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USE OF A MUSIC AND MEMORY PROGRAM BY CAREGIVERS OF
PERSONS WITH DEMENTIA

by

BARBARA MENDEZ CAMPOS

A thesis submitted in partial fulfillment of the requirements
for the Honors in the Major Program in Social Work
in the College of Health and Public Affairs
and in The Burnett Honors College
at the University of Central Florida
Orlando, Florida

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Thesis Chair: Dr. Denise Gammonley

Abstract

Although use of personal music devices by persons with dementia and their caregivers is now widespread, there is limited literature concerning music and memory's effects on caregivers for persons with dementia. Caregivers were provided an iPod by two respite agencies and were encouraged to use it with their care recipient. A mailed survey of 50 caregivers who received an iPod explored: (a) associations between use of an iPod and caregiver self-efficacy, burden, and care recipient functional abilities, and; (b) if the method of presenting the music playlist was associated with use of the iPod. Associations were examined for 10 complete surveys returned by caregiver respondents using non-parametric methods. There was no relationship between self-efficacy, burden, functional abilities and use of the iPod. A content analysis was conducted of caregiver open-ended responses to questions about factors associated with use of the device. Mean caregiver age in this study was 75 years of age, care recipient mean was 79 years of age. On average caregivers used the iPods 2-3 times per month. Scores on caregiver burden measured by the 12-item Zarit Burden Interview had a mean of 12.5 which suggests a moderate level of burden. Emergent themes from caregiver open-ended responses about using the device revealed care recipients as primary users, use mostly in the evening, and in response to caregiving tasks or difficult care recipient behaviors.

Keywords: Music and memory, dementia caregiver burden, self-efficacy

Dedication

To my extremely supportive and encouraging parents Barbara and Fernando, as well as my sister Cristina, and brothers Fernando and Roberto.

To the first person that drove me towards this project Alex, you inspire me to become a better person every day “and then some”. Thank you for being my best friend.

To my amazing committee, you all are my role models and mentors Dr. Denise Gammonley, Dr. Tracy Wharton, and Dr. Dawn Oetjen. I look up to you and aspire to be like you in my future.

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Introduction

Statement of the problem

Caregivers are an extremely valuable population in society. They are given an unfamiliar task that most of the time they have no experience with, also known as informal caregiving because it is not paid. Of those defined as caregivers, in the United States, 14.9 million currently care for someone who has dementia (Alzheimer's Association, 2011). Overall, 83% of the help provided to older adults in the United States comes from family members, friends, or other unpaid caregivers. In 2015, caregivers of people with Alzheimer's and other dementias provided an estimated 18.1 billion hours of informal (that is, unpaid) assistance (Alzheimer's Association, 2016). The stress and burden on dementia caregivers increases substantially with the level of cognitive impairment of the person in their care (Snyder et al., 2016). The social issue revolves around the fact that the number of people around the world living with dementia is predicted to rise from 44 million to 135 million by 2050 (Elliott & Gardner, 2016). As of 2015, there are 46.8 million people living with dementia (Alzheimer's Disease International, 2015).

The rise and prevalence in the population of persons with dementia implies a demand for dementia caregivers. Dementia caregiving requires a significant demand on time and energy to provide appropriate care. As hours of care rise, average well-being of caregivers declines, and perceived negative aspects of caregiving increase (Spillman, Wolff, Freedman and Kasper, 2014). This begs the question of what caregivers can do to support themselves in order to cope with many of the complications associated with providing informal care, such as stress.

Music therapy has been studied in previous years and has shown some benefits for persons with dementia. No one experiences music as just sound; the various elements of music

are processed in the prefrontal cortex of the brain, and emotional memories, such as love and affection, are often well preserved for persons with dementia (DeLauro, 2013). Meaningful musical experiences often resulted in experiences of emotional connectedness with other people such as caregivers, nurses, therapists, and staff (McDermott, Orrell, Ridder, 2014). Although studies show that music therapy has some beneficial impacts in persons with dementia, there has been little studied concerning the impact it has on caregivers.

The overall purpose of the study is to explore the factors that are associated with use of a music and memory program for caregivers of persons with dementia. This study provides a focus on how self-efficacy, levels of burden, caregiver demographics, care recipient level of functioning, and playlist form (whether pre-selected playlist or own CD) affect the use of a music and memory program.

Significance

Dementia can affect anyone; as of today, there are no set prevention methods or cures for this mental illness. According to the Journal of Geriatric Psychiatry and Neurology, “dementia may be defined as a clinical syndrome of mental capacity characterized by a substantial global decline in cognitive function that is not attributable to altered consciousness; it consists of a combination of symptoms attributable to various causes or pathological events” (Breitner, 2006, p.129). Dementia is also defined as the decline of a person’s memory and other mental abilities to the point that the decline interferes with interactions and the ability to do daily tasks on the job or at home (Florida Alzheimer’s Disease Initiative Education Manual, 2012). Alzheimer's disease is the most common form of dementia and accounts for an estimated 60 to 80 percent of dementia cases (Alzheimer’s Association, 2015).

Music and Memory is a program originally created in New York City by Dan Cohen, an MSW. He mainly based this program on his observations of persons with dementia and some nursing homes. The method involves the person with dementia listing their favorite songs and uploading them into an iPod or Mp3 player. One study showed that the personalized music provided improvements in functioning on the persons with dementia and residents of the nursing homes. (DeLauro, 2013).

Theoretical Framework

Both Bandura's (1994) Self-Efficacy Theory and Pearlin's (2009) Stress Model are relevant to the study of music and memory in terms of caregiver outcomes of the use of the program. Perceived self-efficacy is defined as peoples' beliefs about their capabilities to produce designated levels of performance that exercise influence over events that affect their lives. The level of self-efficacy/confidence that the caregiver perceives that they have affects the way they view challenges and approach a situation (Bandura, 1994). This study examined if caregiver self-efficacy may be related to use of a music and memory program and the sources of influence that drive caregivers of persons with dementia to use the program. Bandura contends that there are four major sources of influence in relation to self-efficacy. The first and most effective is mastery experiences; basically, successes build a robust belief in one's personal efficacy and failures undermine it. The second is through the vicarious experiences provided by social models. Seeing people similar to oneself succeed by sustained effort raises observers' beliefs that they, too, possess the capabilities to master comparable activities. Third, is the concept of social persuasion; people who are persuaded verbally that they possess the capabilities to master given activities are likely to mobilize greater effort and sustain it than if they harbor self-doubts and

dwell on personal deficiencies when problems arise. This concept is where the demographics of the caregiver and the situation come into play; for example, things such as whether it is one family caregiver or if there are multiple caregivers in the family. The fourth and last source of influence is the reaction people have to stress and the way that alters negative emotional proclivities and misinterpretations of their physical states (Bandura, 1994).

One focus for this study is to consider if a music and memory program is a form of stress relief or coping mechanism for caregivers of patients with dementia. Stress, as defined by Pearlin (1989) is “an exigency that people confront, and their perceptions about that exigency as threatening or burdensome.” In Pearlin’s Stress Model, the structural context of the stress process includes: exposure to a stressor, social institutions, and their arrangements of statuses and roles (Pearlin, 1989). Stressors appear either in the form of disruptive events or the more persistent hardships and problems built into the fabric of social life. Exposure to one stressor, regardless of whether it is an event or more chronic hardship, may lead over time to exposure to other, secondary, stressors, a process called stress proliferation. It has been observed, for example, that being involved in a caregiving role can lead to additional stress in one’s occupational role (Pearlin, 2009).

In order to analyze a music and memory program, both the positive and negative factors associated with dementia caregiving must be taken into consideration. As Lundh (1999) reported, the caregiver situation includes not only the negative aspects of caregiving but also the positive aspects of caregiving, such as satisfaction. The major theories or models that guide the examination of my research question were Bandura’s Self-Efficacy Model, which has more

emphasis on caregiver confidence and more positive aspects of caregiving, and Pearlin's Stress Model, which emphasizes the more negative factors associated with caregiving.

Literature Review

There are various factors that must be taken into account in relation to understanding how dementia caregivers use a music and memory program with their care partner. Those factors include, self-efficacy level of the caregiver, burden, caregiver demographics, care recipient level of functioning, and playlist form (personalized music: pre-selected songs or own CD).

Use of music and memory

Studies on music's effects on the brain have been expanding in regards specifically to memory. One of music's greatest use that has been explored by many researchers is its benefit for individuals with Alzheimer's and/or dementia. Music and memory programs or music therapy have been implemented for this population in many settings such as, nursing homes or long term care facilities, assisted living facilities, and in the home. The study of why music and memory is helpful to persons with dementia has an extensive literature base. Many of the studies have found that music is uniquely preserved in some persons with Alzheimer's disease, though other cognitive functions have deteriorated (Cuddy et al., 2012; Koelsch, 2014). Some research has found positive effects of music therapy or programs for individuals with Alzheimer's and/or dementia in regards to mood, communication, and agitation (Ridder and Gummesen, 2015). However, there is lack of research in the areas of how it affects caregivers of persons with dementia and methods of implementation for most effective use.

Studies that have focused on the benefits of music and memory for caregivers are limited. One qualitative study aimed to understand how family members perceive the influence of musical experiences on the physical and mental health of a relative living with a terminal illness.

Although the study found that music therapy had improved relationships, it only interviewed seven family members belonging to two families (Sales, Silva, Pilger, and Marcon, 2011). Some other studies have focused on nursing homes and long term care facilities to explore the professional caregiver's attitudes about individual music and memory programs. One study in particular found that most nursing staff held positive attitudes towards use of music for older people with dementia. This study also found a gap in the nurse's attitudes on implementation of the program (Sung, Lee, Chang, Smith, 2011). Another study in a dementia home care setting identified multi-level barriers to the implementation of the use of arts interventions (including music), encompassing issues of training (Argyle and Kelly, 2015). This literature suggests that there is a need for additional research to understand how best to train caregivers and support their efforts to implement music programs for persons with dementia.

In regard to strategies for effectively implementing music and memory programs, the literature suggests more study and clarification is needed. In one study of what professional caregivers and family said about music therapy on behaviors of older people with dementia in residential aged care, some negative effects were identified. Results suggested that providing music therapy in the afternoon was ineffective. They found that, in the afternoon, the older persons were left agitated, with a heightened sundown effect. Consequently, professional caregiver working patterns suffered and delivering the music and memory program compounded their fatigue in the afternoon (Tuckett, Hodgkinson, Rouillon, Balili-Lozoya, and Parker, 2015). This finding suggests that future research on delivering music and memory programs should include consideration of the best time of day to use a music and memory program. In that same study, the authors proposed that mid-afternoons might work better considering the sundown

effect, however, this has not been studied enough for it to be considered the best way to use the program.

Important aspects of effectively using music and memory include frequency, duration, time, form, and setting. The setting can range from in home care, assisted living, nursing homes, long term care facilities, and hospice care. Frequency refers to how many time it is used. Duration means for how long it is used. Time is for when it is used in terms of days or actions, for instance when a patient may be “sundowning”. Form simply refers to how it is used, how caregivers use it with others, or how professional caregivers uses it in groups. Attention to these aspects are lacking in much of the research literature. Most studies focus on the effect the music and memory programs on the individual with Alzheimer’s or dementia rather than the caregivers or methods of use. This is seen in a recent study that attempts to develop further insights into the musical experiences of people with dementia and explores the meaning of music in their lives (McDermott, Crellin, Orrell, and Ridder, 2013). While this study mentions some of the qualitative effects on the individuals, it fails to mention how or when they used it.

Self-Efficacy

Of the literature related to the music and memory programs and its effects on caregivers, self-efficacy seemed to be one of the most common outcomes. A study of the effectiveness of MP3 players to support family caregivers of people living with dementia at home found that the use of the MP3 player significantly decreased psychological distress, significantly improved the mental health and wellbeing of caregivers, significantly increased caregiver self-efficacy to manage symptoms of dementia, and was reported to provide valued respite from the high level of

vigilance required for caring for a person with dementia (Lewis, Bauer, Winbolt, Chenco and Hanley, 2015). Another study suggests that self-efficacy may explain the variability in family caregiver's ability to cope with stressors. The study found positive implications for family caregivers' quality of life, mental and physical health (Crellin, Orrell, McDermott and Charlesworth, 2014). This study in particular attempts to fill the gap of understanding how self-efficacy might be a factor that encourages a caregiver to use services like the music and memory program by discussing self-efficacy and its use as a coping mechanism. Expanding research concerning how self-efficacy contributes to caregiver use of music and memory program might help professionals target delivery of music and memory resources to caregivers.

Burden

Level of burden is often discussed in the literature of music and memory programs as a perceived outcome variable that can be reduced with using music and memory. A study of a spousal caregiver directed music intervention, using group musical therapy designed to prolong fulfilling relationships in couples where one person has dementia, resulted in decreased levels of burden (Baker, Grocke, and Pachana, 2012).

There is a lack of research on whether levels of burden are affected during the use of music and memory, as well as, the association that burden might have as a factor that leads to the use of music and memory services. While being a caregiver can be rewarding, there is clear evidence in the literature that caring for a person living with dementia can have negative effects on the physical and emotional wellbeing of caregivers. The transition to institutional care is more likely when the burden of care remains unattended to, particularly when the behavioral and

psychological symptoms of dementia become more significant (Lewis, Bauer, Winbolt, Chenco and Hanley, 2015). As relieving burden is such an important consideration in meeting the needs of dementia caregivers, greater understanding of how burden might play a part in caregivers' use of a music and memory program is needed.

Caregiver Demographics

There are various types of caregivers of persons with dementia, the most common ones are informal caregivers, which include spousal caregivers or family caregivers, and professional caregivers. Demographic characteristics of caregivers have been well studied in the majority White population (Etters, Goodall, & Harrison, 2008), with most studies demonstrating that caregivers tend to be older wives. In a study about the demographic and socioenvironmental characteristics of caregivers of dementia individuals, the study found significant differences were noted between Black and White caregivers in five demographic characteristics. Black caregivers were younger and more likely to be female, have less education, live in the South, and were less likely to be married. There was only one socioenvironmental difference between Black and White caregivers: Black caregivers were more likely to be an adult child (Cothran, Farran, Whall, Redman et al., 2015). Although the comparisons demonstrate the need for more exploration on populations other than the White population, there is still an overall prevalence of females as the caregivers of persons with dementia.

A study conducted on caregivers of persons with dementia found that out of the 693 participants, the mean age of informal caregivers was 54.5 years, ranging from 21 to 88 years. The majority of caregivers were aged between 50 and 64 years (45.1%), were women (66.0%),

with secondary education (41.8%), and married (65.5%) (Vaingankar, Chong, Abdin, Picco, Jeyagurunathan et al., 2016). Many studies conclude that most caregivers of persons with dementia are women (Springate and Termont, 2014). Although gender has been a major focus in these studies, not much emphasis has been placed on race or ethnicity. There is also a lack of literature on possible associations between demographics of caregivers and factors contributing to use of services, such as a music and memory program.

Care Recipient Level Functioning

One of the factors that may be an important factor in determining the potential benefits of a music and memory program for caregivers is the care recipient diagnosis and stage of dementia. Numerous types of dementia exist including Alzheimer's type, frontotemporal, vascular, Lewy body, as well as dementias arising from medical conditions and substance abuse. The main concern for the purpose of this study is the level of functioning associated with the diagnosis as that has an important impact on the level of support provided by the informal caregiver. Level of functioning for this study refers to a certain level of independence that the care recipient might possess. It also refers to the behavioral manifestations of the dementia and cognitive ability that the care recipients exhibit. A cross sectional study revealed that out of 206 individuals, most patients were diagnosed with Alzheimer disease (78.7%), with the other most common dementia etiologies, including frontotemporal dementia (3.2%), vascular dementia (2.8%), and Lewy body dementia (1.9%) (Springate and Termont, 2014). Another study similarly reported that the majority of the residents in the two nursing homes studied had a diagnosis of dementia recorded in their medical files, and most had moderate to severe cognitive impairment (McDermott, Crellin, Orrell, and Ridder, 2013). In both of these studies, the

researchers mentioned the diagnosis of the patient and slightly touch on how it affects behavior and functioning, however, there is a lack of emphasis on level of functioning in terms of how independent the individuals are and the tasks that may be performed on their own.

Playlist Form

In regards to the Alzheimer's and dementia population, it has been found that music therapy methods and the use of familiar individualized music are important factors for consideration. Type of music and method of presentation were the most important factors affecting results. Most studies (61.1%) used songs familiar to or favored by the participants; most studies delivered 30-minute interventions twice weekly; and most studies used a therapy duration of 6 hours. Finally, most studies (77.8%) had music therapy sessions performed by either music therapists or trained healthcare providers (Li, Chen, Chou, and Huang, 2014). Further studies on how playlists are selected and delivered are recommended in order to expand the knowledge on how to improve the use of music and memory for most effective use. Understanding caregiver preferences for music selections and methods of presentation and how these factors might play a role in determining how caregivers use music and memory with care recipients is an important consideration for future research.

Purpose

The purpose of this study is to explore use of a music and memory program. This study also aims to gain understanding of the factors that may contribute to caregiver use of a music and memory program, which include, self-efficacy, burden, level of functioning, and playlist form. This study also places an emphasis on describing how a music and memory program is used by caregivers of persons with dementia in order to gain insight into what can be done to improve such programs.

The study focuses on informal caregivers providing care for someone with dementia in their home because both agencies (Alzheimer's and Dementia Resource Center and Brain Fitness Club) providing the music and memory programs offer services mainly to that specific population and setting. Both agencies provided the participants with iPod's and headphones and an option of a pre-selected playlist or inclusion of the participant's own music. Caregivers were also provided with an instruction sheet describing the purpose of the program.

The overall goal of this research project is to better understand how caregivers use an iPod based music and memory program and if caregiver self-efficacy, burden, demographic factors, playlist form, or the functional abilities of the person with dementia, may be associated with use of music and memory.

Hypotheses

The research team predicts four directional hypotheses in relation to the multiple predictors regarding the outcome variable of the use of a music and memory program. The hypotheses are as follows:

H1a: Caregivers of persons with dementia with greater self-efficacy in responding to disruptive patient behaviors, will have greater use of a music and memory program.

H1b: Caregivers of persons with dementia with greater self-efficacy in controlling upsetting thoughts about caregiving, will have greater use of a music and memory program.

H2: Caregivers with a perception of greater burden, will have greater use of a music and memory program.

H3: Caregivers of persons with dementia with a greater choice of playlist, will have greater use of a music and memory program.

H4: Lower level of care recipient functioning, will result in a greater use of a music and memory program.

Research Design and Methods

Research Design

This study was an exploratory mixed methods research study using a mailed survey with established outcome measures and space for open-ended comments provided by caregiver participants.

Participants

Up to 50 participants were recruited from the list of caregivers registered in the music and memory programs of the Alzheimer's and Dementia Resource Center and the Brian Fitness Club. Each participant previously received the iPod and instructions for the music and memory program. The participants of this study were the caregivers of the persons with dementia. Participants are primarily family members and informal caregivers who provide care in the home. 50 participants were mailed surveys that included a self-addressed return envelope. From the original sample size of 50, 12 participants mailed back the survey and 10 were used for data analysis based on entire completion of survey.

Measures

In this study, the outcome variable is the frequency of use of a music and memory program. In order to measure this outcome, the research team developed a question that seeks to understand the frequency of use over the past month using a five-point scale ranging from 5 indicating daily use to 0 indicating no use within the past month. To understand how the music and memory program was used by caregivers, additional questions were developed focusing on

the experience and perspective of the caregivers of persons with dementia. These open ended questions about how caregivers use a music and memory program were integrated into the survey (provided in Appendix A).

In regard to the predictor of self-efficacy that leads to the use of music and memory, the self-efficacy scale selected is the “Revised Scale for Caregiving Self-Efficacy (Steffen et al., 2002)” that measures a mean level of confidence in engaging in caregiving tasks rated on a scale of 0-100. A score of 0 indicates the caregiver cannot do the task at all and a rating of 100 indicates they are certain they can do the task. The two specific task subscales chosen from this scale are: self-efficacy for responding to disruptive behavior and self-efficacy for controlling upsetting thoughts about caregiving. The scale itself indicated that these two self-efficacy subscales showed strong internal consistency with Cronbach’s alphas greater than .80 (Steffen et al., 2002). Two-week test–retest reliability scores for the subscales were obtained and reliability coefficients were in the acceptable range. The instrument performed very consistently in terms of internal reliability and construct validity (Steffen et al., 2002).

To measure burden, the 12-item Zarit Burden Interview (ZBI) was used (Bedard, Molloy, Squire, Dubois, Lever & O’Donnell, 2001). The scale’s scoring measures level of burden from 0-48, with 0 being little or no burden and 48 being severe burden. Results from the 12-item ZBI, showed that the measure had good internal consistency reliability, with a Cronbach’s alpha coefficient of .92 (Hébert, Bravo, and Prévile, 2000).

For the playlist form, the research team developed a series of ‘Yes’ or ‘No’ questions. The questions delve into whether the playlist contained music the participants selected or if they

were given a pre-selected limited choice in the playlist. These questions aim to explore an association between choice in the playlist form and frequency and duration of use of a music and memory program.

In order to measure care recipient level of functioning, the Katz Total Activities of Daily Living (ADL) summative scale was used. The scoring of the scale is from 0-6, with 0 standing for no assistance needed and 6 indicating total dependency. In the thirty-five years since the instrument has been developed, it has consistently demonstrated its utility in evaluating functional status in the elderly population (Wallace and Shelkey, 2007).

Procedures

After obtaining approval for the study from the UCF Institutional Review Board, representatives from the two music and memory program organizations were provided a packet of surveys containing the consent information and questionnaire along with a stamped self-addressed return envelope. Each organization mailed the packet to caregivers who were enrolled in the music and memory iPod program at any time between July, 2015 and August, 2016. Anonymous surveys were mailed out in an envelope with the organizations' seal with a paid return address. Detailed instructions accompanied the survey clarifying that the survey was to be answered from the caregiver's perspective and not the care recipient. Completed surveys were returned to the organization's mailing address in care of the UCF research team.

Returned surveys were collected by staff members at each organization and placed in a specific file within the organization labeled music and memory program. Once the survey

administration was completed, staff members at each organization provided the researcher with the set of completed survey forms.

Data Analysis

The data analysis for this study included the use of a variable code book and entering data into an SPSS file. After data cleaning, recoding, and summarizing scales, descriptive statistics for each variable were produced. A demographic profile describing the sample was also developed. The preliminary data analysis showed that the assumptions for multiple linear regression were not met for any of the four proposed hypotheses, thus the research team used non-parametric statistics to analyze the hypotheses. To examine the first, second, and fourth hypotheses about self-efficacy, burden, and level of functioning, the Mann Whitney U Test was used to evaluate self-efficacy, the 12-item Zarit Burden Inventory, and the Activities of Daily Living outcome scores.

To examine the third hypothesis about playlist form, the team used the Kruskal Wallis Test to evaluate the impact of choice in playlist form. Along with all the hypotheses, frequency of use was also analyzed in the study by a nominal question in the survey.

To analyze the qualitative, open-ended questions in the survey, responses from the surveys were compiled in a table (table 4). Furthermore, content analysis was conducted for each question to examine the themes that emerged from each response. An inductive coding list was developed for the content analysis of this study, since there is no well-established set of applicable codes. Two members of the research team independently reviewed the same materials and developed a set of working codes that cover the content from each response. Upon completion of the revision, both researchers compared codes and consolidated differences shown. This provided a way to improve reliability in coding the qualitative section of the study.

Results

Twelve individuals returned the mailed out survey; of the twelve, the ten complete surveys that were returned were used in the analyses. A demographic profile of caregivers and care recipients is provided in Table 1. In terms of demographics of the caregiver, the majority of the respondents marked their sex as female (70%), most identified as White (80%), and with a Bachelor's degree (30%), followed by those with a Master's degree (20%) as the education level of the caregiver. On the other hand, care recipients identified as mainly male (40%), White (90%), and varied from having a High School Diploma (20%), Some College (20%), and/or a Master's degree (20%). Caregiver's median age in our study is around 75 years of age, while care recipient's median age is 79 years of age.

The outcome variable for this study, frequency of use of the iPod, was dichotomized into high users (those who used it daily, 2-3 times per week, and weekly), and low users (those who used it 2-3 times per month, at least once per month, or never). Results indicated that half of the ten caregiver participants were high users and half were low users.

Results from the Mann Whitney Tests for hypotheses one, two, and four, related to burden, self-efficacy, and level of functioning are presented in Table 2. Two subscales of the self-efficacy measure were evaluated to examine Hypothesis 1. The first representing "self-efficacy in responding to disruptive patient behaviors" and the second representing "self-efficacy in controlling upsetting thoughts about caregiving". The first subscale "responding to disruptive patient behaviors" represents items 1-5 on the survey and indicates the degree of confidence experienced by the caregiver in responding to the behavior ranging from 0 indicating "cannot do at all" to 10 representing "certain can do" The mean score obtained from the entire sample of ten

caregivers was a 74.88 indicating a 74.88% confidence in responding to disruptive behaviors. The second sub scale from the self-efficacy scale indicated a mean score of 77.7 meaning that, overall, the ten caregivers had 77.7% confidence in controlling upsetting thoughts related to the role of caregiving. No relationship was found from the Mann Whitney test for caregiver self-efficacy related to responding to disruptive behavior ($z=-.420$, one tailed $p=.690$) or controlling upsetting thoughts ($z=-.314$, one tailed $p=.841$) and use of a music and memory program.

Hypothesis 2 was examined using the 12-item Zarit Burden Interview and a Mann Whitney U test. Results showed that the overall mean score for all 10 the respondents was 12.5 which indicates a moderate level of caregiver burden. Results from the Mann-Whitney test indicate that there is no relationship between caregiver burden and use of a music and memory program ($z=-.736$, one tailed $p=.548$).

As shown in Table 3, the Kruskal Wallis Test conducted for the Hypothesis 3 related to choice in playlist form, the results indicate that there were no significant differences in the groups that had one choice, two choices, or three choices ($\chi^2 = .517$ $p=.772$). Participants (caregivers) had an average of 2 choices when it came to the playlist form inserted in the iPod. In fact, 60% of caregivers indicated they had 2 choices in playlist form, 20% indicated they had one choice, and 20% indicated they had 3 choices.

Hypothesis 4, reported in Table 2, regarding care recipient level of functioning as measured by the Katz ADL Scale led to a median total ADL score of .50 and a mean of 1.600, indicating that care recipients required high levels of assistance or supervision for activities such as toileting, bathing, dressing, grooming, and transferring. Five of the 10 caregivers reported a total ADL score of 0 for their care recipient indicating a very dependent level of functioning.

The results of the Mann-Whitney test indicate that there was no association between the level of care recipient functioning and use of a music and memory program ($z=-.671$, one-tailed $p=.548$).

Results from Open-Ended Questions

Open-ended questions were asked in relation to what specific events prompt use of the music and memory program, what other activities are able to be done while loved one is listening to the iPod, and how the music memory program could be improved. A summary of the content analysis of open-ended questions is presented in Table 4. For the first question regarding specific events, the overall themes found related mainly to behaviors exhibited such as frustration, agitation, and sadness. Some stated that the program was used as a distraction for doctor's appointments and as a relaxation technique. One case stated that the recipient that listened to the music was actually not the best test subject in their opinion since this person had not been very connected to music in the first place. Others stated that the program ceased to be part of the daily routine after a while.

In response to the second question some answered that they were able to do things that required concentration, like pay bills, and participate in leisure activities like reading. A common word used in several responses was "relax". This relaxation for some was in relation to the caregiver, while for others it was for their care recipient.

Lastly, some feedbacks on improvement of the program included to provide more instructions and help, incorporating the program at skilled nursing facilities, and providing music without words.

Discussion

This study examined factors and their relation to the use of a music and memory program for caregivers of persons with dementia. This study provided a focus on how self-efficacy, levels of burden, caregiver demographics, care recipient level of functioning, and playlist form affect the use of a music and memory program.

Results showed that most caregivers were women, age median was 75, whereas majority of care recipients were male with a median age of 79. In terms of race and ethnicity, the majority of caregivers and care recipients was White and Not Hispanic.

Caregivers' frequency of use of the iPod was quite variable with half of the sample indicating low use and half a high level of use. Factors that could contribute to this even split could be: a) sample size, b) iPod/technology challenges, c) reason for use (i.e. if it is used for special circumstances, like doctor's appointments that are usually once a month or so), and d) lack of effectiveness of the music and memory program for caregivers and/or care recipients. The literature review conducted for this study found that some of the factors that seem to contribute to the effects of music are: individualization and level of emotional connectedness to the music. Therefore, the personalized selection of music is important to consider when implementing music therapies or programs (Jiang, Zhou, Rickson, and Jiang, 2013). Since individualization was a consistent theme found in previous literature, one of the factors examined in this study was the playlist form, specifically to assess if caregivers chose to personalize the playlist and were given that opportunity. In this study, we found that all caregivers did have at least one choice, meaning that the music given to the participants to listen to was personalized in at least one way. Most respondents in our study marked that they had brought in their own CD or

music. There could be several reasons for this: a) the pre-selected music sheet given did not reflect their personal preferences, b) they did not want to take the time to fill out the song list, and c) their prior music selections had already shown a positive effect on their care recipient.

Results indicated that, overall, caregivers sampled in this study experienced a moderate level of burden but burden was not associated with use of the music and memory iPod. Lack of impact of the iPod system on caregiver burden is consistent with the literature on factors associated with caregiver burden. For example, a recent systematic review of burden among informal caregivers of persons with dementia found that behaviors and psychological symptoms of the person with dementia were the main variables associated with caregiver burden. Additionally, the caregiver's socio-demographical factors also contributed to caregiver burden (Chiao, Wu, and Hsiao, 2015).

This study included a measure of caregiver rated care recipient Activities of Daily Living and concluded that most care recipients required at least a moderate level of assistance in conducting ADL's. Results from the open-ended comments provided by caregivers helped illustrate one potential role for the iPod as a source of distraction for care recipients when caregivers were attempting to provide ADL assistance to care recipients. Some themes that emerged in responses included using the iPod in response to specific behaviors, such as frustration, agitation, or sadness, including use of the iPod into evening routines, and when events that disrupted daily routine affected the care recipient's emotional state.

Lastly, our hypothesis on self-efficacy in relation to use was measured by two subscales of the Self-Efficacy scale. Interestingly, both subscales yielded a scoring in the 70%'s range. This means that caregivers were 70% confident that they could control upsetting thoughts and

respond to disruptive patient behaviors. However, the hypothesis that use of the iPod was related to caregiver's self-efficacy for responding to disruptive behaviors and controlling upsetting thoughts about caregiving was unsupported by our findings.

Limitations

The main methodological limitations in this study were: a small sample size and delivery method of survey. The participants from each music and memory program totaled to about 50 participants. 50 surveys were mailed out and of those 12 were received and 10 were complete surveys. The sample sized limited our data analysis to use of nonparametric tests since there were not enough cases to conduct the planned regression analyses. The small sample size did not allow us to generalize findings to the overall caregiver population. Only two agencies in the community were approached to conduct this survey and this limited the total sample we had to work with from the start.

In addition, one of the agencies approached has a greater focus on the betterment of the individual with Alzheimer's or dementia which might have presented some confusion in how the respondents interpreted some of the survey questions. In fact, some responses to the open ended questions were things like "I did not know this iPod was for me" or "I (caregiver) do not use the iPod. My husband usually listens to it". The survey could have been misinterpreted by the caregivers of that agency. Use of the the Self-Efficacy Scale may be a limitation as well as some studies have discouraged including this scale in surveys since it is mainly designed to be read aloud to respondents.

Lastly, the survey delivery chosen for this study was a limitation. From the start, the team knew that response rate for mailed surveys was lower than other options, however, since both agencies use mailing systems as their form of communication we assumed it would be familiar to the participants. This form of administration was preferred and facilitated by the agencies.

Limitations presented with this form of survey were not only smaller sample size but also harder to return and longer time to complete.

Conclusions and Recommendations

In future studies, it may be beneficial to conduct a different survey method such as a focus group, telephonic survey, or web based survey. I think by introducing a different survey method, better feedback could be acquired for qualitative analysis and program evaluation purposes. Next, it would be interesting to reach out to more community agencies that have music and memory programs outside of the Orlando area. Not only would this increase sample size, it would also possibly increase our variability in demographics and use. This leads me to my following point of recommending to incorporate a section in the survey on socioeconomic status, not necessarily answered by the participants but done by the research team based on geographical location. Socioeconomic status may play a role in aspects of caregiving. A recent study published in the Journal of the American Geriatrics Society, found that older adult caregivers with financial difficulties had significantly poorer Mental Examination scores than those with no financial struggles (Amer, Mossa, Abdul-Rahman, Mabrook, and Raafat, 2015).

Recommendations for Agencies Using iPod with Caregivers

Feedback gained from the qualitative portions of this study offered insight into future suggestions for music and memory programs. In one case, a participant expressed that following-up for updating the song list, provision of easier instructions to update, deletion of the organization of the iPod, and help line for when technical difficulties arise would be helpful in the future. Another suggested music without words. In the future, my suggestion to address the confusion is to host a music and memory program orientation where one can also pick up the iPod they signed up for. This orientation would include a brief tutorial on using the iPod, and how to manage it on iTunes, as well as provide suggestions on when to use it and provide contact information for the person in charge of the program should any questions arise. In this study, responses to the specific event that prompts caregivers to use the music and memory program had a majority theme of a behavior driven cue. Some used it when their care recipient was agitated, frustrated, or sad. Others used it when their care recipient needed a distraction or as a relaxation technique. In terms of some of the other activities done while implementing the music and memory program, many responses carried the theme of relaxation purposes. Upon reflecting on the results of this study, I would also suggest a system of regularly making contact with those who are part of the program. In my opinion, this would help remind people to use it and obtain constant feedback.

APPENDIX A: MUSIC AND MEMORY QUESTIONNAIRE

Appendix A
MUSIC AND MEMORY QUESTIONNAIRE

Alzheimer's and Dementia Resource Center

INSTRUCTIONS

Answer the following questions by circling the most appropriate answer. Answer the questions as they relate to you.

Part A. Use of Music and Memory Program (iPod)

1. In the last month how often have you used the iPod (Circle a range)?

Daily	2-3 times per week	Weekly	2-3 times per month	At least once per month	Never
5	4	3	2	1	0

2. In the last month when used, how long do you typically use the iPod?

More than 2 hours	1-2 hours	Less than 2 hours
2	1	0

3. In the last month, when using the iPod who uses the iPod during the sessions? (please circle the item):

Myself (the caregiver)	My loved one or care recipient	Sometimes I use it and sometimes my loved one or care recipient uses it.	We both use it simultaneously
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Part B. Demographics

Care giver: Age: _____ Sex: M or F

Race (circle appropriate):

- White
- Asian
- Hispanic or Latino
- Black or African American
- American Indian or Alaska Native
- Native Hawaiian or Other Pacific Islander

Ethnicity (circle appropriate):

- Hispanic or Latino

Not Hispanic or Latino

Education What is the highest degree or level of school you have completed? *If currently enrolled, highest degree received. (Circle appropriate)*

No schooling completed

Nursery school to 8th grade

Some high school, no diploma

High school graduate, diploma or the equivalent (for example: GED)

Some college credit, no degree

Trade/technical/vocational training

Associate degree

Bachelor's degree

Master's degree

Professional degree

Doctorate degree

Care recipient or loved one: Age: _____ Sex: M or F

Race (*circle appropriate*):

White

Asian

Hispanic or Latino

Black or African American

American Indian or Alaska Native

Native Hawaiian or Other Pacific Islander

Ethnicity (*circle appropriate*):

Hispanic or Latino

Not Hispanic or Latino

Education What is the highest degree or level of school you have completed? *If currently enrolled, highest degree received. (Circle appropriate)*

No schooling completed

Nursery school to 8th grade

Some high school, no diploma

High school graduate, diploma or the equivalent (for example: GED)

- Some college credit, no degree
- Trade/technical/vocational training
- Associate degree
- Bachelor's degree
- Master's degree
- Professional degree
- Doctorate degree

Part C. Care Recipient Characteristics

Instructions: Please *circle* the response that you feel best represents the person's ability to do each of the following activities of daily living.

<u>ACTIVITY</u>	Needs no assistance or supervision	Needs some assistance or supervision	Totally dependent/ cannot do at all
Eating	0	1	2
Toileting	0	1	2
Bathing	0	1	2
Dressing	0	1	2
Grooming	0	1	2
Transferring	0	1	2

In your opinion, how long could you leave your loved one or care recipient alone and feel comfortable? (Circle a range)

- Never
- 15 minutes-30 minutes
- 30 minutes-1 hour
- 1 hour- 2 hours
- 2 hours or more
- Anytime

Part D. Playlist form

(Circle Y or N)

Did you fill out a form with a list of pre-selected songs for your iPod? Y or N

Did you bring your own CD's or music? Y or N

Did you write down the specific songs, albums or artists that you wanted on your iPod?
Y or N

Part E. Self-efficacy

Instructions: Please think about the questions carefully, and be as frank and honest as you can about what you really think you can do. Rate your degree of confidence from 0 to 100 using the scale given below:

0 Cannot do at all	10	20	30	40	50 Moderately can do	60	70	80	90	100 Certain can do
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A. PRACTICE RATING: To familiarize caregiver with the rating form, please complete this practice item first.

“If you were asked to lift objects of different weights right now, how confident are you that you can lift each of the weights described?”

PHYSICAL STRENGTH	CONFIDENCE (0–100)
1. Lift a 10 pound object	
2. Lift a 20 pound object	
3. Lift a 50 pound object	
4. Lift a 100 pound object	

Self-Efficacy for Responding to Disruptive Patient Behaviors

___ 1. How confident are you that when your loved one or care recipient forgets your daily routine and asks when lunch is, right after you've eaten, you can answer him/her without raising your voice?

___ 2. How confident are you that when you get angry because your loved one or care recipient repeats the same question over and over, you can say things to yourself that calm you down?

___ 3. How confident are you that when your loved one or care recipient complains to you about how you're treating him/her, you can respond without arguing back?

___ 4. How confident are you that when your loved one or care recipient asks you 4 times in the first one hour after lunch when lunch is, you can answer him/her without raising your voice?

___ 5. How confident are you that when your loved one or care recipient interrupts you for the fourth time while you're making dinner, you can respond without raising your voice?

Self-Efficacy for Controlling Upsetting Thoughts about Caregiving

___ 1. How confident are you that you can control thinking about unpleasant aspects of taking care of your loved one or care recipient?

___ 2. How confident are you that you can control thinking how unfair it is that you have to put up with this situation (taking care of your loved one or care recipient)?

___ 3. How confident are you that you can control thinking about what a good life you had before your loved one or care recipient's illness and how much you've lost?

___ 4. How confident are you that you can control thinking about what you are missing or giving up because of your loved one or care recipient?

___ 5. How confident are you that you can control worrying about future problems that might come up with your loved one or care recipient?

Part F. Burden

INSTRUCTIONS

After each statement, indicate by circling how often you feel that way: never, rarely, sometimes, quite frequently, or nearly always. There are no right or wrong answers.

1. Do you feel that, because of the time you spend with your relative, you don't have enough time for yourself?

0	1	2	3	4
NEVER	RARELY	SOMETIMES	QUITE FREQUENTLY	NEARLY ALWAYS

2. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?

0	1	2	3	4
NEVER	RARELY	SOMETIMES	QUITE FREQUENTLY	NEARLY ALWAYS

3. Do you feel angry when you are around your relative?

0	1	2	3	4
NEVER	RARELY	SOMETIMES	QUITE FREQUENTLY	NEARLY ALWAYS

4. Do you feel that your relative currently affects your relationship with other family members?

0	1	2	3	4
NEVER	RARELY	SOMETIMES	QUITE FREQUENTLY	NEARLY ALWAYS

5. Do you feel strained when you are around your relative?

0	1	2	3	4
NEVER	RARELY	SOMETIMES	QUITE FREQUENTLY	NEARLY ALWAYS

6. Do you feel that your health has suffered because of your involvement with your relative?

0	1	2	3	4
NEVER	RARELY	SOMETIMES	QUITE FREQUENTLY	NEARLY ALWAYS

7. Do you feel that you don't have as much privacy as you would like, because of your relative?

0	1	2	3	4
NEVER	RARELY	SOMETIMES	QUITE FREQUENTLY	NEARLY ALWAYS

8. Do you feel that your social life has suffered because you are caring for your relative?

0	1	2	3	4
NEVER	RARELY	SOMETIMES	QUITE FREQUENTLY	NEARLY ALWAYS

9. Do you feel that you have lost control of your life since your relative's death?

0	1	2	3	4
NEVER	RARELY	SOMETIMES	QUITE FREQUENTLY	NEARLY ALWAYS

10. Do you feel uncertain about what to do about your relative?

0	1	2	3	4
NEVER	RARELY	SOMETIMES	QUITE FREQUENTLY	NEARLY ALWAYS

11. Do you feel that you should be doing more for your relative?

0	1	2	3	4
NEVER	RARELY	SOMETIMES	QUITE FREQUENTLY	NEARLY ALWAYS

12. Do you feel that you could do a better job in caring for your relative?

0	1	2	3	4
NEVER	RARELY	SOMETIMES	QUITE FREQUENTLY	NEARLY ALWAYS

Part G. Additional use

1. Is there a specific event or circumstance that prompts you to use the iPod (i.e.: before taking a shower, before eating dinner, when he/she is behaving a certain way)?

2. When your loved one is listening to the iPod, what other activities are you able to do?

3. How could this iPod music program be improved for you?

We thank you for your participation in this study and we hope to help improve music and memory's services for the future.

APPENDIX B: TABLES 1, 2, 3 & 4

Appendix B

Table 1. Demographic Profile of Participants *Caregiver* *Care recipient*

<i>Age</i>		<i>Caregiver</i>	<i>Care recipient</i>
	<i>Mean (SD) Years</i>	74.6667	79.1000
	<i>Median years</i>	75.3333	79.00000
	<i>Std. Deviation</i>	6.25389	6.95142
	<i>Minimum Years</i>	65	65
	<i>Maximum Years</i>	83	89
<i>Sex</i>			
	<i>Male (% , n)</i>	20, 2	60, 6
	<i>Female (% , n)</i>	70, 7	40, 4
<i>Ethnicity</i>			
	<i>Hispanic or Latino (% , n)</i>	10, 1	10, 1
	<i>Not Hispanic or Latino (% , n)</i>	60, 6	60, 6
<i>Race</i>			
	<i>White (% , n)</i>	80, 8	90, 0
	<i>Hispanic or Latino (% , n)</i>	10, 1	10, 1
<i>Education (Highest Degree Earned)</i>			
	<i>High School or GED (% , n)</i>	10, 1	20, 2
	<i>Some College (% , n)</i>		20, 2
	<i>Trade or Technical Training (% , n)</i>		10, 1
	<i>Associate's Degree (% , n)</i>	10, 1	10, 1
	<i>Bachelor's Degree (% , n)</i>	30, 3	10, 1
	<i>Master's Degree (% , n)</i>	20, 2	20, 2
	<i>Professional Degree (% , n)</i>	10, 1	10, 1
	<i>Doctorate Degree (% , n)</i>	10, 1	

Table 2. Associations between Caregiver Self-Efficacy, Burden, Care Recipient Functioning and Use of a Music and Memory iPod

	N	Low Use		N	High Use		Mann-Whitney	
		<i>Mean</i>	<i>Median</i>		<i>Mean</i>	<i>Median</i>	<i>z</i>	<i>p</i>
Total burden	5	11.64	9.80	5	13.36	11.00	-.736	.548
Self-efficacy responding to disruptive behaviors	5	68.40	82.00	5	81.36	74.00	-.420	.690
Self-efficacy controlling upsetting thoughts	5	78.60	76.00	5	76.80	86.00	-.314	.841
Total Katz ADL	5	2.00	1.00	5	1.20	0.00	-.671	.548

Note:

Range of Burden = 0 (low burden) - 48 (high burden)

Range of Self-efficacy = 0 (Cannot do at all) – 100 (Certain can do)

Range of ADL = 0 (Very dependent) – 6 (Independent)

Table 3: Association between choice in playlist and use of a music and memory iPod

Total Choice	<i>N</i>	<i>Mean Rank</i>	χ^2	<i>p</i>
One Choice	2	6.75	.517	.772
Two Choices	6	5.08		
Three Choices	2	5.50		

Note: Choice options: filling out a form with a list of pre-selected songs; bringing own music for the iPod; requesting specific music.

Frequency of use measures (5= daily, 4= 2-3 times per week, 3= weekly, 2= 2-3 times per month, 1= at least once per month)

Table 4: Caregiver Responses to Open-ended Questions

Specific Event or circumstance that prompt use of iPod	Other activities performed when loved on is listening to iPod	Program Feedback- Improvement suggestions
Actions taken by caregiver or care recipient	Activities needing concentration by caregiver	Expand program to Nursing Homes
In response to difficult behavior expressed by care recipient	Relaxation mechanism for caregiver and/or care recipient	More technology guidance, outreach, and overall assistance
Bathing care recipient	Leisure activities	Follow up for more instrumental musical selections
Night time use	Moving or transporting care recipient	Calming Effect
During, before or after meals	None or none as a result of the iPod	Associated with positive feelings experienced by caregiver or care recipient
During travel		No benefit

APPENDIX C: IRB FORM

Appendix C

UCF Institutional Review Board Approval



University of Central Florida Institutional Review Board
Office of Research & Commercialization
12201 Research Parkway, Suite 501
Orlando, Florida 32826-3246
Telephone: 407-823-2901 or 407-882-2276
www.research.ucf.edu/compliance/irb.html

Approval of Exempt Human Research

From: **UCF Institutional Review Board #1**
FWA00000351, IRB00001138

To: **Denise L. Gammonley** and Co-PI: **Barbara Mendez Campos**

Date: **October 10, 2016**

Dear Researcher:

On 10/10/2016, the IRB approved the following activity as human participant research that is exempt from regulation:

Type of Review: Exempt Determination
Project Title: Use of a Music and Memory Program by Dementia Caregivers
Investigator: Denise L. Gammonley
IRB Number: SBE-16-12562
Funding Agency:
Grant Title:
Research ID: N/A

This determination applies only to the activities described in the IRB submission and does not apply should any changes be made. If changes are made and there are questions about whether these changes affect the exempt status of the human research, please contact the IRB. When you have completed your research, please submit a Study Closure request in iRIS so that IRB records will be accurate.

In the conduct of this research, you are responsible to follow the requirements of the [Investigator Manual](#).

On behalf of Sophia Dziegielewski, Ph.D., L.C.S.W., UCF IRB Chair, this letter is signed by:

A handwritten signature in black ink that reads "Kamille Chaparro" with a horizontal line extending to the right.

Signature applied by Kamille Chaparro on 10/10/2016 10:34:31 AM EDT

IRB Coordinator

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