DYADIC PERSON LIVING WITH DEMENTIA/ CAREGIVER FALLS PREVENTION INTERVENTIONS: A LITERATURE SYNTHESIS

by

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ABSTRACT

People living with dementia experience falls at a disproportionate rate than age-matched adults due to several factors: gait dysfunction, balance disorders, and modifiable external hazards. Currently, falls prevention interventions conducted in this population have had inconclusive results because falls prevention interventions tailored for cognitively normal adults do not translate to those living with dementia, thus leaving a gap in knowledge in this field of research.

Caregivers of people living with dementia may provide a unique aspect to falls prevention interventions as they are in a position to act as co-therapists throughout the course of an intervention. By utilizing caregivers as co-therapists in a dyadic intervention, interventionists are able to rely on them to aid the person living with dementia in the execution of the intervention and to confirm that the person living with dementia is following protocol, which has been shown to be vital in program success in past interventions.

In addition to exploring the relationship between caregiver involvement and outcomes of falls prevention interventions in the dementia population, this literature synthesis will also evaluate the effectiveness of a falls prevention program among people with dementia according to whether people live alone or with family as a proxy for caregiver involvement in falls prevention that has been conducted in Pennsylvania recently.
Dyadic falls prevention in the dementia population is an area of research that requires further exploration. This area of research is significant to public health because public health’s ability to impact society by decreasing hospitalizations and delaying institutionalizations by providing additional years of improved quality of life in the dementia population can save billions of dollars in healthcare costs.
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PREFACE

I would like to thank Dr. Steven Albert for all of his patience and guidance throughout this process and for providing me with the Healthy Steps for Older Adults data. I would also like to thank Dr. Jennifer Lingler and Dr. Jeannette Trauth for their insight and support.
1.0 INTRODUCTION

People living with dementia are disproportionately affected by falls and fall-related injuries as compared to age-matched older adults.\textsuperscript{4,7,9,10,11} The reason for this remains unclear, a complex and overlapping array of factors are involved in both dementia and falls. While there are conflicting results from the limited research done in this field, tailoring of falls prevention programming is likely to be vital to the success of the program in lowering the rate and number of falls in people with dementia.

Scalability and personalized falls prevention are important when designing an intervention that targets populations at risk for falls, such as those living with dementia. The inability of an intervention to be personalized will ultimately lead to the failure of an intervention as shown in many recent studies.\textsuperscript{3,22} Furthermore, the assistance of informal family caregivers during the intervention process is essential for program adherence and success in lowering the rate and number of falls.\textsuperscript{23}

The purpose of this thesis is to serve as a literature synthesis on the importance of fall prevention interventions for people living with dementia, with a special emphasis on dyadic fall prevention interventions involving people living with dementia and their informal caregivers. People living with dementia are more likely to fall, yet their cognitive impairment may prevent them from benefitting from falls prevention efforts that occur in cognitively normal older adults; therefore involving caregivers in falls prevention efforts may show additional achievements. This
paper will also evaluate the effectiveness of a falls prevention program among people with
dementia according to whether people live alone or with family as a proxy for caregiver
involvement in falls prevention.
2.0 METHODS

I utilized Pubmed.gov as the search engine for my research. With the help of Barbara Folb, a librarian at the University of Pittsburgh, we identified keywords to use in our search for dyadic caregiver-person living with dementia falls prevention interventions. Because this area of research is not well explored, our search results were not numerous. However, this further exemplifies why dyadic falls prevention efforts involving caregivers of persons living with dementia needs additional research.

Figure 1 details the PubMed keywords that were used to refine our search of informal caregivers of dementia patients and falls within the dementia population.

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<th>Dementia</th>
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<tr>
<td>Dementia[mesh]</td>
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<tr>
<td>Dementias[tiab] OR Dementia[tiab] OR Dementias[ot] OR Dementia[ot]</td>
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</table>

| Frontotemporal Lobar Degenerations[tiab] OR Frontotemporal Lobar Degeneration[tiab] OR |

Lewy Body[tiab] OR Lewy Body[ot]

Caregivers AND Informal AND Dementia


AND


AND


Falls

Accidental Falls[Mesh]


Figure 1. PubMed search words
A collection of keywords and alternate words used in a search on PubMed.gov to locate articles regarding informal caregivers of dementia patients and accidental falls. This was conducted on May 10, 2016 with assistance from Barbara Folb. The abbreviations following each word indicate where the term can be found. “TIAB” indicates that the keyword should be found in the title or abstract of a study. “OT” denotes other terms. “MESH” terms were included to ensure the search was as complete as possible.

The keywords found in Figure 1 were then used in the advanced search of PubMed. I first started by using the Boolean Operator “OR” to search for articles pertaining to informal caregivers. The fifth search combines the previous searches for “caregivers” and informal”. Next, I used the MESH term search for all articles related to dementia. Additionally, I searched for titles and abstracts of published papers that included the word “dementia”. These two searches were then combined, as seen in the eighth search. Search enquiry number thirteen combines all possible combinations for different dementias; these individual searches and their keywords can be found in searches 8-12. The next search encompassed all of the dementia types accumulated in search thirteen with the informal caregiver search. Many of the next searches are the same as previous ones in the list, and these were done solely to have the string of results in my field of vision in the search engine. Finally, I did a MESH search for “accidental falls” and a keyword search for “accidental falls” these results were then combined with our search for all forms of the words “informal caregiver of dementia patients” to reach our final return of 57 articles.

The appendix outlines the search terms and number of published articles found pertaining to the search words.

In order for an article to be included in this literature synthesis, it needed to meet at least two of the following inclusion criteria:

1) Must be an intervention focused on fall prevention in persons living with dementia
2) Must be dyadic, in that it involves the caregivers as co-therapists
3) Must show how people living with dementia are disproportionately affected by falls
The search was only restricted to publications written in the English language. It was not restricted by publication date or the type of publication due to the small number of studies conducted in this field of research.

The final fifty-seven results that were obtained were scanned for applicability to this project. Articles that did not meet the intervention inclusion criteria were discarded, as they were not relevant. The snowball method, or ancestry method, was then used to scan the references of included studies for additional studies not found from the literature search.

Additional literature searches were conducted between May 10, 2016 and June 30, 2016 using different search engines including Google Scholar and PittCat, utilizing the keywords found in Figure 1. A total of 34 articles were found that fit the inclusion criteria.
Dementia is “a term used to describe a decline in mental ability that is severe enough to interfere with daily life.”¹ In dementia, brain cells are damaged so that they are incapable of intra-cellular communication, leading to disruptions in thinking, feeling, and behavior for the person living with dementia.¹ One in three American senior citizens dies with some form of dementia; over 5.4 million Americans are living with Alzheimer’s Disease, which is now the sixth leading cause of death in the United States.¹ Unfortunately, the number of people living with dementia will increase rapidly in the coming years as the baby boomer generation ages. By the year 2050, it is estimated that 13.8 million Americans will be living with dementia- a number that is unsustainable in the healthcare industry. Currently, the medical and social costs of care for dementia are 1.4% of the United States’ GDP.¹ This cost is expected to increase 85% by 2030, with 60% of people living with dementia (PLWD) living at home in the community.²

Globally, the prevalence of dementia is expected to double every 20 years, leading to higher costs of care for the countries of the world.³ Costs of care for people living with dementia include healthcare costs, costs incurred by family caregivers, and the cost of institutionalization. A great contributor to these costs is hospitalization as the result of a fall.
Falls are the most common means of injury in the elderly population, including both cognitively normal adults and those living with dementia, and are the primary cause of death as a result of an injury in people 65 years and older, with over 14,000 deaths annually.\textsuperscript{3,4} Currently, one-third of individuals over the age of 65 fall each year, and this statistic increases to one-half of individuals over 80 years old.\textsuperscript{3,5} There are numerous definitions to classify falls, but the most comprehensive one is “an event that results in a person coming to rest unintentionally on the ground or another lower level, which is not due to any intentional movement, major intrinsic event, or extrinsic force.”\textsuperscript{6}

Falls can have both serious physical and psychological implications on the victim. Older people who have fallen may suffer from pain, functional decline, loss of confidence, and/or a fear of falling in the future.\textsuperscript{3,4} Ninety-five percent of hip fractures in the elderly are caused by falls.\textsuperscript{7} In addition, loss of confidence and fear of falling can result in self-restricted activities, leading to social isolation which can in turn lead to an increased dependency on the family caregiver, and possibly result in nursing home admission.\textsuperscript{4,7,8} Further, one-third of adults who have fallen require daily assistance with activities of daily living (ADLs), and two-thirds of those require help for more than six months.\textsuperscript{3}

The costs of care for falls and subsequent injuries sustained from falls are unsustainable for the healthcare system. By 2020, healthcare costs associated with falls are projected to reach $32 billion in the United States alone.\textsuperscript{7} Due to the unsustainable nature of this, and the increased number of people afflicted with dementia, fall prevention in those living with dementia is an important public health issue that needs to be addressed. People living with dementia have twice
the risk of falls than cognitively normal older adults, with some reports of up to ten times more likely.\textsuperscript{9,10,11}

### 3.2 FALLS IN PEOPLE LIVING WITH DEMENTIA (PLWD)

In order to understand why those living with dementia are at an increased risk for falls, it is important to understand how walking is related to cognitive functioning. It is a well-known fact that walking is controlled by the basal ganglia.\textsuperscript{12} However, new evidence suggests that walking is not an automatic motor task, as previously thought, but rather it is the result of cognitive function, as demonstrated through the “dual tasking” paradigm in which older adults with dementia have an increased fall risk with a decline in gait and stability as well.\textsuperscript{12,13}

Routine walking requires the use of executive function and attention, primarily when there is an alteration in incoming sensory information such as stairs or broken concrete.\textsuperscript{14} “Executive functions” refer to “a variety of higher cognitive processes that modulate and use information from the posterior cortical sensory systems to produce behaviour”, including processes like attention, working memory, and planning.\textsuperscript{14} Executive function is involved in numerous roles in the walking process. A person’s manner of walking, or gait, is a complex motor task involving executive function; however, better gait does not mean better cognitive functioning. According to Hausdorff, et al., a specific relationship exists between gait and cognitive function in that gait is a complex motor task requiring the use of executive functions.\textsuperscript{12} According to the same study, general markers of cognitive function and memory did not have a relationship to routine walking.\textsuperscript{12}
Walking and walking-derived indicators of fall risk have been shown to be significantly related to cognitive domain performance, but not with memory, according to Hausdorff, et al.\textsuperscript{12} Areas of cognition that have been found to correlate with the development of Alzheimer’s Disease include memory function and a progressive decline in the neuropsychological measurements of executive functioning.\textsuperscript{14}

The association between physical health and mental health in people living with dementia has received very little attention from the research community. The few studies that have been published consistently show a relationship between these two domains: those with dementia are at an increased risk of falls and fall-related injuries due to the fact that they show more signs of undernutrition and have a more rapid decline in ambulation, mobility and home management skills.\textsuperscript{15}

People living with dementia who reside in nursing homes will fall at least once a year\textsuperscript{9} and community-dwelling people living with dementia have an annual incidence of sixty-to eighty percent.\textsuperscript{16,17} Due to the large number of risk factors present, people living with dementia are disproportionately prone to falls and are considered to be among the highest risk group for the number of falls, as well as the severity of falls.\textsuperscript{7} Thus, it is important to identify and understand the modifiable risk factors for falling when developing a more effective intervention.\textsuperscript{11}

3.2.1 Risk factors for falls in the dementia population

In the broadest sense, gait dysfunction and balance disorders are significant risk factors for falling in those living with dementia, as they are inherent to the disease itself. While having dementia is an independent risk factor for accidental falls,\textsuperscript{2} people living with dementia display greater gait and balance disturbances than cognitively normal older adults.\textsuperscript{3} People living with
dementia have a cautious gait pattern; their pattern involves shortened step length, a wide support base, larger step-to-step variability, larger sway, a decreased step height, heel strike, and cadence, as well as difficulty turning around, maneuvering around an obstacle, and visual-spatial deficits.\(^\text{14,16,18}\) As the disease progresses from mild cognitive impairment to end-stage dementia, the frequency and severity in gait dysfunction increases, as these disturbances begin to occur relatively early in the disease pathway.\(^\text{2,14,16}\) However, as the individual reaches severe dementia, these dysfunctions become less important for falls risk because of lower activity levels.\(^\text{3}\)

External, modifiable risk factors for falls are vast. Environmental hazards, comorbidities, use of restraints, lessened physical activity, cardiovascular medicines, orthostatic and postural hypotension, improper footwear, wandering, and ambulatory assistive device usage have all been cited as significant risk factors in this population.\(^\text{11,16,19}\) Orthostatic hypotension occurs when there is a significant drop in blood pressure while standing up.\(^\text{7}\) Many geriatric medications, such as anticholinergics, lead to confusion which can result in a fall; but weaning an individual off of these medications only reduces the rate of falls.\(^\text{3,4,7}\)

Other risk factors that have been identified thus far include Lewy Body dementia, a history of falls, admission to a hospital, duration of dementia, depression, and autonomic neuropathy.\(^\text{5,11}\) Chronic illnesses, such as Parkinson’s disease and diabetes are the known to be the two most common diseases that lead to an increased number of falls in the dementia population.\(^\text{7}\) Finally, those with Lewy Body dementia are at an even further increased fall risk because this dementia causes autonomic dysregulation and confusion.\(^\text{7}\)

Interestingly, urinary incontinence has been identified as an independent fall risk factor.\(^\text{10}\) In those living with dementia, urinary incontinence is significantly more prevalent than in cognitively normal age-matched adults (53% vs. 13%), and the prevalence increases as the
individuals progress down the disease pathway. A person’s inability to interpret and react to the feeling of a full bladder, due to a flaw in a person’s cognitive ability, has the potential to affect a person’s continence.

Protective factors include an increased level of physical activity and younger age. Those with a history of physical activity have shown a delayed onset and a slowed progression of dementia. This is because fitness has been shown to be strongly associated with different measures of attention, cognitive- and executive functioning.

It is known that dementia affects a person’s ability to walk, but it is important to recognize the different mechanisms behind why dementia is an independent risk factor for falling. Attention is needed to maintain normal walking. Evidence exists that independently links cognitive and attentional deficits with postural instability and falls. It is believed that the balance problems a person living with dementia experiences have developed from their inability to process incoming sensory information in a new environment and not from reduced motor control or poor vestibular functioning. They also have difficulty when they are in a situation that requires additional concentration in maintaining balance and they must discern contradictory visual cues in the environment. Cognitively impaired individuals have a higher risk of falls due to their inability to recognize “risky” situations and make the appropriate modifications to prevent falls, though a higher frequency of falls does not indicate an increased severity of the PLWD’s neurological deficit.

When faced with a dual task paradigm, those with cognitive impairment have altered gait performance when presented with any extra cognitive load, such as those mentioned above. The impaired cognitive abilities of people living with dementia reduces their attentional resource allocation while they are walking, which can impact an individual’s ability to prevent a fall.
Injuries resulting from falls are much more severe in the cognitively impaired as compared to cognitively normal older adults, further supporting the stance that this is an important public health issue.\textsuperscript{22} Twenty-six percent of all hospital admissions for people living with dementia are a result of falls.\textsuperscript{23} These injuries are as related to adverse drug reactions, musculoskeletal complications, and physical environmental factors as they are to the severity of the disease.\textsuperscript{15} People living with dementia sustain fall-related injuries 6.4 times higher than cognitively normal individuals and have a fracture rate three times higher.\textsuperscript{24} People living with dementia who fall are institutionalized at a rate five times greater than people living with dementia who do not fall, thus increasing the healthcare costs related to falls.\textsuperscript{19} Consequently, it is necessary for public health professionals to address this issue.

### 3.2.2 Falls prevention in PLWD

Current literature offers conflicting and inconclusive results for fall prevention interventions dealing with people living with dementia. Most of the existing studies aimed at preventing falls in cognitively impaired individuals have been unsuccessful, whereas both multifactorial and single interventions targeting cognitively normal adults have shown great successes. Unfortunately, interventions do not translate from cognitively normal adults to people living with dementia.\textsuperscript{9} In cognitively normal older adults, exercise interventions have had the greatest effect on executive processes, such as spatial perception, reaction speed, and problem solving.\textsuperscript{20} Interventions involving high-level balance challenges have been shown to reduce falls by forty-two percent in cognitively normal individuals, exercise interventions have reduced falls by seventeen percent, and home safety interventions in the cognitively normal population have
reduced falls by thirty-nine percent, but no evidence for fall prevention was shown in those participants with dementia.\textsuperscript{23}

However, there are some studies that show promising results and strategies for success in this population. Interventions that use dance as the basis for balance strengthening have shown significant improvements in the Timed Up and Go (TUG) scores and increased gait speed, which are vital aspects in fall prevention success.\textsuperscript{4} Dance and other music therapies are efficacious because they improve mood while stimulating speech and mental processes and motor integration.\textsuperscript{4}

Other successful interventions include tai-chi and yoga, which benefits those with dementia through simple, repetitive movements coupled with active attentional and mindfulness components.\textsuperscript{3,25} Positive changes have been seen across many physical measures in a yoga-based intervention, but the only statistically significant change was in the balance of the participant.\textsuperscript{25}

As of 2007, only three randomized-controlled fall prevention interventions in community-dwelling people living with dementia had been conducted, and none of these have shown a clear benefit to falls prevention interventions.\textsuperscript{19} Though it is still undetermined and debatable whether a fall prevention intervention can be successful in the dementia population, lessons can be learned through past studies that will help shape future investigations. Contrary to many assumptions, people living with dementia are capable of complying with multifactorial interventions, exercise programs, and strength and flexibility assessments, with appropriate adaptations.\textsuperscript{15,19} Many studies have demonstrated similar conclusions, so it can be reasoned that negative results from past interventions are not the result of participant’s inability to participate fully. In fact, the most effective interventions in reducing the number of falls in this population are exercise-based and include focus on two or more motor performance skills.\textsuperscript{3}
However, no evidence exists that supports the efficacy of exercise interventions that are accessed irregularly as part of a respite or adult day program. Additionally, physical activity programs offered in long-term care facilities have not been shown to significantly prevent falls. Lastly, home environment safety evaluations are only effective in reducing the number of falls in those individuals with visual impairments.

A promising intervention, the Resources and Activities for Life Long Independence (RALLI), utilizes behavioral and social learning theory and adapts interventions to meet the needs of those living with mild cognitive impairment. RALLI experienced interesting results: exercise time increased per day, participant’s Mini Mental State Exam (MMSE) scores improved, the way PLWD perceived their health and emotional well-being to be improved, and both cognitive and physical improvements were seen in the person living with dementia. Understandably, falls prevention programs need to be tailored to the needs and severity of the demented. RALLI, unfortunately, would not be ideal for those who are more severely affected by dementia for numerous reasons. For instance, the session times are 90 minutes long and consist of both an exercise and a discussion component. In the discussion portion of the intervention, participants discuss health promotion topics. For those with more severe dementia, a discussion of goal setting and nutrition may not be effective; these discussions may need to be had with family caregivers instead.

While the results of fall prevention interventions vary widely between cognitively normal adults and their impaired counterparts, the challenges interventionists face are very similar in these populations. Both populations can display a reluctance to begin exercise, especially if they have low physical activity levels. All older adults are capable of experiencing fear of injury or pain as a result of an intervention, lack of social support in their quest for lowering their risk of
falling, and lack of guidance on appropriate exercises to prevent falls. What makes the cognitively impaired unique are their difficulties with learning new exercises and remembering how to properly execute these exercises.

Along with this, targeting people in the early stages of cognitive decline is vital to reducing falls. In studies of cognitively normal individuals, effects of improved balance can last up to two years. If an intervention is instituted early in the dementia disease pathway, these exercises may be able to be continued and practiced, rather than starting them later in disease progression because repeated motor practice is necessary for motor recovery, neuroplasticity, and motor learning.

Disagreement exists among interventionists regarding which exercises are most beneficial to this population. One author details that successful fall prevention strategies for community-dwelling people with dementia include progressive muscle strengthening, practice responding to hazards and imbalances, resistance training that increases muscle performance, balance training, and ambulation, whereas another believes that balance training is essential while cardio and strength training is unnecessary. One aspect that can be agreed upon is that no two participants are the same, so personalized exercise programs are effective for those with moderate severity of dementia, even if simply increasing physical activity is the catalyst for these results.

With so many unknowns in this area of fall prevention, it is crucial to engage in techniques that can aid in a successful intervention. The foundation for effective fall-management interventions requires effective methods of communication that can effectively manage repetitions of speech or action, navigate through irrational topic deviations during conversation, and can cope with the participant’s difficulty initiating speech. Strategies to

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foster effective communication between the interventionist and the person living with dementia. Incorporates gestures, simple verbal cues and facial expressions, soft voices, slow speech and short sentences when talking to the person living with dementia, positive feedback responses, and time to allow the participant to process commands. An interventionist must create an environment that fosters the trust and cooperation between the interventionist and the participant in order to ensure the success of the intervention. He/she can do so by making and maintaining eye contact with the person living with dementia while staying at their eye level. Standing above a demented person is intimidating and may make them resistant to participation.

3.2.3 Dyadic falls prevention interventions

In addition to making the interventions personalized and enjoyable, another critical technique to engage the participant and assist in the success of the intervention is to involve the caregiver. “All treatment interventions fail in dementia unless the unit of dementia assessment and management is recognized to be the family caregiver/person living with dementia dyad.” In fact, several interventions that have shown encouraging results have involved the caregiver. The tai chi intervention referenced earlier involved caregivers as co-therapists and facilitators by utilizing a “sticky hands technique” in which the caregiver maintained physical contact with the person living with dementia while practicing tai chi while in the group setting and also at home. This intervention improved the TUG score, which indicates that it can reduce fall risk in demented participants. The design of this intervention, through the use of kinesthetic facilitation by the caregiver, reduced the cognitive load and demand on the person living with dementia, thus lowering the dual-tasking paradigm and optimizing attention and motivation, leading to better results. An implication of this intervention was that those with mild dementia
had larger gains in TUG than those more severely affected, which was likely the result of
caregivers needing more help with the severely demented in order to adhere to the protocol.\textsuperscript{22}
The severity of the disease impacted the home stage response.

Others have also found success in utilizing caregivers in fall prevention interventions. The Kenosha County falls prevention study found that living with a caregiver mediated the lower rate of falls in those people living with dementia with an MMSE score less than 28.\textsuperscript{27} This subgroup was the only one to see a reduction in the rate of falls (45%), so caregiver support appears to be essential.\textsuperscript{27} Caregivers provide an essential role in maintaining the results of an intervention. Several studies have found that caregiver supervision of the person living with dementia leads to longer-lasting intervention benefits.\textsuperscript{17, 28}

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<th>Table 1. Dyadic falls prevention intervention summaries</th>
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<tr>
<td>Participant’s Severity of Dementia</td>
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<td>-----------------------------------</td>
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<tr>
<td>Dyadic Tai Chi\textsuperscript{22}</td>
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<tr>
<td>Kenosha County Falls Prevention Study\textsuperscript{27}</td>
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This table represents dyadic falls prevention interventions that have subsets of participants with dementia and the corresponding results.
3.3 FALLS AND THE CAREGIVER

Caregivers are in an ideal position to engage and motivate an older person in these prevention programs. Therefore, it is important to educate caregivers about the benefits of fall prevention, fall risk factors, and explore their perceptions of falls and fall prevention interventions so that they have a positive outlook on these studies. Most times, caregivers are under a lot of pressure to keep their loved one safe and healthy when providing care. Additionally, adult children caregivers also have to attend to the anxiety caused by the change in the relationship between their parent and themselves. Caregivers must now make decisions for two people when they take over the person living with dementia’s ability for insight, communication, and ability to reason, as people living with dementia can no longer fully participate in making decisions regarding their care and activities of daily living. The relationship between the caregiver and person living with dementia, although ever-changing, is vital to the care of the person living with dementia. Family involvement in care leads to better psychological and psychosocial well-being of the person living with dementia, as well as better patient life satisfaction. Having an informal family caregiver allows the person living with dementia to live at home longer and delays institutionalization. However, the increased burden on the caregiver due to challenges in providing care leads to earlier institutionalization.

Falls are associated with an increase in caregiver burden. Some caregivers report that they live in constant fear of falls and consequences of falls. They may also experience stress, anger, helplessness, and frustration when the person living with dementia is unable to obey fall prevention advice. In order to lower the level of burden they feel, some caregivers may manage fall risk by controlling all of the person living with dementia’s actions, which ultimately increases the person living with dementia’s dependence on the caregiver. In a study that used
the Transtheoretical Model of Behavior Change (TTM), researchers explored caregiver perceptions of safety problems, their management of safety issues, and explored the application of health behavior change models in the caregiver situation. Caregivers need more direct guidance on providing safety measures; accidents have occurred as a result of caregivers waiting too long to implement environmental modifications because they were not aware of the potential dangers.\textsuperscript{29} Although caregivers have reported that their biggest barrier to change is not knowing when and which changes to make to prevent falls, they have identified four ways they manage home safety: supervision, changes in the home environment such as grab rails and anti-wandering devices, changes in social and recreational activities, and ultimately moving the person living with dementia into a nursing home.\textsuperscript{17, 29} Falls prevention interventions aim to tackle this last option for caregivers, as admittance to a nursing home would increase the cost associated with care.

Involvement of caregivers in interventions targeting people living with dementia does have some complications. Caregivers need to be reminded to use simple and easy-to-follow one-step instructions, to be very specific and concrete when guiding the person living with dementia, and to use frequent visual demonstrations with hands-on guidance during the intervention.\textsuperscript{15} These techniques are universal in all dyadic caregiver-person living with dementia interventions to support health.

3.4 DYADIC INTERVENTIONS TO SUPPORT PHYSICAL HEALTH

Numerous dyadic interventions dedicated to community-dwelling people living with dementia and their caregivers have been conducted since 2005. This section aims to highlight the
successes of such interventions in terms of benefit to both members of the dyad, quality of life for the person living with dementia, effect on activities of daily living (ADLs), and institutionalization. Although the objectives of these studies were not aimed at falls prevention, these studies show the potential for greater involvement of caregivers in falls prevention interventions for people living with dementia. Five of the key studies and their results are described below.

The Care of Persons with Dementia in their Environments (C.O.P.E) intervention is a randomized control trial involving two groups of person living with dementia-caregiver dyads living in the community. This intervention uses non-pharmacologic and biobehavioral aspects to support the PLWD’s quality of life through physical functioning and to increase the well-being of their caregivers. By targeting modifiable environmental stressors and re-engaging the person living with dementia in their ADLs to increase their daily functioning, this intervention will also lower the burden felt by caregivers. This intervention consisted of ten sessions over a period of four months with an occupational therapist and included one in-person and one phone session with an advanced practice nurse. The control groups received three 20-minute phone calls from research staff and were mailed brochures regarding home safety, caregiver stress, and the management of PLWD behaviors. During the first session for the intervention group, the occupational therapist conducted cognitive functioning tests to identify deficits in many executive functions and then presented the caregiver with a tailored action plan. This intervention was found to not be burdensome on either group and the caregivers reported a “great deal” of improvement in their lives as a result of the intervention. However, the outcomes of the study heavily relied on caregiver reporting and therefore cannot determine which components of the intervention were most effective. Also, because the participants volunteered for the
study, and therefore may be more motivated for change than the general population, this study is not very generalizable.  

Graff, et al’s intervention aimed to determine the effects of occupational therapy on the quality of life of persons living with mild to moderate dementia and their caregivers. This intervention is a randomized control trial and the groups were stratified by level of dementia. The components of the intervention focused on both the caregiver and the person living with dementia, and were delivered through ten one-hour sessions over five weeks. The first four sessions allowed the caregiver and the person living with dementia to define goals and prioritize which aspects they wanted to improve upon. Occupational therapists then observed the person living with dementia during their ADLs and used compensatory (adaptation of ADLs to the PLWD’s abilities) and environmental (adapt the home environment to their cognitive disability) strategies to increase functionality. During these sessions, the caregiver’s supervision skills were observed as well. The final six sessions were used to improve the compensatory and environmental strategies to increase ADL functioning. Caregivers were also trained, through cognitive and behavioral intervention, effective supervision- and problem solving skills, as well as coping strategies to lessen the burden they feel. Outcome assessments were administered post-intervention at 12 weeks. The strengths of this intervention include a large number of participants at the 12 week follow-up, because of the direct importance on the participants’ lives, its ability to meet the Consort Guideline Quality Criteria for randomized control trials, and this intervention was pilot-tested. Unfortunately, this intervention is also not generalizable because the participants were recruited from a local memory clinic and not from the general population. The design of the intervention did not make it possible to double blind the intervention, either.
Another randomized control trial on community-dwelling people living with dementia and their caregivers sought to determine whether home-based exercise programs coupled with training the caregiver in behavior management would reduce the person living with dementia’s dependence on the caregiver and subsequently delay institutionalization attributed to caregiver burden. The Reducing Disability in Alzheimer Disease (RDAD) included participants whose dementia ranged from moderate to severe, as long as they remained ambulatory. Home health professionals who are experienced in dementia conducted the 12 one-hour sessions. This intervention had two primary components. An exercise component involved aerobic activities and balance, strength, and flexibility training with a goal of engaging the person living with dementia in at least thirty minutes of moderate exercise daily. In addition to the exercise component, there was a behavioral management aspect that trained caregivers to identify and modify PLWD behavior issues that cased negative PLWD-caregiver interactions. Caregivers were told to identify and engage in pleasant activities with their person living with dementia and to increase physical and social activities. This aspect also educated caregivers about dementia progression. A new topic was introduced in each of the first ten sessions, allowing the remaining two to focus on teaching the caregivers how to maintain the results after the study was completed. The control group received routine medical care from their primary care physician. The outcome assessments were based upon PLWD performance and caregiver proxy reports at three months post-treatment, and at six, twelve, eighteen, and twenty-four months for follow-up. This study had high adherence, demonstrated that caregivers can be trained to supervise a home-based exercise program, and it can be generalized to the population. However, the nature of the caregiver benefit was not determined, and I therefore could not determine the efficacy of exercise and behavior management on the results of the study.
In the six-month long Dementia Family Care Programme (DFCP), the researchers sought to test the effect of a multi-component, comprehensive family caregiver program aimed at improving caregiver burden, increasing the quality of life for both the caregiver and the person living with dementia, increasing support service utilization, and ultimately reducing the rates of institution. This is a randomized controlled trial in which the case manager and study nurse met with the caregivers bi-weekly for a total of ten, two-hour sessions over five months. During the first visit, the nurse and case manager created a personalized education and support program for each caregiver that was based on the results of a needs assessment that identified important caregiving problem areas. The outcome assessments were administered at pre- and post-intervention time points through caregiver self-reporting by means of numerous scales—the Family Caregiving Burden Inventory, World Health Organization Quality of Life Measure—brief version, Social Support questionnaire, Family Support Services Index, and the Neuropsychiatric Inventory Questionnaire. The control group received traditional dementia care. This study had several successes; for example, it demonstrated that a multidisciplinary program can be adopted for the Chinese population and had a low attrition rate. However, this study is not generalizable for the same reasons as the other studies discussed in this paper: the participants volunteered to participate, and therefore may be more motivated and more highly educated than those caregivers in the general population. The sample size was also too small.

Finally, the last dyadic caregiver-person living with dementia to support health is a randomized control trial for people living with dementia and their spousal caregivers. The aim of this study was to determine if a two-year multicomponent intervention could delay institutionalization. The people living with dementia had a maximum Mini Mental State Examination score of 23, indicating mild to severe dementia. Control group participants received
medical care through their own primary care physician and were also given information about, and referrals to, resources within the community and educational material. The intervention was a support program consisting of a family care coordinator (FCC), visits to a geriatrician, caregiver support groups that focused on creating goals, and personalized services. These components were chosen by the investigative staff as a result of successes from previous interventions. Furthermore, all services were planned in partnership with the participants in order to respect their autonomy and enhance their sense of empowerment. An initial support plan was created during the initial home visit by the FCC. In addition to the meetings with the FCC, caregivers had five support group meetings during the first year. These meetings were comprised of various themes relevant to caregiving. Respite care was available so that caregivers could more easily attend these meetings. Other elements of this intervention include information sessions on dementia progression for other interested family members and home-based exercise activities based on the person living with dementia’s individual needs. The outcome assessments of scales to evaluate the well-being and functional abilities of the caregivers and persons living with dementia were conducted at six-, twelve-, and twenty-four-month follow-up. Several strengths of this intervention can be identified such as empowering the participants through collaboration and the use of elements that have been shown to be effective. The only weakness is the small sample size.
### Table 2. Dyadic interventions to support physical health summaries

<table>
<thead>
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<th>Study design</th>
<th>Intervention</th>
<th>Outcome assessments</th>
<th>Generalizable?</th>
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<tr>
<td><strong>Gitlin (2010)</strong></td>
<td>Mild to severe</td>
<td>RCT</td>
<td>10 sessions over 4 months, plus 1 in-person and 1 phone session with a nurse to target modifiable environmental hazards and to “re-engage” participants in ADLS.</td>
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</table>

| **Graff (2007)** | Mild to moderate | RCT | 10 1-hour sessions over 5 weeks. Involved the CG and PLWD in defining goals. Used compensatory and environmental strategies to improve ADLs. | 6 weeks, and 12 weeks post-intervention | No |

| **Teri (2003)** | Moderate to severe | RCT | 12 1-hour sessions to determine whether a home-based exercise program, coupled with CG behavior-management training would delay institutionalization. | 3 months (after final treatment), and 6-12-18- and 24-month follow-up | Yes |

| **Chien and Lee (2011)** | Unknown | RCT | 10 2-hour sessions over 5 months | Pre-and post-intervention | No |

| **Eloniemi-Sulkava (2009)** | Mild to severe | RCT | Multi-component support program consisting of family care coordination, geriatrician’s treatments, and CG support groups | 6-12-and 24-month follow up | No |

Many interventions seek to only benefit one member of the party, depending on the design of the study. However, it is possible to have positive indirect effects as a result of the direct effects on the other member of the dyad. In fact, of the nine sources reviewed here, three
had statistically significant effects on both the caregiver and the person living with dementia. These studies encapsulated many topics including case management, occupational therapy, and ADL function.  

Those interventions that benefitted the person living with dementia affected numerous aspects of the person living with dementia’s life. Independence and functions of activities of daily living had statistically significant improvements in four of the nine studies reviewed. Additionally, the person living with dementia’s quality of life had statistically significant improvements in four of the nine studies. Finally, dyadic interventions to support physical health positively impacted the rate of, or time to, institutionalization in several of the interventions.
A recent study conducted through the University of Pittsburgh has focused on falls prevention in people living with dementia. Healthy Steps for Older Adults (HSOA) has been improving the lives of over 35,000 of Pennsylvania’s senior residents since 2005 through the use of balance and mobility assessments, physician referrals, home safety assessments, and a two-hour falls prevention workshop. Here, we can explore the relationship between living with a caregiver and the success of the HSOA falls prevention through preliminary data.

While dementia was not concretely determined, study staff administered a brief Memory Impairment Screen by Telephone (MIS-T) and classified scores between 0-5 as those with potential memory impairment.39
Of the 784 Healthy Steps for Older Adults participants, 429 live alone. Of these 429, 98 have possible dementia, scoring a five or below on the Memory Impairment Screening on the telephone. 35% of those possibly demented adults who live alone have fallen since the end of the intervention. 355 HSOA participants live with a caregiver. 62 of these participants have possible dementia and 29% of them have fallen during follow-up. There is no statistical significance in falls between those possibly demented participants who live alone and those who live with a caregiver (p=0.60).

Figure 2 represents participants in the Healthy Steps for Older Adults, recruited for an evaluation effort across the state in 2011-13. These participants have been stratified by living arrangements and the percent of those participants who have fallen after completing the intervention was calculated.

The HSOA participants who have been stratified into “living with a caregiver” reported living with a spouse (n=35), their grown children (n=25), grandchildren (n=4), parents (n=1), siblings (n=1), other relatives (n=4), friends (n=2), and paid caregivers (n=1).

Among those participants with possible dementia, there was no statistically significant difference between those who live with a caregiver and those who live alone (p=0.6).
no difference in falls in the cognitively normal participants who live alone or with a caregiver, either (p=0.34). Furthermore, when looking at the raw number of falls post follow-up, there was no statistically significant difference in the sum of falls for either the cognitively normal or possibly demented participants who live alone or with a caregiver (p=0.79 and p=0.98, respectively).

Those with possible dementia who live alone have shown more fallers per 100 person-months of follow up, as compared to those with possible dementia who reside with a caregiver (5.1 and 3.8, respectively), although this data is not statistically significant. Age may be a confounding factor in this as those who live alone were older and more likely to report fair or poor balance.

However, even though the results did not reach significance, positive outcomes as a result of the Healthy Steps for Older Adults were seen. Regardless of living arrangements, the majority of participants, both possibly demented and cognitively normal, did not report a fall during the follow-up period. Additionally, as expected, the participants who lived alone reported more falls than those living with a caregiver, providing support to the theory that the presence of a caregiver can lower the incidence of falls.

These results are only from preliminary data. Perhaps an increase in the number of participants could lead towards a statistically significant difference in the number of falls when living with a caregiver.
5.0 DISCUSSION

People living with dementia in the community are disproportionately affected by accidental falls, leading to healthcare costs that will become unsustainable as the population of the United States ages. Falls prevention interventions have wide applicability in the field of dementia research because of this population’s high risk for falls, increased risk of injury and hospitalization as a result of falling, and the burden associated with balance problems on the care of the person living with dementia within the home environment. It is important that research focuses on lessening this burden, not only for people living with dementia, but also for their caregivers. Because the health of the caregiver is impacted by the burden they feel from providing care to a person with dementia, the public health community is able to assist two populations of people with one intervention.

The evidence for falls prevention in the dementia population is conflicting. While there are many techniques and strategies to explore, more research needs to be conducted on specifically which strategies are effective in this population. It is the duty of public health professionals to aid this population, which is so disproportionately affected by accidental falls. Even with studies that produced negative results, I believe that the increasing number of studies with positive effects reflects the need for more interventions for this target group and their caregivers.
Inclusion of family caregivers in falls prevention interventions is a unique characteristic, and not one to be overlooked. Their integral role as co-therapists in these interventions has led to many successes. Out of the five interventions discussed in this paper that utilized caregivers in the falls prevention intervention, three had significant positive successes. Caregivers have the ability to influence, to some degree, the person living with dementia’s adherence to the intervention, demonstrate the proper technique used in the intervention, and are able to communicate effectively with the interventionists. These aspects are all important in developing and disseminating any intervention for the dementia population.

It is important to note that the attitude of the caregiver can affect the outcome of the intervention; therefore, it is important that the caregiver is educated on the importance of preventing falls, while also being sensitive to the caregiver’s perception of the intervention. Without the complete investment of the caregiver, an intervention will not succeed.

As this literature synthesis is to support the Health Steps for Older Adults intervention in Pennsylvania, I have only evaluated the effectiveness of physical activity interventions on fall prevention in the dementia population. Obviously, there are other risk factors for falls that can be modified to help reduce falls such as medication adjustment, pharmaceutical therapies, focus on orthostatic hypotension, and the modification of the home environment. However, since those are best done either by physicians, or in the home of the participant rather than in an adult day center, these risk factors are not the focus of the HSOA intervention and therefore not necessary to cover in this synthesis.
5.1 LIMITATIONS OF THIS REVIEW

Unfortunately, very few relevant sources were found, as dyadic falls prevention in the dementia population is a large gap in the research. Furthermore, locating literature on dyadic health support interventions involving caregivers of persons living with dementia and the person living with dementia is difficult because the majority of interventions focused on this population are focused on the health of the caregiver and not on the physical health of the person living with dementia.

With this in mind, it is important to note that many studies that would normally be discarded from the literature synthesis due to incompatibility with the subject matter were not in this instance. It was essential that I use resources that can provide necessary contextual information on the subject matter, and sometimes these articles did not discuss dyadic interventions.

5.2 FUTURE DIRECTIONS

The limitations of this review, which is indicative of this field of public health research, provides opportunities for future research on the effectiveness of a dyadic caregiver-person living with dementia falls prevention intervention.

Based on the research available thus far, however preliminary it may be, we have a framework of guidance on potentially effective strategies to incorporate into future interventions:
Interventions must be personalized to meet the individual needs of the participant. Dementia has the ability to affect individuals differently, so there is no definitive, uniform method to deliver a falls prevention intervention.

Close supervision by the caregiver and caregiver participation in the intervention demonstrated success in the tai-chi intervention. Supervision alone may be effective in reducing the number of falls. Interventions involving the caregiver as a co-therapist also establish precedence for effectiveness in reducing the number of falls.

People living with dementia are able to learn new techniques to improve balance if taught early enough in the disease pathway. It is important to target participants for the intervention while they are still capable of active participation and learning.

Simple techniques that target balance and gait improvement have shown some effect on reducing falls. These motions should be easy to remember and execute.

Any future interventions should utilize these strategies if they aim to be effective and successful. Additionally, it is important to recognize that in addition to providing care, many caregivers work during the day. Therefore, it may be more beneficial to conduct the intervention during evening or weekend hours to ensure program adherence and participation.
Falls prevention in the dementia population is an area of research that requires further exploration. Public health’s ability to impact society by decreasing hospitalizations and delaying institutionalizations by providing additional years of improved quality of life can save billions of dollars in healthcare costs. By utilizing caregivers as co-therapists in a dyadic intervention, interventionists are able to rely on them to aid the person living with dementia in the execution of the intervention and to confirm that the person living with dementia is following protocol, which has been shown to be vital in program success in past interventions. In brief, a joint intervention utilizing the personalization of interventions to accommodate individual abilities and preferences as well as the inclusion of caregivers may have a positive impact on falls prevention in this high-risk population.
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