accounting for improvement in outcomes.

Active control groups may help adjust for placebo effects, but only if active control participants have the same expectation of improvement as do those in a treatment group (Boot, Simons, Stothart, & Stutts, 2013). Unfortunately, expectations for improvement are rarely considered in non-pharmacological interventions for persons living with AD; left unmeasured and uncontrolled, expectations for improvement may drive effects that otherwise appear to be due to an experimental treatment/intervention. Such omissions may inhibit our ability to pinpoint causal mechanisms behind intervention benefits for persons living with AD (Boot et al., 2013). With the need for more consistent control group conditions in the intervention science of non-pharmacological treatments for persons living with AD, we recommend improving the quality of control group designs by addressing differential expectations of benefit.

Aligning Science with Community Efforts

A grassroots movement that has coalesced to meet the needs of persons living with AD is the dementia-friendly community. One of the 1st statewide efforts in the U.S. to galvanize communities to become more capable in facilitating how people live with dementia was ACT on Alzheimer's® in Minnesota. ACT on Alzheimer's® grew out of the 2011 Minnesota's Alzheimer's Disease Working Group (a group of stakeholders and experts in dementia and aging who were directed by the Minnesota legislature to develop recommendations to better "prepare" the state as dementia-capable). The five goals of ACT on Alzheimer's® were to: "1) increase detection of Alzheimer's disease and improve ongoing care and support; 2) equip communities to become 'dementia capable' to support residents who live with AD; 3) sustain caregivers by offering them information, resources and in-person support; 4) raise awareness and reduce stigma by engaging communities; and 5) identify and invest in promising approaches that reduce costs and improve care" (Paone, 2015, p. 2), p.2). ACT on Alzheimer's®, through several leadership groups, initially developed free toolkits and resources to help entire communities become better prepared and organized to meet the needs of persons living with AD. Among the resources ACT on Alzheimer's® provided for communities included worksheets and algorithms to enhance the detection of AD and the quality of care delivered in primary care and other healthcare settings, as well as a Dementia-Capable Community Toolkit that allowed communities to self-initiate recommended processes and activities (Paone, 2015). At the conclusion of the ACT on Alzheimer's® funding period (2013-2015), over 34 Minnesota communities were designated ACTion communities that featured hundreds of individuals and organizations. ACT on Alzheimer's® is now a model for national efforts to build dementia-friendly education and communities (i.e., the Dementia Friendly America Initiative) throughout the U.S.

The dementia capable/dementia friendly grassroots movement aims to address the public health challenge of AD directly and in many ways outside of the traditional biomedical research silo. At one level, this has led to exciting innovation that may lead to new community-level delivery approaches. Although some initial, descriptive research of dementia-capable/friendly communities has begun to emerge (Lin, 2017), greater alignment between dementia friendly efforts and scientific research may be beneficial. For example, it remains unclear how "success" is assessed in dementia friendly communities: are dementia friendly communities more likely to facilitate aging in place for people living with AD and to achieve less family caregiver stress? Do dementia friendly communities help to better support persons with AD living alone, which is a growing concern? Do dementia friendly communities demonstrate success in changing local service delivery to provide more optimal dementia care? These are all important, likely stakeholder-relevant questions that researchers well-versed in intervention evaluation could help address. In doing so, stakeholders and scientists together could better document the potential of dementia capable efforts at the community level.

National Summit Recommendations

The 2017 *Research Summit on Dementia Care: Building Evidence for Services and Supports* was a first-of-its-kind national gathering of researchers and key stakeholders with the sole focus of advancing the science of dementia care. Over its 2-day period, over 700 individual recommendations were generated to advance dementia care research, which were later distilled into 12 broad themes with four to seven recommendations each (Gitlin & Maslow, 2018; Kolanowski et al., 2018). Here we highlight those themes and recommendations most pertinent to the science of non-pharmacological interventions for persons living with AD that we have not already.

Accommodating Multiple Factors that Influence Care and Service Needs

The state of the science in non-pharmacological interventions for persons living with AD has generally not captured the important diversity and heterogeneity of individuals and their families in terms of stage of dementia; cultural, ethnic, and linguistic differences; living arrangements (including persons with AD living alone); LGBT persons living with AD and their social networks; and geography. In addition, addressing such diversity among those who may eventually *deliver* non-pharmacological interventions for persons living with AD adds a further layer of complexity. As noted above, attention to intervention process and multiple methodologies to more fully understand why given interventions and their components are effective are essential to the implementation of evidence-based programs into highly diverse familial, clinical, and community contexts.

To date, most samples included in interventions for persons with AD are cis-gendered Caucasians. Although older cohorts remain less racially, culturally, and sexually diverse than younger ones in the U.S., the heterogeneity of older cohorts is rapidly changing with each passing decade. Such trends have magnified the gaps in dementia care science. For example, essential questions about the stigma of AD across diverse communities, such as how and when individual of diverse racial and ethnic background, demographic location, or sexual orientation seek out diagnosis and these underrepresented groups' perceptions of AD (e.g., as a "normal" process of aging, thus perhaps influencing the timing of diagnosis and service utilization) remain, at best, partially answered. Understanding and acknowledging the need to broaden samples and research aims to incorporate this population diversity is critical in the evolving science of non-pharmacological interventions for persons with AD.

Aligning Science with the Progression of AD

Non-pharmacological interventions for persons living with AD often do not assess the long-term implications of their programs. Core to intervention work in this area is greater refinement of current longitudinal studies to better understand how people living with dementia and their caregivers adjust to and manage symptom changes of AD over time. By doing so, interventions could be targeted more effectively towards the symptom clusters and time points of dementia progression that may exert the greatest benefit. Another key recommendation is the need for future researchers to better understand how non-pharmacological and pharmacological interventions for persons with AD operate effectively in concert when alleviating behavioral and psychological challenges related to dementia progression (Atri, 2019).

Comprehensive Models of Care

Comprehensive models of care for persons living with dementia are "intended to reduce difficulties, frustration, and negative health-related and emotional outcomes experienced by such persons and their caregivers as they try to understand and access care, services, and supports that can help them" (Gitlin & Maslow, p. 19)." Although not featured in our synthesis of recent systematic reviews, several individual evaluations of comprehensive care models suggest considerable promise for these approaches (Bott et al., 2019; Callahan, 2014, 2017; French et al., 2014; Reuben et al., 2019; Tan, Jennings, & Reuben, 2014; Thyrian et al., 2017). Examples include the utilization of a care managers or lay care guides that collaborate with primary care physicians and nurse practitioners to develop personalized care plans for persons living with AD and their family caregivers.

Participants of the 2017 Summit identified six principal elements of comprehensive models of care as listed in Table x-2. Identification of variation among models in terms of staffing and location of delivery are important when ascertaining how and what elements of these models are most important when improving key outcomes of persons with AD. As noted earlier, including outcomes that are meaningful to persons living with AD as well as outcomes that can provide some indication of sustainability and implementation potential are other considerations for future evaluations of comprehensive care models. Determining how/if such models are effective for persons with AD across the spectrum of dementia as well as other subgroups (e.g., those without a caregiver or who live alone; LBGT persons with AD and their caregivers) may yield answers of great relevance to individuals with dementia and their caregivers as we better understand how comprehensive models of care result in optimal outcomes.

Physical/Living Environment Considerations

Randomized controlled evaluations of non-pharmacological interventions for persons with AD are often solely focused on the individual: contextual concerns are either not considered or controlled for as a “confound.” However, many evidence-based interventions for persons with AD will often be delivered in the living environment of someone with AD, and whether interventions can effectively occur in such contexts requires attention. Understanding how the physical environment, neighborhoods, or other complex contexts may: 1) influence or modify the effectiveness of interventions; or 2) serve as the primary target of interventions are largely missing from the science of dementia care. Such concerns extend to understanding the complex social networks of persons living with AD. These perspectives may be relevant to those who rely heavily on their environments to maintain quality of life and independence, such as people with dementia living alone. Relatedly, understanding how interventions operate across "space transitions" when a person living with AD moves from one living environment to another, as well as identifying how environments can be modified to help the person with AD maintain their quality of life are additional areas ripe for future scientific inquiry.

Understanding the Financial Burdens of AD

The financial burdens and out-of-pocket costs associated with living with AD exert a significant impact on people's daily lives, but research on non-pharmacological interventions has rarely considered financial burden as an important outcome. The development and evaluation of informational materials or decision-making tools to reduce the financial burdens of living with AD is recommended; in addition, considering financial burdens and personal expenses more regularly when evaluating the effects of non-pharmacological interventions would advance the state of the science in this area.

Integrating Workforce Issues into Dementia Interventions

Additional research recommendations include the study of what comprises effective training for healthcare providers to enhance dementia care. This would include a specification of skills, competencies, and other key milestones that should be incorporated into workforce training programs. Recommendations from the Summit included the following: "health inequities, cultural competence, health literacy, addressing caregiver stress, and training persons living with dementia and their caregivers in how to access and navigate health care and supportive services” (Gitlin & Maslow, 2018, p. 27). Focusing interventions on existing workforce models to ensure that evidence-based intervention components are sustainable in various healthcare and community-based environments is another key recommendation.

Understanding Technology

Rapid advancements in various technologies, including electronic health records, virtual reality, remote monitoring, voice-activated technology, and artificial intelligence will likely change how AD is experienced, managed, and treated (Chung, Demiris, & Thompson, 2016; Demiris, 2015; Gold et al., 2018; Schulz et al., 2015). The ability of technology to personalize intervention delivery (e.g., “precision” health/medicine strategies) requires greater study to ensure that technological innovations are accessible to the people who need them and are effective for various subgroups of people living with AD. For example, innovative precision health technologies for persons with AD may be perceived differently for individuals from diverse ethnic and racial backgrounds, and may require culturally-tailored strategies to refine such technologies and how they are described and delivered (Gaugler, McCarron, & Mitchell, 2019). Given the pace of science, it is unlikely that high quality, RCT-level evidence will be disseminated by the time certain technologies are widely available; technologies are often obsolete once RCT analyses are disseminated due to the rapidity of the technology advancement “curve.” For these reasons, adopting alternative methods including feasibility and acceptability studies as well as other strategies (such as those adopted in engineering sciences) may offer greater insights as to how to optimize technologies to meet the diverse needs of people living with AD.

An extension of enhancing scientific understanding of whether certain technologies work is also determining which type of technology can best address the diverse personal, familial, and environmental needs of someone living with AD. Technologies are easily available (at least to those who can afford them) and are directly marketed to older persons and their families, but data as to whether such technologies actually achieve the goals they are purported to (e.g., aging in place) remain rare. Of greatest use to families and persons living with AD would be the development of scientifically validated tools that match technology type to needs; these tools could better inform end-users of technology. Ongoing validation of technology tools used to collect real-time data and their utility in understanding the efficacy and effectiveness of non-pharmacological interventions for persons living with AD could also advance this area of research significantly.

CONCLUSION

The National Alzheimer's Project Act has spurred increased research activity and excitement among scientists as well as the AD community at-large. There is new energy in the development, design, and evaluation of non-pharmacological interventions for persons with AD. However, there are significant challenges to conducting rigorous research in this area. Questions remain about how positive results and interventions can benefit *all* persons living with AD. Reframing the dementia experience as one that encapsulates resilience as well as decline is a rallying point for researchers and can improve the design, measurement, and implementation potential of non-pharmacological interventions for persons living with AD.

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TABLE 1 Synthesis of Reviews of Non-Pharmacological Interventions for Persons Living with Alzheimer's Disease

Author **Method**	**Dates of Studies Reviewed** **Population**	**# of Studies Included** **Included Study Designs**	**Types of Interventions**	**Person with Dementia Outcomes**	**Key Findings**
(Cotelli et al., 2019) Systematic review	2005-2016 Persons living mild cognitive impairment, Alzheimer's disease, or frontotemporal dementia	5 Randomized controlled trial	Cognitive telerehabilitation	Cognitive ability	• Overall studies were of low quality. • Telerehabilitation may be comparable to face-to-face cognitive rehabilitation.
(Tay et al., 2019) Systematic review	1998-2017 Persons living with dementia	11 Randomized controlled trial Quasi-experimental	Cognitive Behavioral Therapy	Anxiety Depression	• Preliminary evidence indicates cognitive behavioral therapy is effective at reducing anxiety and depressive symptoms among persons with dementia.

					- More rigorous trials are need.
(Lim et al., 2019) Systematic review	2009-2017 Persons in the early stages of dementia or mild cognitive impairment	9 Randomized controlled trial Non-randomized controlled trial Non-randomized prospective study	Tai Chi	Short term cognitive function Global cognitive functions Working memory and executive function Verbal learning and memory Self-perception of memory Attention and concentration Semantic memory	- Tai Chi has the potential to improve short-term cognitive function in the early stages of dementia.

				Visuospatial skills	
(Bahar-Fuchs et al., 2019) Systematic review & meta-analysis	1988-2018 Persons living with mild to moderate dementia.	33 qualitative synthesis 32 meta-analysis Randomized controlled trial	Cognitive training	Global cognition Clinical disease severity Delayed memory ability Capacity to perform activities of daily living Mood and well-being of participant Mood and well-being of informant/caregiver Participant/Treatment burden (retention rates).	• Moderate quality evidence indicates cognitive training relative to control, but not alternative treatment, is associated with small to moderate effects on global cognition and verbal semantic fluency. • Medium to long-term follow up evidence of cognitive training is low.

(Yen & Lin, 2018) Systematic review	2004-2010 Older adults living with and without dementia	16 Randomized controlled trial Nonexperimental studies Qualitative studies	Reminiscence Therapy	Daily functioning Cognition Depression Mood status Self-esteem Life satisfaction	• Findings were not separated for populations with and without dementia. • Reminiscence therapy is associated with improved quality of life and depressive symptoms among older adults.
(van der Steen et al., 2018) Systematic review & meta-analysis	1993-2016 Persons living with dementia	22 (21 included in meta-analysis) Randomized controlled trial	Music Therapy	Emotional well-being (quality of life and positive affect) Mood and affect Behaviors Cognition	• Low quality evidence indicates music-based interventions may improve emotional well-being and quality of life and reduce anxiety. • Moderate-quality evidence indicates music-based interventions reduce depressive symptoms

					and overall behaviors, but there is no effect on agitation/aggression. • Low-quality evidence indicates music-based interventions have no effect on cognition. • Conclusions could not be made regarding the effect of music-based interventions on social behavior or outcomes at long-term follow up.
(van den Berg, Kruithof, Kok, Verwijk, & Spaans, 2018) Systematic review	1991- 2017 Persons living with dementia	17 Prospective cohort Case reports Chart review	Electroconvulsive Therapy	Agitation and aggression	• Clinical improvements were observed in most of the studies, but lack of randomized controlled trials limits inference.

(Spencer, Johnson, & Smith, 2018) Systematic review	2009 Persons living with dementia	1 Cluster randomized controlled study	De-escalation techniques for managing aggression.	Aggression Behaviors	• A single study with high risk of bias found no difference in change in overall behavior.
(Russell-Williams et al., 2018) Review	2010-2016 Persons living with dementia, mild cognitive impairment, or subjective cognitive decline	10 Randomized controlled trial Quasi-experimental	Meditation: • Mindfulness • Kirtan kriya medication • Mindfulness-based Alzheimer's stimulation	Stress Cognition Quality of life	• Medication may result in improvements in stress, cognition, and quality of life. • More rigorous studies are needed.
(Peluso et al., 2018) Review	1995-2016 Persons living with dementia and/or psychiatric disorders	16 Randomized controlled trial Non-randomized clinical trial	Animal-assisted therapy	Cognition Behavior Depression Physical function Quality of life	• Preliminary evidence from studies of low quality indicate that in persons with dementia animal-assisted therapy may decrease behaviors and improve quality of life and social skills.

				Social function	
(Oltra-Cucarella et al., 2018) Systematic review and meta-analysis	1993-2016 Persons living with Alzheimer’s disease or mixed dementias	33 Randomized controlled trial non-randomized clinical trial	Cognition-focused interventions: • cognitive rehabilitation • cognitive training • cognitive stimulation	Cognition Attention Memory Naming Executive functioning Physical functioning	• Cognition focused interventions have limited effects on cognition or function compared to non-cognition focused interventions.

(Mohler, Renom, Renom, & Meyer, 2018) Systematic review and meta-analysis	2000-2015 Persons living with dementia	8 (7 included in meta-analysis) Randomized controlled trial Controlled clinical trial	Tailored activities	Behavior Quality of life Affect Mood Cost	• For persons with dementia living in long-term care facilities, low-quality evidence indicates tailored activities may marginally improve behaviors. • Evidence was inconclusive for quality of life, affect, and mood related outcomes.
(Lorusso & Bosch, 2018) Systematic review	2001-2014 Persons living with dementia	12 Randomized controlled trial Quasi-experimental	Multisensory environments	Behavior Mood	• Multisensory interventions may reduce behaviors and have a positive impact on mood. • Long-term effects are mixed and rigorous studies are needed.
(Liang et al., 2018) Systematic review and network meta-analysis	2004-2016 Persons living with Alzheimer's disease	17 Randomized controlled trial	Physical exercise Music therapy	Cognitive functioning Behavior	• For persons with mild to moderate dementia, physical exercise may improve cognition. • For persons with mild to moderate dementia,

	or mild cognitive impairment		Computerized cognitive training Nutrition therapy		computerized cognitive training may improve behavior.
(Hu et al., 2018) Systematic review and meta-analysis	1999-2016 Persons living with cognitive impairment including dementia and mild cognitive impairment.	10 Randomized controlled trial Quasi-experimental	Animal-assisted intervention	Behaviors Daily living activities Cognition Quality of life	• For persons with cognitive impairment, animal-assisted interventions may reduce behaviors. • For persons with cognitive impairment, animal-assisted interventions may have no effect on daily activities, cognition, or quality of life.
(Herke et al., 2018) Systematic review	1986-2015 Persons living with dementia	9 Randomized controlled trial	Environmental or behavior modifications for food and fluid intake	Food and fluid intake Nutritional status Secondary outcomes: Mealtime behavior	• Conclusions could not be made due to heterogeneity in interventions and poor study design.

				Global and specific cognitive function Daily function Quality of life (QoL)	
(Fusar-Poli, Bieleninik, Brondino, Chen, & Gold, 2018) Systematic review and meta-analysis	2009-2014 Persons living with dementia	6 Randomized controlled trial	Music therapy	Cognition Attention Executive function Learning and memory Language Motor skills	• Overall music therapy had no effect on all outcomes. • A secondary analysis found that active music therapy had a positive effect on global cognition.
(Frederiksen, Gjerum, Waldemar, & Hasselbalch, 2018)	2006-2017 Persons living with no cognitive	8 (6 studies in healthy older adults and 2	Physical exercise	Hippocampal volume	• For persons with dementia, two small studies found physical exercise had no effect biomarker outcomes.

Systematic review	impairment, subjective memory complaints, mild cognitive impairment, or Alzheimer’s disease.	studies in adults with dementia) Randomized controlled trial		Biomarkers: CSF, amyloid-B, tau	
(Duan et al., 2018) Systematic review and network meta-analysis	2006-2016 Persons living with dementia	10 Randomized controlled trial	Home-based exercise Group exercise Walking program Reminiscence therapy Art therapy Psychosocial interventions + acetylcholinesterase inhibitor Cognitive stimulation + acetylcholinesterase inhibitor	Cognition Compliance	• Psychosocial interventions including, walking, home/group exercise, reminiscence therapy, and art therapy are more effective than usual care on measures of cognition. • Nonpharmacologic + acetylcholinesterase inhibitor is more effective than acetylcholinesterase inhibitor alone on measures of cognition. • Compliance was greater for persons in walking and home-based exercise interventions compared to group exercise and art therapy.

			Mindfulness-based Alzheimer's stimulation + acetylcholinesterase inhibitor Progressive muscle relaxation + acetylcholinesterase inhibitor Cognitive training + acetylcholinesterase inhibitor		
(Deshmukh, Holmes, & Cardno, 2018) Systematic review	2006-2011 Persons living with dementia	2 Randomized controlled trial	Art therapy	Cognition Depression Quality of life	• Evidence is insufficient to draw conclusions regarding the effect of art therapy on outcomes.
(Theleritis, Siarkos, Politis, Katirtzoglou, & Politis, 2018) Systematic review	1998-2016 Persons living with dementia	43 Randomized controlled trial	Non-pharmacologic: • Staff training • Multisensory • Walking • Emotion oriented care • Individualized activity • Reminiscence therapy • Music • Art therapy	Apathy	• Most studies do not include apathy as a primary outcome measure. • Non-pharmacologic treatment for apathy is safe and may be effective, but overall

		Quasi-experimental study	- Cognitive therapy		more rigorous studies are need.
(Wu, Wang, & Wang, 2017) Systematic review and meta-analysis	2005-2015 Persons living with dementia	11 Randomized controlled trial quasi-experimental studies	Massage Touch therapy	Behaviors	- Low-quality evidence is insufficient to draw conclusions.
(Wood et al., 2017) Systematic mapping review	2001 - 2015 Persons living with dementia	10 Randomized controlled trial Quasi-experimental studies	Animal-assisted therapies incorporating dogs	Quality of life	- For persons with dementia residing in long-term care facilities, animal assisted therapy may improve quality of life. - More rigorous studies are needed.

(Theleritis, Siarkos, Katirtzoglou, & Politis, 2017) Systematic review and meta-analysis	2004-2016 Persons living with Alzheimer’s disease	22 Randomized controlled trial Quasi-experimental studies	Non-pharmacologic: • cognitive training (group sessions) • reminiscence therapy (group sessions) • individualized cognitive rehabilitation program (individual sessions) • Biography-orientated mobilization • Music and art therapy • Nursing home staff education program • Multisensory • Cognitive stimulation, physical activity, and socialization • Activities	Apathy	• Most studies do not include apathy as a primary outcome measure. • Heterogeneity of studies and poor study design limit inference, but several non-pharmacologic interventions are effective in reducing apathy.
(Streater, Coleston-Shields, Yates, Stanyon, & Orrell, 2017) Systematic and scoping review	1982-2013 Persons living with dementia	7 Randomized controlled trial Quasi-experimental studies	Crisis management: • Psychiatry service • Outreach support • Crisis resolution home treatment team • Mental and behavioral health • Individualized care plan	Hospitalizations Institutionalization Quality of life Cognition	• The overall effectiveness of crisis management on key outcomes is inconclusive. • More rigorous studies are needed

				Activities of daily living Mortality Use of medication Patient/caregiver satisfaction	
(Smallfield & Heckenlaible, 2017) Systematic review	2006- 2014 Persons living with Alzheimer’s disease and related neurocognitive disorders	52 Randomized controlled trial Quasi-experimental studies	Interventions to maintain self-care and leisure: Occupation-based Sleep Cognitive Physical exercise Multicomponent interventions	Physical functioning Sleep Leisure Social engagement	• For persons with dementia, evidence is strong for the effect of occupation-based interventions and cognitive interventions on maintaining functional performance. • Evidence is strong for physical exercise for improving sleep and physical function.
(Lewis et al., 2017) Systematic review	2008-2015	7 (6 included in meta-analysis)	Supervised home or community-based exercise programs longer than 3 months	Function (basic and instrumental activities of daily living)	• For older adults with cognitive impairment, long-term exercise programs improved functional

	Persons living with cognitive impairment	Randomized controlled trial		Falls Hospital readmission	independence compared to usual care. • Two randomized trials suggest long-term exercise programs may reduce falls.
(Karssemeijer et al., 2017) Systematic review and meta-analysis	2008-2017 Persons living with mild cognitive impairment or dementia	10 Randomized controlled trial	ombined cognitive-physical interventions	Cognitive function Activities of daily living Mood	• For persons with dementia, there is a small-to-medium positive effect of combined cognitive-physical interventions on global cognitive function compared to usual care. • There is a moderate-to-large positive effect of combined cognitive-physical interventions on activities of daily living. • There is a small-to-medium positive effect of combined cognitive-physical interventions on mood.

(Karkou & Meekums, 2017) Systematic review	N/A Persons living with dementia	0 Randomized controlled trial	Dance movement therapy	Behavior Social interaction	• No studies met the inclusion criteria.
(Ijaopo, 2017) Systematic review	2008-2017 Persons living with dementia	10 non pharmacologic (3 reviews and 7 primary studies) Reviews Randomized controlled trial	Therapeutic Touch Tailored Activity Program Lavender oil . Music therapy Electroconvulsive therapy Acupressure Reviews of various nonpharmacologic strategies	Agitation Behavior	• Evidence is limited on the effect of nonpharmacologic interventions on reducing severe agitation.

(Garrido et al., 2017) Critical synthesis	2006-2016 Persons living with dementia	28 Randomized controlled trial Non-randomized clinical trial	pre-recorded music alone or in combination with other musical activities	Behaviors	• For persons with dementia, pre-recorded music can be effective in reducing behavioral symptoms including agitation.
(Dimitriou & Tsolaki, 2017) Systematic review	1998-2013 Persons living with dementia	11 Randomized controlled trial	Sensory stimulation interventions: • Massage • Acupuncture • bright light	Sleep disturbances	• Bright light therapy may help reduce sleeping problems compared to usual care.
(Anderson, Deng, Anthony, Atalla, & Monroe, 2017) Systematic review	2008-2015 Persons living with dementia	7 Randomized controlled trial	Complementary and alternative medicine: • Reflexology • Aromatherapy • Therapeutic touch • Foot massage • Aromatherapy and Hand massage • Aromatherapy with donepezil	Behavior Pain	• Complementary and alternative medicine may reduce behavioral symptoms compared to control conditions.

(Abraha et al., 2017) Systematic review	1997-2007 Persons living with dementia	3 Randomized controlled trial Quasi-randomized controlled trial	Simulated presence therapy (audio of video recording)	Behaviors Quality of life	• Low quality evidence indicates the effects of simulated presence on behavioral outcomes is uncertain.
(Charry-Sanchez, Pradilla, & Talero-Gutierrez, 2018) Systematic review	2000-2017 Persons living with dementia, depression and other conditions.	23 (8 on dementia) Randomized controlled trial Quasi-experiential	Animal assisted therapies	Cognition Behavior Mood Physical function	• For persons living with dementia, animal assisted therapy shows promise in short-term management of behaviors, but study design limits inference.
(Chiu et al., 2018) Systematic review and meta-analysis	1981-2016 Persons living with dementia	11 Randomized controlled trial	reality orientation therapy alone or combined with reminiscence therapy or cognitive training.	Cognition Behavior Depressive symptoms	• Reality orientation is associated with a moderate effect on cognitive function. • Intervention has no effect on behavior or depressive symptoms.

(Creighton, van der Ploeg, & O'Connor, 2013) Systematic review	1989-2012 Persons living with dementia	34 Randomized controlled trial Quasi-experimental	spaced retrieval: • name-face associations • object-name associations • cue-behavior associations • mixed goals/other	Recall Behavior	• Spaced-retrieval interventions are viable and may be effective in improving recall and reducing behaviors, but more rigorous study designs are needed.
(Fakhoury, Wilhelm, Sobota, & Kroustos, 2017) Literature review	2000-2015 Persons living with dementia	6 Randomized controlled trial	Music therapy	Behavior	• Findings across studies are mixed.
(Fleiner, Leucht, Forstl, Zijlstra, & Haussermann, 2017) Systematic review	1994-2009 Persons living with dementia	5 Randomized controlled trial Quasi-experiential	Short-term structured exercise	Behavior	• Structured exercise may reduce behaviors. Larger and more rigorous study designs are needed.

(Folkerts et al., 2017) Systematic review & meta-analysis	1981-2016 Persons living with dementia	27 systematic review 15 meta-analysis Randomized controlled trial Quasi-experiential	Cognitive intervention: • reminiscence therapy • cognitive training • cognitive rehabilitation • cognitive stimulation • multimodal interventions	Cognition Global scales for dementia symptoms Quality of life Behavior Mood Physical function	• Cognitive interventions moderately improve global cognition, autobiographical memory, and behaviors. • Cognitive interventions are associated with small improvements in quality of life.
(Garcia-Casal et al., 2017) Systematic review and meta-analysis	2003-2014 Persons living with dementia	12 Randomized controlled trial Quasi-experiential	Computer-based cognitive training: • cognitive recreation • cognitive rehabilitation • cognitive stimulation • cognitive training	Cognition	• Computer-based cognitive training is associate with moderate improvements in cognition and anxiety. • Computer-based cognitive training is associate with a small reduction in depression.

					- Computer-based cognitive training is associate with no effect on activities of daily living.
(Jutkowitz et al., 2016) Systematic review and meta-analysis	1999-2014 Persons living with dementia	19 Randomized controlled trial	Care-delivery interventions: - dementia care mapping - person centered care - clinical protocols - emotion-oriented care - staff education	Agitation Aggression Behaviors Psychotropic use Depression	- Evidence was insufficient to draw conclusions on the effect of care-delivery interventions on agitation/aggression or behaviors.
(Klimova, Valis, & Kuca, 2017) Literature review	2010-2014 Persons living with dementia	6 Randomized controlled trial Quasi-experiential	Dancing therapy	Any outcomes	- Limited data suggests dancing therapy may positively impact cognition, physical function, and mood.

(Woods, Farrell, Spector, & Orrell, 2018) Systematic review and meta-analysis	1987-2016 Persons with dementia	22 (16 included in meta-analysis) Randomized controlled trial	Reminiscence therapy	Quality of life Communication Depression Cognition	• Heterogeneity in study design makes inference challenging, but overall effects are small and inconsistent.
(Levy, Attias, Ben-Arye, Bloch, & Schiff, 2017) Systematic review	1995-2015 Older adults	40 (39 on dementia) Randomized controlled trial Quasi-experiential	Complementary and alternative medicine: • Acupressure • Aromatherapy • Massage • Therapeutic touch • Reflexology • Natural products • Japanese medicine • Osteopathy • Healing touch	Agitation Delirium	• Complementary and alternative medicine had a small effect on reducing agitation. • Conclusions could not be made regarding the effect of complementary and alternative medicine on delirium.
(Morrin, Fang, Servant, Aarsland, & Rajkumar, 2018)	1995-2017	15 Quasi-experiential	Non-pharmacologic interventions: • deep brain stimulation;	Cognition Physical function	• Evidence for the effect of non-pharmacologic interventions for persons with Lewy

Systematic review	Persons living with Lewy body dementia		• transcranial direct current stimulation; • Exercise • electroconvulsive therapy; • repetitive transcranial magnetic stimulation	Quality of life Behavior Mood	body dementia is inconclusive. • More rigorous study designs are needed.
(Nyman, Adamczewska, & Howlett, 2018) Systematic review	2003-2015 Persons living with dementia	19 articles from 9 trials Randomized controlled trial	Behavior change (e.g., goal setting, social support, credible source) to promote physical activity	Participation in physical activity Physical activity Adherence	• Some behavior change strategies are associated with increased participation in physical activity. • More rigorous study designs are needed.
(O'Caoimh et al., 2019) Systematic review and meta-analysis	1992-2018 Persons living with mild cognitive impairment or dementia	48 Randomized controlled trial Quasi-experiential	Non-pharmacologic interventions: • light therapy • Multimodal • Transcutaneous electrical nerve stimulation • Exercise • Acupressure/acupuncture • Cognitive behavioral therapy	Sleep Cognition Mood Behavior	• Non-pharmacologic interventions may significantly improve sleep efficiency outcomes compared to control but overall evidence is insufficient. • More rigorous study designs are needed.

				Quality of life	
(Zhang et al., 2017) Systematic review and meta-analysis	1987-2016 Persons living with dementia	34 Randomized controlled trial Controlled clinical trial	Music therapy	Behavior Cognitive function Depression Anxiety Quality of life	• Music therapy compared to inactive control is associated with reductions in behaviors and anxiety. • The effect of music therapy on cognitive function, depression, and quality of life is unclear.

TABLE 2 Six Principal Elements of Comprehensive Models of Care

1. Inclusion of both the person living with dementia and the caregiver.
2. Ongoing, long-term assistance that spans the trajectory of dementia from early to late stage and end-of-life, addresses the changing needs and preferences of the person living with dementia and caregivers over time, and follows the person with dementia as he/she transitions from one living place to another.
3. Inclusion of both medical care and long-term services and supports.
4. Assessment and ongoing, systematic reassessment to identify changing medical and non-medical problems and concerns, care needs, goals, and preferences of the person living with dementia and his/her caregivers.
5. Care planning to establish and update action steps to address unmet needs and concerns of the person living with dementia and caregivers.
6. Connection of the person living with dementia and his/her caregivers to information, care, services and supports to meet needs, address concerns, and improve outcomes.

FIGURE 1 The Good Life Model. Source: Laura Gitlin, data from Gitlin and Hodgson, 2018.

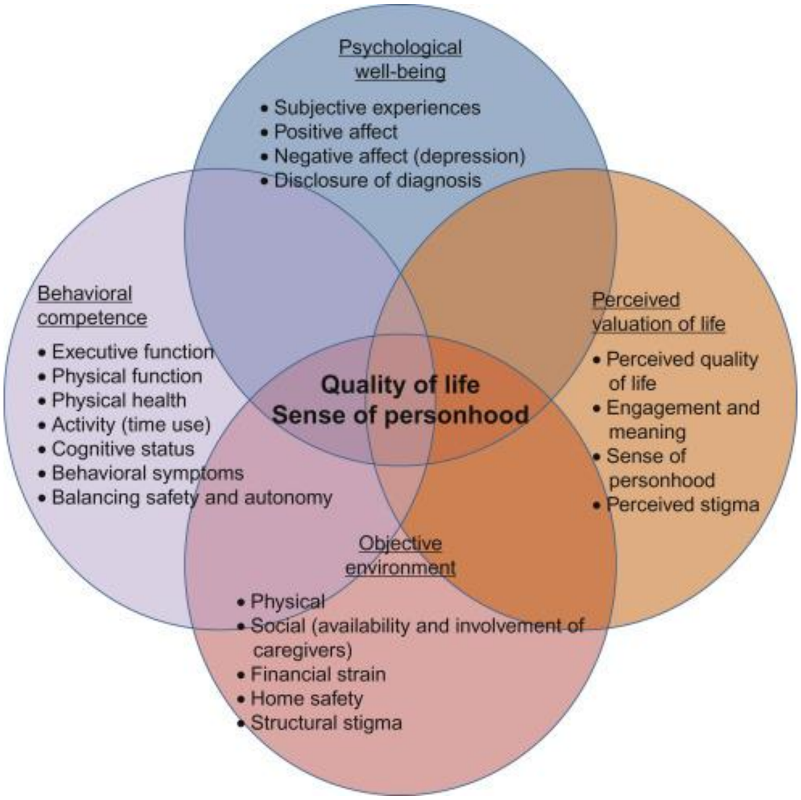

FIGURE 2 Alzheimer's Association Dementia Care Practice Recommendations. (Fazio et al., 2018).