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INTERPERSONAL APPROACH TO DEMENTIA: AN IPAD-BASED PROGRAM FOR CAREGIVER EDUCATION AND DECREASING PROBLEM BEHAVIORS IN OLDER ADULTS WITH COGNITIVE IMPAIRMENTS

A Capstone Project

Submitted to the Rangos School of Health Sciences

Duquesne University

In partial fulfillment of the requirements for the degree of Doctor of Occupational Therapy

By

Anna Olexsovich

December 2016

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Anna Olexsovich

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By

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Approved November 1, 2016

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ABSTRACT

INTERPERSONAL APPROACH TO DEMENTIA: AN IPAD-BASED PROGRAM FOR

CAREGIVER EDUCATION AND DECREASING PROBLEM BEHAVIORS IN OLDER

ADULTS WITH COGNITIVE IMPAIRMENTS

By

Anna Olexsovich

December 2016

Capstone Project supervised by Dr. Ann Stuart, OTD, OTR/L.

Overall Problem

More than 10 million family members care for an older adult with dementia in the community. Due to the progressive nature of dementia, a high burden of care is placed on caregivers. Adult day centers offer respite, but while providing families temporary relief from caregiving responsibilities, they do not emphasize interventions for individuals with dementia. Agitation, a symptom of dementia, can affect both the older adult and others around them negatively. When the caregivers of older adults with dementia receive proper education about interacting with and caring for someone with this progressive disease, the quality of life of the older adults and caregivers improve.

Aim and Purpose

The aim of this Capstone project was to create a program for older adults with dementia and their caregivers. The program was designed to decrease older adults' agitation and provide education to caregivers about appropriate strategies for managing agitation and utilizing effective communication. The Capstone project incorporated technology through the use of applications (apps) on an iPad to deliver both interventions and education.

Methods

Repeated measures included the Agitated Behavior Scale and observation of nonverbal satisfaction. A revised Learning About Dementia: Test Questions and Family Education Questionnaire were used as pre/posttest and posttest only measures, respectively.

Sample

A total of five older adults with dementia participated in the agitation component of the program. For the educational component of the program, a total of eight family caregivers received educational information, but data was only collected from six of the participants.

Implementation

The Interpersonal APProach to Dementia program was conducted at Community LIFE: East End, an adult day center in Wilkinsburg, Pennsylvania. Four apps were utilized for the agitation component of the program. For the educational component, meetings or email correspondence with caregivers occurred to discuss important information about dementia, including common symptoms and how to interact with individuals with this diagnosis.

Key Findings

The long-term effects of the apps on decreasing agitation were not statistically significant. However, multiple factors, including small sample size and consistent ABS scores for participants, were taken into consideration. Caregivers' knowledge about dementia increased significantly after program participation.

ACKNOWLEDGEMENT

I would like to thank everyone who helped make my program a reality.

A huge thank you to **Dr. Ann Stuart**, my faculty mentor, **Dr. Edmund LoPresti**, my external advisor, and **David Graziano**, my site mentor. These individuals made up my Capstone Advisory Committee, and they all supported me throughout the development and implementation of my program.

A special thank you to **Lisa Jenkins**, the dementia coordinator at Community LIFE, **the program assistants of Loving Hearts**, where I spent the majority of my time during the DEC,
and the **staff at Community LIFE: East End** for showing interest in my program and
supporting implementation of the Interpersonal APProach to Dementia program.

A massive thank you to **everyone who participated in my program**, from the individuals who attend Community LIFE to caregivers both affiliated with this site and in the community.

Finally, last but not least, I would like to thank the **OT faculty at Duquesne University**, who constantly pushed me to create the most effective program that I could. A particular thank you to **Dr. Jaime Muñoz** for providing very helpful feedback on all of my Capstone drafts.

I could not have done it without them.

Thank you.

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Chapter One: The Practice Scholar Capstone Project

One in eight Americans have Alzheimer's, the most common type of dementia, which impacts 5.4 million older adults and 14.9 million unpaid family members who care for them (Anderson, Dabelko-Schoeny, & Johnson, 2012). Because of the complexity of this diagnosis, caregivers utilize respite care, and approximately half of adults who attend adult day centers have dementia (Fields, Anderson, & Dabelko-Schoeny, 2014). In these centers, however, therapeutic treatments targeting agitation and family education are not commonly addressed (Abramson, 2009; Silverstein, Wong, & Brueck, 2010). During a needs assessment, this gap in service delivery was reiterated by the staff at Community LIFE, specifically the occupational therapist and dementia coordinator. The aim of the Capstone project was to develop a program for older adults with cognitive impairments, specifically dementia, and their caregivers through a technology-based intervention. The program was designed to target agitation while providing education that encouraged use of pertinent de-escalation strategies and supported effective communication between the older adult, family, and staff. The specific objectives of the project were to decrease agitation in older adults with dementia and increase caregivers' knowledge to improve care for individuals with dementia, which would positively affect the quality of life for all concerned.

Chapter Two: Review of Relevant Literature

Thesis Statement

Addressing both caregiver education and agitation of older adults with cognitive impairments in adult day centers may lead to an increase in the quality of life for the older adults, their family members, and the staff.

Synthesis of the Literature

Adult day care centers in the United States serve over 260,000 older adults and their families, and dementia impacts approximately half of the participants (Fields et al., 2014). These statistics will continue to increase since the number of individuals 85 years and older is increasing (Topo, 2009). Adult day centers are beneficial for families caring for a loved one in the community because they provide respite, which reduces caregiver stress (Fields et al., 2014). However, these facilities have limitations that need to be noted. Adult day centers do not focus on interventions for older adults with dementia, and services offered do not pertain to specific stages of the older adults' diagnosis (Abramson, 2009; Silverstein et al., 2010). The latter fact is important to consider when half of a day center's population have dementia, which is a progressive disease. Individuals with dementia have cognitive decline, which include memory loss and poor recall and retrieval of information (Anderson, Hobson, Steiner, & Rodel, 1992). Along with cognitive decline, people with dementia may exhibit challenging behaviors, including anxiety, agitation, and restlessness (Topo, 2009).

Agitation is important to address because it is one of the most common behavioral symptoms of dementia and it can manifest in wandering, restlessness, and verbal and physical outbursts (Bartels et al., 2003). It can also lead to increased stress for staff and family members as well as a decrease in quality of life in older adults (Bartels et al., 2003). Behavioral aspects of

dementia do not receive as much attention as cognitive effects in the literature, but the prevalence of agitation can range from 57%-71% in individuals with dementia, with an increased frequency as the disease progresses (Bartels et al., 2003; Hendriks, Smalbrugge, Galindo-Garre, Hertogh, & van der Steen, 2015). These behaviors can interfere with interactions with staff and family members, which lowers the older adults' quality of life and success in engaging in occupational activities (Bartels et al., 2003).

According to Anderson et al. (1992), Chien & Lee (2011), and Livingston et al. (2014), these problem behaviors can be reduced when family caregivers are properly educated and adult day center staff utilize therapeutic interventions. Caring for an individual with dementia in the community requires high levels of support because of the progressive nature of dementia and problem behaviors that are often exhibited (Brodaty & Donkin, 2009; Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999). However, due to other commitments, the family caregivers may not have the time to search for information about effective strategies for managing agitation and communicating with their loved ones with dementia. Because of this lack of knowledge combined with the difficulty of care, caregivers can become depressed, anxious, or stressed (Brodaty & Donkin, 2009). If families are provided with appropriate education, then agitation in older adults with dementia decreases, and the caregivers' quality of life increases (Anderson et al., 1992; Chien & Lee, 2011; O'Connor, Ames, Gardner, & King, 2009). When staff are trained to incorporate interventions that are shown to decrease agitation into services provided in an adult day center, a reduction in both older adults' problem behaviors as well as caregiver stress occurs (Nobili et al., 2004). According to Cohen-Mansfield (2001), Livingston et al. (2009), Nobili et al. (2004), & O'Connor et al. (2009), successful interventions for decreasing agitation include sensory integration, such as music and white noise, and structured activities. When these methods are

utilized to engage older adults with dementia in an adult day center setting, the staff become more involved in the older adults' care, which leads to increased quality of life for both the staff members and the older adult (Anderson et al., 1992; Rosen et al., 2003). Refer to the table in Appendix A for more information about the key studies informing this needs assessment.

Summary

While adult day centers provide support to family caregivers and delay institutionalization, staff members focus on respite instead of therapeutic interventions for older adults with cognitive impairments (Abramson, 2009; Silverstein et al., 2010). These individuals not only experience cognitive decline but they also exhibit challenging behaviors (Anderson et al., 1992; Topo, 2009). Agitation in older adults with cognitive impairments is a common occurrence, and it proves to be detrimental not only to the older adult but also to those around him or her. Lack of family education can also aggravate these problem behaviors. Providing families and staff education about the progress of dementia, its symptoms, and how to deal with them properly may limit the negative effect of these problem behaviors, leading to improved quality of life for everyone involved. These two needs, decreasing agitation through therapeutic interventions and providing caregiver education, are addressed in this program.

A scoping review revealed there is little research specifically related to the use of technology in regular elder care (Savenstedt, Sandman, & Zingmark, 2006). Even though a small amount of evidence exists for technology being implemented with older adults, the research that is available supports its positive effects. According to a literature review conducted by Topo (2009), information and communications technology, specifically computer and telephone moderated services and monitoring systems, have been utilized to provide information, education, and support from professionals to family caregivers. The technology helped to increase the caregivers' coping skills and overall well-being

(Topo, 2009). Access to information that was diagnosis specific also decreased the older adults' challenging behaviors, which alleviated the stress of the caregivers (Topo, 2009). Another study by Rosen et al. (2003) evaluated the effectiveness of a web-based training system that targeted family members of residents with dementia in a nursing home setting. This system was successful for improving the family members' knowledge of interacting with their loved ones, which increased their involvement as an informal caregiver in the nursing home (Rosen et al., 2003).

Because of the availability and increased effective use of technology with different populations as well as the general public, it would be beneficial to incorporate technology into adult day centers for older adults with cognitive impairments and their caregivers (Czaja & Rubert, 2002; Magnusson, Hanson, & Borg, 2004). Specifically, the Interpersonal APProach to Dementia program integrates apps that have been identified to decrease agitation levels of older adults with cognitive impairments and results in staff incorporating these approaches into practice.

Chapter Three: Theoretical, Conceptual, or Quality Improvement Framework

The program utilizes the Ecology of Human Performance (EHP) model as a guiding theory (Dunn, Brown, & McGuigan, 1994). The EHP model can be applied in a variety of settings, including community-based ones, which is fitting for an adult day center. The model focuses on the relationship between a person and his or her context, which directly affects task performance during activities of daily living, such as getting dressed and feeding oneself. Since a person's performance is determined by both personal and contextual variables, a change in any of the aforementioned components can result in different behavioral outcomes (Cole & Tufano, 2008). In terms of the Capstone project, the older adults' agitation can produce a negative result since it hinders their occupations (Cole & Tufano, 2008). This agitation can also hinder occupational performance of family members and staff caregivers. Refer to Figure 1 for a visual representation of the task performance of an older adult with dementia who exhibits agitation and those working with him or her using the EHP model. According to the figure, these individuals are influenced by both their environment and personal factors. Since agitation is a problem behavior that many older adults with dementia display, it affects their daily activities by limiting the scope of tasks that they can complete, which is represented by the gray area on the figure. This decrease in occupational performance is also experienced by the family members and staff members who provide direct care to the older adult. By incorporating interventions and education geared to managing this dysfunction into the Interpersonal APProach to Dementia program, a better personal-context-task transaction is created, resulting in an extended scope of task completion, which is depicted by a larger gray area in Figure 2.

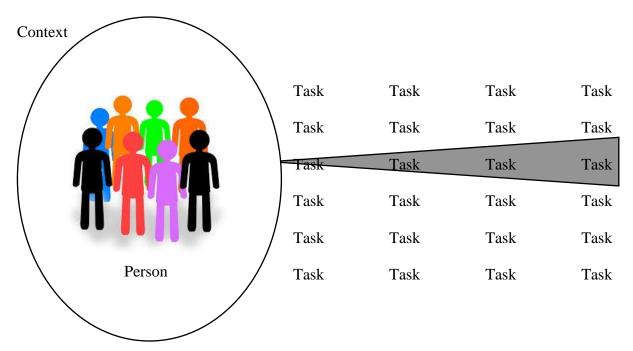


Figure 1: Task Performance of Older Adults with Dementia Who Exhibit Agitation, Family Members, and Staff Caregivers

The EHP model includes five different strategies for intervention: establish and restore, alter, adapt/modify, prevent, and create (Cole & Tufano, 2008). These are all addressed in the Capstone project. "Establishing and restoring" consists of enhancing one's abilities by teaching him or her new skills. Since family caregivers do not have the time to research various aspects of their loved ones' disease, providing them with easy to understand information can increase their capability to care for someone with dementia. During the educational portion of the program, caregivers learn new information that can enhance their abilities to alter, adapt, and modify the environment or specific task. After participating in the Interpersonal APProach to Dementia, caregivers understand how to choose a context that allows the older adults to perform a task with their current abilities and modify different tasks for successful completion. By addressing these two aspects of the older adults' context, the caregivers are successfully "altering" and "adapting/modifying" respectively. The four apps that target decreasing agitation are used to

"prevent" the risk of problem behaviors in the future. Therapeutic interventions, which are incorporated into the apps, can decrease the occurrence of agitation, which negatively impacts an older adult's performance in daily life. When caregivers use the apps with older adults with dementia, they are more likely to engage in activities of daily living without agitation hindering them. Finally, "creating" is addressed in the educational portion of the program because opportunities are created for family members to promote their performance in a caregiver role within the community. These strategies are delivered using a technology-based approach. Refer to Figure 2, which represents a change in the task performance of older adults, family members, and staff caregivers after participating in the Interpersonal APProach to Dementia. The five strategies of intervention positively impact both personal factors and context, which results in a larger scope of task completion that is represented by the gray area.

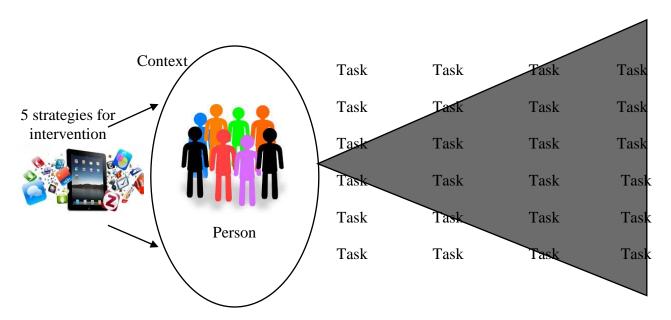


Figure 2: Task Performance of Older Adults, Family Members, and Staff Caregivers with the Interpersonal APProach to Dementia

Chapter Four: Description of the Practice Scholar Capstone Project

Title of Project

Interpersonal APProach to Dementia

Program Goals

- 1. Goal: Older adults with cognitive impairments who have agitation and completed the program will not display challenging behaviors 50% of the time after 2 months.
 - a. Objective 1: 80% of older adults with cognitive impairments who display agitated behaviors in the program will have a 3-point reduction of their score on the Agitation Behavior Scale in order to better participate in meaningful occupations in 3 months.
 - b. Objective 2: The older adults in the program will actively participate (interact with the iPad by selecting options on the screen) in at least 50% of the one-on-one sessions in 2 months.
- Goal: Family members of older adults with cognitive impairments will be able to independently find information concerning dementia utilizing at least 2 resources in 5 months.
 - a. Objective 1: Family members will be able to identify any 3 sources that contain information concerning dementia with minimal assistance in 3 months.
 - b. Objective 2: 90% of family members will choose either a "3" or "4" on a questionnaire item rating their comfort using technology (i.e. iPad) to increase knowledge about dementia in 1 month.

- 3. Goal: Apps that are shown to decrease agitation levels will be incorporated by 50% of the staff who work directly with older adults with cognitive impairments and measured via self-report in 1 year.
 - a. Objective 1: 70% of the trained staff will learn how to use at least 2 apps to decrease agitation levels in older adults with cognitive impairments during an informal training session in 3 months.
 - b. Objective 2: 70% of trained staff members who work directly with participants with cognitive impairments will be comfortable operating the iPad in 1 month.

Program Description

The Interpersonal APProach to Dementia program consisted of two components: decreasing agitation and caregiver education. Four apps, *Classic Melody, White Noise, Recolor,* and *Flower Garden*, that focus on sensory stimulation and structured activities were utilized during one-on-one sessions to decrease agitation in older adults. At program completion, the apps were downloaded to a Community LIFE iPad. Caregiver education was delivered through meetings at Community LIFE to educate family members about dementia. If the caregiver was unable to come into the center, then the information was either emailed to them or the researcher went to their house. While the educational component is primarily theoretical in nature, if the caregiver had a family member participating in the agitation component of the program, introducing and teaching about the apps added a practical element to the education. Since this component was flexible to accommodate the families, the meeting with the caregiver was based on his or her schedule, and all of the meetings during the program were one-on-one. Depending on how quickly each person was able to learn the material, the length of each meeting varied from 30 minutes to an hour. Education materials were saved in the *Google Docs*TM app on one of

Community LIFE's iPads. These materials contain general information about dementia so that the content was applicable to a variety of caregivers. Appropriate resources that are accessible to the caregivers were also included in the app so that they are able to find answers to any future questions. With the caregiver's increased comfort with technology and finding information, they will become more self-assured with accessing and utilizing knowledge about dementia, which may positively impact their role as a caregiver and increase quality of life.

The use of technology, specifically the iPad, throughout the program provided an easy and convenient way to deliver both interventions and education. Since apps can be downloaded for little to no cost, the program is very cost-efficient. The staff would also have everything that they need in one place for both education and intervention purposes, which may support sustained long-term use at Community LIFE. While an informal training session was conducted to teach the current Loving Hearts staff members how to use the apps, the dementia coordinator at Community LIFE was trained to operate the apps and given both a USB and a YouTube link to a training video. She was also given the educational resources so that she can share this knowledge with new staff members and other family caregivers.

New/Existing Program

Community LIFE provides a locked dementia unit called Loving Hearts. The Interpersonal APProach to Dementia program is an addition to Loving Hearts, because even though individuals with dementia have their own unit, the focus of the staff is geared toward completing routine activities with these individuals and not necessarily decreasing agitation. Agitation, however, is a daily interference to optimizing the environment, care, and quality of life of older adults with dementia, their peers, and the staff members of Loving Hearts.

Theoretical Framework

The Ecology of Human Performance (EHP) model, which emphasizes the relationship between people and their contexts, is used as a guiding theory for the program. This Capstone project focuses on the temporal and physical contexts, which directly affect the older adults' performance. Along with context, an individual's dysfunction also affects his or her daily occupations (Cole & Tufano, 2008). By addressing the older adults' agitation, they will be able to participate more easily in activities that are meaningful to them, including social interaction. When these problem behaviors decrease, the environment in Loving Hearts will become calmer without the presence of outbursts caused by the agitation. The EHP model contains strategies for intervention, which include "establishing and restoring", "altering", "adapting/modifying", "preventing" and "creating" that are incorporated into the program through an iPad-based approach (Cole & Tufano, 2008).

Rationale for Program Design

After reviewing the literature, many non-pharmacological interventions were found to be helpful for decreasing agitation levels of older adults with cognitive impairments. These types of intervention are beneficial because in a study by Burgio, Scilley, Hardin, Hsu, & Yancey (1996), only one out of five people with dementia who exhibited problem behaviors responded to pharmacotherapy. The benefits of pharmacotherapy are small, which has been proven through multiple trials, and medications are often associated with adverse effects, including mortality (Reus et al., 2016). Nonpharmacologic interventions result in less side effects when compared to pharmacological approaches (Howard, Ballard, O'Brien, & Burns, 2001). Auditory stimulation, in particular, is effective in reducing agitation levels since verbal outbursts may be an attempt for the older adults to fill the auditory environment (Burgio et al., 1996; Gitlin, Kales, & Lyketsos, 2012).

Two forms of auditory stimuli that have been utilized in multiple studies are calming music and white noise (Cohen-Mansfield, 2001; O'Connor et al., 2009; Livingston et al., 2014). Structured activities have also been shown to decrease agitation in older adults with cognitive impairments (Cohen-Mansfield, 2001; Howard et al., 2001; Livingston et al., 2014). A type of structured activity that has shown to not only decrease agitated behaviors but also increase the ease of care is Montessori-based activities (Lin, Yang, Kao, Wu, Tang, & Lin, 2009). Montessori-based activities are activities that older adults are familiar with, which include art, such as painting, and tending a garden (Lin et al., 2009; Preschl, Wagner, Forstmeier, & Maercker, 2011). The agitation component of the Interpersonal APProach to Dementia program was delivered individually since the older adults have cognitive impairments. By working with one participant at a time, the older adult received cues that were specific to him or her.

The educational aspect of this program contained similar topics as the study conducted by Rosen et al. (2003), which focused on educating family members of older adults with cognitive impairments in a nursing home setting. This education focused on behavioral management and communication between the caregivers and the older adult (Cooper et al., 2012). A majority of the education was provided face-to-face in an interactive way so that the families gained a better understanding of the information (Rosen et al., 2003). However, if the caregivers were unable to meet face-to-face, the information was sent via email so that they could still receive the educational resources.

In order to keep the information consistent between the family caregivers and staff at Community LIFE, both parties have access to the same educational resources. To ensure that the staff members are up-to-date with practice, the dementia coordinator holds a meeting with the staff at the beginning of every month. The staffing in Loving Hearts is consistent; the same

program assistants work with the participants from eight in the morning to four in the afternoon. Education and training of the staff using an iPad occurred during one of these staff training meetings. When family members as well as staff are properly educated, the number of problem behaviors exhibited by the older adult with cognitive impairments decreases (Chien & Lee, 2011; Nobili et al., 2004). In the study by Nobili et al. (2004), these positive effects lasted at least 12 months after the education was given, which shows the importance of providing appropriate information. While no follow-up occurred during this Capstone project, the short-term effects of the educational portion of the program were assessed using the Learning About Dementia: Test Questions and the Family Education Questionnaire immediately following program completion.

By using the iPad, caregivers of older adults with cognitive impairments were able to obtain information in a faster and easier way (Magnusson et al., 2004). Throughout the program, the use of apps was a convenient way to deliver interventions and information for little to no cost (Waite, 2012). Since they can be downloaded immediately, if one of the apps was not working to produce appropriate results, a new app could be quickly obtained (Waite, 2012). This was not needed during program implementation, and all the apps used during the Interpersonal APProach to Dementia were added to one of Community LIFE's iPad.

Sample or Population

Two target populations for this Capstone project included older adults with cognitive impairments, specifically dementia, and their caregivers, both family members and staff at Loving Hearts. The total number of older adults with dementia participating in the program was five (n=5). Out of these participants, two (n=2) displayed agitated behavior, which included verbal agitation and changes in mood, while the researcher observed the Loving Hearts unit, and two (n=2) had displayed agitated behavior in the past per dementia coordinator and Loving Hearts staff report.

Only 1 participant (n=1) had never shown signs of agitation, and she served as a control. All of the participants were women, aging from 70-92, and had mild forms of dementia as determined by their medical records. To recruit these participants with the permission from the facility, the researcher used the Agitated Behavior Scale (ABS) as a guide for observation of potential problem behaviors related to agitation. The older adults who did not display agitation during the observation period were recruited through report from the dementia coordinator and staff in Loving Hearts. The number of caregivers who received the educational resources was eight. The inclusion criteria for the participants was that they cared for someone with a cognitive impairment, were willing to learn more about dementia, and were at least 18 years old in order to understand the information. To recruit family members, the social worker at Community LIFE provided the researcher with a list of six family caregivers who were appropriate for the program. An initial phone call was completed to recruit the caregivers for the program after approval was given by the center administrator. Out of these six, three family members responded. Only one came into the center, while the other two preferred the information emailed to them because of their busy schedules. This cohort included two daughters and one wife of three different Loving Hearts participants. The researcher then expanded the program to family caregivers in the community (n=5). This cohort included two daughters, one son-in-law, one son, and one grandson. Prior permission from a power of attorney for participation was not needed due to consent obtained from the participants and their families during initial signing to Community LIFE and supervision of the researcher by the occupational therapist on site. The researcher documented the services provided, particularly the interventions with the older adults that targeted agitation.

Program Structure

The first component of this program consisted of using apps with clients and to train

both families and staff to use these apps to reduce agitation in older adults with dementia. Successful interventions for decreasing agitation include sensory stimulation and structured activities (Cohen-Mansfield, 2001). To incorporate auditory stimulation into the program, two apps were used: Classic Melody for calming music and White Noise for white noise. The Classic Melody app had 19 different songs, and the participants were able to choose which song(s) they wanted to listen to during each session. The White Noise app had 40 different sounds, and like the music app, the participants chose which sound(s) they listened to. Two apps that contain simple, structured activities included Recolor for painting structured pictures and Flower Garden for tending a garden. Recolor allowed the individual to paint a picture that was split into many different sections in order to simplify the process. Each segment could be made a different color, like a mosaic. With Flower Garden, the participant planted, watered, and cut flowers for bouquets with provided directions. The process was very structured because the individual repeated the same steps in order to produce bouquets of flowers. Refer to Appendices B-E for screenshots of the apps that were utilized during the program.

The agitation component of the program lasted a total of 8 weeks from June 6, 2016 to July 31, 2016. To decrease agitation in older adults with cognitive impairments, a total of four apps were included in the program: two for sensory integration and two for structured activities. The older adults participated in this component of the program for 15-30 minutes a day (depending on the participant), 5 days a week (Clark, Lipe, & Bilbrey, 1998). However, because of participant call-offs and the center being closed for holidays, some sessions were missed. Each app was used for 2 weeks so that enough time was given for each type of intervention. Since brief, structured interventions are most beneficial for older adults with cognitive impairments, the apps were used in the same way during the 2 weeks (Howard et al., 2001). For the *Classic*

Melody and White Noise apps, the participants chose which songs and sounds they would listen to. For the painting app, the participants selected the picture that they wanted to color. Finally, for the gardening app, the resident would be completing the same activity of planting, watering, and gathering flowers. The sessions with the participants were delivered one-on-one because the older adults have cognitive deficits (Bartels et al., 2003). One-on-one interventions ensured the older adults could be given individualized cues to complete the tasks, an approach that could not happen in a group setting. Observations of each session were documented in an Excel spreadsheet, which contained information about the types and frequency of individualized cueing as well as immediate agitation level changes. This component of the program addressed decreasing agitation in the older adults and hopefully leads to continued use at Community LIFE to deal with problem behaviors in the future.

The second component of the program focused on caregiver education. Pertinent information about dementia was collected and stored in the *Google Docs*TM app, which is easy to navigate and read. Since *Google Docs*TM was utilized, the information has opportunities for updates, either by the researcher or the dementia coordinator. The information that was part of the families' education included:

- 1. Dementia
 - a. What is dementia?
 - b. Types of dementia
 - c. Common symptoms
- 2. Agitation
 - a. Types of agitation
 - b. Causes of agitation
 - i. Internal stimuli
 - ii. External stimuli
 - c. Strategies to prevent and manage agitation
- 3. Family members' role as caregiver
 - a. Common challenges that caregivers face
 - b. How to communicate with individuals with dementia
 - c. Appropriate skills and qualities that a caregiver should have

In Google DocsTM, each topic had its own document; a total of three educational materials were created. Within each document, subheadings were clearly marked so that the information was organized and easy to find. Along with this information, a list of easily accessible websites was included, such as the Alzheimer's Association website and various caregiver support websites, so that the families have a way to access information in the future. Refer to Appendix F for screenshots of the educational resources that the caregivers were provided during the program. Once they are presented with this information and relevant sources, the families' knowledge about their loved ones' diagnosis may increase as well as their ability to find new information by themselves in the future. Meetings occurred with the families whenever they were available and visiting the adult day center to discuss this information and answer any questions that they had. However, if the caregiver did not have time to come into the center, the materials were emailed to them. The researcher also expanded the program to family caregivers in the community and met with them at their homes. One session was completed for each family caregiver, which lasted anywhere from 30-60 minutes. The researcher was available throughout the session if the caregivers had any questions.

Program Implementation

The Interpersonal APProach to Dementia was conducted in the Loving Hearts unit, which is the locked dementia unit at Community LIFE. While the whole center can accommodate 90 participants total, Loving Hearts usually contains less people than the main day center, so the environment is generally quieter. The materials required for this program included an iPad, various apps that were downloaded on it, and a pair of over-ear headphones. Refer to Appendix G for all of the apps used during the program. Since all of the apps are free, the cost of the program included the iPad (\$500) and headphones (\$15). However, Community LIFE had

previously purchased both iPads and headphones, so the program required no additional costs for the Loving Hearts unit.

The researcher was the sole implementer and evaluator of the program. Training occurred at the end of the program to educate the dementia coordinator and current staff of Loving Hearts in order to promote success of future implementation of the program at Community LIFE. A video was also created that demonstrated how to use apps that can be shared with future staff and other Community LIFE centers. The dementia coordinator at Community LIFE: East End was given a copy of the video on a USB, and the video was uploaded to YouTube at https://www.youtube.com/watch?v=axyMYe8V7Kk. The dementia coordinator also received the email and password for the educational materials for the caregivers on *Google DocsTM*. For a more detailed description of program implementation, refer to Appendix H for an infographic of the timeline.

Program Evaluation

Outcome Evaluation

The two outcome measures used for evaluation were the Agitated Behavior Scale (ABS) and Learning About Dementia: Test Questions. The ABS is a rating scale based on observations of the client. It consists of 14 items with a 4-point rating scale (1 being an absence of the behavior and 4 being that the behavior is present to such an extreme level that it cannot be redirected). Observation of the client occurred for 5 seconds each minute for 10-20 minutes at selected times (Curyto, Van Haitsma, & Vriesman, 2008). The ABS demonstrates the ability to rate the severity of agitation, which can show the effectiveness of treatments (Amato, Resan, & Mion, 2012). The test-retest reliability of the ABS is 0.7, which was stable over multiple populations, including individuals with dementia (Bogner, Corrigan, Stange, & Rabold, 1999).

Two studies have determined the interrater reliability of the ABS. Bogner et al. (1999) determined the interrater reliability to be 0.92, and in the study by Bogner, Corrigan, Bode, & Heinemann (2000), the value was 0.91. The construct validity of the ABS was found to be good in two separate factor analyses, meaning that the scale measures agitation with its included items (Bogner et al., 2000). The ABS was used as a repeated measure throughout the program to assess the older adults' agitation levels. The ABS was conducted at the same time of day, two days a week; the selected times included Wednesday and Friday starting at 2 pm. However, if a participant was not at the center on these days, the assessment was completed on a different day. By keeping the time of the assessments consistent, the influence of external factors that affect the participants' agitation levels was decreased. The ABS also has a section, titled "observation environment," where the evaluator can record the participant's environment for a more specific assessment. Refer to Appendix I for a copy of the ABS.

The Learning About Dementia: Test Questions is a 16-question test that was developed by Rosen et al. (2003) to assess family members' knowledge about dementia. Since this test was made specifically for the study, the interrater reliability and the test-retest reliability of this measure are unknown. While these values were not tested, this particular assessment was selected because it was the only previously created assessment that addressed information that was presented in the educational section of the program. The Learning About Dementia: Test Questions was revised by the researcher, and a 12-question version was used for evaluation of the Interpersonal APProach to Dementia program since these questions directly related to the information in the educational resources. The Learning About Dementia: Test Questions was administered two times, once before the program started and once at program completion, to

assess family members' knowledge about dementia. Refer to Appendix J for the revised copy of the Learning About Dementia: Test Questions.

Process Evaluation

The two data collection tools that were utilized for process evaluation included the Family Education Questionnaire and structured observation of the older adults using a checklist of nonverbal behaviors. The researcher created both of these assessment tools. The Family Education Questionnaire focused on the helpfulness and organization of the information as well as usability of the iPad and Google DocsTM app. An existing questionnaire called the Post-Study System Usability Questionnaire (PSSUQ) has been used to quantify subjective usability (Lewis, 1993). The PSSUQ has excellent reliability (0.91-0.97), and its convergent validity was 0.8 when compared with another questionnaire, the After-Scenario Questionnaire (Lewis, 1993). Because the PPSUQ has established reliability and validity, it was used as a guide to structure questions for the Family Education Questionnaire, which was created specifically for the Interpersonal APProach to Dementia program. Like the PPSUQ, the items on the questionnaire are answered using Likert scales so that quantitative data can be gathered about the participants' satisfaction (Ju & Gluck, 2005; Lewis, 1993). The last three questions on the Family Education Questionnaire are open-ended qualitative questions that encourage the participants to include more detailed feedback. These three items on the questionnaire elicited feedback on the strengths and weaknesses of the program that may guide future use at the site. The questionnaire was directly administered at the end of program implementation in order to have a 100% response rate from the participants. Refer to Appendix K for a copy of the Family Education Questionnaire.

Observation provided immediate information about how the program was running, focusing on the older adults with cognitive impairments (University of Wisconsin-Extension, n.d.). Since these individuals have difficulty communicating verbally, their nonverbal communication needs to be assessed (Roter, Frankel, Hall, & Sluyter, 2006). Since it can be difficult to interpret nonverbal cues and the information gathered may be biased based on the person observing, a checklist was utilized to focus on specific observable behaviors, like smiling and laughing, that could be used to gauge which apps the participants liked and which ones they did not (Wisconsin-Extension, n.d.; Saunders, Evans, & Joshi, 2005). Since a checklist of nonverbal indications of satisfaction does not exist, a checklist was created to assess the older adults' emotions. The study by Roter et al. (2006) mentioned common nonverbal cues that can show satisfaction, such as smiling and nodding one's head, which were incorporated into the checklist. Like the ABS, observation utilizing the checklist occurred twice a week on Wednesdays and Fridays during the participants' individualized sessions. Refer to Appendix L for a copy of the checklist regarding observation of nonverbal satisfaction.

Chapter Five: Results

The goals of the Interpersonal APProach to Dementia were to address decreasing agitation in older adults with dementia as well as provide education to family caregivers about pertinent information concerning this diagnosis. Since the Capstone project has a dual focus, the results section is divided into two sections to represent the two components of the program. Overall, the long-term effects of the apps were not statistically significant (p>0.05), but a notable reduction in the participants' agitation during use of the apps was noted. For family caregivers, their knowledge about specific aspects of dementia increased significantly after participating in the program.

Agitation

Two evaluation questions that pertained to the agitation component of the program included:

- 1. Did the program decrease the long-term agitation levels of older adults with cognitive impairments?
- 2. Which apps did the older adults enjoy using?

Throughout the Capstone project, repeated measures, which included the ABS and observation of nonverbal satisfaction, were utilized. For each of the participants, the ABS was administered five times for each app: pre-intervention (Monday before the participant's session began) and every Wednesday and Friday around 2 pm. If the participant was not at the center during any of the given time periods, then the assessment would occur during a different day of the week.

Refer to Table 1 for the participants' scores on the ABS.

Table 1: Participants' Scores on the Agitated Behavior Scale (ABS)

Subject	App	Pre	1 st	2 nd	3 rd	Post
-		(Monday)	Wednesday	Friday	Wednesday	(Friday)
Participant	White	22	21	20	20	19
1	Noise					
Participant	Recolor	20	20	21	19	21
1						
Participant	Classic	20	20	21	19	21
1	Melody					
Participant	Flower	18	18	19	21	19
1	Garden					
Participant	White	14	14	14	14	14
2	Noise					
Participant	Recolor	14	14	14	14	14
2						
Participant	Classic	14	14	14	14	14
2	Melody					
Participant	Flower	14	14	14	14	14
2	Garden					
Participant	White	14	14	14	14	14
3	Noise					
Participant	Recolor	14	14	14	14	14
3						
Participant	Classic	14	14	14	14	14
3	Melody					
Participant	Flower	14	14	14	14	14
3	Garden					
Participant	White	14	14	14	14	14
4	Noise					
Participant	Recolor	14	14	14	14	14
4						
Participant	Classic	14	14	14	14	14
4	Melody					
Participant	Flower	14	14	14	14	14
4	Garden					
Participant	White	17	14	14	14	14
5	Noise					
Participant	Recolor	14	14	14	14	14
5						
Participant	Classic	14	14	14	14	14
5	Melody					
Participant	Flower	14	14	14	14	14
5	Garden					

Examination of the ABS scores revealed that the three participants who started with the lowest score on the ABS, which is 14, stayed consistent throughout the duration of the program. For Participant 5, she started with a score of 17, but after participating in the program, her ABS scores decreased to 14 consistently. Participant 1 had the highest score on the ABS, compared to the other participants, and her scores changed by 1-4 points during the 8-week program. Refer to Participant 1's rows in Table 1 for more specific scores. While some long-term effects of the program were observed, in Participant 1's case, more drastic changes in ABS scores occurred during app use. With the *White Noise* and *Classic Melody* apps, Participant 1's ABS scores were at times 14 while she was listening to the auditory stimulation.

A Mixed ANOVA test was conducted to analyze the data in order to determine if the changes in agitation levels of older adults with cognitive impairments were statistically significant. A Mixed ANOVA consists of a combination of between-subjects and within-subjects analyses (Portney & Watkins, 2009). The between-subjects analysis focused on the independent factors, which in this case were the different apps that the participants used throughout the course of the program. The within-subjects analysis incorporated the repeated measures, which were the ABS scores that the researcher assessed over time. The researcher used SPSS Version 22.0 to conduct the Mixed ANOVA analysis after data collection. Using directions provided by *Laerd Statistics* (2013), the researcher transferred data from Excel to SPSS and ran the Mixed ANOVA test. Refer to Tables 2-5 and Figure 3 for the analysis of data.

Table 2: Two-Way $(4 \ X \ 5)$ Analysis of Variance with One Repeated Factor (Mixed Design): ABS Scores with Variation of App and Time (N=5)

Mean Scores									
	White Noise	Recolor	Classic Melody	Flower Garden					
	(n=5)	(n=5)	(n=5)	(n=5)					
Pre (Monday before session)	16.20	15.20	15.40	14.80					
1 st (Wednesday)	15.40	15.20	15.20	14.80					
2 nd (Friday)	15.20	15.40	15.20	15.00					
3 rd (Wednesday)	15.20	15.00	15.00	15.40					
Post (Friday after 2 weeks of app usage)	15.00	15.40	14.60	15.00					

Profile Plots

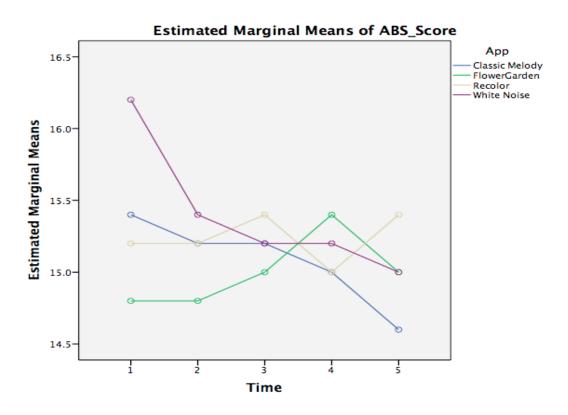


Figure 3: Graph of Estimated Means of ABS Scores When Using Apps Over Time

Table 3: Test of Within-Subjects Effects

Measure: ABS Scores Sphericity Assumed

Source	Sum of Squares	df	Mean Square	F	Sig.
Time	1.660	4	0.415	1.186	0.326
Time*App	6.340	12	0.528	1.510	0.144
Error (Time)	22.400	64	0.350		

Table 4: Test of Between-Subjects Effects

Measure: ABS Scores

Source	Sum of Squares	df	Mean Square	F	Sig.
App	2.360	3	0.787	0.024	0.995
Error	528.000	16	33.000		

Table 5: Summary of Research Report

Source of Variance	df	SS	MS	F	p
Between subjects					
App	3	2.360	0.787	0.024	0.995
Error	16	528.000	33.000		
Within subjects					
Time	4	1.660	0.415	1.186	0.326
Time X App	12	6.340	0.528	1.510	0.144
Error	64	22.400	0.350		

^{*}Sections of the Mixed ANOVA printout have been omitted for clarity. **Tables taken from pg. 475 of Portney & Watkins (2009)

After completing the Mixed ANOVA analysis, the researcher determined that the apps were not statistically significant in decreasing the agitation levels of older adults with dementia long-term. The significance level was set at 0.05, and the p value was 0.144 (p>0.05).

Observation of nonverbal satisfaction was used twice a week on Wednesdays and Fridays during the program while the participants were engaged in the individualized sessions. Refer to Figure 4 for each of the participant's checklists from Week 1 when the *White Noise* app was used and Table 6 for a summary of the observable behaviors from Week 1.

Figure 4: Week 1 Nonverbal Satisfaction Checklists

Participant #1: Falls asleep- helps with agitation but does not display behaviors in the checklist
Wednesday

Smiling			
Laughing			
Nodding Head			
Interacting with app			

Friday

Smiling			
Laughing			
Nodding Head			
Interacting with app			

Participant #2:

Wednesday

Smiling	X			
Laughing				
Nodding Head				
Interacting with app	X	X		

<u>Friday</u>

Smiling	X	X		
Laughing				
Nodding Head				
Interacting with app				

Participant #3:

Wednesday

Smiling				
Laughing				
Nodding Head	X	X		
Interacting with app				

<u>Friday</u>

Smiling	X				
Laughing					
Nodding Head	X	X	X	X	
Interacting with app					

Participant #4:

Wednesday

Smiling				
Laughing				
Nodding Head				
Interacting with app	X	X		

<u>Friday</u>

Smiling			
Laughing			
Nodding Head			
Interacting with app	X		

Participant #5:

Wednesday

Smiling	X	X			
Laughing	X	X	X		
Nodding Head					
Interacting with app	X	X	X	X	

Friday

Smiling	X				
Laughing	X	X	X		
Nodding Head					
Interacting with app	X	X	X	X	X

Table 6: Summary of Week 1 Observable Behaviors of Nonverbal Satisfaction

	Partic	-	Partic 2		Partic 3	-	Partic 4	ipant	Partio 5	cipant 5
Behavior	Wed	Fri	Wed	Fri	Wed	Fri	Wed	Fri	Wed	Fri
Smiling	0	0	1	2	0	1	0	0	2	1
Laughing	0	0	0	0	0	0	0	0	3	3
Nodding Head	0	0	0	0	2	4	0	0	0	0
Interacting with app	0	0	2	0	0	0	2	1	4	5
Total behaviors	C)	5	5	7	,	3		1	8

^{*} Participant 1, during app use, would fall asleep and did not display behaviors in checklist.

To analyze the information, a total number of behaviors for each participant per app was determined. Since the checklist was utilized twice a week, four data collections occurred for each app. Refer to Table 7 for the participants' total number of behaviors observed for each app.

Table 7: Total Behaviors for Each Participant (4 Observation Periods for Each App)

App	Participant	Participant	Participant	Participant	Participant
	1*	2	3	4	5
White Noise	0	7	15	7	34
Recolor	68	41	42	45	40
Classic	0	26	17	17	24
Melody					
Flower	28	28	29	34	31
Garden					

^{*} Participant 1 had no observable behaviors when using the *White Noise* and *Classic Melody* apps because she fell asleep when exposed to the auditory-focused apps.

According to the totals from the nonverbal satisfaction checklist, the *Recolor* app was the most liked by the participants, and the *White Noise* and *Classic Melody* apps were the least enjoyed for the participants, based on the low numbers of nonverbal behaviors (i.e. smiling, laughing, nodding head, and interacting with app) observed during the specified sessions. Since the participants only had mild dementia, they expressed their likes and dislikes in terms of the apps; self-report was used alongside observation. An informal interview occurred at the end of the program to see which apps they most enjoyed. Participant 1 liked the auditory stimulation (*White Noise* and *Classic Melody*) because she stated that they relaxed her. Participants 2 and 4 did not have a preference; they said that they enjoyed using all of the apps. Participant 3 liked the *White Noise* app the best, specifically the "heartbeat" sound. Participant 5 enjoyed the *Recolor* app because she is very artistic and enjoyed painting various pictures. Overall, the self-report data was not consistent with the observational data, except for Participant 5. She reported that the *Recolor* app was her favorite, and her nonverbal behaviors during its use, compared to the other apps, reflected this fact.

Family Caregiver Knowledge

Three outcome evaluation questions that pertained to the family education component of the program included:

- Did the family members' knowledge about dementia increase after participating in the program?
- 2. Did the families find the information that was included helpful?
- 3. Was the information appropriately organized and easy to understand?

The revised version of the Learning About Dementia: Test Questions was administered before implementation of the program as well as after completion to evaluate the caregivers' change in knowledge. The number of questions that the participants answered correctly was recorded. While eight caregivers initially received the educational materials, data was collected from only six due to poor response rate of emails (n=2). Refer to Table 8 for the pre/posttest scores.

Table 8: Family Members' Scores on the Learning About Dementia: Test Questions

Participant	1	2	3	4	5	6
Pretest	8	8	8	9	7	8
Posttest	12	12	12	12	12	12

All of the participants' scores on the Learning About Dementia: Test Questions increased after participation in the Interpersonal APProach to Dementia program. Participants 1, 2, 3, and 6 improved their knowledge about dementia by four points. Participant 4's knowledge increased by three points, while Participant 5's understanding improved by five. All of the caregivers' posttest scores were 12, which is the highest value that they could achieve.

A Wilcoxon signed-rank test was completed to analyze the family members' change in knowledge about dementia. This type of test is appropriate for use with small clinical samples

that may not be representative of larger normal distributions (Portney & Watkins, 2009). Refer to Table 9 for the analysis of the data.

Table 9: Wilcoxon Signed-Rank Test

Subject	Pretest Score	Posttest Score	d	Rank of d
1	8	12	4	+3.5
2	8	12	4	+3.5
3	8	12	4	+3.5
4	9	12	3	+1
5	7	12	5	+6
6	8	12	4	+3.5

Calculated value of T=0 (sum of the ranks of the less frequent sign)

For significance level=0.05 with n=6, the critical value of T is 0.**

The absolute calculated value of T must be less than or equal to the critical value to achieve significance.

Calculated value of T=0 is significant.

The caregivers' change in knowledge was statistically significant since the calculated value (T=0) was equal to the critical value (T=0).

To analyze the Family Education Questionnaire, both quantitative and qualitative approaches were utilized. For questions with Likert scale answers, the total number of participants who selected each number was tallied. For the open-ended questions, regarding the strengths and weaknesses of the program, the researcher coded all of the answers and found common themes. Refer to Figure 5 for the results of the data analysis.

^{*}Table adapted from Table 22.6 in Portney & Watkins (2009) on pp. 515

^{**}Appendix A.10 for critical values of T for the Wilcoxon Signed-Ranks Test on pp. 820 of Portney & Watkins (2009)

Figure 5: Data Analysis of Family Education Questionnaire

Demographics

Age:

18-25: 1 26-35: 0 36-45: 1 46-65: 4 66-75: 0 76-85: 0 86+: 0

Technology Use:

Smart phone (i.e. iPhone or Android)

Mean amount of time used: 6 years

Tablet (i.e. iPad or Kindle)

Mean amount of time used: 2 years

Laptop

Mean amount of time used: 5.5 years

Desktop computer

Mean amount of time used: 16.25 years

Questions with Likert Scale:

Question	4: Strongly	3: Somewhat	2: Somewhat	1: Strongly					
	Agree	Agree	Disagree	Disagree					
	Usability of iPad and App Section								
I felt	6	0	0	0					
comfortable									
using the iPad.									
It was easy to	6	0	0	0					
learn how to use									
the iPad.									
I felt	6	0	0	0					
comfortable									
using the app.									
It was easy to	6	0	0	0					
learn how to use									
the app.									
The organization	6	0	0	0					
of the									
information on									
the app was									
clear.									

		Content Section		
The information was easy to understand.	6	0	0	0
The information that was taught increased my understanding of dementia and its symptoms.	5	1	0	0
The information that was taught helped me manage my loved one's agitation.	5	1	0	0

Yes/No Question

Question	Yes	No
I would have liked to learn about a particular topic during the program.	0	6
If yes, what is it?	N/A	

Open-Ended Questions

Strengths of Program	Information was clear and educational.Layout easy to follow.
Weaknesses of Program	 Include apps that researcher used for program in written materials to compliment in-person demonstration Case studies should be added to further increase the caregivers' understanding of the information
Other Comments/Feedback	 One participant will start implementing ideas given immediately. One participant gave another resource to include for caregivers (online support group)

The family caregivers of individuals with dementia who participated in the program reported being very comfortable using the iPad and the *Google Docs*TM app. The mean amount of time using a table per self-report was 2 years, but the participants had used different forms of technology (i.e. smart phone, laptop, and desktop computer) for a minimum of 5 years, on average. In the "Usability of iPad and App" and "Content" sections of the questionnaire, the participants selected mostly 4s (strongly agree) with a few 3s (somewhat agree). All six participants reported that appropriate content areas were included in the program and would not add information.

Regarding the strengths of the program, many of the participants reported that the information was easy to read and educational. The areas of improvement included adding information about the apps that were used throughout the program into the materials and creating case studies that would build upon the information that was learned during the program.

Chapter Six: Discussion

In terms of the agitation component of the Interpersonal APProach to Dementia program, the long-term effects of the apps were not statistically significant, and the methods to determine app preference, which included observation and self-report, did not produce consistent results. For family caregivers, their knowledge about specific aspects of dementia increased significantly after participating in the program. The participants were also very comfortable with iPad use and found the information easy to understand and helpful. Similar to the results section, the discussion is split into the two focuses of the Interpersonal APProach to Dementia program: agitation and family education. Along with additional factors to take into consideration for these program components, limitations of this project and implications for future research are also included.

Agitation

Some factors to take into consideration about the nonsignificant changes of participants' agitation levels after completing the program include small sample size, the consistent ABS scores of some of the participants, and the short-term effects of the apps. The program had five participants who had a restricted range of agitation levels with only one outlier. Many of the participants (n=3) started off the program with the lowest score on the ABS and maintained the same score throughout the program. Since there was no change over time, this resulted in nonsignificant results. Finally, assessments were completed to determine long-term effects of the apps on agitation. ABS scores were collected hours after the individualized sessions occurred and were not gathered consistently during app use. While the apps did not have much carryover on decreasing agitation levels later during the day, short-term effects, especially with Participant 1, were noted.

As previous studies have shown (Livingston et al., 2014), the researcher of this

Capstone project observed that during program implementation, the interventions targeting
agitation reduced clients' agitation levels during the session. However, as Livingston et al.

(2014) has pointed out, studies have primarily focused on the short-term effects of interventions
and have provided limited insight into their long-term use. This program was designed to address
this gap in the literature, but the results pertaining to the long-term effects of the interventions
were not significant. More research is required.

In terms of the participants' nonverbal satisfaction with the apps, this researcher's observations suggest a need to define more sensitive and effective measurement tools may be required. For example, when the participants were using the apps, the researcher noted that other nonverbal behaviors besides the ones that were included on the checklist were shown. When the participants were listening to the *Classic Melody* app, some would hum along with the music, dance in their seats, and tap their fingers on the table. Verbal behaviors occurred as well. When the White Noise app was used, some of the participants reminisced about the past, which promoted prosocial tendencies. The sound of a grandfather clock reminded one woman of her childhood home, while "cars driving" reminded another participant about her old car. These behaviors show that the participants enjoyed the app, but they were not included in the totals. Another factor that needs to be taken into consideration is that some of the apps allowed for more interaction, depending on the nature of the intervention. For the White Noise and Classic Melody apps, if the participants found a sound or song that they liked, they stopped interacting with the app because they were content to listen to the selected song/noise. If the participant did not like a particular sound or song, then they would interact with the app in order to change it. The Recolor and Flower Garden apps required the participants to touch the screen more, whether to paint a picture or maintain a flower garden, respectively, which caused their total nonverbal behaviors to be higher.

By determining if the apps were effective in decreasing agitation and the participants enjoyed using them, Community LIFE could incorporate these apps into its daily routines to manage problem behaviors. The staff saw firsthand how effective the apps were while the program was being implemented. While the long-term effects were not significant, the staff can still use the iPad for activities, whether for prosocial purposes or a creative outlet. In order to choose an appropriate app, both its effect on agitation as well as the participant's preferences should be taken into account. To promote future implementation at Community LIFE, the researcher met with the center administrator to discuss using one of the center's iPads exclusively for Loving Hearts. Permission was granted, and all of the apps used during the program were downloaded to the iPad. The dementia coordinator, because of the effectiveness of the White Noise app with Participant 1, also decided to buy a white noise machine for SNF use, where Participant 1 is permanently placed.

Family Education

Knowing if the information included in the caregiver education component of the program was effective for increasing knowledge as well as easy to understand would help the staff of Loving Hearts to provide important information to future caregivers. The results were statistically significant, which means that the program successfully increased the caregivers' knowledge about caring for someone with dementia that will help them in their daily lives. The caregivers also reported that they did not have difficulty using the iPad or *Google Docs*TM app and the information presented was clear and easy to understand. Only one caregiver rated the items "The information that was taught increased my understanding of dementia and its

symptoms" and "The information that was taught helped me manage my loved ones' symptoms" with a 3 (somewhat agree) because she shared that her mother had been diagnosed with dementia over 10 years ago. She was already knowledgeable about this diagnosis and how to manage problem behaviors. While the educational materials were beneficial to caregivers whose loved ones were recently diagnosed and therefore had less experience managing dementia, different information could have been accumulated based on a needs assessment that is more appropriate for caregivers who have dealt with problem behaviors longer.

The program's weaknesses and general feedback gathered from the Family Education Questionnaire were taken into consideration to improve the program for future use at the site. Additional information was added to the resources on *Google Docs*TM including the four apps that were utilized for the agitation component of the program, case studies, and an online support group that one of the caregivers utilized. These changes may enhance the effectiveness of the educational resources for family caregivers who will use them in the future.

Limitations

One limitation of the Capstone project was convenience sampling used to recruit participants. The participants of the agitation component of the program all attended Community LIFE: East End, and not only did this lead to a small sample size but also a lack of diversity. The participants all had mild dementia, so the apps were only tested with individuals who were at the earlier stages of the diagnosis. Uniformity was also found in the caregivers. While the participants ranged in age from 19-60 years old, they all had previous technological experience, which played a factor in their comfort level with using the iPad. The final limitation was that some of the individualized sessions were missed due to center closure or outside appointments.

While the researcher planned for 40 consecutive days for program implementation, none of the participants received treatment for this time period.

Future Research

Further research is required to study the long-term effects of specific interventions on agitation. A larger sample size should be used with a variety of participants. This Capstone project focused on older adults with mild dementia, but future studies could incorporate individuals with moderate to severe dementia to assess the differences. According to Bartels et al. (2003), problem behaviors increase as the dementia progresses, which would result in higher levels of agitation in its later stages. However, during the older adult's last week of life, agitation drops from 57%-71% to only 35% (Hendriks et al., 2015). Research focused on these different stages would assess the effectiveness of the apps on various frequencies of agitation and possibly suggest different apps that could be more effective in the later stages of dementia. Focus could also be placed on how the structured activities on the apps, which included coloring and tending a garden, compare to the "real-life" counterparts in terms of effectively decreasing agitation. Future investigators could concentrate on different ways that agitation presents itself and how effective the apps are with targeting the specific behavior. The two participants who exhibited agitation during the program were verbally agitated and experienced changes in mood. Future studies could focus on other behaviors that are included on the ABS, including pacing, pulling at restraints, or wandering. Extra consideration could also be taken to assess the prosocial interactions that resulted from app use, along with agitation changes. In regards to family caregivers, a comparison could be made for those who are familiar with dealing with problem behaviors and those who are not. Based on the caregivers' previous knowledge, appropriate information would be included in the educational resources.

If the Interpersonal APProach to Dementia program was replicated, several changes would be made. Regarding the agitation component of the program, one modification would focus on the assessment utilized to evaluate the older adults' satisfaction with the apps. The checklist of nonverbal satisfaction that was created did not accurately capture the specific behaviors that participants exhibited with different apps, and it did not have established reliability and validity. An effective substitute for the checklist would be the Volitional Questionnaire, which allows for a more uniform approach for assessing satisfaction despite the particular app used. This assessment would be a valid and reliable way to gather more robust information. Since the Volitional Questionnaire is observation-based, it can be utilized with individuals of various cognitive and verbal abilities, which are both affected by dementia.

Staff training would also be handled differently. While one informal training session was held to share the benefits of the apps and teach the staff of Loving Hearts how to operate them, the researcher could have observed them using the apps directly with the participants so that carryover of skills was assessed. For the family education component, all caregivers should have completed their educational sessions at the center. While emails were sent to those who had busier schedules, this resulted in a low response rate; data was not collected on two of the family participants. The number of sessions for the caregivers could also increase from one to three. If the education was spread over three sessions, then the caregivers could incorporate the information that they learned during the program at home and share their experiences with the researcher for direct feedback. Instead of just using a multiple choice test before and after participation in the program to assess knowledge, a case study could also be utilized as a pre/posttest measure. This method of evaluation would provide the researcher with information on the caregivers' reasoning and how they would approach handling challenging behaviors,

specifically agitation. Finally, if this program was repeated, an evaluation of the caregivers' quality of life should be included. Similar to the changes for the evaluation of the older adults' satisfaction when using the apps, an assessment with established reliability and validity should be selected. The Quality of Life Scale would be an appropriate pre/posttest tool for the program because it focuses on different domains of individuals' well-being. By including a quality of life outcome, future implementation at Community LIFE would be better supported. Quantitative data regarding the program's impact on the staff's well-being, which plays an important factor in quality of care, would reinforce the benefits of the Interpersonal APProach to Dementia program.

Chapter Seven: Summary

Through the use of an iPad-based program, the needs of older adults with cognitive impairments and their caregivers were addressed. For one component of the program, to decrease the older adults' agitation, apps that focus on sensory stimulation and structured activities were used during one-on-one sessions. While the long-term effects were not statistically significant, beneficial short-term effects of the apps were noted. Caregiver education was addressed through educational resources on the *Google* DocsTM app, which contained pertinent information about dementia. The change in caregivers' knowledge was statistically significant, and the participants reported that the information was easy to understand and helpful.

The use of technology, specifically the iPad, provided an easy and convenient way to deliver both interventions and education for older adults with dementia and their caregivers. To support long-term use of the Interpersonal APProach to Dementia at Community LIFE, the staff in Loving Hearts were trained to use the apps, and the dementia coordinator was given the educational resources and the app training YouTube video, to share with future caregivers at this site. The dementia coordinator can also incorporate systematic evaluation of the program to ensure its ongoing effectiveness. She can utilize the assessments included in this study, which are the ABS and the Learning About Dementia: Test Questions, for more objective information. Observation of the older adults and gathering verbal feedback from the family caregivers are also appropriate strategies to gather informal data. After participating in the program, the older adults' agitation decreased, while their caregivers' knowledge increased. These results show that the Interpersonal APProach to Dementia program positively impacted the well-being of all involved and will hopefully assist Loving Hearts at Community LIFE: East End for years to come.

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Appendix A: Tables Outlining Key Studies Informing Needs Assessment

Citation (1st author & year only)	Study Purpose/Research Question	Design	Sample	Data Collection Strategies	Findings that Inform This Study
Abramson (2009)	What are the operations of a typical adult day center?	Ethnography	Individuals at an adult day care center in San Francisco	Observation for 6.5 hours a day	Findings: Respite focus in adult day care center and not on improving quality of life of older adults
Anderson (1992)	Does family involvement have a positive effect on residents with dementia in terms of behavior and interactions with others?	RCT	Patients with dementia	Interview with family to determine appropriate intervention for resident; content in nursing documentation was used to develop results of study	Findings: Increased knowledge of dementia is important for family to become more involved; integration of family helped decrease behavioral changes in residents
Burgio (1996)	Is white noise effective in decreasing agitation in residents with dementia?	Pilot study	16 older adults with dementia	Computer-assisted data collection system; Cohen- Mansfield Agitation Inventory	Key findings: Decrease in residents' agitation

Chien	Is a 6-month dementia	RCT	92 families caring for	Family Caregiver Burden	Findings:
(2011)	care program more		older adults with	Inventory; WHO Quality	Significant improvement
	effective than routine		dementia in home	of Life Measure; Social	in older adults' symptoms
	support services in			Support Questionnaire;	and caregivers' QOL
	improving the older			Family Support Services	
	adults' symptoms as well			Index; Neuropsychiatric	
	as caregivers' QOL?			Inventory Questionnaire	
Clark	Is music effective in	RCT (cross-	18 older adults with	Observations of problem	Key themes: Decrease in
(1998)	decreasing problem	over design)	cognitive impairments	behaviors of older adults	problem behaviors as
	behaviors in people with				well as improvement in
	dementia?				affect
Howard	To develop guidelines for	Development	Older adults with	Literature review of	Key themes: Non-
(2001)	the management of	of a CPG	dementia	CINAHL and MEDLINE	pharmacological
	agitation in dementia			for RCTs	interventions should be
					used first; general brief
					structured interventions
					are effective
Lin	Are acupressure and	RCT (cross-	133 residents with	Cohen-Mansfield	Findings:
(2009)	Montessori-based	over design)	dementia	Agitation Inventory,	Participants in the
	activities effective in			Ease-of-Care Inventory,	Montessori-based
	decreasing problem			and Apparent Affect	activities group had a
	behaviors of residents			Rating Scale	decrease in agitated
	with dementia?				behaviors and an increase
					in affect; ease of care
					increased for caregivers
Nobili	Does a structured	RCT	69 families (caregivers	Relative's Stress Scale	Findings: Decrease in
(2004)	intervention help		and older adults with	and Spontaneous	caregiver's stress level
	decrease caregiver stress		dementia)	Behavior Interview	with education; Decrease
	and the rate of problem				in problem behaviors
	behaviors in patients with				(agitation) of older adults
	dementia?				with dementia
				l .	

Rosen	Does a web-based system	Pilot study	Families of older	16 question pre/posttest;	Findings:
(2003)	improve family		adults with dementia	satisfaction surveys	Knowledge of dementia
	participation in		in nursing homes		care improved, which
	caregiving?				helped family members
					take on an increased role
					of care with residents
Silverstein	How are providers	Mixed methods	93 provides of adult	78 item questionnaire;	Findings:
(2010)	addressing the specific		day care services for	interviews	Providers are adapting
	need of participants with		quantitative data;		services to match
	Alzheimer's disease and		8 providers for		participants' abilities, but
	other related disorders in		qualitative data		there is a need for
	adult care centers?				enhancing stage-specific
					services

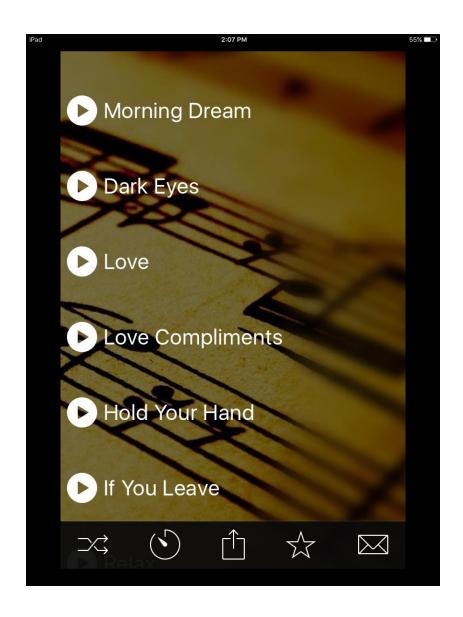
Systematic Reviews:

Citation (1st author & year only)	Study Purpose/Research Question	# and types of articles	Inclusion/exclusion criteria	Sample sizes	Findings that Inform This Study
Cohen- Mansfield (2001)	What nonpharmacological interventions decrease agitation for older adults with dementia?	83 articles that were classified based on different nonpharmacological interventions	Inclusion: Published in a scientific book or journal; participants 60+ years and had a cognitive impairment; measure of change of behavior was used	Ranges from 3-205 participants	Key themes: Sensory enhancement (music and white noise) and structured activities decrease agitation in older adults with dementia
Cooper (2012)	Which nonpharmacological interventions improve QOL or well-being of people with dementia	20 RCTs	Inclusion: Published in English; focused on nonpharmacological interventions for individuals with dementia Exclusion: Subscales used to measure QOL	Ranges from 12-198 participants	Key themes: Interventions for family caregivers (increase in knowledge about dementia) improve older adults' QOL
Fields (2014)	How effective are adult day services in regards to caregiver and participant outcomes?	61 articles; studies included longitudinal, quasi-experimental, RCT, and cross-sectional designs	Inclusion: Peer-reviewed; empirically-based; published in English; focus on the effectiveness of adult day services	Ranges from 9-4761 participants	Key themes: Decreased levels of stress for caregivers

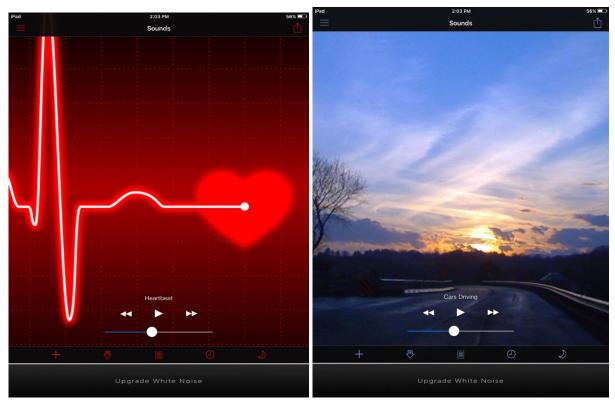
Gitlin	How do professionals	A total number of	Inclusion:	Specific sample sizes	Key themes:
(2012)	integrate	articles was not	Peer-reviewed; published	were not reported	Caregiver
	nonpharmacologic	specified;	from 1992-2012; focused		education and
	approaches into daily	17 controlled studies	on nonpharmacologic		training reduces
	practice?	for cognitive training	behavioral management;		behavioral
		strategies	participants included		symptoms;
			community-dwelling		changes in
		23 RCTs focused on	individuals with dementia		physical
		caregiver education			environment
		and training			(music)
					decrease
T · · ·	******	160 (1 1 1)	Y 1 .	D 6 7 206	agitation
Livingston	Which	160 articles; studies	Inclusion:	Ranges from 5-306	Key themes:
(2014)	nonpharmacological interventions are	included RCTs, non-	Psychological, behavioral,	participants	training staff,
	effective for reducing	randomized, within subjects	sensory, or environmental intervention to manage		pleasant activities, and
	agitation in adults with	Subjects	agitation; comparative		sensory
	dementia immediately		group; quantitative		integration
	and in the longer term,		results; participants have		decreases
	considering agitation		dementia		agitation
	severity, setting and		Exclusion:		ugraaron
	whether the intervention		Medications were given		
	is with the person with		to participants		
	dementia, their carer, or		1 1		
	both?				
Preschl	Can older adults with	35 articles; studies	Inclusion:	Ranges from 2-301	Key themes:
(2011)	multiple diagnoses	included RCTs,	Peer-reviewed; 65+ years	participants	Enjoyable
	benefit from health	conference	old		activities
	services provided	proceedings, and pilot			including
	through technology?	studies			games and art
					had positive
					effects on older
					adults with
					dementia

O'Connor	What psychosocial	12 RCTs	Inclusion:	Ranges from 5-127	Key themes:
(2009)	treatments are effective		Published in English;	participants	music is
	in reducing		published before 2008;		effective for
	psychological		focused on experimental		treating
	symptoms in dementia?		treatments of		problem
			psychological symptoms		behaviors;
					family
					education
					reduced
					irritability in
					older adults
Topo	What types of	46 articles; studies	Inclusion:	Ranges from1-299	Key themes:
(2009)	technology support	included RCT, cross-	Published between 1992-	participants	Technology
	people with dementia	sectional,	2007; contained original		helps increase
	and their caregivers?	retrospective,	data from		quality of life,
			intervention/assessment		decrease
					challenging
					behaviors, and
					address
					problems in
					access to
					information that
					is diagnosis
					specific

Appendix B: Classic Melody App

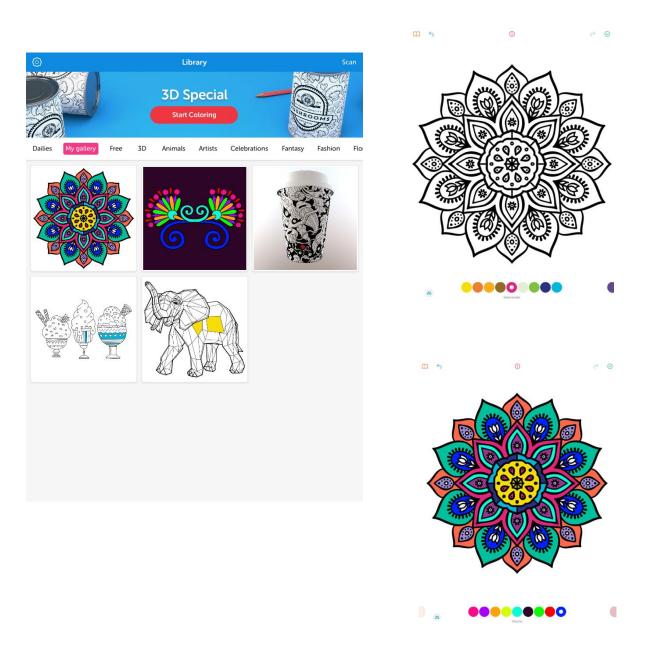


Appendix C: White Noise App





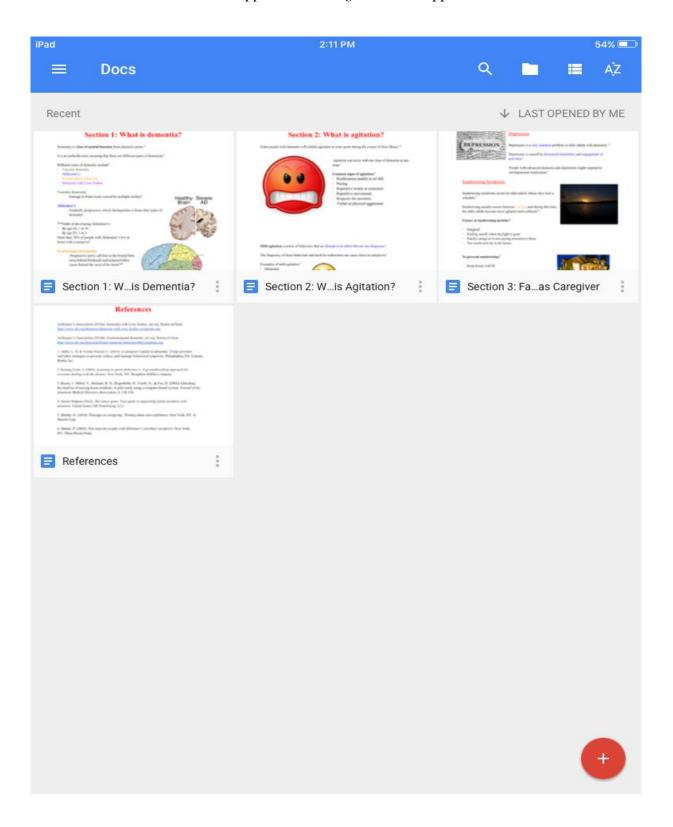
Appendix D: Recolor App



Appendix E: Flower Garden App



Appendix F: Google DocsTM App







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Section 1: What is dementia?

Dementia is a loss of mental function from physical causes.6

It is an umbrella term, meaning that there are different types of dementias.4

Different types of dementia include6:

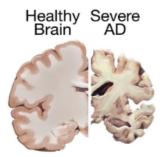
- · Vascular dementia
- · Alzheimer's
- · Frontotemporal dementia
- Dementia with Lewy bodies

Vascular dementia

Damage to brain tissue caused by multiple strokes⁶

Alzheimer's

Gradually progressive, which distinguishes it from other types of dementia6



- ***Odds of developing Alzheimer's:
- · By age 65, 1 in 10
- · By age 85, 1 in 2

More than 70% of people with Alzheimer's live at home with a caregiver2

Frontotemporal dementia

Progressive nerve cell loss in the frontal lobe (area behind forehead) and temporal lobes (areas behind the ears) of the brain AAb







Agitation can occur with any type of dementia at any stage.1

Common signs of agitation:1

- · Restlessness-unable to sit still
- · Pacing
- · Repetitive words or sentences
- · Repetitive movements
- · Requests for attention
- · Verbal or physical aggression

Mild agitation consists of behaviors that are disruptive to others but are not dangerous.1

The frequency of these behaviors and need for redirection can cause stress in caregivers.1

Examples of mild agitation:1

- · Moaning
- Crying







Section 3: Family Members' Role as Caregiver





Section 3: Family members' role as caregiver

Common challenges that caregivers face

Depression



Depression is a very common problem in older adults with dementia.3,5

Depression is caused by decreased stimulation and engagement in activities.5

People with advanced dementia and depression might respond to antidepressant medication.³

Sundowning Syndrome



Sundowning syndrome occurs in older adults whose days lack a schedule.5

Sundowning usually occurs between 3-8 pm, and during this time, the older adults become more agitated and confused.^{2,5}

Causes of sundowning include:6

- Fatigued
- · Feeling unsafe when daylight is gone
- · Family caregiver is not paying attention to them
- · Too much activity in the house





References





References

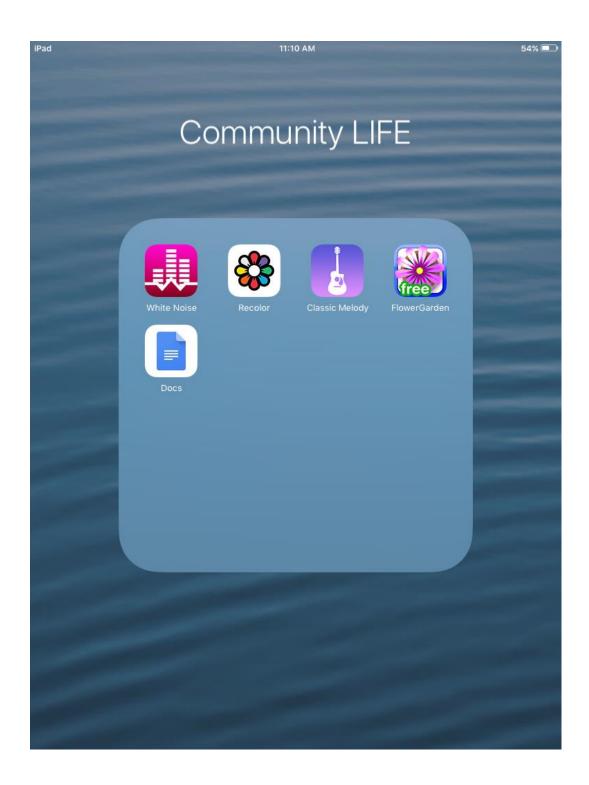
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Appendix G: All Apps Used During the Program



Appendix H: Program Implementation Timeline

Interpersonal Approach to Dementia **Program** imeline March/April 2016 Mid May Beginning of May 2016 2016 Recruit participants for agitation Finalize all Continue with component of program aspects of program Participants need to have a cognitive impairment and display agitated behaviors development program Beginning of August 2016 June/July End of May 2016 2016 Recruit participants for Implementation of Initial evaluation of older adults caregiver education program with older adults using the Agitated Behavior Scale (ABS) component of program Ongoing evaluation using ABS and observation of satisfaction Participants need to care for someone with a cognitive impairment, willing to learn about dementia, and 18+ years old Throughout August 2016 Throughout August 2016 Throughout August 2016 Implementation of Initial evaluation of Complete final caregivers using the Learning About Dementia: Test evaluation Learning About Dementia: Test Questions, and family program with caregivers (1 session) Questions member questionnaire **End of August** 2016 Train staff about use of iPad and apps

Appendix I: Agitated Behavior Scale¹

AGITATED BEHAVIOR SCALE

Patient		Period of	Period of Observation:			
			a.m.			
Observ.	Environ	From:	p.m			
entally a fracti			a.m.			
Rater/Di	sc	To:	p.m	_/_		
At the en	nd of the observation per	iod indicate whether	the behavi	or des	cribed i	
	was present and, if so,					
	ollowing numerical valu				·	
	sent: the behavior is no					
	resent to a slight degree:					
	the conduct of other, con may redirect spontaneou	textually appropriat	e behavior.	(The	individu	
	does not disrupt approp		ion or the a	gitatet	Denavi	
	resent to a moderate dep		needs to be	redire	cted fro	
	an agitated to an approp	riate behavior, but b	enefits from	such	cueing.	
$4 = p_1$	resent to an extreme deg	gree: the individual i	s not able t	o enga	ge in	
	appropriate behavior du			ted bel	havior,	
	even when external cueir	ng or redirection is p	rovided.			
DONO	CELEAVE DE ANIZE					
DONO	T LEAVE BLANKS.					
1.	Short attention span, ea	asy distractibility, ina	ability to co	ncentr	ate.	
2.	Impulsive, impatient, le	ow tolerance for pair	or frustrat	ion.		
3.	Uncooperative, resistar	nt to care, demanding	g.			
4.	Violent and or threaten	ing violence toward	people or p	roper	ty.	
5.	Explosive and/or unpr	redictable anger.				
6.	Rocking, rubbing, moa	ning or other self-sti	mulating be	ehavio	r.	
	Pulling at tubes, restrai					
8.	Wandering from treatn					
	Restlessness, pacing, ex					
10.	Repetitive behaviors, n	notor and/or verbal.				
11.	Rapid, loud or excessiv	re talking.				
12.	Sudden changes of mo	od.	12000000			
13.	Easily initiated or excess	ssive crying and/or	laughter.			
14.	Self-abusiveness, physi	ical and/or verbal.				
To	otal Score					

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Appendix J: Revised Version of Learning About Dementia: Test Questions²

- 1. Reality orientation
 - a. will usually help someone with dementia adjust to the environment.
 - b. can cause increased agitation or aggression.
 - c. is the preferred technique for working with people with dementia.
- 2. Telling lies or "fibs" to your family member with dementia
 - a. is OK if it brings comfort.
 - b. should be avoided since it is disrespectful.
 - c. is never acceptable.
- 3. Most people with dementia
 - a. will exhibit some agitation or aggression at some time during the course of their illness.
 - b. are unable to enjoy life.
 - c. will tell you if they feel depressed.
- 4. Testing your family member's memory
 - a. is important to give them needed practice.
 - b. should be avoided since it might cause agitation.
 - c. is an important part of each interaction with your loved one.
- 5. Agitation and aggression are
 - a. caused by some stimulus.
 - b. simply expected in the Alzheimer's process.
 - c. usually due to too much stimulation in the environment.
- 6. To reduce agitation
 - a. it is essential to eliminate stimulation from the environment.
 - b. the person should be placed in a quiet room.
 - c. it is essential to understand what is causing the agitation by trying to find the stimulus.
- 7. Internal stimuli causing agitation
 - a. cannot be prevented since it is happening inside the person.
 - b. can include pain or depression.
 - c. are impossible to figure out if the person has lost their verbal skills.
- 8. People with dementia can respond with agitation or aggression
 - a. if the caregiver is overly stressed.
 - b. if they are bewildered.
 - c. both a and b.

² Reprinted from *Journal of the American Medical Directors Association*, 4, Rosen, J., Mittal, V., Mulsant, B. H., Degenholtz, H., Castle, N., & Fox, D., Educating the families of nursing home residents: A pilot study using a computer-based system, 128-134, Copyright (2003), with permission from Elsevier.

9. Depression

- a. is a common problem for caregivers.
- b. should not be treated if there is a "good reason" to be depressed.
- c. is an indication of personal weakness.
- 10. Someone with Alzheimer's disease may exhibit agitation or aggression if
 - a. they are in pain.
 - b. they are delirious.
 - c. both a and b.

11. Delirium

- a. is rare in people with Alzheimer's disease.
- b. is often caused by infection or medications.
- c. is not a common cause of agitation.
- 12. People with advanced dementia and depression
 - a. will usually tell you they feel sad.
 - b. should not be given antidepressant medications.
 - c. might respond to antidepressant medications.

^{***}Correct answers are **bolded**.

Appendix K: Family Education Questionnaire

Interpersonal APProach to Dementia Program Family Education Questionnaire

A-Demographics:

1. How old are you? a. 18-25

b.	26-35	
c.	36-45	
d.	46-65	
e.	66-75	
f.	76-85	
g.	86+	
2. Which	h of the following types of technology l	have you used before? Circle all
that a	pply.	
a.	Smart phone (i.e. iPhone or Android)	
b.	Tablet (i.e. iPad or Kindle)	
	Laptop	
d.	Desktop computer	
using a. b. c. d.	f the options that you circled in question these devices? Please write your answer Smart phone: Tablet: Laptop: Desktop computer: B & C, circle the number that best man	er below.
		J
B- Usability	y of iPad and App:	
1. I felt	comfortable using the iPad.	
		Strongly agree

2.	It was easy to learn how to use the iPad.	
		Strongly agree
3.	I felt comfortable using the app.	
		Strongly agree
4.	It was easy to learn how to use the app.	
		Strongly agree
5.	The organization of the information on the	app was clear.
		Strongly agree
C- C	ontent:	strongly ulsugive
1.	The information was easy to understand.	C4
		Strongly agree
2.	The information that was taught increased rand its symptoms.	my understanding of dementia
	»,	Strongly agree

	Somewhat disagree
3. The information that was taught helped me agitation.	e manage my loved one's
	Strongly agree
4. I would have liked to learn more about a pa	articular topic during the program.
a. If yes, what is it?	Yes
For the next 3 questions, please write your answer	ers in the space provided:
What were the strengths of the program?	
What were the weaknesses of the program?	
Any other comments/feedback?	

Thank you very much for completing this questionnaire! Your feedback is very valuable to the Interpersonal APProach to Dementia program and its continued use.

Appendix L: Checklist for Observation of Nonverbal Satisfaction

Checklist for Observation of Nonverbal Satisfaction

Observe the participant for 5 minutes during a one-on-one session. If the action is noted, place a check in the box next to it.

Smiling		
Laughing		
Nodding Head		
Interacting with app		