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Documented Outcomes of Informal Caregivers Delivering Home-based Interventions to Persons Living with Dementia: A Scoping Review

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DOCUMENTED OUTCOMES OF INFORMAL CAREGIVERS DELIVERING HOME-BASED INTERVENTIONS TO PERSONS LIVING WITH DEMENTIA: A SCOPING REVIEW

by

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THESIS

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ABSTRACT

Documented Outcomes of Informal Caregivers Delivering
Home-Based Interventions to Persons Living with Dementia:
A Scoping Review

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The University of Texas at Arlington, 2024

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Most people living with dementia in the United States reside at home with informal caregivers. Yet research regarding non-pharmacological interventions for persons living with dementia is mainly conducted in institutional settings. Also, research into the impacts of interventions for persons with dementia on informal caregivers is scarce. This scoping review aims to map the breadth of literature on outcomes of informal caregivers delivering home-based interventions to people with dementia through the lens of the stress process model. Using the Arskey & O'Malley framework, an initial database search yielded 3,977 studies of which 22 were included in this review. Results revealed a high degree of heterogeneity in research with ten different types of home-based interventions delivered by informal caregivers to persons with dementia. Nine out of 10 types showed some positive benefits for caregivers. No intervention had only negative impacts on caregivers. In general, flexible, cost-efficient, easy to implement interventions are preferred by caregivers. While home-based interventions for persons living with dementia seem to have limited impacts on informal caregivers, more research is needed, especially regarding persons of color. Future research would benefit from longer studies with larger sample sizes.

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INTRODUCTION

About 1 in 10 older adults in the United States have some form of dementia (Population Reference Bureau [PRB], 2021). Over 7 million Americans had dementia in 2020 and that number is expected reach over 12 million by 2040. (PRB, 2021). Dementia is an umbrella term encompassing many types of cognitive impairment conditions including Alzheimer's disease, vascular dementia, Lewy body dementia, and frontotemporal dementia (Alzheimer's Association [AA], 2023). Dementia is characterized by memory loss, difficulty reasoning, problems with language and communication, withdrawal, and personality and behavior changes that impact a person's daily life (AA, 2023; PRB, 2020). These mental and physical challenges lead to the need for a caregiver.

Family, friends, and neighbors who serve as caregivers are known as informal caregivers. There are more than 11 million informal dementia caregivers (AA, 2023). Almost half of all informal caregivers in the U.S. (48%) assist a person living with dementia (AA, 2023). Due to the slow progression of many forms of dementia, 57% of informal caregivers of persons with dementia provide care for four or more years (AA, 2023; Brodaty & Donkin, 2009).

In 2011, 80% of people living with dementia resided at home in a traditional community setting (PRB, 2020). Persons living with dementia receive 41% of all caregiving hours for adults ages 65 and older in the U.S., making dementia caregiving one of the most time-consuming types of caregiving (PRB, 2020; Stall et al., 2019). Sixty-five percent of informal caregivers of persons living with dementia help with activities of daily living (ADL) such as bathing, toileting, and feeding (Brodaty & Donkin, 2009). Informal dementia caregivers report greater stress and depression and lower overall health than other caregivers (Brodaty & Donkin, 2009; Campbell, et al., 2008 Moon & Dilworth-Anderson, 2015).

Research into non-pharmacological interventions for persons living with dementia has gained popularity in recent years (Couch et al., 2020; Hayden et al., 2022). Non-pharmacological treatments do not change the overall biological prognosis for people living with dementia, but focus on maintaining or improving cognition, physical functioning, social interactions, quality of life, and calming behavioral and psychological symptoms of dementia (AA, 2023). Unlike drug interventions, non-pharmacological interventions have no potential side effects or negative drug interactions (AA, 2023). They are cost effective because "the cost relates to human endeavor rather than expensive technology or medication" (Olazaran et al., 2010, p. 172). They are recommended as the first choice for some dementia-related issues, such as calming behavioral and psychological symptoms of dementia (BPSD) (AA, 2023; Schneider et al., 2019). Examples of non-pharmacological interventions are aromatherapy, cognitive training, light therapy, massage, music, physical activity, and reminiscence therapy.

Even though most persons living with dementia reside at home and non-pharmacologic interventions are the recommended approach to managing dementia symptoms, research on home-based interventions is limited. Most intervention studies are conducted in nursing facilities or group settings (Bessey & Walaszek, 2019; Bowes et al., 2013; Schneider et al., 2019).

Even though the relationship of the caregiver and the person living with dementia is an important aspect of caregiving, dyadic interventions are not common and are under-studied (Rausch et al., 2017). Additionally, caregiver outcomes are sporadically measured in interventions designed for a person living with dementia (Couch et al., 2019). A scoping review of non-pharmacologic interventions in mild dementia found that only 9 out of 91 studies measured caregiver outcomes (Couch et al., 2019). It is important to consider how interventions for people living with dementia may create unintended consequences for informal caregivers. If the caregiver finds the intervention too stressful, complicated, or time-consuming, the person living with dementia will never benefit from the intervention.

To date, there are five systematic or scoping reviews limited to home-based non-pharmacologic interventions for persons living with dementia (Balvert et al., 2024; de Almeida et al., 2020; Elliot & Gardener, 2018; Schneider et al., 2019; Tan et al., 2022). These reviews covered physical activity programs (de Almeida et al., 2020); music interventions (Elliot & Gardener, 2018); interventions designed for behavioral and psychological symptoms of dementia (Schneider et al., 2019); and a range of interventions including occupational therapy, cognitive rehabilitation, music therapy, personal reminiscence, and multicomponent interventions (Balvert et al., 2024; Tan et al., 2022). However, some reviews included studies utilizing specialists working from the home without the input of caregivers. (Tan et al., 2022). Some studies involved group homes, assisted living or memory clinics, which may involve professionals instead of informal caregivers (Schneider et al., 2019; Tan et al., 2022). Two reviews included interventions in group settings (Balvert et al., 2024; Elliot & Gardener, 2018). None of the reviews focused only on informal caregiver outcomes. In contrast to the above reviews, this scoping review will include only dyadic interventions with informal caregivers in the place where most people living with dementia spend the most time, the home.

While some reviews of home-based interventions for people living with dementia include impacts on informal caregivers, the literature is incomplete. The goal of this scoping review is to map the full breadth of literature available on caregiver outcomes when delivering home-based, dyadic, non-pharmacological interventions targeting persons living with dementia.

LITERATURE REVIEW

Older Adults Living with Dementia

More than 55 million people globally live with dementia (WHO, 2023). There are around 10 million new cases worldwide reported each year (WHO, 2023). As the population of older adults grows in the U.S., the number of people living with dementia will also grow to an estimated 14 million by 2060 (CDC, 2023; PRB, 2021). Adults 65 and over are most affected by dementia, with age being the strongest known risk factor (CDC, 2023). Women have higher disability and mortality rates from dementia than men (WHO, 2023). Blacks and Hispanics are more likely to develop dementia than Whites (CDC, 2023).

Dementia is an umbrella term encompassing many types of cognitive impairment diseases that lead to the inability to remember, think, and make decisions such that it interferes with daily living (CDC, 2023). There is no cure for dementia (WHO, 2023). The most common types of dementia are Alzheimer's disease, vascular dementia, Lewy body dementia, and frontotemporal dementia (AA, 2023; CDC, 2023). Traumatic brain injury may also cause dementia (National Institute on Aging [NIA], n.d.).

Alzheimer's disease accounts for 60-80% of all cases of dementia, making it the most common form of dementia (CDC, 2019). The first sign of Alzheimer's is typically forgetting recent events, such as a conversation that happened moments before (CDC, 2019). There are three stages of Alzheimer's dementia: mild, moderate, and severe. Persons living with mild dementia can remain independent with assistance with complex tasks, such as paying bills (AA, 2023). They may be able to drive, work, and engage in social activities (AA, 2023). Persons with moderate dementia may have difficulty with some activities of daily living that require multiple steps to complete, such as bathing and dressing, and may develop incontinence (AA, 2023). They may have trouble remembering family and friends and become easily confused (AA, 2023). The severe stage of Alzheimer's is marked by struggles with language and communication. The areas of the brain controlling movement are hindered which may result in confinement to bed or difficulty swallowing (AA, 2023). All forms of dementia result in both cognitive and functional declines that affect the person's ability to live independently and lead to the need for a caregiver.

Pharmacologic treatments have limited effectiveness on biological and psychological aspects of the disease (Hayden, et al., 2022). All forms of dementia are progressive in nature and symptoms worsen with time (WHO, 2023). Eventually, people living with dementia require assistance with activities of daily living such as bathing, toileting, and dressing, as well as instrumental activities such as paying bills and grocery shopping (AA, 2023).

In addition to functional challenges, about 5 out of every 6 persons living with dementia will develop behavioral and psychological symptoms of dementia (BPSD) at some point during the disease progression (Abraha et al., 2017). This is true regardless of whether they live at home or in an institutional setting (Abraha et al., 2017). BPSD symptoms include depression, anxiety, agitation, aggression, psychosis, apathy, disinhibition, irritability, sleep disturbances, wandering, and care refusal (Bessey & Walaszek, 2019; Ijaopo, 2017). During the progression of the disease, 90% of people living with dementia will exhibit BPSD (Bessey & Walaszek, 2019; Ijaopo, 2017). Agitation is the most common BPSD, occurring in 70% of people living with dementia (Ijaopo, 2017). Agitation consists of restlessness accompanied by physical or verbal actions that caregivers may find troubling (Ijaopo, 2017). Fifty percent of people living with dementia exhibit significant BPSD every month (Abraha et al., 2017).

Many people living with dementia also experience social changes. Over time, persons living with dementia may disengage from social activities outside of their home (Duggan et al., 2008; Margot-Cattin et al., 2021). Reasons for disengagement may include a lack of confidence or a fear of saying the wrong thing (Duggan et al., 2008; van Wijngaarden, et al., 2019). Persons living with dementia may feel they are being judged and develop anxiety around others (Duggan et al., 2008; van Wijngaarden et al., 2019). People living with dementia may also prefer to stay in a familiar environment, such as their home (Duggan et al., 2008).

Informal Caregivers of Persons with Dementia

Informal dementia caregivers are mostly spouses, followed by children and children-in law of the person living with dementia (Brodaty & Donkin, 2009). Women comprise the bulk of family caregivers, although the percentage of male caregivers is rising (Brodaty & Donkin, 2009). Women report higher caregiving burden and poorer mental health than male caregivers (Zhao et al., 2022).

Dementia caregivers report higher levels of burden compared with caregivers to persons with a physical disability alone (Brodaty & Donkin, 2009; Campbell, et al., 2008; Moon & Dilworth-Anderson, 2015). Dementia caregivers provide more extensive support and more hours of assistance than caregivers for other conditions that do not affect cognition (Isik et al., 2019). Caregiving tasks for persons living with dementia may include but are not limited to: managing finances, cleaning the home, cooking dinner, driving the care recipient to medical appointments, assisting with bathing, dressing, brushing teeth and hair, ensuring the care recipient takes the proper medication, helping with toileting, doing the laundry, managing behaviors such as wandering, aggression, or agitation, and providing emotional support for the person living with dementia (AA, 2023). Due to the slow progression of the disease, over 50% of informal caregivers of people living with dementia provide care for four or more years (AA, 2023; Brodaty & Donkin, 2009).

Over half (59%) of informal caregivers of people living with dementia rate the emotional strain of caregiving as high or very high (AA, 2023). Dementia caregivers report more depression than non-dementia caregivers (Bessey & Walaszek, 2019; AA, 2023). Spousal caregivers of persons living with dementia report higher levels of caregiver burden than non-spousal caregivers (AA, 2023). Spousal caregivers also report lower marital and relationship satisfaction than non-caregiver peers (Pote & Wright, 2018).

The behavioral and psychological manifestations of dementia have a greater impact on caregiver subjective burden and depression than the physical and cognitive decline (Isik et al., 2019; Schneider et al., 2019; Zhao et al., 2022). Agitation, aggression, anxiety, apathy, and depression in the care recipient are some of the most distressing symptoms to caregivers and contribute to caregiver burden, burnout, and overload (Bessey & Walaszek, 2019; Ijaopo, 2017; Isik et al., 2019).

Caregiver burden may lead to decreased overall health for the caregiver (AA, 2023). The list of health issues for dementia caregivers is long. Thirty-eight percent of dementia caregivers report high or very high physical stress due to caregiving (AA, 2023). Caregivers of people living with dementia have increased risk of chronic conditions such as cardiovascular disease, diabetes, anemia, ulcers, and arthritis (Brodaty & Donkin, 2009). They report more use of prescription medication, more doctor visits, more alcohol consumption, and more tobacco use than non-caregivers (Brodaty & Donkin, 2009). Dementia caregivers have increased susceptibility to illness and are less likely to engage in preventative health measures such as exercise (Brodaty & Donkin, 2009). Dementia caregivers report less overall health than non-dementia caregivers (Brodaty & Donkin, 2009).

Caregiver burden correlates to deterioration in the quality of life of the care recipient (Stall et al., 2019). High caregiver burden is associated with significant increases in institutionalization of people living with dementia (AA, 2023; Stall et al., 2019).

Aging in Place/Place Attachment

According to a 2021 American Association of Retired Persons survey, 77% of US adults aged 50 and over preferred to remain in their homes as they age (Davis, 2022). This is especially true for people living with dementia. As cognitive function declines, the familiarity of home makes the living environment more comfortable and easier to navigate (Gould & Basta, 2013). Most people living with dementia reside in their own homes (de Almeida et al., 2020). Home can provide a sense of security as one ages (LeBrusan & Gomez, 2022; Mayo et al., 2021).

The concept of place attachment describes an emotional bond between a person and a geographic place which results in the preference to age at home (LeBrusan & Gomez, 2022). A person’s identity and concept of self is at least partially determined by attachments to places they have lived (LeBrusan & Gomez, 2022). The home serves to connect the older adult with previous stages of his/her life (LeBrusan & Gomez, 2022). This can help an older person connect to the past when identity is threatened with the multiple losses of aging (LeBrusan & Gomez, 2022). Thus, aging at home may help people living with dementia to retain memories tied to the home. Because of place attachment, many older adults choose to stay at home even when a home no longer meets their functional needs (LeBrusan & Gomez, 2022).

A consequence of aging in place for people living with dementia is greater reliance on and need for informal caregivers (Mayo et al., 2021). Seventy percent of dementia caregivers are spouses of their care recipient (Pote & Wright, 2018). According to a 2014 Alzheimer’s Association poll, 65% of dementia caregivers indicated that a desire to keep a family member or friend at home contributed to their decision to become a caregiver (AA, 2023). Aging in place or aging in the home of a relative or friend has financial benefits also. Some older adults may be willing to move, but cannot afford to relocate, downsize, or enter long-term care (Davis, 2022).

Symptoms of depression for both the care recipient and the caregiver are a reported consequence of moving from home into long-term care (Mayo et al., 2021).

An important component to helping persons living with dementia remain at home is understanding and addressing the challenges experienced by the person and their caregivers (Mayo et al., 2021). Preventing excessive caregiver burden and enabling the caregiver to effectively assist the person living with dementia is crucial to allowing that person to age in place. Home-based interventions provide options to address those challenges.

Home-based Interventions for People Living with Dementia

Because most people living with dementia reside at home, the creation and implementation of home-based interventions is key to effective care (de Almeida et al., 2020). Home-based interventions for people living with dementia are designed for a variety of purposes: to improve cognition (Chalfont, et al., 2018); to improve functional/physical abilities such as balance or decrease fall risks (Barrado-Martin et al., 2021); to manage BPSD or promote well-being (Abraha et al., 2017; Cheung et al., 2022; Xu et al., 2023); or to increase the quality of the relationship between caregiver and care recipient (Stedje et al., 2023).

The American Geriatric Society and the American Association for Geriatric Psychiatry recommend non-pharmacological interventions at the best approach to managing BPSD (Abraha et al., 2017; Ijaopo, 2017). This is fueled by concerns over the efficacy and side effects of common medications used to treat BPSD (Ijaopo, 2017; Schneider et al., 2019). The FDA has issued black box warnings on several common BPSD medications (especially antipsychotics) citing increased risk of stroke or mortality for use with persons living with dementia (AA, 2023; Ijaopo, 2017). Some medications may cause excessive drowsiness and increased risk of falls or fractures (Abraha et al., 2017; Ijaopo, 2017). Many people living with dementia take multiple medications and drug interactions may exacerbate BPSD (Bessey & Walaszek, 2019).

In addition to calming BPSD, non-pharmacological interventions may create meaningful activities for people living with dementia and their family caregivers, which has been reported as a critical need for this population (Bessey & Walasznek, 2019). Types of activity-based, non-pharmacological interventions include art, aromatherapy, cognitive stimulation, dance, music, animals/pets, exercise, nature, touch, reminiscence, multisensory stimulation, and taste (Abraha et al., 2016; Hayden et al., 2022; Schneider, Bristol, & Brody, 2019). Individualized interventions tailored to the interest and ability of the person living with dementia provided in a community setting are more effective than those in a group setting (Tan et al., 2022). Also, some people living with dementia may face challenges with travel or prefer to interact in a familiar setting (Tan et al., 2022).

Most home-based interventions require a trained specialist such as a music therapist, occupational therapist, or physiotherapist. Therefore, it is difficult to ascertain the generalizability of the interventions to home-based people living with dementia (Schneider et al, 2019). For example, in a systematic review of 10 music-based interventions for community-dwelling persons living with dementia, only one study was found that was implemented at home by informal caregivers (Hofbauer et al., 2022). Most music interventions are carried out by music therapists or other professionals in a group setting (e.g., assisted living facilities, nursing homes) (Hayden et al., 2022; Hofbauer et al., 2022).

Gaps in Literature

The current scoping review seeks to synthesize the literature on dyadic interventions in the most common living arrangement for persons living with dementia and their caregivers, the home. This review will report on interventions completed independently in a dyadic relationship and how those interventions impact caregivers. As more interventions for persons living with dementia focus on home, it is imperative to consider unintended consequences on caregivers.

Most reviews of non-pharmacological interventions designed for persons living with dementia are limited to specific kinds of interventions, such as music therapy, reminiscence therapy or exercise. Two systematic reviews of home-based non-exercise interventions for people living with dementia were found that discussed the effects of interventions on informal caregivers (Balvert et al., 2024; Tan et al., 2022). The reviews included cognitive rehabilitation, tailored activity program, cognitive stimulation, occupational therapy, reminiscence, music therapy, reality orientation, biobehavioral intervention, physical activity, and multi-component interventions (Balvert et al., 2024; Tan et al., 2022). The caregiver outcome variables examined were quality of life, burden, depression, anxiety, distress, relationship quality, and mood (Balvert et al., 2024; Tan et al., 2022).

Unlike the Balvert et al. (2024) and Tan et al. (2022) reviews, this scoping review will consider interventions conducted by the caregiver and exclude interventions solely led by a professional or group interventions or interventions conducted outside of the home, such as in a memory clinic. Not every dyad has access to or the ability or desire to have continued interaction with a professional therapist. Some people living with dementia become uncomfortable around new people and may not want to engage with a professional (Duggan et al., 2008; van Wijngaarden et al., 2019). Even though most persons living with dementia reside at home and may prefer to stay at home, research on home-based interventions is limited. Research focusing on home-based interventions involving only the caregiver/care recipient dyad is even more scarce .

The literature on how interventions impact caregivers is not easily accessible and varies greatly. One review of exercise interventions reported that physical activity interventions generally decreased caregiver burden, but some caregivers found the effort “excessive” or burdensome, lost interest, or did not have time to complete the intervention (de Almeida et al., 2020, p. e603). In a reminiscence review, some informal caregivers stated that the intervention provided quality time for the dyad and facilitated conversation (Ingersoll-Dayton et al., 2019). On the other hand, some informal caregivers expressed feeling burdened to collect and organize mementos (Ingersoll-Dayton et al., 2019). One review of music therapy interventions noted inconsistencies in continued use of music and suggested more caregiver support would be beneficial (Hofbauer et al., 2022).

While there are scoping and systematic reviews covering many non-pharmacologic interventions and some of the reviews note caregiver outcomes, no review was found which coalesces different kinds of interventions from the viewpoint of informal caregiver outcomes. Caregiver outcomes are important because caregivers implement the interventions. If an activity is viewed as too burdensome for the caregiver to complete, it will never benefit the care recipient. Also, how an intervention affects the relationship between the caregiver and the care recipient should be considered given that a perception of low relationship quality contributes to higher caregiver burden (Campbell et al., 2008).

Theoretical Framework: Stress Process Model

The stress process model espoused by Pearlin et al (1990) presents a framework for understanding how caregiving stress affects mental health among informal caregivers of people living with dementia. The stress process model acknowledges the intersectionality of multiple aspects of life that result in increased or decreased caregiver burden. Pearlin et al (1990) outlined four areas contributing to caregiver stress: 1) the background and context of the caregiver (environmental and socioeconomic); 2) primary stressors associated with the care recipient’s medical condition and demands of caregiving; 3) secondary stressors outside of caregiving tasks, such as social isolation or tense family dynamic; and 4) the psychosocial resources of the individual caregiver such as the personality or competence of the caregiver (Brodaty & Donkin, 2009; Campbell et al., 2008).

Primary stressors are divided into two categories: objective stressors and subjective burdens (Zhao et al., 2022). Objective stressors are those that can be observed, such as level of cognitive or physical impairment of the care recipient and physical need for assistance or emotional disturbances arising from the disease (Zhao et al., 2022). Subjective burdens represent the gravity that the caregiver places on caregiving responsibility, such as feeling overwhelmed or trapped in the role of caregiver (Zhao et al., 2022). Subjective burdens are the result of the intensity of objective stressors (Zhao et al., 2022). Over time, the combination of primary and secondary stressors mixed with environmental, social, and psychological factors result in “stress proliferation” and can lead to increased burden and lower mental health for the caregiver (Zhao et al., 2022, p. 2).

While Pearlin et al (1990) recognized the complex interaction of these four areas on caregiver burden, the stress process model did not specify which variable created the most caregiver stress (Campbell et al., 2008). Expanding on the stress process model, Campbell et al. (2008) found the following predictor variables increased caregiver stress: 1) a sense of “role captivity” or being stuck in the role of caregiver and losing a sense of one’s self; 2) a feeling of “overload,” burnout, or excessive fatigue by the caregiver; 3) adverse life events outside of the caregiving role; and 4) a lower caregiver/care recipient relationship quality (Campbell et al., 2008, p. 1081-1082). Furthermore, caregivers who felt a lack of communication and affection in their relationship expressed greater burden (Campbell et al., 2008). Because dyadic home-based interventions rely on the human capital of the caregiver to complete, a caregiver may view the intervention as another task on the chore list, which could lead to the caregiver feeling trapped or fatigued, thus increasing caregiver stress. This is one example of the importance of understanding the caregiver’s perspective to any intervention designed for a person living with dementia and the basis for this scoping review. Improvement for the person living with dementia at the expense of the caregiver does not benefit the dyad.

Mediating factors, called buffers in the stress process model, can lessen the impact of primary and secondary stressors (Zhao et al., 2022). Mastery, self-esteem, a feeling of competency as a caregiver, strong social support, religious coping, and positive thoughts regarding caregiving are examples of potential mediating factors (Zhao et al., 2022). Even factors thought to be buffers may instead lead to stress. For example, if a caregiver finds an intervention designed to lower BPSD for the care recipient too time-consuming to conduct, the caregiver may suffer in the areas of mastery and confidence in caregiving, thus leading to more stress. The intervention itself may become a stressor for the caregiver instead of a mediator.

Using the stress process framework, this review seeks to determine if, whether, and how home-based interventions designed for persons living with dementia impact caregivers. This scoping review considers whether non-pharmacological home-based interventions are buffers or subjective stressors for the caregiver.

Objectives

The objective of this scoping review is to describe the scope and nature of evidence on informal caregiver outcomes when delivering home-based non-pharmacological interventions to persons living with dementia. The review aims to document which outcome measures are used for informal caregivers and if and how such interventions impact the health and well-being of informal caregivers.

Research Question

What are the documented outcomes of informal caregivers in delivering home-based dyadic interventions designed to support people living with dementia?

METHODS

Study Design

A scoping review method was chosen to examine and map the full breadth of literature regarding caregiver outcomes in delivering home-based interventions designed for people living with dementia. A scoping review is appropriate to map available evidence, identify how research is performed, and locate gaps in knowledge about a given field (Munn et al., 2018). Scoping reviews are applicable to synthesize large quantities of literature that are complex or heterogeneous and disseminate the information in a manageable way (Couch et al., 2020; Wang et al., 2022). Given the broad scope and variability of interventions for persons living with dementia and the lack of previous comprehensive studies of the subject, a scoping review is the best choice for this study.

This review followed the five stages from Arksey and O’Malley’s scoping review framework: 1) identify the research question; 2) identify relevant studies; 3) determine study inclusion and exclusion; 4) examine and chart the data; and 5) synthesize, summarize, and report the results (Arksey & O’Malley, 2005). To ensure reliability and reproducibility, this study also followed the PRISMA extension for scoping reviews (PRIMSA-ScR) (Page et al., 2020).

Covidence software was utilized for screening and data extraction. As this is not a systematic review, quality assessments of the studies included were not conducted (Arksey & O'Malley, 2005). A priori protocol for this scoping review was registered with the Center for Open Science at osf.io/w49s8.

Databases

The search included the following databases: Academic Search Complete, AgeLine, APA PsychInfo, CINAHL, Global Health, Health Source: Nursing/Academic Edition, MEDLINE, Psychology and Behavioral Sciences Collection, and Social Work Abstracts. This scoping review includes quantitative, qualitative, and mixed methods studies published from inception through May 3, 2024. Research protocols were excluded. Other systematic, scoping, or rapid reviews will not be considered for inclusion, but reference lists of any applicable reviews will be searched for additional articles for inclusion. Only sources published in English are included due to funding constraints for this current review.

Search Strategy

The three-step search strategy aimed to locate only published sources. A preliminary search of CINAHL was undertaken to identify articles on the topic. Consulting with a university librarian, the text words contained in titles and abstracts of relevant articles and the index terms describing the articles were used to create a broad Boolean search strategy to identify the maximum number of relevant studies (see Appendix I).

The population/concept/context framework for scoping reviews recommended by the Joanna Briggs Institute (JBI) guided the search. The population search terms included: "informal care*" OR "family care*" OR "care* partner*" combined with Alzheimer* OR dementia* OR "cognitiv* impair*" OR "memory loss." The concept search terms included: intervention* OR therap* OR program* OR treatment*. The context terms included: “home-based” OR “home-deliver*” OR “community-based” OR “home setting” OR home.

Inclusion Criteria

Participants

The population of this scoping review is informal caregivers of persons living with dementia. Informal caregivers include spouses, children, in-laws, any familial relation, and friends. Professional, formal caregivers, including direct care workers in the home, are excluded from this review. The care recipient must be diagnosed with some form of cognitive impairment. The intervention must involve recruitment of the informal caregiver/care recipient dyad as it emphasizes the important role that the informal caregiver plays in delivering the intervention.

Concept

The concept of this scoping review is non-pharmacologic interventions designed for the benefit of people living with dementia and administered by an informal caregiver. In this review, non-pharmacologic interventions include any non-drug intervention designed to benefit people living with dementia, including but not limited to improving cognition, improving functional or physical capabilities, managing BPSD, or promoting the well-being or mental health of the person living with dementia. Examples of relevant interventions are animal assisted therapy, art therapy, cognitive stimulation, dance, massage, music therapy, physical activity, and reminiscence. The informal caregiver must conduct the intervention independently. The caregiver may receive training from a professional or a research team, but studies based solely on a professional delivering an intervention in a person’s home will be excluded. Informal caregiver involvement must be crucial to the success of the intervention. Informal caregiver outcomes must be reported for inclusion in the review.

Context

The context of the scoping review is the home. The interventions must be delivered at home by the informal caregiver. Interventions delivered in professional settings like adult daycare centers or nursing facilities will be excluded. Interventions delivered exclusively in group settings outside of the home, such as at art museums or recreation centers, will be excluded.

Study Selection

Following the search, all identified citations were uploaded into Covidence and duplicate studies removed. Titles and abstracts were imported into Covidence and screened by two independent reviewers for assessment against the predetermined inclusion criteria. Potentially relevant studies were retrieved in full. The full text materials were assessed in detail against the selection criteria by the same two independent reviewers. Reasons for exclusion of sources of evidence at full text that do not meet the inclusion criteria are recorded in the PRISMA flow diagram. A third reviewer decided conflicts that arose between the reviewers at each stage of the selection process. The search results and the inclusion process are presented in the PRISMA flow diagram in Figure 1 (Page et al., 2020).

Synthesizing, Summarizing and Reporting the Results

The primary independent reviewer extracted data from sources using a data extraction tool designed by the reviewers. A second independent reviewer verified the accuracy of the extracted information. The data included specific details about the participants, concept, context, study design, country of origin, and key findings relevant to the review question.

Relevant data from each source was extracted to identify and map documented informal caregiver outcomes when delivering interventions designed for persons living with dementia. Extracted data is presented in the supplementary tables.

RESULTS

The PRISMA-ScR flowchart presented in Figure 1 illustrates the evidence review and selection process (Page et al., 2020). A total of 3,977 studies were identified from the electronic database search. All identified citations were uploaded into Covidence and 1,915 duplicates removed. Thirty-three duplicates were removed manually from screening. Two independent reviewers screened titles and abstracts for assessment against the inclusion criteria. A total of 1,912 studies were excluded as irrelevant. A full text review of 116 studies resulted in 21 articles for inclusion in this scoping review. One article was hand-selected for inclusion from other relevant articles equaling 22 articles total.

Study Characteristics

The United States represented the largest share of the included studies, with 10 articles (Table 1) (Gitlin et al., 2010; Gitlin et al., 2018; Gitlin et al., 2008; Hanser et al., 2011; Harris & Titler, 2022; Hutchinson & Marshall, 2000; Kulibert et al., 2019; Mc Curry et al., 2005 Quayhagen & Quayhagen, 1989; Tappen & Hain, 2014). Northern Europe accounted for the second highest number of studies with three from the United Kingdom, two from England, one from The Netherlands, and one from Germany (Barrado-Martín et al., 2021; Barrado-Martín et al., 2019; Orrell et al., 2017; Prick et al., 2015; Ross et al., 2024; Ryan et al., 2020). The largest study in this review involved 432 dyads from 5 countries, Australia, the United Kingdom, Norway, Poland, and Germany (Baker et al., 2023). Two studies were based in Taiwan (Chiu et al., 2014; Liu et al., 2023). There was one study from Hong Kong and one from Australia (Kor et al., 2024; Vreugdenhil et al., 2012).

The number of caregiver/care recipient dyads participating in the included studies ranged from 10 – 432 (Table 1). Only 5 studies involved more than 100 dyads (Baker et al., 2023; Gitlin et al., 2018; Kor et al., 2024; Orrell et al., 2017; Prick et al., 2015). Thirteen studies examined less than 50 dyads, with two articles including only 10 dyads (Barrado-Martín et al., 2021; Barrado-Martín et al., 2019; Hanser et al., 2011; Harris & Titler, 2022; Hutchinson & Marshall, 2000; Kulibert et al., 2019; Laird et al., 2018; Liu et al., 2023; McCurry et al., 2005; Quayhagen & Quayhagen, 1989; Ross et al., 2024; Ryan et al., 2020; Vreugdenhil et al., 2012).

Eleven studies utilized randomized controlled trials (Baker et al., 2023; Gitlin et al., 2010; Gitlin et al., 2018; Gitlin et al., 2008; Kor et al., 2024; Liu et al, 2023; McCurry et al., 2005, Orrell et al., 2017; Prick et al., 2015; Tappen & Hain, 2014; Vreugdenhil et al., 2012). Six studies were qualitative in design (Barrado-Martín et al., 2021; Barrado-Martín et al., 2019; Hanser et al., 2011; Hutchinson & Marshall, 2000; Ross et al., 2024; Ryan et al., 2020). Mixed method, quasi-experimental, and exploratory study types were also reported (Chiu et al., 2014; Harris & Titler, 2022; Kulibert et al., 2019; Laird et al., 2018; Quayhagen & Quayhagen, 1989).

Intervention Design

This scoping review found 10 different types of non-pharmacological interventions designed for persons with dementia and delivered at home by informal caregivers: cognitive stimulation therapy *(n* = 3); exercise *(n* = 3); multicomponent *(n* = 3); music *(n* = 3); tailored activity program (TAP) *(n* = 3); reminiscence *(n* = 2); leisure activity-based *(n* = 2); cognitive training *(n* = 1); massage *(n* = 1); and weighted blanket *(n* = 1) (Table 2). The most common primary goal of the interventions studied was to reduce BPSD (Table 1) (Baker et al., 2023; Chiu et al., 2014; Gitlin et al., 2010; Gitlin et al., 2018; Gitlin et al., 2008; Harris & Titler, 2022; Kor et al, 2024; Kulibert et al., 2019; Liu et al., 2023; Prick et al., 2015; Quayhagen & Quayhagen, 1989**)**. Other goals included improved function (*n* = 6), improved cognition (*n* = 5); improved mood (*n* = 3); quality of life (*n* = 3), stimulation (*n* = 1); and improved sleep (*n* = 1) (Table 1).

The intervention time frames varied from 1 week to 8 months (Table 1) (Chiu et al., 2014; Quayhagen & Quayhagen, 1989). The most common time frame for the studies was between 3 – 4 months, with 10 studies falling in that range. Twenty studies reported some form of caregiver training, ranging from one general training session to 12 hours of direction and independent study. Two broad exploratory studies did not consider caregiver training (Chiu et al., 2014; Ross et al., 2024).

Participant Characteristics

Caregivers and care recipients in the included articles align with U.S. data regarding gender and relationship status of persons living with dementia and their care partners. Most caregivers in the included articles are female (Table 3). According to the Alzheimer's Association, women make up about two-thirds of dementia caregivers (AA, 2023). In 18 articles, women accounted for between 60% - 97.5% of the caregivers studied (Baker et al., 2023; Barrado- Martín et al., 2021; Barrado- Martín et al., 2019; Gitlin et al., 2010; Gitlin et al., 2018; Gitlin et al., 2008; Hanser et al., 2011; Harris & Titler, 2022; Hutchinson & Marshall, 2000; Kor et al., 2024; Laird et al., 2018; Liu et al., 2023; McCurry et al., 2005; Orrell et al., 2017; Prick et al., 2015; Ross et al., 2024; Ryan et al., 2020). Three studies did not report caregiver gender (Kulibert et al., 2019; Tappen & Hain, 2014; Vreugdenhil et al., 2012). In one notable exception, less than 40% of the study participants included women caregivers (Quayhagen & Quayhagen, 1989).

Most care recipients are male (Table 3). In 14 articles, men represented 55% - 97% of the persons living with dementia (Baker et al., 2023; Barrado- Martín et al., 2021; Gitlin et al., 2010; Gitlin et al., 2018; Gitlin et al., 2008 Harris & Titler, 2022; Hutchinson & Marshall, 2000; Kulibert et al., 2019; Laird et al., 2018; McCurry et al., 2005; Prick et al., 2015; Ryan et al., 2020; Tappen & Hain, 2014). Five articles reported a higher percentage of female care recipients (Chiu et al., 2014; Hanser et al, 2011; Kor et al, 2024; Quayhagen & Quayhagen, 1989; Vreugdenhil et al., 2012). In one article, the number of persons living with dementia was split evenly between men and women (Barrado- Martín et al., 2019).

In fourteen studies, most caregivers were the spouse or partner of the person living with dementia (58% - 92%). In three studies, children or children-in-law represented the majority of caregiver participants (61% - 79%) (Chiu et al., 2014; Kor et al, 2024; Liu et al., 2023). Other caregivers included grandchildren (Kor et al., 2024; Liu et al, 2023; Ryan et al., 2020), siblings (Barrado-Martín et al., 2021; Kor et al., 2024), and a niece (Barrado-Martín et al., 2019). Four studies did not report on the care partner relationship beyond unspecified informal caregivers (Laird et al., 2018; Quayhagen & Quayhagen, 1989; Tappen & Hain, 2014; Vreugdenhil et al., 2012).

The majority of study participants were White (Table 3). In six studies, more than 90% of participants were White, with three of the studies having only White participants (Barrado-Martín et al., 2021; Barrado- Martín et al., 2019; Hanser et al., 2011; Harris & Titler, 2022; Orrell et al., 2017; Tappen & Hain, 2014). Twelve studies did not report participant race or ethnicity (Baker et al., 2023; Chiu et al., 2014; Hutchinson & Marshall, 2000; Kor et al., 2024; Kulibert et al., 2019; Laird et al., 2018; Liu et al., 2023; Prick et al., 2015; Quayhagen & Quayhagen, 1989; Ross et al., 2024; Ryan et al., 2020; Vreugdenhil et al., 2012). The lowest percentage of White participants listed in any article was 77% (Gitlin et al., 2008; Gitlin et al., 2010). Of 800 dyads (1600 persons total) participating in studies that reported race/ethnicity, only 28 persons identified as Black, 5 as Asian/Pacific Islander; 2 as Native American; and 2 as Hispanic (Gitlin et al., 2008; Harris & Titler, 2022; McCurry et al., 2005; Tappen & Hain, 2014). Two participants are listed as "other" and 26 as "non-White" (Gitlin et al., 2010; Gitlin et al., 2008).

Five studies included some information regarding caregiver employment status (Chiu et al., 2014; Gitlin et al., 2018; Hanser et al., 2011; Kor et al., 2024; Liu et al., 2018). None included information on care recipient employment. In four of those studies, a majority of caregivers were either unemployed or retired (56.9% - 100%) (Chiu et al., 2014; Gitlin et al., 2018; Hanser et al., 2011; Kor et al., 2024). The exception was a study on massage in which 66% of caregivers were employed either full-time or part-time (Liu et al., 2023).

Fifteen studies reported educational background (Table 3). Three of these studies did not report the education history for the person living with dementia (Kor et al., 2024; Liu et al., 2023; Ross et al., 2024). Generally, caregivers attained higher levels of education than the care recipients. The exception was one cognitive stimulation therapy study out of the UK in which 60% of persons living with dementia were "school leavers" compared to only 44% of caregivers (Orrell et al., 2017).

Data Measurement Tools

Forty-four different scales were used to measure caregiver and care recipient outcomes (Table 4). Caregiver data included: attitude toward caregiving, depression, anxiety/stress, burden, health, quality of life, relationship with the person living with dementia, resilience and well-being (Table 4). The most common data sought from caregivers was depression, considered by 13 studies, followed by burden, examined in 9 studies (Baker et al., 2023; Chiu et al., 2014; Gitlin et al., 2010; Gitlin et al., 2018; Gitlin et al., 2008; Kor et al., 2024; Kulibert et al., 2019; Liu et al., 2023; McCurry et al., 2005; Orrell et al., 2017; Prick et al., 2015; Quayhagen & Quayhagen, 1989; Tappen & Hain, 2014; Vreugdenhil et al., 2012**)**. Care recipient data included: anxiety, BPSD, cognition, depression, function, quality of life, relationship with caregiver, sleep, and well-being (Table 4). The most common data collected from care recipients was BPSD, examined in 12 studies, followed by cognition, considered by 11 studies (Table 4).

Documented Outcomes of Caregivers

Depression, Anxiety, and Stress

Non-pharmacological home-based interventions delivered by a caregiver to a person living with dementia did little to improve caregiver depression, anxiety, or stress (Table 5). Of the thirteen studies examining caregiver depression, anxiety, or stress, only three studies reported marginal improvements (Kulibert et al., 2019; Liu et al., 2023; Vreugdenhil et al., 2012). These studies involved music (Kulibert et al., 2019); massage (Liu et al., 2023); and exercise (Vreugdenhil et al., 2012) (Table 6). One study on CST reported that intervention caregivers maintained their mental health status compared to the control group which worsened (Quayhagen & Quayhagen, 1989). Eight studies covering music, TAP, CST, multicomponent, and cognitive training interventions reported no change in caregiver depression, anxiety or stress (Table 6) (Baker et al., 2023; Gitlin et al., 2018; Gitlin et al., 2008; Kor et al, 2024; McCurry et al., 2005; Orrell et al., 2017, Prick et al., 2015; Tappen & Hain, 2014). One exploratory study reported that more dyadic leisure time physical activities resulted in less caregiver distress (Chiu et al., 2014).

Burden

Nine studies involving leisure-based activity, CST, exercise, music, multicomponent, and TAP and examining caregiver burden reported mixed results (Table 5; Table 6) (Gitlin et al., 2010; Gitlin et al., 2018; Gitlin et al., 2008; Hanser et al., 2011; Hutchinson & Marshall, 2000; Kor et al., 2024; Prick, et al., 2015; Quayhagen & Quayhagen, 1989; Vreugdenhil et al., 2012). Two TAP studies reported an objective decrease in caregiver burden by a reduction of one hour per day of doing things for the care recipient and a reduction of 5 hours per day of being on duty (Gitlin et al., 2010; Gitlin et al., 2008). Yet this objective decrease in burden did not result in a subjective decrease in the caregiver's perceived burden. There was no change reported by caregivers on subjective burden when using TAP (Gitlin et al., 2008; Gitlin et al., 2018). Multicomponent and CST intervention studies also reported no change in caregiver burden (Kor et al., 2024; Prick et al., 2015; Quayhagen & Quayhagen, 1989). One study involving daily exercises and walking reported slight, not statistically significant improvements in caregiver burden (Vreugdenhil et al., 2012). One music intervention reported an increase in burden, although it was not statistically significant (Hanser et al., 2011). One qualitative study on an activity kit designed for persons living with dementia reported that some caregivers felt the kit to be a burden that competed with other caregiving duties (Hutchinson & Marshall, 2000).

Quality of Life and Well-being

Six studies examined caregiver quality of life, well-being, or mood (Table 5; Table 6) (Baker et al., 2023; Hanser et al., 2011; Laird et al., 2018; McCurry et al., 2005; Orrell et al., 2017; Quayhagen & Quayhagen, 1989). Both studies on CST found no change in reported quality of life or well-being (Orrell et al., 2017; Quayhagen & Quayhagen, 1989). Laird et al. (2018) found a non-significant decrease in well-being for caregivers utilizing the InspireD reminiscence app. Baker et al. (2023) found that caregivers' quality of life remained the same when delivering a music intervention to persons living with dementia, but Hanser et al. (2011) reported increased happiness, relaxation, and comfort for caregivers delivering a music intervention. A multicomponent sleep intervention resulted in no change in caregivers' reported mood (McCurry et al., 2005).

Caregiver Attributes

Results on caregiver attitudes toward caregiving, feelings of competence or confidence in caregiving and resilience when delivering home-based interventions to persons living with dementia varied (Table 5; Table 6). Two music interventions reported mixed results (Baker et al., 2023; Kulibert et al., 2019). Baker et al. (2023) found an increase in resilience at 90-days, but no change from baseline at 180-days and no change in the caregiver's sense of competence throughout the study. Kulibert et al. (2019) reported a qualitative increase in caregivers' sense of coping abilities, but a marginal decrease in caregivers' attitudes toward caregiving. Regarding studies utilizing CST, Quayhagen & Quayhagen (1989) reported an increase in caregiver coping abilities, but Orrell et al. (2023) found no change. Kor et al. (2024) found that caregivers delivering CST experienced improvements in their attitudes toward caregiving and towards persons with dementia. One cognitive training study found that caregivers' satisfaction with caregiving did not change with the intervention but did increase with the control of Life Story Review (Tappen & Hain, 2014). Gitlin et al. (2008) found that caregiver self-efficacy improved when delivering TAP to a person living with dementia.

Relationship with Care Recipient

Six studies considered the impact of non-pharmacological interventions on the care partner relationship (Baker et al., 2023; Hutchinson & Marshall, 2000; Laird et al., 2018; Orrell et al., 2017; Quayhagen & Quayhagen, 1989; Ryan et al., 2020). Two studies on the reminiscence iPad app InspireD reported positive effects on the caregiver/care recipient relationship, although not statistically significant (Laird et al., 2018; Ryan et al., 2020). Qualitative interviews of caregivers delivering an activity kit intervention to persons living with dementia found that *The Bag* served as a positive connection for the care partners. Qualitative data from a 16 dyad CST intervention showed improvement in the spousal relationship (Quayhagen & Quayhagen, 1989). But data from a larger (356 dyads) RCT on CST reported no change in care partner relationship quality (Orrell et al., 2017). A music intervention study involving 432 dyads reported no change in the caregiver/care recipient relationship (Orrell et al., 2017).

Health

Two multicomponent studies and one CST study reported no change in caregiver self-reported health when delivering interventions to persons living with dementia (McCurry et al., 2005; Orrell et al., 2017; Prick et al., 2015).

DISCUSSION

This review is the first to investigate caregiver outcomes while delivering home-based non-pharmacological interventions to persons living with dementia considering only research in which the caregiver plays an integral role in implementation of the intervention.

This scoping review covered 22 studies of 10 different types of home-based interventions delivered by caregivers to persons living with dementia. Only two studies had all positive results for caregivers, massage and weighted blanket interventions (Harris & Titler, 2022; Liu et al., 2023). The weighted blanket study covered the feasibility and acceptability of use and did not report caregiver outcomes beyond positive responses regarding ease of use (Harris & Titler, 2022). In addition to significantly lowering depression and agitation for the person living with dementia, the massage intervention lowered caregiver stress (Liu et al, 2023). Nine out of 10 interventions had some kind of positive impact on caregivers, even if it was a small impact, except cognitive training which found no change in any measured outcome (Tappen & Hain, 2014). Positive impacts included less distress, more positive attitudes toward caregiving, better relationship with the person with dementia, and improved well-being or enjoyment of doing an activity together.

While most studies did not report significant positive impacts for caregivers when delivering non-pharmacological interventions to persons living with dementia, they also did not report significant negative impacts. No intervention had all negative impacts on caregivers. The negative impacts included finding the intervention burdensome or another chore on a to do list. Some caregivers reported emotional distress from interventions such as reminiscence which could illicit unhappy memories (Ryan et al., 2020). A couple of music studies found a decrease in caregiver satisfaction and attitude toward caregiving (Hanser et al., 2011; Kulibert et al., 2019). These decreases could be completely unrelated to the intervention and more tied to health declines.

Qualitative and mixed method studies revealed that interventions which are flexible, inexpensive, easily implemented, and enjoyable for both members of the dyad are desirable (Chiu et al., 2014; Kulibert et al., 2019; Ross et al., 2024; Ryan et al., 2020). In a study of an iPod music intervention, caregivers appreciated that they could use the music when it was convenient for them and when it could help distract the care recipient (Kulibert et al., 2019). This was true of the iPad reminiscence studies also in which caregivers noted that they appreciated the portability of the device so that they could use the iPad when they felt it was needed (Laird et al., 2018; Ryan et al., 2020). Interventions that are easily implemented into daily life are also preferred. A qualitative study found that socialization, cognitive stimulation, cognitive rehabilitation, and time in nature were the most popular home-based interventions (Ross et al., 2024). Least popular were interventions which required organizing and planning (Ross et al., 2024). Activities that are cost effective are also popular. Chiu et al. (2014) found that walking, gardening, and Chinese breathing exercises, all inexpensive activities, were the most popular leisure-time physical activities among 58 dyads. Ross et al. (2024) found that self-paid interventions are rarely used because of the high financial burden.

Home-based interventions for people living with dementia delivered by informal caregivers that are easy to implement have better adherence. Complicated interventions, such as tailored activity programs and cognitive stimulation therapies, had poor adherence rates (Gitlin et al., 2018; Orrell et al., 2017). But caregivers who completed a CST intervention according to protocol showed significant improvements in depression (Orrell et al, 2017).

The largest RCT studies in this review reported no significant effects on any analyzed caregiver outcomes (Baker et al., 2023; Orrell et al., 2017). The lack of impact on caregiver outcomes for burden, depression, stress, and anxiety covered multiple types of interventions: music (432 dyads); CST (356 dyads); CST (241 dyads); TAP (160 dyads); and multicomponent (111 dyads) (Baker et al., 2023; Kor et al., 2024; Orrell et al., 2017; Prick et al., 2015). Kor et al. (2024) reported some improvement in 241 dyads on caregivers' views on the positive aspects of caregiving and improvement in negative attitudes towards persons with dementia while delivering CST to care recipients. Gitlin et al. (2018) found caregivers from 160 dyads had less distress with BPSD than the control group at 4 months.

Smaller RCT studies involving between 36 – 68 dyads showed similar non-significant effects on caregiver outcomes as the larger studies. A multicomponent sleep intervention for persons living with dementia involving 36 dyads found no change in caregiver self-reported sleep, mood, or health (McCurry et al, 2005). Cognitive therapy for care recipients showed no change in depression, reactions to BPSD, or satisfaction with caregiving for 68 dyads (Tappen & Hain, 2014). A massage intervention resulted in marginal, but statistically significant improvement in caregiver stress (Liu et al., 2023). An exercise intervention study of 40 dyads found non-statistically significant improvements in caregiver depression and burden (Vreugdenhil et al., 2012).

Even when the intervention has positive results for the care recipient, it did not necessarily lead to improvement for the caregiver. For example, in a TAP intervention study, people with dementia showed improvement in the number and severity of BPSD, a lower number of functional activities needing assistance, and lower functional dependence, yet caregivers reported no change in depression, burden, or time caregiving (Gitlin et al., 2018). In a multicomponent intervention to improve sleep, persons living with dementia had reduced nighttime awakenings, reduced total time awake at night, and reduced depression scores (McCurry et al., 2005). Yet caregivers reported no improvement in sleep, mood or health during the study (McCurry et al., 2005).

Heterogeneity of Studies

This review highlights the diverse nature of non-pharmacologic home-based interventions designed for persons living with dementia and delivered by informal caregivers. The review revealed 10 different types of interventions with differing implementation, instructions, and dosage. Even among similar types of interventions, the methods, protocols, and data measures are so diverse as to make comparisons difficult. The time for the studies ranged from 1 week to 8 months. At least seven different goals were identified for the person living with dementia. They included: to reduce BPSD, improve function, improve cognition; improve mood; increase quality of life, stimulation; and improve sleep. Over 44 different outcomes measures for caregivers and persons living with dementia were employed.

Stress Process Model Analysis

Pearlin's caregiver stress process model is the theoretical framework for this scoping review. Part of the theory for the model is that improvements for a person with dementia will result in improvements for the caregiver. In one study involving walking and strength building exercises, improved cognition, mobility, balance, strength, and increased independence in IADLS and ADLS for the person living with dementia also resulted in improvements in depression and burden for the care partner (Vreugdenhil et al., 2012). But this is not a linear or one to one effect. Even when the intervention has positive results for the care recipient, it did not necessarily lead to improvement for the caregiver. For example, in a TAP intervention, people living with dementia showed improvement in the number and severity of BPSD, a lower number of functional activities needing assistance, and lower functional dependence, yet caregivers reported no change in depression or burden (Gitlin et al., 2018). In a multicomponent intervention to improve sleep, persons with dementia had reduced nighttime awakenings, reduced total time awake at night, and reduced depression scores (McCurry et al., 2005). Yet caregivers reported no improvement in sleep, mood or health during the study (McCurry et al., 2005).

Using the Stress Process Framework for caregiver stress, interventions included in this scoping review have been examined as either buffers or secondary stressors for caregivers. In dyadic home-based interventions for persons living with dementia, the impact of the intervention on the caregiver must be considered. Improvement for the person living with dementia at the expense of the caregiver challenges the integrity of the care partner dyad. This could result in institutionalization for the person living with dementia (Stall et al., 2019). Based on this review and the mixed results of the research, it is unclear which type of intervention is best or worse for caregivers. Each intervention has both positive and negative impacts on caregivers. Instead, a balance must be reached with ease of the intervention and success for the person with dementia.

For example, caregivers in a music intervention reported immediate and rest-of-day reduction in BPSD for their care partners (Baker et al., 2023). Despite these positive results, the study showed low adherence to the intervention protocol of interacting with music for 30 minutes 2 – 5 times per week (Baker et al., 2023). Only 67% of study participants used music at least twice a week (Baker et al., 2023). Participants used the passive music technique (listening) more than the active music techniques (singing, dancing, etc.) (Baker et al., 2023). Baker et al. (2023) concluded that the low adherence rates and greater use of passive listening to music could indicate that the music intervention was burdensome to the caregiver.

In a Tai Chi intervention involving attendance at one Tai Chi class per week and dyadic home practice for 20 minutes per day, caregivers reported pleasure in learning a new activity, laughing together, and improved balance (Barrado-Martín et al., 2021; Barrado-Martín et al., 2019). On the other hand, caregivers also reported difficulty finding time to practice, challenges in motivating the person living with dementia to complete the exercises and expressed feelings that Tai Chi practice amounted to another chore (Barrado-Martín et al., 2021; Barrado-Martín et al., 2019). Of the recommended 50 hours of home practice over the course of the study, most dyads completed only 18-20 hours (Barrado-Martín et al., 2021).

Caregivers may react differently to the same intervention, which aligns with one of the four areas that contribute to caregiver stress under Pearlin's stress process model, the psychosocial resources of the individual caregiver. In a qualitative study on an activity kit (The Bag) designed for persons living with dementia that contained 20 recreational, art, and reminiscence activities, Hutchinson & Marshall (2020) found that some caregivers valued The Bag as a tool for evaluating a care recipient's abilities, while other caregivers found the evaluation upsetting. One daughter appreciated learning what skills her father retained, while a husband found The Bag to be a stark reminder of his wife's cognitive decline (Hutchinson & Marshall, 2020). Some caregivers appreciated The Bag as a therapeutic tool to provide active engagement options and ways for the person with dementia to connect with others. Other caregivers found The Bag a burden that competed with their other caregiving responsibilities (Hutchinson & Marshall, 2020).

This difficulty in striking a balance between benefit and burden is illustrated by a tailored activity program (TAP) where objective caregiver burden decreased, but subjective burden did not (Gitlin et al., 2008). TAP is designed to reduce BPSD by engaging the person living with dementia in activities tailored to their interests and abilities. The caregiver also receives occupational therapy training and education about dementia. The study found that TAP reduced caregivers' time spend "doing things" for the care recipient by one hour per day and that caregivers reported 5 hours less "hours on duty" per day (Gitlin et al., 2008). Caregivers also reported an enhanced ability to derive pleasure from and engage in activities with the person living with dementia (Gitlin et al., 2008). Yet caregiver subjective burden and depression scores did not improve over the study (Gitlin et al., 2008).

This stress process analysis illustrates the importance of person-centered care when using home-based interventions for persons living with dementia. Each dyad is different. Interventions that work for some caregivers may be overly burdensome for others. Considering the highly variable outcomes in the 10 types of home-based interventions and the mixed results of the studies, the importance of person-centered, individualized approaches to dementia and caregiving is apparent. There is a balance between secondary stressors and mediating factors that must be reached – and that balance is different for each dyad. In general, flexible, cost-efficient, easy to implement interventions are preferred. But more complicated or intensive interventions (such as TAP or CST) should not be discarded as some caregivers are willing and able to devote time and resources to those interventions.

Evidence Gaps

There is an overall lack of research on dyadic, home-based intervention strategies even though this is the most common living situation for informal caregivers and their care recipients (Rausch et al., 2017). Most non-pharmacological interventions for persons living with dementia are investigated in institutional settings (Bessey & Walaszek, 2019; Bowes et al., 2013; Schneider et al., 2019). New methods of recruitment may be needed to locate dyadic home-based research participants (Harris & Titler, 2022).

This review highlighted a lack of research on home-based interventions for persons of color. Of the studies that reported racial or ethnic data, 96% of the total participants were White (1535 of 1600) (Barrado- Martín et al., 2021; Barrado- Martín et al., 2019; Gitlin et al., 2008; Gitlin et al., 2010; Hanser et al., 2011; Harris & Titler, 2022; McCurry et al., 2005; Orrell et al., 2017; Tappen & Hain, 2014). There is a greater cultural expectation of filial obligations in Black and Latino families compared to White families (Pinquart & Sörensen, 2005). The experiences of persons of color in utilizing these interventions may be completely different than those reported by White caregivers.

Future Research

Future research into home-based interventions delivered by caregivers to persons living with dementia should include longer intervention periods and greater analysis of long-term effects. Eight months was the longest time measured of all the reviews in this study (Gitlin et al., 2018). A longitudinal, multi-year study of intervention efficacy over the course of the disease may improve overall knowledge of how home-based interventions can impact disease progression or be adapted to match the capabilities of the person living with dementia. Many studies in this review recognized the need for long-term examination of the interventions (Hanser et al., 2011; Kor et al., 2024; Liu et al., 2023; McCurry et al., 2005; Tappen & Hain, 2014; Vreugdenhil et al., 2012).

Most studies in this review included only persons with mild to moderate dementia. Future studies should include people living with severe dementia. People living with advanced dementia could be included in research by instituting longitudinal intervention studies through the course of the disease, from mild to severe dementia.

Larger sample sizes are needed for future research (see Baker et al., 2023; Barrado-Martín et al., 2019; Gitlin et al., 2010; Gitlin et al., 2008; Gitlin et al., 2018; Ryan et al., 2020; Vreugdenhil et al., 2012). With studies with as few as 10 dyads participating, it is difficult to achieve generalizability (see Barrado- Martín et al., 2019; Kulibert et al., 2019). New recruitment strategies may be needed to broaden the number of participants and encourage diversity of the samples (Harris & Titler, 2022).

As discussed under the stress process model, different caregivers perceive different interventions as easy or burdensome. Research into traits, characteristics, or personalities of caregivers and interest or compatibility of interventions could result in improved outcomes for PLWD and their care partners.

Limitations of Review

This review has several limitations. First, only studies written in English were included, which excludes potentially relevant research in other languages. Second, this study did not consider the heterogeneity of the interventions, which made comparisons difficult between and among interventions. However, this review confirmed the importance of person-centered, individualized interventions for persons living with dementia and their care partners. The lack of standardization of outcome measures could have affected the accuracy of the reported results. Many outcome measures such as quality of life, well-being and mood can be highly subjective, not well-defined, and difficult to quantify. However, qualitative findings provided more insights about the informal caregivers' experience and perceived outcomes. Finally, many studies are based on caregiver self-report or satisfaction surveys, which may be too subjective (Harris, 2022; Kor, 2024).

IMPLICATIONS FOR SOCIAL WORK

Research

Because most people living with dementia live in the community, there is a need for more research on dyadic home-based interventions for persons with dementia. Research into simple interventions that do not place undue burden on caregivers are needed for community-dwelling care partner dyads. Cost-effective interventions should be researched as a lack of funds can prevent caregivers from engaging in certain interventions (Ross et al., 2024).

There is also a need for more diversity in participant populations. Persons of color are underrepresented in the studies in this review, amounting to only 4% of participants.

Many studies in this review focus on the deficits or limitations of the person with dementia. A shift in research perspective to focusing on the strengths or what remains in the person may result in different ideas for interventions or different outcomes for people living with dementia and their caregivers.

Education

This review highlights the range of non-pharmacological, home-based intervention available for people living with dementia. Social work students should be educated on the variety of interventions. Using a person in environment approach, students and educators should consider how these interventions affect not only the person with dementia, but their informal caregivers. Evidence-based practice approaches can help students distinguish between viable interventions and those with no benefits.

Practice

Social workers should use a person-centered, individualized approach to implement non-pharmacological interventions for persons living with dementia into practice. There were 10 different types of intervention in this study, showing how diverse the options are. If one intervention is not successful, social workers should offer alternatives to clients.

This review discussed the importance of aging in place to many older adults. Social workers should look for ways to support client autonomy and aging in place for all older adults including persons living with dementia and their informal caregivers.

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Appendix I: Boolean Search

Search	PCC Framework	Terms
S1	Population	“informal care*” OR “family care*” OR “care* partner*”
S2	Population	Alzheimer* OR dementia* OR “cognitiv* impair*” OR “memory loss”
S3	Population combined	S1 N6 S2
S4	Context	“home-based” OR “home-deliver*” OR “community-based” OR “home setting” OR home
S5	Concept	intervention* OR therap* OR program* OR treatment*
S6		S3 AND S4 AND S5

Figure 1. PRISMA Flow Diagram

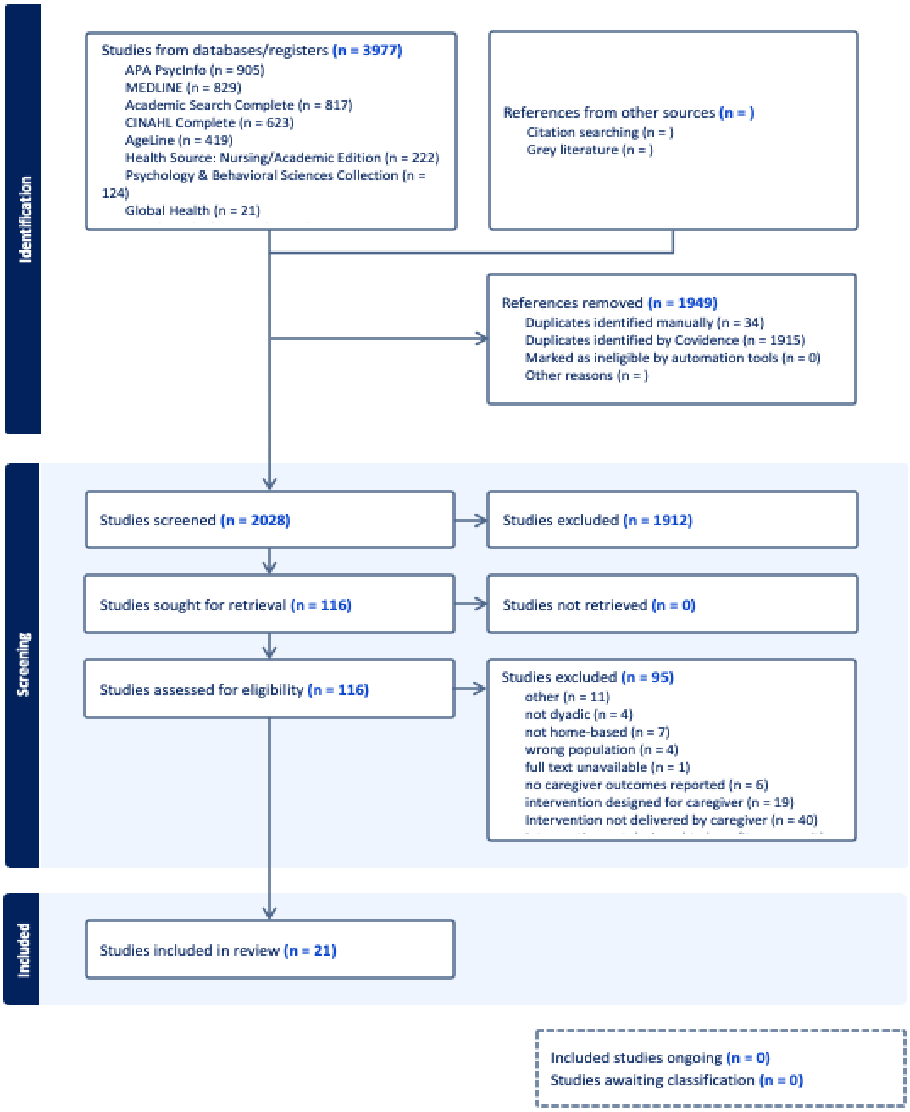

Table 1. General, Study Design and Intervention Details

Citation	Location	Study Design	Intervention Type	Intervention Goals	Intervention Dosage	Caregiver Training
Baker et al. (2023).	Australia, UK, Norway, Poland, Germany	RCT 432 dyads	Intervention: Music: 30 mins. 2 – 5 times/week; Control: Reading: 30 mins 2-5 times/week	BPSD	12 weeks; assessment at 90 and 180 days	Music: 3 2-hour online training with music therapist Reading: 3 online training sessions with OT
Barrado-Martín et al. (2021).	England	Qualitative 15 dyads	Tai Chi	Improve balance, prevent falls	20 weeks; 1 Tai Chi class/week and home practice 20 mins./day	1 home visit by instructor
Barrado-Martín et al. (2019).	England	Qualitative 10 dyads	Tai Chi	Improve balance, prevent falls	3 or 4 weeks; 1 Tai Chi class/week and home practice 20 minutes/day	1 home visit by instructor (60% of dyads)
Chiu et al. (2014)	Taiwan	Exploratory 58 dyads	Leisure-time physical activities	BPSD CG distress	1 week	None
Gitlin et al. (2010).	USA	RCT 60 dyads	TAP	BPSD	4 months 8 months	8 OT sessions (6 home; 2 phone)
Gitlin et al. (2018).	USA	RCT 160 dyads	TAP	BPSD and function	4 months 8 months	8 OT sessions
Gitlin et al (2008).	USA	RCT 60 dyads	TAP	BPSD; CG burden	4 months 8 months	6 90-mins. OT home visits; 2 15-mins. telephone calls with OT
Hanser et al. (2011).	USA	Qualitative exploratory 14 dyads	Music	CR: Improve mood; psychological state CG: reduce distress; enhance satisfaction w/CG	3 days/week Range 7 – 19 sessions	2-hours with MT

Harris & Titler (2022).	USA	Quasi-experimental 21 dyads	Weighted blanket	Calming effect; BPSD	4 weeks; at least 20 mins/day	1 virtual training session; weekly phone calls
Hutchinson & Marshall (2000).	USA	Qualitative 21 dyads	Activity kit (20 recreational, art, & reminiscence activities)	stimulation	None specified; use as wanted	1 session with case manager, instruction book
Kor et al. (2024).	Hong Kong	RCT 241 dyads	CDCST (CG-delivered cognitive stimulation therapy)	Cognition; QoL; BPSD	15 weeks, 45 mins.; 3 times/week	12 hours (4 hours with nurse or SW & 8 hours self-directed practice with instruction booklet)
Kulibert et al. (2019).	USA	Mixed method 24 dyads recruited; 10 completed study	Music & Memory (personalized music in iPod shuffle)	BPSD; QofL; CG/CR relationship; CG distress; improve CG’s view of role	3 months Use as desired	Instructions on how to use iPod Shuffle, headphones, & speaker; 1-page activities to do while listening to music; 1 training session with researcher
Laird et al. (2018).	UK	Quasi-experimental 30 dyads	Reminiscence iPad app (InspireD)	Mutuality; quality of CG/CR relationship; subjective well-being	19 weeks	5 reminiscence training sessions; 3 IT sessions
Liu et al (2023).	Taiwan	RCT 38 dyads	Massage	BPSD; CG stress	8 weeks, 30-mins, 3 times/week	3-hr home-based training by licensed nurse
McCurry et al. (2005).	USA	RCT 36 dyads	Sleep hygiene, daily walking, and light exposure	Improve sleep	Walk 30 mins./day; 1-hr/day light box (measured 2 & 6 months)	6 1-hr in home sessions with geropsychologist; 1 session on sleep hygiene education
Orrell et al. (2017).	UK	RCT 356 dyads	CST	CR: cognition; QoL CG: mental & physcial health	25 weeks, 30-mins. 3 times/week	60-90 mins. in-home by unblinded researcher
Prick et al. (2015).	The Netherlands	RCT 111 dyads	Multicomponent: physical exercise, psycho-education, communication training, & pleasant	CR: mood, behavior & physical health CG: mood, burden, general health, salivary cortisol	3 months 30 mins. Exercise, 3 times/week; plan pleasant activities	8 1-hr in home sessions

			activities training			
Quayhagen & Quayhagen (1989).	USA	Quasi-experimental 16 dyads	CST	CR: cognition; BPSD CG: physical and mental well-being	1-hr./day 6 days/week Assessed at 4 months and 8 months	1 training in clinic; unspecified training sessions at home
Ross et al. (2024).	Germany	Qualitative 30 CGs	Varied	Perceived effects of non-pharmacological interventions on CR; barriers to implementation	Varied	None
Ryan et al. (2020).	UK	Qualitative 15 CRs & 17 CGs	Reminiscence iPad app (InspireD)	Explore impact of home-based reminiscence app on persons living with dementia and carers	12 weeks	IT and reminiscence training
Tappen & Hain (2014).	USA	RCT 68 dyads	Intervention: Cognitive Training Control: Life Story Review	CR (CT): function; cognition CR (LSR): language performance CG: mood, reactivity & satisfaction	12 weeks 1-hour in-home 2 times/week CGs reinforced CT on non-treatment weekdays (3/week)	12 weeks 1-hour in-home session with interventionist 2 times/week
Vreugdenhil et al. (2012).	Australia	RCT 40 dyads	Exercise	Cognitive & physical function, ADLs	4 months Daily exercises & walking	Unspecified training and provided an exercise manual

NOTES: ADL = activities of daily living; BPSD = behavioral and psychiatric symptoms of dementia; CG = Caregiver; CR = Care recipient; CST = Cognitive Stimulation Therapy; CT = cognitive training; LSR = Life Story Review; OT = occupational therapy; QoL = quality of life; RCT = randomized controlled trial; TAP = tailored activity program

Table 2. Types of Interventions

Type of Intervention	# of Studies	Citations
CST	3	Kor et al. (2024); Orrell et al. (2017); Quayhagen & Quayhagen (1989)
Exercise	3	Barrado-Martín et al. (2021); Barrado-Martín et al. (2019); Vreugdenhil et al. (2012)
Multicomponent	3	McCurry et al. (2005); Prick et al. (2015); Ross et al. (2024)
Music	3	Baker et al. (2023); Hanser et al. (2011); Kulibert et al. (2019)
TAP	3	Gitlin et al. (2010); Gitlin et al. (2008); Gitlin et al. (2010)
Reminiscence	2	Laird et al. (2018); Ryan et al. (2020)
Leisure Activity-Based	2	Hutchinson & Marshall (2000); Yi-Chen Chiu et al. (2014)
Cognitive Training	1	Tappen & Hain (2014)
Massage	1	Liu et al. (2023)
Weighted Blanket	1	Harris & Titler (2022)

NOTE: CST = cognitive stimulation therapy; TAP = tailored activity program

Table 3. Participant Characteristics

Citation	Participants: Age (mean)	Participants: Gender	Participants: Race/Ethnicity	Participants: Employment Status	Participants: Education	Participants: Relationship of Care Partners
Baker et al. (2023).	N/A	CG: 19% male; 81% female CR: 55% male; 45% female	N/A	N/A	CG: HS 17% Trade/community 24% Bachelor 29% Master 27% PhD 3% CR: none 10% HS 26% Trade/community 25% Bachelor 20% Master 16% PhD 3%	63% Spouse/partner 34% Child 3% other
Barrado-Martín et al. (2021).	CG: 72 CR: 79	CG: 27% male, 73% female CR: 55% male, 45% female	CG: 100% White CR: 100% White	N/A	CG: Primary 9% Secondary 50% College 23% Professional 14% Missing data 4% CR: none 4% Primary 4% Secondary 59% College 23% Professional 9%	82% Spouse/partner 9% Child 9% Sibling
Barrado-Martín et al. (2019).	CG: 72.4 CR: 78.2	CG: 40% male, 60% female CR: 50% male, 50% female	CG: 100% White CR: 100% White	N/A	CG: Primary 10% Secondary 30% College 30% Professional 30% CR: Primary 20% Secondary 40% College 10% Professional 30%	90% spouse/partner 10% niece
Chiu et al. (2014)	CG: 50.9 CR: 79.2	CG: 33.3% male; 66.7% female CR: 32.8% male; 67.2% female	N/A	CG: Unemployed 56.9% Business 13.79% Service 8.62% Part-time 8.62% Other 12.07%	CG: none 5.3% Primary 15.5% Junior HS 12.1% HS 25.9% College 41.2% CR: none 37.9% Primary 27.6% Junior HS 13.8% HS+ 19%	29.3% son 22.4% daughter-in-law 21.7% daughter 15.52% wife 5.17% husband 5.17% other
Gitlin et al. (2010).	CG: 65 CR: 77	CG: 12% male 88% female; CR: 57% male; 43% female	CG: 77% white; 23% non-white CR: 77% white; 23% non-white	N/A	CG: > HS 48%; < HS 52% CR: > HS 73%; < HS 27%	62% spouse 38% non-spouse

Gitlin et al. (2018).	CG: 72.4 CR: 80.4	CG: 2.5% male; 97.5% female CR: 97% male; 3% female	CG: 81% white CR: 79% white	CG: 89% unemployed CR: N/A	CG: 38% HS or less; 62% more than HS CR: 40% HS or less; 60% more than HS	87% spouse 13% unspecified
Gitlin et al (2008).	CG: 65 CR: 79	CG: 12% male; 88% female; CR: 57% male; 43% female	CG: 77% White; 21% African American; 2% other CR: 77% White; 21% African American; 2% other	N/A	CG: 27% < HS; 56% < college; 17% graduate CR: 54% < HS; 32% < college; 14% graduate	62% spouse; 38% non-spouse
Hanser et al. (2011).	CG: range < 65- >85; CR: 75% 76-85; 25% >85	CG: 37% male; 63% female CR: 37% male; 63% female	CG: 100% White CR: 100% White	CG: Retired 62.5% Unemployed 12.5% Homemaker 25% CR: N/A	CG: 25% HS 12% some college 25% college degree 38% advanced CR: 12% HS 12% technical 25% some college 50% advanced	75% spouse 25% daughter
Harris & Titler (2022).	CG: 66.4 CR: 77.7	CG: 20% male; 80% female CR: 65% male; 35% female	CG: 95% non-Hispanic White; 5% non-Hispanic Black CR: 95% non-Hispanic White; 5% non-Hispanic Black	N/A	CG: 20% HS 10% some college 70% college and above CR:10% < HS 15% HS 20% some college 55% college and above	80% partners 20% child
Hutchinson & Marshall (2000).	CG: range mid-40s to mid-80s CR: 56 - 92	CG: 24% male; 76% female CR: 62% male; 38% female	N/A	N/A	N/A	70% spouse 25% child 5% daughter-in-law
Kor et al. (2024).	CG: 63 CR: 83	CG: 20% males; 80% female CR: 41% male; 59% female	N/A	CG: 10% unemployed 62% retired 28% employed CR: N/A	CG: 2% no formal education 22% primary 44% secondary 32% college+ CR: N/A	34% spouse 61% children/in-laws 3% grandchild 2% sibling/other relative
Kulibert et al. (2019).	N/A	CG: N/A CR: 58% male; 42% female	N/A	N/A	N/A	92% spouse 8% daughter
Laird et al. (2018).	CG: 67 CR: 79	CG: 20% male; 80% female CR: 67% male; 33% female	N/A	N/A	N/A	N/A

Liu et al (2023).	CG: 56 CR: N/A	CG: 24% male; 76% female CR: N/A	N/A	CG: 40% full time; 26% part time; 34% unemployed CR: N/A	CG: 3% elementary; 3% middle; 34% HS; 60% college CR: N/A	13% spouse 79% child/in-law 8% grandchild/in-law
McCurry et al. (2005).	CG: 21-87 CR: 63-93	CG: 28% male; 72% female CR: 56% male; 44% female	CG: 89% white; 8% Asian/Pacific Islander; 3% Native American CR: 92% white; 5% Asian/Pacific Islander; 3% Native American	N/A	N/A	58% spouse 33% child 9% other
Orrell et al. (2017).	CG: 65.73 CR: 78.2	CG: 27% male; 73% female CR: 54% male; 46% female	CG: 92% White CR: 93% White	N/A	Highest level of education: CG: 44% school leaver (14-16 years) CR: 60% school leaver (14-16 years)	63% spouse 37% other relative or friend
Prick et al. (2015).	CG: 72 CR: 77	CG: 28% male; 72% female CR: 63% male; 37% female	N/A	N/A	CG: 4.08 CR: 4.01 0 = less than elementary 6 = university	90% spouse 10% child/other
Quayhagen & Quayhagen (1989).	CG: CST 67 Control 64.8 CR: CST 68.3 Control 66.5	CG: CST: 60% male; 40% female Control: 67% male; 33% female CR: CST: 40% male; 60% female Control: 17% male; 83% female	N/A	N/A	In years CG: CST 14.4 Control 13.7 CR: CST 13.2 Control 12.7	Family (unspecified)
Ross et al. (2024).	CG: 63.07 CR: N/A	CG: 30% male; 70% female CR: N/A	N/A	N/A	CG: Secondary 6.67% Professional 43.33% College 23.33% University 26.67%	30% spouse 70% other relative
Ryan et al. (2020).	CG: 65.5 CR: 78.1	CG: 24% male; 76% female CR: 60% male; 40% female	N/A	N/A	N/A	76% spouse 18% child 6% grandchild

Tappen & Hain (2014).	CG: N/A CR: 81	CG: N/A CR: 60% male; 40% female	CG: N/A CR: 97% White 3% Hispanic	N/A	N/A	Family (unspecified)
Vreugdenhil et al. (2012).	CG: N/A CR: 74	CG: N/A CR: 40% male; 60% female	N/A	N/A	N/A	Informal carers (unspecified)

NOTE: CG = caregiver; CR = care recipient; CST = cognitive stimulation therapy; HS = high school; N/A = not available, data not reported

Table 4. Data Collection Measures

Caregiver Outcome	Number	Data Collection Measures
Attitude toward caregiving	4	FAS; GAIN; PAC; QCPR
Depression	6	CES-D; Cornell; DASS; GDS; HADS; PHQ-9
Anxiety/Stress	6	CDS; DASS; HADS; NPI-Q; PSS; SPICC
Burden	2	Zarit; SPICC
Health	1	SF-12
Quality of Life	1	EQ-5D
Relationship with CR	1	QCPR
Resilience	1	RS-14
Well-Being	2	CWBS; WHO-5

Care Recipient Outcome	Number	Data Collection Measures
Anxiety	1	RAID
BPSD	5	CMAI; MBPC; NPI; NPI-C; RMBP
Cognition	9	ADAS-Cog; CDR; DRS; MBPC; MMSE; MoCA; OME; RMBP;WMS-FII
Depression	4	Cornell; GDS; GDS-S; MADRS
Function (ADLs & IADLs)	6	B-ADL; BADLS; CAFU; CBI; CI-BIC-plus; DAFS
Quality of Life	3	BASQID; DEMQOL; QoL-AD
Relationship with CG	1	QCPR
Sleep	2	ESS; PSQI
Well-being	1	WHO-5

NOTES: ADAS-Cog = Alzheimer’s Disease Assessment Scale-Cognitive; ADL = Activities of Daily Living; B-ADL = Bayer Activities of Daily Living Scale; BADLS = Bristol Activities of Daily Living Scale; BASQID = Bath Assessment of Subjective Quality of Life in Dementia; CAFU = Caregiver Assessment of Function and Upset Scale; CBI = Chinese Barthel Index; CES-D = Centre for Epidemiologic Studies - Depression; CDR = Clinical Dementia Rating; CDS = Caregiver Distress Scale; CI-BIC-plus = Clinician’s Interview-Based Impression of Change plus Caregiver Input; CMAI = Cohen-Mansfield Agitation Inventory-Relatives; Cornell = Cornell Scale for Depression in Dementia; CWBS = Caregiver Well-being Scale; DAFS = Direct Assessment of Functional Status; DASS = Depression, Anxiety, and Stress Scale; DEMQOL = Dementia Quality of Life; DRS = Dementia Rating Scale; EQ-5D = European Quality of Life – 5 Dimensions; ESS = Epworth Sleepiness Scale; FAS = Family Attitude Scale; GAIN = The Gain in Alzheimer Care Instrument; GDS = Geriatric Depression Scale; GDS-S = Geriatric Depression Scale – Short Form; HADS = Hospital Anxiety and Depression Scale; IADL = Instrumental Activities of Daily Living; MADRS = Montgomery Asberg Depression Rating Scale; MBPC = Memory and Behavior Problems Checklist; MMSE = Mini Mental State Exam; MoCA = Montreal Cognitive Assessment Test; NPI = Neuropsychiatric Inventory; NPI-C = Neuropsychiatric Inventory-Clinician; NPI-Q = Neuropsychiatric Inventory Questionnaire; OME= Fuld Object Memory Evaluation; PAC = Positive Aspect of Caregiving Scale; PSQI =

Pittsburg Sleep Quality Index; PSS = Perceived Stress Scale; QCPR = Quality of the Carer-Patient Relationship Scale; QoL-AD = Quality of Life Alzheimer's Disease Scale; PHQ-9 = Patient Health Questionnaire-9 (depression); RAID = Rating Anxiety in Dementia Scale; RS-14 = Resilience Scale; RMBP = Revised Memory & Behavior Problems Checklist; SF-12 = Short Form-12 Health Survey; SIP = Sickness Impact Profile; SPICC = Dutch Self-Perceived Pressure from Family Care; WHO-5 = World Health Organization-Five Well-Being Index; WMS-FII = Wechsler Memory Scale Form II; Zarit = Zarit Burden Interview/Scale

Table 5. Data Collection Measures and Outcomes

Citation	Data Collection Measures: Person Living with Dementia	Data Collection Outcomes: Person Living with Dementia	Data Collection Measures: Caregiver	Data Collection Outcomes: Caregiver
Baker et al. (2023).	NPI-Q severity subscale; MADRS; QoL-AD; MMSE	Music 90-days and 180-days: No significant changes in BPSD, QoL, depression or cognition Reading superior to UC at 180-days, but not 90-days QoL decreased over time in all groups	NPI-Q distress scale; PHQ-9; RS-14; Short Sense of Competence Questionnaire; QoL-6D; Quality of Caregiver-Patient Relationship	90-days: increased resilience (music); 180-days: no significant change from baseline (music); increased resilience (reading); lower distress from BPSD (reading); lower QoL (reading)
Barrado-Martín et al. (2021).	Interviews; exercise logs (most completed by CG)	54% of recommended home practice completed (18 hours total) Themes: Supportive materials, behavior change elements, ways of practicing, barriers and facilitators	Semi-structured interviews; exercise logs (70% return rate)	60% of recommended home practice completed (20 hours total) Themes: Supportive materials, behavior change elements, ways of practicing, barriers and facilitators
Barrado-Martín et al. (2019).	Observation (semi-structured checklist), field notes, focus groups	Difficulty getting and maintaining attention on intervention (20%); Perceived benefit to participation as a dyad	Observation, field notes, focus groups	Difficulty getting and maintaining attention on intervention (20%); Perceived benefit to participation as a dyad
Chiu et al. (2014)	MMSE; CDR; GDS-S; CBI; NPI; 7-day Physical Activity Recall log	Most common: strolling; qigong; & gardening; Mean weekly activity: frequency (4.52 times), duration (3.7 hrs.), and energy expenditure (771.47 kcal) More activity types = less BPSD; better mood	CDS	More activity types = less distress
Gitlin et al. (2010).			Caregiver Vigilance Scale : “hours doing” and “hours on duty”	“hours doing” reduced by 1 hr/day at cost of $2.37/day; “hours on duty” reduced by 5hr/ day Cost to reduce “hours on duty” by 1 hr was $1.10/day

Gitlin et al. (2018).	NPI-C; CAFU; # of ADLs requiring assistance; Pain Intensity Scale; CG rated CR affect	4 months: 70% of CR showed improvement in # of BPSD; improvement in severity score; lower # of functional activities needing assistance; lower functional dependence; lower pain; no change in affect	CES-D; Zarit; # of hours on duty; # of hours on ADL and IADL; # of hours “doing things” for CR; distress score based on NPI-C	At 8 months, 35.6% attrition rate 4 months: less distress with BPSD than control; no significant change in depression, burden, or time caregiving
Gitlin et al (2008).	Frequency of BPSD; Cornell; activity engagement reported by CG; QoL-AD	Treatment effect for behaviors, statistical significance for shadowing and repetitive questioning, agitation and argumentation; no effects for depression or QoL; total # of BPSD reduced but not to statistical significance	Cornell; mastery; subjective burden (measured as upset from BPSD); Zarit; objective burden (measured by CG report of # of hours “doing things” and “on duty”); CES-D; confidence using activity; Task Management Strategy Index	1 hour less “doing things”; 5 hours less “on duty”; greater mastery; enhanced self-efficacy; no difference for subjective burden; no effect on depression
Hanser et al. (2011).	CGs rated CR’s relaxation, comfort, & happiness	Increase in relaxation, comfort, & happiness	CGs rated their relaxation, comfort, & happiness; Caregiving Satisfaction Scale (burden)	Increase in relaxation, comfort, & happiness Decrease in CG satisfaction
Harris & Titler (2022).	RAID; QoL-AD; MoCA; NPI; CMAI; PSQI; ESS; total # of minutes blanket used; CR response to blanket; Weighted Blanket Acceptability Tool	High scores of tolerability, acceptability & benefit	CWBS; self-reported health status; Weighted Blanket Acceptability Tool; challenges in using blanket	High degrees of intervention acceptability
Hutchinson & Marshall (2000).	Interviews with CGs	Themes: *The Bag* as fun; insulting; a test	Interviews	Themes: *The Bag* as therapeutic; transformer; connector; burden; evaluation; supplemental; springboard; adapted
Kor et al. (2024).	MoCA; NPI-Q; QoL-AD	No significant changes immediately after intervention; at 3 months, improvement in cognition, BPSD, & QoL	PAC; FAS; DASS; Zarit; NPI-Q	Improvements in positive aspects of CG and in negative attitudes towards persons with dementia; no change in CG burden, distress, depression, anxiety or stress

Kulibert et al. (2019).	BASQID; Music Listening Experience Scale; RMBPC; interviews	No significant change in BASQID, MLES, & RMBPC. Themes: calming effect, positive feelings, engagement with music, use of music with other activities	CDS; GAIN; interviews	Slight improvement on CDS; slight decrease on GAIN. Themes: help CGs cope with duties; selective use of M&M
Laird et al. (2018).	Mutuality; QCPR; WHO-5	Statistically significant increase in mutuality, QCPR, and WHO-5	Mutuality; QCPR; WHO-5	Non-significant increase in mutuality & QCPR; non-significant decrease in WHO-5
Liu et al (2023).	Cornell; CMAI	Significant improvement in depression and agitation	PSS	Marginal improvement in stress
McCurry et al. (2005).	Sleep diary kept by CG (Total night sleep; % of time asleep; # of awakenings; duration of time awake); ESS; Cornell; RMBPC; mood	Reduced nighttime awakenings, reduced total time awake at night, reduced depression, increased exercise	PSQI; CES-D; mood	No difference in self-reported sleep, mood, or health
Orrell et al. (2017).	Primary: ADAS-Cog; QoL-AD Secondary: DEMQOL; NPI; BADLS; GDS; QCPR	Improved relationship quality; no change in depression, BPSD, QoL, and cognition	Primary: SF-12 Secondary: HADS; EQ-5D; RS-14; QCPR	No change in depression, anxiety, distress, QoL, mental & physical health and relationship quality
Prick et al. (2015).	RMBP	No change in behavior	CES-D; SPICC; RMBPC; self-rated general health; salivary cortisol	No change
Quayhagen & Quayhagen (1989).	DRS; WMS-FII; 10 arithmetic problems; Geriatric Coping Schedule; MBPC	Maintained cognitive functioning compared to control; no change in behaviors	Zarit; Hopkins Symptom Checklist; Health Assessment Scale; CG written logs	Maintained mental health and burden compared to control which worsened; no improvement in well-being

Ross et al. (2024).	Structured interviews with CGs re: use of non-pharmacologic interventions for persons with dementia	Most common: socialization, cognitive stimulation, cognitive rehabilitation, time in nature Least common: sensory measures (except massage); music/art/dance therapies; household baking, handicrafts; drawing, learning a foreign language Perceived effects: Enjoyment, competence, well-being. Social inclusion perceived as most effective in general. Time in nature perceived as most effective for behavioral issues. For aggression, physical activity, communication, and behavioral training for family caregivers. For sleeping problems, routine. Other interventions reported by over 20% of CGs were leisure activities, cognitive training, and a stable structure of daily routines and environmental surrounding to help navigate surroundings and reduce confusion.	Structured interviews with CGs re: use of non-pharmacologic interventions for persons with dementia and barriers to implementation	Barriers: cost/funding; organizing/participating in activity, poor local accessibility; no discernible benefit to intervention
Ryan et al. (2020).	Interviews with CR	Themes: ‘It’s Part of My Life Now’ (Usability); ‘Memories that are important to me’ (Revisiting the past); ‘It was Homely’ (Home use); ‘It helped me find myself again’ (Impact on the person living with dementia), ‘There is still so much inside’ (Gains and abilities) and ‘It’s become very close’ (Impact on relationships).	Interviews with CG	Themes: ‘It’s Part of My Life Now’ (Usability); ‘Memories that are important to me’ (Revisiting the past); ‘It was Homely’ (Home use); ‘It helped me find myself again’ (Impact on the person living with dementia), ‘There is still so much inside’ (Gains and abilities) and ‘It’s become very close’ (Impact on relationships).
Tappen & Hain (2014).	OME; DAFS; B-ADL; Face-Name-Association; Phonemic Fluency and Controlled Oral Word Association; Picture Description Test	CT: increase in face/name association, money-related task, & 1 of 2 event-related memory tasks; no change in B-ADL or OME. LRS: no change in language performance; no change in B-ADL or OME	CES-D; RMBP; Satisfaction with Caregiving subscale of the Family Caregiving Inventory (mutuality)	No change in CES-S; RMBP. LSR reported increased satisfaction. No change in satisfaction for CT.
Vreugdenhil et al. (2012).	ADAS-Cog; MMSE; functional reach test; Timed Up and Go; Sit to Stand test; Barthel Index of ADLs; IADL assessment; GDS; CI-BIC-plus	Improved cognition, improved mobility, balance, and lower body strength, increased IADL scores and independence in ADLs	Zarit	Improvements in depression and burden, but no statistical significance

NOTES: ADAS-Cog = Alzheimer’s Disease Assessment Scale-Cognitive; B-ADL = Bayer Activities of Daily Living Scale; BADLS = Bristol Activities of Daily Living Scale; BASQID = Bath Assessment of Subjective Quality of Life in Dementia; BPSD = behavioral and psychological symptoms of dementia; CAFU = Caregiver Assessment of Function and Upset Scale; CBI = Chinese Barthel Index; CES-D = Centre for Epidemiologic Studies - Depression; CDR = Clinical Dementia Rating; CDS = Caregiver Distress Scale; CI-BIC-plus = Clinician’s Interview-Based Impression of Change plus Caregiver Input; CMAI = Cohen-Mansfield Agitation Inventory-Relatives; Cornell = Cornell Scale for Depression in Dementia; CWBS = Caregiver Well-being Scale; DAFS = Direct Assessment of Functional Status; DASS = Depression, Anxiety, and Stress Scale; DEMQOL = Dementia Quality of Life; DRS = Dementia Rating Scale; EQ-5D = European Quality of Life – 5 Dimensions; ESS = Epworth Sleepiness Scale; FAS = Family Attitude Scale; GAIN = The Gain in Alzheimer Care Instrument; GDS = Geriatric Depression Scale; HADS = Hospital Anxiety and Depression Scale; MADRS = Montgomery Asberg Depression Rating Scale; MMSE = Mini Mental State Exam; MBPC = Memory and Behavior Problems Checklist; MoCA = Montreal Cognitive Assessment Test; NPI = Neuropsychiatric Inventory; NPI-C = Neuropsychiatric Inventory-Clinician; NPI-Q = Neuropsychiatric Inventory Questionnaire; OME= Fuld Object Memory Evaluation;

PAC = Positive Aspect of Caregiving Scale; PSQI = Pittsburg Sleep Quality Index; PSS = Perceived Stress Scale; QCPR = Quality of the Carer-Patient Relationship Scale; QoL-AD = Quality of Life Alzheimer's Disease Scale; PHQ-9 = Patient Health Questionnaire-9 (depression); RAID = Rating Anxiety in Dementia Scale; RS-14 = Resilience Scale; RMBP = Revised Memory & Behavior Problems Checklist; SF-12 = Short Form-12 Health Survey; SIP = Sickness Impact Profile; SPICC = Dutch Self-Perceived Pressure from Family Care; WHO-5 = World Health Organization-Five Well-Being Index; WMS-FII = Wechsler Memory Scale Form II; Zarit = Zarit Burden Interview/Scale

Table 6. Caregiver Outcomes by Intervention Type

Intervention	Positive	Negative	No Change
Cognitive Training			Tappen & Hain (2014): Depression, mutuality, CG satisfaction
CST	Kor et al. (2024): Positive aspects of CG; Better attitude toward person living with dementia Quayhagen & Quayhagen (1989): Maintained mental health and burden compared to control		Kor et al. (2024): Burden, distress, depression, anxiety, stress Orrell et al. (2017): Depression, anxiety, distress, QoL, resilience, mental & physical health, relationship quality Quayhagen & Quayhagen (1989): Well-being
Exercise	Barrado-Martín et al. (2021): Enjoyment of Tai Chi and improvement over time Barrado-Martín et al. (2019): New pleasurable activity; improved balance Vreugdenhil et al. (2012): Non-statistically significant improvements in depression and burden	Barrado-Martín et al. (2021): Some CGs viewed Tai Chi as another chore Barrado-Martín et al. (2019): Difficulty motivating CR to practice	
Leisure-Based Activity	Chiu et al., (2014): Less distress with more activity types Hutchinson & Marshall (2000): *The Bag* as therapeutic, transformer, connector, supplemental, springboard, adapted	Hutchinson & Marshall (2000): *The Bag* as burden, evaluation	
Massage	Liu et al. (2023): Marginal improvement in stress		
Multicomponent	Ross et al. (2024): Enjoyment, perceptions of confidence & well-being	Ross et al. (2024): Barriers to interventions – cost/funding, organizational burden, poor local accessibility	McCurry et al (2005): Self-reported sleep, mood, or health Prick et al. (2015): Depression, stress, health Ross et al. (2024): No discernible benefit

Music	Baker et al. (2023): 90-days resilience Hanser et al. (2011): Relaxation, comfort, & happiness Kulibert et al. (2019): Slight improvement in distress; Music helped cope with CG duties	Hanser et al. (2011): Decrease in CG satisfaction Kulibert et al. (2019): Marginal decrease in CG attitude toward caregiving	Baker et al. (2023): 180-days distress, depression, competence, resilience, QoL, relationship
Reminiscence	Larid et al. (2018): Non-significant increase in mutuality & relationship quality Ryan et al. (2020): Positive impact on relationship; Focus on strengths of person living with dementia; easy to use app; value of home-use & privacy	Larid et al. (2018): Non-significant decrease in well-being Ryan et al. (2020): Negative impact with distressing memories	
TAP	Gitlin et al. (2010): 1 less “hours doing” 5 less “hours on duty” Gitlin et al. (2018): 4 months – less distress with BPSD Gitlin et al. (2008): Greater mastery; enhanced self-efficacy	Gitlin et al. (2018): 8 months – 35.6% attrition rate	Gitlin et al. (2018): 4 months depression, burden, time caregiving Gitlin et al. (2008): Burden, depression
Weighted Blanket	Harris & Titler (2022): High degrees of intervention acceptability		

NOTES: CG = caregiver; CR = care recipient; CST = cognitive stimulation therapy; TAP = tailored activity program