

Literature Review

The Impact of Reading Groups on Engagement and Social Interaction for Older Adults with Dementia: A Literature Review

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Abstract

The purpose of this review is to explore the impact of therapeutic shared reading groups on the engagement and social interaction of older adults with dementia. Using a systematic process to search a variety of databases, research articles that examined reading groups, and in particular a format known as shared reading, were identified and examined related to older adults with dementia. The results indicate a variety of benefits that impact older adults in the areas of engagement and social interaction, as well as other areas such as quality of life and cognitive skills. No specific studies were found within the recreational therapy profession, even though reading groups are frequently utilized by recreational therapists working in skilled nursing facilities and other older adult settings. A protocol is included based on the existing research on shared reading groups to aid in the development of evidence-based practice within recreational therapy.

Keywords

Dementia, engagement, older adults, shared reading, social interaction

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Most people understand the basics of Alzheimer's disease and the significant impact it has on individuals living with the disease, their caregivers, and families. In 2017, one in 10 people age 65 and older had a diagnosis of Alzheimer's dementia, which is approximately 5.3 million Americans (Alzheimer's Association [AA], 2017a). Since cognitive functioning is affected, individuals who have Alzheimer's or other related dementias experience memory problems, language difficulties, and impairments such as problem solving and safety awareness (AA & CDC, 2013; Agency for Healthcare Research and Quality [AHRQ], 2017). Impaired cognitive function negatively impacts a person's daily life, productivity, ability to function independently, and quality of life (AA, 2013; AHRQ, 2017). However, by utilizing cognitive skills and abilities, one may be able to reduce symptoms that may occur after onset (Acevedo & Loewenstein, 2007; AHRQ, 2017; Baumgart et al., 2015; Coyle, 2003; National Academy of Sciences [NAS], 2017). Keeping "socially engaged, intellectually stimulated, and physically active to promote well-being and reduce the risk of developing dementia" is beneficial for all older adults (Nyman & Szymcznska, 2016, p. 99). This belief is supported by the theory of neuroplasticity, which "suggests that cognitive training could be useful to stimulate the brain to build additional neural pathways and to retain existing ones to build brain research against future decline" (AHRQ, 2017, p. 5).

In addition to cognitive impairments, individuals who have dementia experience a variety of secondary issues, specifically lack of social engagement and interaction related to isolation or withdrawal. Withdrawal from work or social activities is a commonly observed symptom (AA, 2017a). Due to the cognitive changes a person experiences, he or she typically has difficulty following conversation and remembering information about tasks, social activities, and people, thus, impacting social engagement. Another common symptom is a change in mood and/or personality (AA, 2017a). Specific behaviors may be manifested such as becoming easily upset, problems with sleep, wandering, apathy, agitation, confusion, suspicion, anxiety, depression, and fearfulness (WHO, 2017b). Each of these behaviors can impact mood, motivation, and social engagement/interaction (AA, 2017a).

Currently, the first line of treatment to manage dementia symptoms is the use of psychotropic medication (James & Hope, 2013). Psychotropic medication is a term for psychiatric medications that alter chemical levels in the brain, impacting mood and behavior. However, empirical evidence suggests such treatments are largely ineffective and problematic in individuals with dementia (Fitzsimmons, 2015). Psychotropic medications cause severe social, emotional, and personality side effects, as well as increase confusion and falls (Buettner, Fitzsimmons, & Atav, 2006; Fitzsimmons, 2015; Gitlin, & Vause Earland, 2013). In one percent of individuals receiving psychotropic medications, these medications are lethal (James & Hope, 2013). These statistics are concerning and create an urgency to find and establish effective interventions to manage symptoms of dementia, while decreasing the use of psychotropic medications.

Over the last 30 years, there has been significant attention to non-pharmacological interventions for individuals who have dementia (Maslow, 2012; Toms, Clare, Nixon, & Quinn, 2015). Non-pharmacological interventions are those that "do not involve medication... (and have [sic]) the goal of maintaining or improving cognitive function, the ability to perform activities of daily living or overall quality of life... or reducing behavioral symptoms" (AA, 2017a, p. 14) and include therapeutic use of music,

relaxation, massage, reminiscing, and nurturing activities (Fitzsimmons, Barba, & Stump, 2014). Research has suggested that these interventions should be implemented as a first treatment to manage behavioral and psychological symptoms of dementia (James & Hope, 2013; Maslow, 2012) and that these interventions often decrease behaviors before the behaviors escalate (Fitzsimmons et al., 2014).

One type of non-pharmacological intervention is that of cognitive stimulating activities. These activities, such as brain training games, puzzles, crossword, and reading, may serve as protective factors reducing the risk of dementia (Baumgart et al., 2015; Suzuki et al., 2014) and can address the secondary issues that affect people with dementia. Reading, as the focus of this review, is one such intervention that has been shown to improve mental well-being and changes in cognition (O'Sullivan, Davis, Billington, Gonzalez-Diaz, & Corcoran, 2015). The use of books as a non-pharmacological intervention has been shown to positively impact the psychosocial and emotional domains of older adults with dementia, including decreased agitation, anxiety, and depression; improved coping skills; enhanced familial interactions; improved cognitive skills; relief from emotional or mental stressors; and development of self-concept (Buettner et al., 2006; Fitzsimmons et al., 2015; Foubert-Samier et al., 2014; Gardiner, Furois, Tansley, & Morgan, 2000). The question remains, do reading groups impact individuals with dementia by encouraging engagement and social interaction?

Purpose Statement

The purpose of this literature review is to examine the cognitive and social impact of reading groups on older adults with dementia, and to gather information on the most appropriate structure for implementation. Specifically, this piece focuses on four research questions:

1. How can a reading group be used with older adults with dementia?
2. What are the benefits of reading groups to older adults with dementia?
3. Can reading groups increase social interaction and engagement of older adults with dementia?
4. What is the best method for implementing a reading group for individuals with dementia?

This literature review aims to increase the knowledge base about using reading groups with older adults living with dementia, and encourage implementation of evidence-based practice related to this intervention. The benefits of this intervention will be explored as this literature review is designed to condense the research on reading groups with older adults who have dementia, and specifically on a model known as shared reading. From this paper, there is the potential for professionals to apply this intervention within their treatment plans as evidence-based practice. Additionally, a protocol for implementation of reading groups will be provided based on the literature review and research from The Reader Organisation (for more information on TRO, visit <https://www.thereader.org.uk/>).

Background

Dementia and Alzheimer's

Dementia and Alzheimer's disease are a global issue affecting millions of people around the world, with approximately 47 million people living with the disease (WHO, 2017b), 5.3 million of whom live in the U.S. (AA, 2017a). The National Institute of Neurological Disorders and Stroke (2015) defined dementia as a descriptive term for "a collection of symptoms that can be caused by a number of disorders that affect the brain." Of the 10 leading reasons for death, dementia is the only one that cannot be prevented or cured (AA, 2017a); and according to WHO (2017c), it is the seventh leading cause of death globally. The cost of care provision in the U.S. alone is \$259 billion (AA, 2017a), and global projections are \$818 billion (WHO, 2017c). For these reasons, the WHO (2017c) has declared dementia a public health priority. An important fact is that diagnosis and intervention have been found to improve the quality of life of individuals living with dementia (WHO, 2017a).

Cognitive Stimulation, Social Interaction, and Engagement

Cognitive stimulation is one of the interventions found to positively impact cognition, functioning, and quality of life. Coyle (2003) wrote, "having greater intellectual resources may buffer the underlying damage associated with the early stages of dementia, thereby delaying the onset of symptoms" (p. 2490). It is also believed that using cognitive abilities in leisure activities and through social engagement can also offer protective factors. Coyle further stated:

Effortful mental activity may not only strengthen existing synaptic connections and generate new ones; it may also simulate neurogenesis, especially in the hippocampus. Thus, persistent engagement by the elderly in effortful mental activities may promote plastic changes in the brain that circumvent the pathology underlying the symptoms of dementia (p. 2490).

Other researchers have identified leisure and social engagement as protective factors (Verghese et al., 2003).

In their article, Hutchinson and Warner (2015) talked about activity engagement for older adults living with dementia in their homes for the purpose of maintaining physical and cognitive functioning. The authors summarized the benefits of leisure-related activity participation for older adults with dementia. Benefits of leisure participation

provide opportunities for people to prevent declines in their health; serve as a positive distraction, resulting in improved mood, enhanced coping efficacy, and hope for the future; and contribute to wellbeing and successful aging when the participation is personally meaningful, or affirming of valued self-attributes (Hutchinson & Warner, 2015, 7th para.).

Being active physically and cognitively using leisure helped maintain people's independence, reduced the risk of falls, created experiences of enjoyment, served as a coping mechanism, and provided opportunities to feel and do something meaningful.

Social interaction and engagement have also been shown to have a positive effect on overall well-being and health in older adults, and there has been an increase in exploring the possibility of social engagement as a protective factor against dementia and continued cognitive decline (Windsor, Curtis, & Luszcz, 2016). Due to decreasing social supports and networks, changes in physical and cognitive health, and declines in social motivation, many older adults experience reduced social interaction and engagement. Social interaction and engagement, including activities such as reading, reduce social isolation and have been shown to improve health and well-being of older adults, as well as to reduce negative behaviors and moods such as agitation, apathy, and depression (Buettner, Fitzsimmons, & Atav, 2006; Cohen-Mansfield et al., 2010; Cohen-Mansfield et al., 2011; Windsor et al., 2016).

Nyman and Szymczynska (2016) conducted a systematic literature review examining the theories of aging and related studies that examined the provision of meaningful activities to people living with dementia. These researchers focused specifically on mental well-being, which they defined as “positive aspects of an individual’s mental health such as enjoyment and fulfilling one’s potential” (Nyman & Szymczynska, 2016, p. 100). For people who have dementia, engagement in meaningful activities contributed to well-being. The researchers found support for the use of the life review and life stories as opportunities to self-reflect one’s life, and other meaningful activities and interventions (i.e., spiritual and/or religious activities in which people have the chance to express or practice their beliefs and values or intergenerational activities allowing interaction between different age groups). Benefits to engagement in individually meaningful activities included reduced dependence on others for care, reduced isolation, increased social interaction, increased enjoyment, and enhanced functioning and well-being. Using activities previously of interest or engaging in new interests are both beneficial to individuals with dementia; what is essential is individualizing the activities to the person.

Methodology

In order to identify relevant literature related to the use of reading groups with older adults who have dementia, a systematic process of review was conducted. The purpose of the review was to locate appropriate peer-reviewed research, not necessarily to evaluate the quality of the research studies. Databases at Grand Valley State University were utilized, including CINAHL, ProQuest Medical Library, ProQuest PsycINFO, SocIndex, and the Cochrane Library. Keywords utilized included dementia or Alzheimer’s; cognitive impairment; older adults, elderly, seniors, or geriatrics; reading group; and shared reading. Originally, the term bibliotherapy was included in the search, but was later removed as group reading became the focus of the review. The term “shared reading” emerged as a common term for group reading, and, therefore, this term was added to the original search in place of bibliotherapy.

Inclusion criteria included being related to dementia or Alzheimer’s disease, a specific focus on older adults over the age of 65 years old, and included the interventions of poetry, short stories, or shared reading. Exclusion criteria included articles that focused on the use of bibliotherapy to improve depression or anxiety in older adults, research that utilized bibliotherapy as part of psychotherapy interventions, the use of books in support groups, and independent reading of books by older adults.

A total of 21 articles were found on the topics of reading groups for older adults with dementia. The criteria used for inclusion within this review were that the research was published within the last 10 years in peer-reviewed research journals and described shared reading with older adults who had dementia. Research that only mentioned reading as an intervention in passing (i.e., not a focus of the research) or that focused on prevention of dementia were removed. Following this, six articles were found specifically related to the topic of shared reading groups with older adults living with dementia. All six articles were found within peer-reviewed research journals, but one was not classified as a research study. The search made it clear that there was minimal research on reading groups specifically with older adults who have dementia, and more specifically, no articles were found within the recreational therapy literature. The articles selected for inclusion in this review provided evidence and support for the use of shared reading groups with older adults who have dementia. The following section details the results from the authors' review of the literature on shared reading with older adults who have dementia.

Literature Review on Shared Reading Groups

Shared reading is a literature-based invention that has been shown to be beneficial to older adults with dementia. Shared reading is designed to bring people together and engage them with a variety of types of literature that has been shown to have positive outcomes in the areas of emotional, cognitive and interpersonal functioning (Gray, Keimle, Davis, & Billington, 2015; Longden, Davis, Carroll, Billington, & Kinderman, 2016). According to the Reading Organisation (TRO), shared reading is when all of the reading material is read out loud by members of the group, followed by open-ended discussion facilitated by a trained project worker (Carroll, Kinderman, & Davis, 2013). This allows for participants to share their immediate reactions and thoughts as they read together. "Shared reading is about re-experiencing life from off the page, and as a result, being useful to the lives of its group members" (Davis et al., n.d., p. 8). The concept of shared reading is based on the belief that reading is an active, participatory, and creative activity, not one of passivity and contains elements of reading theory, psychoanalytic theory, and linguistic theory (Billington et al., 2010). It is not classified as therapy but has "therapeutic effects by fostering a sense of purpose, achievement, and self-worth" (Gray et al., 2015, p. 250).

The basic structure of the Shared Reading model developed by the TRO is widely used throughout the United Kingdom (U.K.) for people with dementia and has been the subject of qualitative, quantitative, and anecdotal evidence (Carroll et al., 2013; Centre for Research into Reading, Information and Linguistic Systems [CRILS], 2012). Developed by TRO director Jane Davis in 2001, the purpose of TRO is to connect people to each other and to literature through reading communities (Billington et al., 2013). It has been recognized as a "non-pharmacological/medical intervention that can help improve quality of life" for older adults through the "Get into Reading" program (CRILS, 2012, p. 8). The shared reading model is flexible and can be modified to fit various settings and needs of different population groups (Carroll et al., 2013; CRILS, 2012). Sessions run for one to one and a half hours depending on the population. For example, groups for individuals with dementia run for a maximum of 60 minutes (Billington et al., 2013; CRILS, 2012) with shorter materials such as short stories

and poems rather than entire novels (Carroll et al., 2013; CRILS, 2012). A typical 90-minute session consists of 10 minutes of transition time, 50-60 minutes of reading and discussion, 20-30 minutes of poetry reading and discussion, and session ending (Billington et al., 2010). It is facilitated by a trained staff member of the TRO called a project worker (Carroll et al., 2013; CRILS, 2012). Varied facilitation techniques are used based on the needs and functional abilities of participants. With individuals who have dementia, the facilitator might spend more time describing the poem or talking in a louder voice (Carroll et al., 2013). Participants are welcome to share their experiences and reminisce, but the focus is on enjoying the literature itself (Carroll et al., 2013). Table 1 provides a summary of the research on the topic of shared reading groups for older adults with dementia.

Carroll and colleagues (2013) conducted a mixed-methods study on the shared reading model. Facilitated in four care homes in the U.K., the homes were randomly assigned to a wait-reading program (no intervention for three months, followed by three months of reading intervention) or a reading-wait program. Interviews were conducted with care home staff before and after the intervention, and following the interventions with family members, participants, and the project worker. Furthermore, case studies were written by one of the researchers. Sessions were facilitated in accordance with the shared reading model previously described and utilized poems as the primary type of literature. Qualitative results of this study were positive. Prior to the intervention, staff expressed that they hoped the group would have cognitive and social benefits to participants; staff also identified that they felt it would be beneficial to them to see the participants engaged. At post-intervention, staff expressed that they thought the participants benefitted cognitively and socially, impacting people's overall quality of life and engagement. For example, "One of the major benefits staff perceived came from the reading groups was the interaction residents had with each other" (Carroll et al., 2013, p. 13). Staff felt the groups improved the relationships between participants and themselves, participants and their family, and participants with other residents. Family members reported similar benefits—participant enjoyment, changes in mood and behavior, engagement in past interests, communication, social interaction, awareness, and improved interactions between them and their loved ones. Participants expressed many of the same benefits as staff and family members, such as enjoyment, improved memory, use of one's imagination, communication, and interaction with others, creating a sense of community. Observations by the project worker reemphasized these benefits and added observations such as seeing participant breakthroughs and memory.

Quantitative analysis focused on the impact of engagement in a shared reading group on individuals with dementia. Forty people with dementia participated from the four care homes, with two homes doing the wait-read format and two engaging in the read-wait. Due to the small sample, statistical significance was challenging, yet the results offered some insight. The DEMQOL-Proxy and Neuropsychiatric Inventory Questionnaire (NPI-Q) were used for evaluation. The DEMQOL-Proxy was used to assess perceived quality of life expressed by the staff and family. Data on the NPI-Q evaluated behavioral symptoms on severity and level of distress to determine if there were any improvements in behavior symptoms following the intervention. Comparison was made between the two conditions (waiting-reading versus reading-waiting). Results showed the individuals in the waiting-reading group had improved DEMQOL-

Table 1
Article Summaries on Shared Reading

Researchers and Year	Subjects	Intervention or Activity	Theoretical Foundation	Focus	Measure/s	Outcome(s)
Billington, Carroll, Davis, Healey, & Kinderman (2013)	n=61 senior adults, and 20 staff people from 3 care homes, 2 hospitals, 1 day center	"Get into Reading" a shared reading program	Shared reading model	Understand impact of literature interventions on behaviors	Neuropsychiatric Inventory Questionnaire (NPI-Q), interviews with staff	Engagement in reading group reduced the severity of symptoms in people with dementia
Carroll, Kinderman, & Davis (2013)	n=40 with individuals with dementia residing in 4 care homes	Shared reading groups of 6-10 people using poetry for 6 months; groups 3 days/week	Shared reading model Reading-wait group (3 months reading, 3 months no intervention), Wait-Reading group (3 months no intervention, 3 months reading)	Improvement of behavior symptoms and quality of life for people participating in a shared reading group - case studies, qualitative and quantitative research	Interviews with care staff, family members, participants and facilitators DEMCOOL-Proxy, Neuropsychiatric Inventory Questionnaire (NPI-Q)	Staff reported increased stimulation and engagement, positive social benefits Families reported reading brought back memories, enjoyment, engagement, increased eye contact Participants reported enjoyment, use of the imagination, feeling part of a community Facilitator reported breakthrough moments, memory Shared reading group had impact on quality of life Potential cost savings for care homes due to decreased challenging behaviors

Table 1 (cont.)

Longden, Davis, Carroll, Billington, & Kinderman (2016)	<i>n</i> =31 from 4 care homes in the U.K. 16 females, 15 males Informally recognized diagnosis of dementia	Shared reading group 60-minute group of 6 – 10 participants	Shared reading model	Quality of life measured by DEMQOL-Proxy and psychopathological symptoms by Neuropsychiatric Inventory Questionnaire	Positive effect on quality of life, which was maintained after the intervention ended Possible benefits of social contact with others, engagement, and enjoyment
	Not display violent or disruptive behavior; not agitated or distressed in group; ability to attend to group			Periods of alertness or remembering	
McLaine (2012)	<i>n</i> =42, plus 5 staff from nursing homes; 7 facilitators and 1 program coordinator	Shared reading program called Book Well 60-minute group of up to 10 participants with dementia	Shared reading model Benefits of shared reading groups	Reaction and feelings after each session Surveys Semi-structured interviews face to face or via telephone Journals of facilitators Group observation	Positive impact for participants offering new way to connect and opportunities to connect Improved communication between participants and staff Increased overall mental health
Skraner & Camp (2007)	<i>n</i> =6 older adults with early to mid-stage dementia over the age of 60, MMSE above 23 <i>n</i> =22 older adults with dementia who participated in small groups, over the age of 60 with MMSE below 23, all but one were female	Reading group called "Question Asking Reading," facilitated by older adults with early to mid-stage dementia, in which read story aloud and then share facts/questions to facilitate discussion	Montessori-based programming	Leader Assessment form for leaders, Menorah Park Engagement Scale, satisfaction survey	Individuals in early to middle state of dementia successfully lead small group activities with appropriate training and prompts Participants showed positive observed engagement and affect when compared to regular activity programming

Proxy scores after the reading period, while individuals in the reading-waiting group results maintained their scores. “When compared with the waiting condition, the beneficial effects of the reading group in respect of quality of life can be seen once the group begins and appear to be maintained once the activity finishes” (Carroll et al., 2013, p. 59). Results suggested that engaging in the reading groups benefitted people with dementia in quality of life, but no change in behaviors was observed due to the length of the study and lack of behaviors displayed.

Billington and colleagues (2013) researched TRO’s shared reading program called “Get into Reading” (GIR), which specifically supports the use of reading groups with older adults. The GIR program focused on individuals who are classified as “vulnerable” such as individuals who were homeless, having mental health problems, or living in nursing homes. Outcomes identified by this study included staff reports of improved well-being for participants, support for the structure of the shared reading groups and role of the facilitator, increased social engagement, improved attention, and enjoyment (CRILS, 2012). While the quantitative data were limited, the qualitative evidence from interviews and observations supported a significant reduction in observed severity of dementia symptoms. A spin-off entitled “Book Well Program” (BWP) was developed and implemented in Australia (McLaine, 2012).

Both GIR and BWP sessions involved small groups of 10 or less people with dementia, who listened to readings by a trained facilitator (Billington et al., 2013; McLaine, 2012). The facilitator read short stories, selections from narratives, and poetry. Due to decreased attention and short-term memory limitations, shorter pieces of literature were easier for participants to process and discuss (Billington et al., 2013; Carroll et al., 2013; CRILS, 2012; McLaine, 2012). Poetry was also used as the generation of people participating learned poems as part of their education (Billington et al., 2013). The readings were printed in large print to accommodate vision challenges of older adults (McLaine, 2012). Additionally, the facilitator explained parts of the story or poem as needed to facilitate understanding and dialogue (McLaine, 2012). After the readings, participants voluntarily shared their thoughts on the readings and interacted with each other.

McLaine (2012) described the benefits and impact of the Book Well Program on individuals who had dementia and lived in nursing homes in Australia. The discussion presented was based on evaluations of the group by nursing home staff. Comments indicated positive well-being, including improvements in mood, active engagement and communication, and smiling and laughter. In a study conducted on the BWP programs in 2012, seven programs ran for eight weeks in community-based organizations; five of the programs included people with dementia who lived in area nursing homes. A total of 53 sessions were conducted, and data were collected at the end of each session, as well as through surveys, semi-structured interviews, and journals completed by facilitators and group observers. Three main outcomes emerged during data analysis: 1) positive impact on participants by offering a new way to connect and opportunities for connection, 2) positive impact on connecting and communicating between participants and staff, and 3) benefits to overall mental health (McLaine, 2012).

Billington et al. (2013) studied shared reading and its impact on behaviors of individuals who had dementia in the U.K. related to “Get into Reading.” Individuals voluntarily participated in a 60 minute session by listening to literature, talking about the reading and sharing their experiences. Literature included excerpts from novels

or short stories, and poetry. And while reminiscing and personal memories were important and often shared, this was not the focus of the groups; rather the focus was on allowing people to experience the literature as a form of enjoyment “however they choose—whether that be in terms of the past, present, or an imagined hypothetical future” (Billington et al., 2013, p. 167).

In this study, the “Get into Reading” program was presented to 61 participants who lived in different settings (three residential care homes, two hospitals, and one day center) with a focus on understanding how reading affected the behaviors of individuals with dementia. The NPI-Q was used to measure behaviors, such as delusions, agitation, depression, apathy, and irritability. Additionally, 20 staff members were interviewed to explore staff perceptions of the shared reading group’s impact on the individuals. The time frames for the intervention were three to 18 weeks. Results of the GIR program revealed a decrease in symptom scores on the NPI-Q throughout the program, indicating a reduction in symptoms of disruptive behaviors. The interviews with staff indicated they felt the reading group was “stimulating and interesting” (Billington et al., 2013, p. 168).

Results of the GIR shared reading program showed that participants enjoyed the group engagement. Participants had the opportunity to meaningfully interact and connect with others. Other perceived benefits were communication that was purposeful and made sense versus random or disconnected comments; creation of a sense of identity by triggering and sharing of memories and being a part of something; improvement of the environment; opportunities for self-expression; stimulating conversation inside and outside of the group; and potential impact on short-term memory (Billington et al., 2013). The researchers also commented about the impact of social interaction through the reading group: “Social contact has been shown to be an important subjective need for people living with dementia and it is possible that this could help explain the lack of symptom prevalence at this time” (Billington et al., 2013, p. 171). This study was also explained in an evaluation report by the Liverpool Centre for Research into Reading, Information and Linguistic Systems (2012) where the researchers worked.

Longden et al. (2016) evaluated a shared reading group developed by The Reading Organisation for 31 individuals living with dementia in four U.K. care homes. For these groups of six to 10 people, participants self-selected to attend a 60-minute reading group. Poetry was frequently used in this study due to the conciseness of the language and the rhyme of the words promoted increased attention and understanding. Following the reading, the leader facilitated discussion and sharing of memories. Group frequency was daily, three times per week, or weekly over a six-month period. One group, consisting of two care homes, waited three months for the group and then participated for three months, while the other group of two care homes participated for three months and then was monitored for three months. Perceptions of quality of life were measured using the DEMQOL-Proxy, while behaviors were measured using the NPI-Q. Data showed increased scores on both the DEMQOL and the NPI-Q during and following the interventions, indicating improvement in perceived quality of life and behaviors.

Due to the small sample and lack of control, limited statistical analysis was presented in the article and the researchers caution that the results are not conclusive.

However, the researchers stated that there was “a quantifiably positive effect on quality of life... and appears to have been maintained once the activity ended” (Longden et al., 2016, p. 79). The researchers further expressed that these results are supported by other research that showed that reading and arts-based interventions enhance well-being in individuals with dementia. While not proven by this study on shared reading, the researchers hypothesize that these improvements can be attributed to 1) social contact and engagement with others that leads to enjoyment, 2) experiences of self in which the person shared personal experiences, and 3) periods of “awakening” in which the person had increased alertness or memory triggered by the story.

While not based on the shared reading program of TRO, Skrajner and Camp (2007) studied the ability of people with early to middle stages of dementia to be trained to lead reading activities for people with more advanced dementia in an adult day center and a skilled nursing facility. The focus was on providing cognitive stimulation and social engagement to reduce agitation, depression, wandering, and the use of medications—factors that have been identified as essential to the provision of services to individuals with dementia. In order to provide meaningful activities, the researchers trained six people in early to middle stages of dementia to lead a Montessori-based reading intervention called “Question Asking Reading” (QAR). These six people facilitated the QAR activities for 22 people (6 in assisted living, and 15 in a skilled nursing facility’s special care unit).

In the QAR, participants were given a large print copy of an age-appropriate and interesting story in which individuals took turns reading. Following the reading of the story, each person was given a unique fact or discussion question to share with the group. Participants were asked to read their card following a prescribed color sequence to facilitate discussion. The procedure of reading short stories and then discussing facts and questions was used in each session, creating a common structure. Staff assisted the trained leaders, gradually increasing the leaders’ independence. Participants were evaluated on constructive engagement, passive engagement, non-engagement and other engagement. The results showed that individuals with early to middle stages of dementia can be trained to successfully lead small group activities such as the QAR. For participants, data analysis revealed positive engagement and affect when compared to regular activities programming.

Discussion

Recreational therapists around the U.S. are using the concept of group reading within their programs with individuals who have dementia. However, little research exists on the impact of this intervention outside of the U.K., and there are few evidence-based recommendations on how to structure these groups to achieve positive outcomes. This paper seeks to consolidate research on shared reading groups with older adults and the potential impact on cognitive stimulation, social interaction and engagement for individuals living with dementia. As the U.K. has more evidence-based practice in this area, The Reader Organisation’s shared reading model provides the best source of information for developing and implementing reading groups with older adults who have dementia.

Limitations

While shared reading programs show promise and the potential to improve the lives of those with dementia, this study has a number of limitations that must be considered. As previously mentioned, five of the six articles used in this review are based on The Reader Organisation's work and, specifically, their shared reading model. The protocol included in this article was based on limited articles available and the TRO model with additional adaptations based on experience and information on modifications for individuals with dementia. Additionally, these articles presented information on individuals at various stages of dementia. Further research is needed with larger samples and more diverse populations of those with dementia.

Summary of Shared Reading

Based on the literature reviewed, shared reading is best described as a small group activity of six to 10 individuals that uses literature, particularly poetry and short stories, to promote emotional, cognitive, and interpersonal functioning (Gray et al., 2015; Longden et al., 2016). Developed and used throughout the U.K. by The Reading Organisation, materials are read out loud by members of the group, and discussion and reactions to the literature are facilitated by staff (Billington et al., 2010; Carroll et al., 2013; CRILS, 2012). The focus is not on reminiscing but on experiencing the literature and interacting with others (Davis et al., 2015). The intervention can be modified to fit a variety of groups, but for individuals with dementia, it is generally reduced to a maximum of 60 minutes depending on cognitive level, using large-print materials and including description and explanation by the facilitator (Billington et al., 2013; Carroll et al., 2013; CRILS, 2012; Longden et al., 2016; McLaine 2012).

The existing literature on shared reading groups primarily comes out of the United Kingdom's "care home" settings. Care homes appear to be the equivalent to assisted or independent living facilities in the United States. Care homes are defined as a residential home where people may live either for a short stay or long term (CareHome.co.uk), and assistance is provided with personal care like bathing and toileting, meals, and assistance with medications (National Health Service [NHS], 2015). Care homes may also provide social activities (Age UK, 2017). Additionally, there are care homes with nursing staff that equate to nursing homes in the U.S. as they have nurses on staff to provide for more complex healthcare services (Care Home). A variety of types of care homes exist for people with alcohol or substance dependence, dementia and Alzheimer's, learning disabilities, mental health issues, physical disabilities, and sensory impairments. Each of these types of care homes is regulated by the Care Quality Commission in England and must demonstrate compliance with regulations on quality of care and safety (NHS, 2015); these appear to be similar to regulations established within the U.S. by the Centers for Medicare and Medicaid Services and state licensing agencies for the long term care continuum. Based on these similarities in types of care facilities, there appears to be a potential to implement similar shared reading groups in U.S. facilities based on the United Kingdom's evidence. As a non-pharmacological intervention, shared reading in community settings such as PACE programs, assisted living centers, and skilled nursing facilities could prove to be a cost effective intervention for addressing cognitive and emotional issues that face people living with dementia.

Prior to implementation of shared reading as evidence-based practice, a word of caution must be given. Of the five studies and one article specifically detailed here on

shared reading, one of them was not directly related to The Reading Organisation in Liverpool, England—the Skrajner and Camp (2007) study. Three of the research studies occurred in the United Kingdom (Billington et al., 2013; Carroll et al., 2013; Longden et al., 2016) and were affiliated with the University of Liverpool, while the other study (McLaine, 2012) occurred in Australia. While this does not mean that the studies have bias or are invalid, the reader must be careful to take this into consideration in evaluating the outcomes and research results. This further demonstrates the need for additional research outside of The Reader Organisation to further validate the efficacy, outcomes and benefits of shared reading with individuals who have dementia.

One must also consider the evidence on cognitive stimulation to reduce the risk of developing dementia and the potential impact of the maintenance of cognitive skills. While there is evidence that the use of cognitive skills helps to maintain functioning, there are still questions as to how this occurs and what factors influence these abilities. AHRQ (2017) summarized it this way:

There is good evidence to show that cognitive training can improve performance on a trained task, at least in the short term, but debate has centered on evidence for long-term benefits and whether training in one domain (e.g., processing speed) yields benefits in others (e.g., memory, reasoning) and can translate to maintaining independence in instrumental activities of daily living, such as remembering to take medications and driving (p. 7).

Of course, any intervention that shows potential to improve cognitive functioning or quality of life for individuals with dementia is worth exploring.

Conclusion

This literature review began with four research questions. Through this review, the authors believe answers to these four questions have been identified.

Regarding the first question, the answer is obviously yes. Reading groups can be used with older adults living with dementia. Studies in the U.K. and Australia showed the use of shared reading groups with older adults who have dementia in care homes, hospitals, a day center, and community-based organizations (Billington et al., 2013; Carroll et al., 2013; McLaine, 2012). While modifications were made to the shared reading format developed by the TRO, these adaptations did not change the function of the group, but matched and enhanced interaction and engagement to the functional levels of individuals living with dementia. Adaptations such as a 60-minute group instead of 90-minute group, large-print reading materials, and more descriptors provided by the facilitator assisted individuals with dementia in actively participating in discussion and social interaction (Billington et al., 2013; Carroll et al., 2013; CRILS, 2012; Longden et al., 2016; McLaine, 2012). These are typical adaptations that recreational therapists use when working with individuals with dementia (Fitzsimmons, Sardina, & Buettner, 2014).

One adaptation that appeared to be missing from the research on using shared reading for mid to late stage dementia/Alzheimer's was the use of props and visual stimuli to assist in setting the stage and to create a sensorimotor experience. This is another adaptation recreational therapists utilize with individuals who have dementia (Fitzsimmons et al., 2014; Tortosa-Martinez & Yoder, 2016). Props provide visual and

tactile stimulation to promote sharing, encouraging reminiscing to stimulate cognitive abilities (Fitzsimmons et al., 2014; see also Porter [2016] chapters on Montessori Methods, Reminiscence, and Sensory Integration). The addition of props to enhance social engagement and interaction may be worth further exploration in future studies on shared reading.

The second question sought to explore the benefits of shared reading, while the third question specifically focused on the impact of shared reading on social engagement and interaction. The five research studies reviewed described a variety of benefits and outcomes to individuals who participated in shared reading. Identified benefits included the following:

- Improved social engagement and interaction (Billington et al., 2013; Carroll et al., 2013; Longden et al., 2016; McLaine, 2012; Skrajner & Camp, 2007)
- Enhanced quality of life (Carroll et al., 2013; Longden et al., 2016)
- Improved relationships and environment with other group members, staff, family members, and residents of the care home (Billington et al., 2013; Carroll et al., 2013)
- Improved mood and behavior (Carroll et al., 2013; McLaine, 2012)
- A sense of enjoyment expressed by participants and observed by staff and family (Billington et al., 2013; Carroll et al., 2013)
- Improved communication (Billington et al., 2013; Carroll et al., 2013; McLaine, 2012)
- Creating a sense of identify (Billington et al., 2013)
- Opportunities for self-expression (Billington et al., 2013; Longden et al., 2016)
- Increased appropriateness of comments and conversation (Billington et al., 2013; Carroll et al., 2013; Longden et al., 2016)

Two of the studies found that benefits lasted beyond the intervention period of six months (Carroll et al., 2013; Longden et al., 2016). Additionally, the Skrajner and Camp (2007) study added that individuals with early stages of dementia could be trained to facilitate shared reading groups in a nursing home.

As for the fourth question, the research studies reviewed provided guidance on the format that was perceived to be most effective. However, none of the studies specifically focused on exploring the most effective format for implementation of a shared reading program. The literature from the five studies and additional article (described in Table 1) provided the background and foundation for the development of the protocol on shared reading. Appendix A provides a detailed protocol that may serve as a guide for developing an evidence-based shared reading group and is another potential source of a future study on shared reading. In addition to the information obtained from the research articles, additions related to the use of props for sensory stimulation and cueing were added related to encouraging and increasing engagement of older adults with dementia in the shared reading group. Using the existing literature and accepted recreational therapy practices to develop this protocol provided an evidence-base for the use of shared reading groups.

With the significant impact and growing numbers of individuals living with dementia, the use of cognitively stimulating activities, such as a shared reading program, shows significant potential to assist in maintaining cognitive skills and promoting the

use of cognitive abilities in a social environment (AHRQ, 2007; Nyman & Szymcznska, 2016;). The potential impact on social engagement and interaction warrant further exploration and research.

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Appendix A

Shared Reading Protocol

SHARED READING GROUP	
Purpose	Engage older adults in a reading program using various types of literature to facilitate social interaction and engagement to enhance outcomes in emotional and cognitive functioning.
Staff Requirements	One CTRS per group. A volunteer or nurse's aide may assist participants with page turning, attention, cueing or other types of assistance as needed.
Entrance Requirements	Participant must have a willingness and interest to attend. The ability to read is not required, but beneficial.
Exit Requirements	Participant no longer wishes to participate. Significant emotional or behavioral issues that disrupt the group.
Group Size	4 – 10 participants depending on cognitive, emotional and behavioral functioning. A lower number of participants (4 – 6) may be ideal for individuals with more cognitive limitations and for creation of a therapeutic environment.
Duration	Maximum of 60 minutes for individuals with dementia. Minimum of weekly groups that meet for three successive months.
Safety Consideration	Potential for emotional release trigger by some themes/poems and memories. Potential for frustration if difficult to read or understand.
Facility and Equipment	<ul style="list-style-type: none"> • Room appropriate for size of group. • Minimal to no noise, interruptions or distractions. • Large print reading materials on a single page if possible to reduce confusion with turning pages. • Props related to reading or theme that provide stimulation for all senses.
Methods	<ol style="list-style-type: none"> 1. Welcome participants, introduce self and have participants introduce themselves. 2. Introduce the day's theme. Show props related to the theme, and/or have background sounds or video related to the theme. For example, on beach day, have a bucket of sand, a shovel, sunscreen, sunglasses, a towel, a video or sounds of waves and sea gulls, popsicles or lemonade. 3. Ask participants about their thoughts or memories on the theme. Pass around props for participants to experience via senses. 4. Encourage participants to enjoy and experience the literature, and to participate as much as possible. 5. Distribute large print poem 1. 6. Facilitator read 1 paragraph. 7. Have different participants read next paragraphs until the poem is completed. It is okay if a participant skips their turn reading. 8. Discuss participant comments as they come up if appropriate. You may need to reread a line or two of the poem to get the group back on track. Use cues and/or props as needed to encourage responses.

Appendix A (cont.)

	<ol style="list-style-type: none"> 9. Reread the poem – this can be done by the facilitator or can continue with participants taking turns. 10. Review the key points of the poem with the participants such as what happened in the poem and what is the setting/where is it happening. Point out props that were used to emphasize points. 11. Ask participants questions about the poem and/or respond to their comments by asking further questions. <ol style="list-style-type: none"> a. What do you think happened in this poem? b. How did this poem make you feel? c. Whose perspective is portrayed in the poem? Who's telling the story? d. What is the poem telling us? e. What sticks out to you about the poem? f. What did you like about the poem? What didn't you like? 12. Each poem and discussion will take 10 – 15 minutes depending on the poem length and participant engagement in the discussion. 13. Observe non-verbal cues and in particular body language to ensure that people understand, are engaged, and are not frustrated. 14. Introduce poem 2 and then follow steps 5 – 9. 15. Introduce poem 3 and then follow steps 5 – 9 if needed. 16. Summarize group theme and any key points. 17. Thank participants for coming.
<p>Possible Client Goals</p>	<p>Participant will:</p> <ol style="list-style-type: none"> a. Offer two appropriate comments for each poem/related to the topic covered in the shared reading group 2x/wk. b. Respond to one other participant's comments during the shared reading group with an appropriate verbal comment or reaction at least 1x/group. c. Demonstrate attention to task AEB remaining alert/awake/attentive for 10 minutes during the presentation of the poem and discussion in the shared reading group each time attended. d. Take turns in reading when prompted by the facilitator during each shared reading group. e. Engage in social interaction by talking to another participant/facilitator for 3 – 5 verbal exchanges during the shared reading group each time attended. f. Increase verbalizations by answering one question when asked with verbal cue by the facilitator during each group. g. Demonstrate social engagement by asking one appropriate question of another participant/facilitator during the shared reading group at least one time per group. h. Demonstrate long-term memory by connecting personal experiences with the topic covered through 3 verbal comments made during the shared reading group. i. Demonstrate short term memory by answering 1 question about the poem read within 5 minutes of the reading during the shared reading group with 75% accuracy 3 out of 5 times. j. Demonstrate reduced social isolation by actively engaging and participating in the shared reading group 3x/wk. with minimal encouragement and verbal cueing to attend. k. Display socially appropriate behavior AEB not calling out, answering questions when asked, and taking turn to read during each reading group.

Appendix A (cont.)

Possible Client Outcomes	<ul style="list-style-type: none"> • Increase social interaction through participation in conversation with peers, staff, and family members (Carroll et al., 2013; McLaine, 2012). • Increase engagement with others in a group setting (Longden et al., 2016). • Reduced social isolation through engagement and participation in group (McLaine, 2012). • Increase alertness, remembering and attention to task during reading activity (Longden et al., 2016). • Improve socialization and engagement (Skrajner & Camp, 2007). • Increase quality of life and enjoyment through meaningful activity (Carroll et al., 2013; Longden et al., 2016). • Reduce severity of symptoms and behaviors related to dementia (Billington et al., 2013; Carroll et al., 2013). • Increase sense of community and connection to others (Carroll et al., 2013; McLaine, 2012). • Increase stimulation (Carroll et al., 2013). • Enhance sharing of memories and experiences (Carroll et al., 2013). • Enhance quality of life (Carroll et al., 2013). • Improve mental health such as mood and affect (McLaine, 2012; Skrajner & Camp, 2007).
Sample Themes and Suggested Literature	<p>CTRS should take individual interests and cognitive levels into consideration when selecting literature. A few suggested themes and poems follow:</p> <p><u>School Days/Growing Up/Childhood</u> Skipping to School R. A. Foss I remember, I remember T Hood Portrait of a child by L. Untermeyer What does your father do? By R. McGough The Railway Children S. Heaney Letty's Globe by C. Tennyson Turner Before you were mine by C. A. Duffy</p> <p><u>Growing Old/Memories</u> Outlook A. Lampman And yet the books C. Milosz Oh Life or Me by W. Whitman The Waking by T. Roethke This Morning by R. Carver Where the sidewalk ends by S. Pugh Handbag R. Fainlight In Flanders' Field J. McCrae Nostalgia B. Collins Mirror by S. Plath Walking Away by C. Day Lewis</p> <p><u>Summer/Beach</u> Maggie and Milly and Molly and May E.E. Cummings Phantom Horsewoman T. Hardy Neither Far out nor in Deep by R. Frost</p>

Appendix A (cont.)

	<p><u>Nature</u> Silver by W. de la Mare Postscript by S. Heaney The Way through the Woods by R. Kipling Apple Blossom by L. MacNiece Freshen the Flowers by M. Oliver Sympathy by P. L. Dunbar Flying Crooked by Robert Graves</p> <p><u>Adventure/What If</u> What if this Road by S. Pugh The Lake Isle of Innisfree by W. B. Yeats Wilde Geese by M. Oliver This Morning by Ray Carver Leisure by W. H. Davies</p> <p><u>Winter</u> Stopping by the Woods on a Snowy Evening by R. Frost Stone Beach by S. Armitage Cold Hill Pond by M. McCarthy Boy at the Window by R. Wilvur The Christmas Life by W. Cope Coming by P. Larkin</p> <p><u>Feelings</u> I Carry You in My Heart by Cummings The Great Lover by R. Brooke The Peace of Wild Things by Wendell Berry Thunderstorms by W. H. Davies The Clause by C. K. Williams Kindness by N. Shihab Nye Desert Places by R. Frost Acquainted with the Night by R. Frost</p>
<p>Websites for Poetry *all identified poems above can be found for free on the Internet</p>	<p>Poetry Foundation Poem Tree Good Reads Poem Hunter Poetry Archive.org Poetry Prescription – www2.open.ac.uk/openlearn/poetryprescription PoetrybyHeart.org Poets.org Allpoetry.com Poetrynook.com</p>
<p>References</p>	<p>Billington, J., Dowrick, C., Hamer, A., Robinson, J., & Williams, C. (2010). <i>An investigation into the therapeutic benefits of reading in relation to depression and well-being</i>. Liverpool, United Kingdom: University of Liverpool.</p> <p>Carroll, J., Kinderman, P., & Davis, P. (2013). <i>Read to care: An investigation into the quality of life benefits of shared reading groups for people living with dementia</i>. Retrieved from</p>

Appendix A (cont.)

	<p>https://www.liverpool.ac.uk/media/livacuk/instituteofpsychology/Read,to,Care,with,Melvyn,Bragg-1.pdf</p> <p>Cohen-Mansfield, J., Marx, M. S., Dakheel-Ali, M., Regier, N. G., Thein, K., & Freedman, L. (2010). Can agitated behavior of nursing home residents with dementia be prevented with the use of standardized stimuli? <i>Journal of the American Geriatrics Society</i>, 58, 1459-1464.</p> <p>Hutchinson, S. L., & Warner, G. (2015). Meaningful, enjoyable, and doable: Optimizing older adults' activity engagement at home. Retrieved from http://www.aginglifecarejournal.org/meaningful-enjoyable-and-doable-optimizing-older-adults-activity-engagement-at-home/</p> <p>The Reader Organisation. (2018). <i>Research and impact</i>. Retrieved from https://www.thereader.org.uk/research/</p>
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Protocol was adapted from the Shared Reading program developed by The Reader Organisation. For more information on The Reader Organisation, visit <https://www.thereader.org.uk/>