Music and Dementia: A Caregiver’s Perspective of the Effects of Individualized Music Programming on Quality of Life for Seniors Living in Assisted Living Environments

David James Gentner
St. John Fisher College, david@gentner.us

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Music and Dementia: A Caregiver’s Perspective of the Effects of Individualized Music Programming on Quality of Life for Seniors Living in Assisted Living Environments

Abstract
For senior-care and service providers, the issue of quality of life has moved beyond marketing to, in effect, the measuring of health-related outcomes. Particularly when the challenge of caring for those with Alzheimer’s disease and related dementias is daunting, as it cannot be prevented or cured and treatment possibilities are framed in a broader perspective to include alternative interventions such as music. Through the eyes of the caregivers, this 6-week, longitudinal quantitative study investigated individualized (passive) music programming and its effect on the health-related quality of life of residents in assisted living. The Alzheimer’s Disease Related Quality of Life instrument (ADRQL) was used to assess quality of life, and the importance of music was captured by the Assessment of Personal Music Preference. The data revealed an increase in quality of life from baseline through the final assessment; and when using only the home health aide staff, a series of multivariate repeated-measures analysis of variance found statistically significant improvements in overall quality of life and in all five ADRQL domain subscales ($F = 9.54$, $p = 000$, $\eta^2 = .52$). The data also showed no significant correlation between the importance of music prior to cognitive impairment and quality of improvements ($r = -.09$, $p = .786$). The study had limitations, most importantly the small convenience sample ($N = 11$); therefore, a formal inductive inference concerning the population cannot be made. More rigorous studies increasing the sample size, using a control group, including confounding variables, and qualitative interviews are recommended.

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Music and Dementia: A Caregiver’s Perspective of the Effects of Individualized Music Programming on Quality of Life for Seniors Living in Assisted Living Environments

By

David James Gentner

Submitted in partial fulfillment of the requirements for the degree Ed.D. in Executive Leadership

Supervised by

Dr. Byron K. Hargrove

Committee Member

Dr. Debra R. Lamb

Ralph C. Wilson, Jr. School of Education
St. John Fisher College

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Dedication

To those committed to medical research, therapeutic applications of music, organizational practices, physical environments, workforce models, advances in technology, and relationships at all levels in an effort to improve the quality of life of the millions suffering with Alzheimer’s disease and related dementias.

In addition, I’d like to acknowledge Dr. Byron K. Hargrove, Dissertation Committee Chair; Dr. Debra R. Lamb, Committee Member; Stephanie M. Townsend, Ph.D.; Leslie Locke, Ph.D.; Rev. Dr. Amandus J. Derr; and all of the professors at St. John Fisher College, Ralph C. Wilson, Jr. School of Education. Also, without the support of Matt Anderson, Adreinne Rynne, Melissa Daniels, Brittney Jones-Alleyne, and those so very generous with their time (Elizabeth, Joan, Leuenteen, Veronica, Rosena, and Olive), this research would not have been possible.
Abstract

For senior-care and service providers, the issue of quality of life has moved beyond marketing to, in effect, the measuring of health-related outcomes. Particularly when the challenge of caring for those with Alzheimer’s disease and related dementias is daunting, as it cannot be prevented or cured and treatment possibilities are framed in a broader perspective to include alternative interventions such as music.

Through the eyes of the caregivers, this 6-week, longitudinal quantitative study investigated individualized (passive) music programming and its effect on the health-related quality of life of residents in assisted living. The Alzheimer’s Disease Related Quality of Life instrument (ADRQL) was used to assess quality of life, and the importance of music was captured by the Assessment of Personal Music Preference.

The data revealed an increase in quality of life from baseline through the final assessment; and when using only the home health aide staff, a series of multivariate repeated-measures analysis of variance found statistically significant improvements in overall quality of life and in all five ADRQL domain subscales ($F = 9.54, p = .000, \eta^2 = .52$). The data also showed no significant correlation between the importance of music prior to cognitive impairment and quality of improvements ($r = -.09, p = .786$).

The study had limitations, most importantly the small convenience sample ($N = 11$); therefore, a formal inductive inference concerning the population cannot be made. More rigorous studies increasing the sample size, using a control group, including confounding variables, and qualitative interviews are recommended.
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Chapter 1: Introduction

Given that there are almost 900 million people aged 60 years and over living in the world today, health and an aging population are becoming topics of significance in academic and policy circles (Alzheimer’s Disease International, 2015). By the year 2030, 17% of the world’s population will be 60 years or older (World Economic Forum, 2012). In the United States, this number will be 26% of the population (U.S. Census Bureau, 2013). According to the World Economic Forum (2012):

The impending flood of baby boomers [born between the years 1946 and 1964] entering retirement, the unsettled landscape for retiree healthcare, and the fears of creating burdens of mounting debt for generations to come have framed the financial landscape in recent years. (p. 1)

According to the Alzheimer’s Association (2015), it is estimated that approximately 4.5 million Americans suffer from Alzheimer’s disease or related dementia, with projections of 13 million by the year 2050. Worldwide, in 2015, there were 46.8 million people with some form of the disease, and according to Alzheimer’s Disease International (2015), this number will almost double every 20 years, reaching 74.7 million by 2030 and 131.5 million by 2050. The global costs of this disease has increased from $604 billion in 2010, to $818 billion in 2015—an increase of 35.4%, which represents 1.09% of the annual global gross domestic product (Alzheimer’s Disease International, 2015). In the United States, without a means of prevention or a cure, this disease will contribute cumulative costs of almost $20 trillion to Medicare and
Medicaid spending in this country by 2050 (Alzheimer’s Study Group, 2009). The rising prevalence of those with cognitive impairments, coupled with the aging of the population, poses economic, social, and senior care and service provider challenges (Nair, Brown, Marley, & Heim, 2013).

Dementia is a syndrome characterized by a progressive decline in memory and cognitive functioning (Terada et al., 2002). Caused by loss of function or structure of neurons in the brain, it is closely followed by progressive declines in cognitive abilities and the ability to perform activities of daily living (Popescu et al., 2014; Raetz, 2013). Alzheimer’s disease is the most common cause of degenerative dementia, accounting for up to 80% of all cases (Alzheimer’s Association, 2015). Physicians reference the Diagnostic and Statistical Manual of Mental Disorders: DSM-5 (DSM-5) (2013) to help determine if an individual has dementia as well as to identify the conditions causing the dementia. For major and mild neurocognitive disorders, DSM-5 codes, first, (G30.9) Alzheimer’s disease as 331.0, followed by 294.11, indicating (F02.81) major neurocognitive disorder due to Alzheimer’s disease (American Psychological Association [APA], 2013). Vascular dementia is the second most-common type of dementia, accounting for approximately 10% of the cases, and it commonly is caused by blood vessel blockage, post-stroke, or because of some type of brain injury (Bandyopadhyay et al., 2014). The code 290.40 is the DSM-5 code for probable major vascular neurocognitive disorders (APA, 2013).

Three common stages of dementia include: (a) preclinical phase whereby there are measurable changes in the brain, but there are no noticeable symptoms or behavior changes; (b) the mild cognitive impairment (MCI) phase implies that there are noticeable
changes in thinking, however the ability to perform activities of daily living are still possible; and (c) the dementia phase, which is characterized by noticeable memory, logic, and behavioral symptoms that impair a person’s ability to perform the activities of daily living (Alzheimer’s Association, 2015). As activities of daily living become complicated by the gradual loss of cognitive abilities, what often occurs are poorly understood behaviors and what has come to be known as the long goodbye, a tumultuous journey that families take through the disease process. Not surprisingly, great pressure is brought to bear on senior care and service providers to do something to control these behaviors.

Although the greatest risk factor is age, a common misconception is that regardless of the type, the disease is a normal aspect of aging and that it is part of the typical trajectory of age-related cognitive declines (Alzheimer’s Association, 2015; Alzheimer’s Study Group, 2009). In fact, contrary to that misconception, healthy aging has been found to be associated with generally stable performance on measures of cognitive functioning (Burock & Naqvi, 2014). However, as individuals live to advanced ages, it is more challenging to differentiate between the subtle changes of aging and those caused by early dementia. Statistically, the incidence of dementia doubles with every 6.3-year increment increase in age (Alzheimer’s Disease International, 2015). This can be particularly difficult for family members who either fail to recognize or may possibly be in denial about the significance of their loved one’s cognitive decline, leading to a delayed diagnosis and, later, delayed treatment when behavioral problems become much more chronic and challenging (Burock & Naqvi, 2014).

Pathologically, Alzheimer’s disease is characterized by amyloid-beta deposits and accumulation of tangles in the neocortex region of the brain (Buchanan, 2006). These
changes can start decades prior to the onset of the disease, and little is known about the etiology until there are obvious clinical manifestations. There are two key biomarker categories of tests for Alzheimer’s disease and related dementias: (a) the level of amyloid-beta accumulation in the brain, and (b) evidence of injured neurons in the brain or actual degeneration of the brain tissue (Alzheimer’s Association, 2015). Buchanan (2006) noted, “As the disease progresses, cognitive and behavioral functioning deteriorate to the point where the individual becomes increasingly dependent on others to complete most tasks of daily living such as money management, driving, cooking, bathing, dressing and toileting” (p. 521).

The symptoms of Alzheimer’s disease and related dementia differ for each individual patient. In some patients at the onset of dementia, certain personality traits that had been well controlled in the past become accentuated; whereas in other patients, the uniqueness of the patient’s personality is lost (Takeda, Tanaka, Okochi, & Kazui, 2012). Benveniste, Jouvelot, and Pequignot (2014) noted, “Demented patients’ skills deteriorate at surprisingly different rates. Some simple aptitudes such as the ability to remember a few objects may be long gone before seemingly higher-level ones such as singing a song begin to decline” (p. 4). Some patients show a more rapid deterioration of cognitive function, whereas with others, cognitive declines are much slower to manifest. Takeda et al. (2012) suggested, “The tasks of daily life are different for each individual, and the timing of diagnosis of dementia may depend on the previous occupational complexity and social factors in the patient’s life” (p. 2).

Although Alzheimer’s disease and related dementia usually begin with the degeneration of short-term memory, people with dementia, including those who are
severely impaired, can often times retain the capacity to access aspects of their long-term memory if tapped with appropriate stimulation (Pringle & Somerville, 2013). Long-term memory, because of the location of where implicit memories are stored in the brain, remains fairly well intact as we age, while recent memories are more vulnerable to decay—almost as if memory impairments tend to progress in reverse order (Thomas & Smith, 2009). Therefore, in reverse order, it is memories from our youth that become more accessible, while more recent memories are forgotten.

While family history is not necessarily a predictor, those with more than one first-degree relative with the disease are at higher risk (Alzheimer’s Association, 2015). The apolipoprotein E (APOE) gene provides the roadmap for a particular protein that transports cholesterol throughout the body. While not a guarantee than an individual will develop the disease, 20 to 30% of individuals have a form of the APOE gene, generally called e4, and those with the gene have a threefold higher risk than those without the e4 form of the gene (Alzheimer’s Association, 2015).

People with fewer years of formal education are also at a higher risk for the disease than those with more years of formal education. The hypothesis purports that more years of education increases the connections between neurons in the brain and enables the brain to compensate for brain changes by using alternate routes of neuron-to-neuron communication to complete cognitive tasks (Alzheimer’s Disease International, 2014). Brain health is, however, closely linked to the overall health of one’s heart and blood vessels, and many factors that increase the risk of cardiovascular disease are also associated with higher risks of dementia such as smoking, obesity, and diabetes (Alzheimer’s Association, 2015).
Families are essential in the treatment of relatives with Alzheimer’s disease and related dementias as they provide significant care and supervision at an incredible economic value. According to the Alzheimer’s Association (2015), “In 2014, the 15.7 million family and other unpaid caregivers of people with Alzheimer’s disease and other dementias provided an estimated $17.9 billion hours of unpaid care” (p. 35). From the point of disease onset to the point of death, an average American family can expect to spend $215,000 to care for a relative with the disease. The Alzheimer’s Study Group (2009) stated:

Up to $40,000 of the total expenditure can be attributed to direct costs, such as purchasing medications and assistance with activities of daily living tasks with the balance attributed to the indirect cost of quitting one’s job to provide uncompensated care at home. (p. 9)

Of the individuals with cognitive impairments, 7% are cared for by families in homes, and many family caregivers, themselves, are in declining health, which only compounds the challenges (Alzheimer’s Study Group, 2009).

Social justice is rooted in the belief that all individuals are of equal worth and thus entitled to meet their basic human needs and experience equality of opportunity. Unjust inequalities should be reduced, and where possible, eliminated (Commission on Social Justice, 1994). Yet, increasingly, more of the world’s seniors will be affected directly by discrimination and ageism (World Economic Forum, 2012). While seniors have the same intrinsic rights as everyone else, oftentimes they experience limited access to services, various forms of abuses, and perhaps, most importantly, abandonment, which gives rise to one of the fastest growing vulnerable population groups in society. At the root of the
violations is prejudice, where there is a perspective that after a certain age, seniors, particularly those who are frail or compromised, have become inferior (World Economic Forum, 2012).

**Behavioral symptoms.** The non-cognitive symptoms of dementia, referred to as behavioral and psychological symptoms, affect almost 90% of those with a diagnosis (Raetz, 2013). While behavioral symptoms can occur at any time during the course of the disease, they will most often become obvious when the condition enters the MCI phase. Aberrant behaviors include refusal of care, yelling, aggressive behavior, agitation, restlessness, reversal of the normal sleep cycle, wandering, hoarding, sexual disinhibition, culturally inappropriate behaviors, hallucinations, delusions, anxiety, depression, apathy, and psychosis (Moyle, Murfield, O’dwyer, & Van Wyk, 2012; Raetz, 2013; Vasionytė & Madison, 2012). Sleep disturbances are also common with patients with cognitive impairments including diurnal rhythm disturbance, rapid eye movement behavior disorders, myoclonus, periodic leg movements, fragmented sleep, early morning awakenings, and delayed sleep onset (Zec & Burkett, 2008). Zec and Burkett (2008) noted, “The most common sleep disturbance is diurnal rhythm disturbance, which can result in an overall decrease in sleep time and an increase in daytime napping, thus decreasing the patient’s energy, alertness, and cognitive functioning” (p. 430). These types of behaviors often overwhelm families, and lack of interventions or treatment may increase patient morbidity and result in physical harm or some other form of crisis management.

Behavioral disturbances come in many different forms, but increased aggression presents the most challenging and dangerous situations faced by families and caregivers.
Aggression is defined by a variety of physical behaviors (e.g., hitting, pinching, biting, pushing, intentional falling, throwing things) and verbal behaviors (e.g., cursing, threatening, constant requests for attention), which are strongly correlated with greater dependence on others, thus more likely as the disease progresses (Moyle et al., 2012; Schreiner, Yamamoto, & Shiotani, 2005). Aggression is typically treated using conventional antipsychotic medications, however, side effects can result in a reduction in the patient’s behavioral repertoire, impaired language skills, gait disturbances that can result in falls, reducing the ability to participate in life events, causing further cognitive declines (Buchanan et al., 2007). Co-morbidities compound the risk for injury and may not be recognized by the persons with dementia who are acting based on their own understanding of self (Kolanowski, Fick, Frazer, & Penrod, 2010).

**Institutional models of care.** Alzheimer’s disease and related dementias are the leading cause of institutionalization of seniors in this country (Alzheimer’s Association, 2015). For senior care and service providers, the issue of independence is at the highest level of importance, and developing restraint-free interventions for managing aggression includes pharmacological interventions (Buchanan et al., 2007). The interdisciplinary balance of controlling behaviors with medication administration, while also maintaining the least-restricted environment, is evident across the senior care and service continuum.

The “Adult Day Health Care Program” (N.Y. Stat. Ch. 10 § 425 Part 1 Definitions (a) Adult Day Health Care, 2014, p. 10,273) in New York provides health care and services to a group of people with functional impairments to maintain their health status and enable them to remain living independently in the community. Services are
sponsored by a residential health care facility. The term *assisted living*, in New York, refers to an entity that provides housing, on-site monitoring, and personal care services in a home-like setting to five or more adult residents. Services include daily food service, 24-hour on-site monitoring, case management, and the development of an individualized service plan for each resident (N.Y. Stat. Ch. 10 § 4662 Part 10011001.2 Definitions (a) Assisted living, Assisted Living Residence or ALR, 2008). A nursing home, also referred to as a *residential health care facility*, provides lodging for 24 or more consecutive hours to three or more residents, who need regular nursing services or other professional services, including but not limited to basic and skilled nursing care, rehabilitation, and a full range of other therapies, treatments, and programs (N.Y. Stat. Ch. 10 § 415 Part 2 Definitions (k) Nursing Home, 1998).

In the aforementioned institutional-based models of care, caregiving can be overwhelming, as staff are reported to experience high rates of illness and stress (Zec & Burkett, 2008). One reason for this is that patients with dementia often experience a reality and time that is out of sync with other residents and staff, and this may result in staff frustrations, leading to burn-out (Cooke, Moyle, Shum, Harrison, & Murfield, 2010). Curtin (2010) noted, “If the context in which the behavior occurs is not considered, staff may intervene inappropriately causing the behavior to escalate” (p. 369). “Given the potential prevalence of agitation and anxiety in those with dementia and the evident negative impact both have, it is perhaps surprising that relatively little research has been undertaken regarding their relationship” (Cooke et al., 2010, p. 906).

**Public policy.** Policy makers have a growing interest in Alzheimer’s disease and related dementias because these diseases are now among the world’s 21st century health
and economic challenges. Popescu et al. (2014) suggested, “Although focused primarily on direct medical costs, economists can also consider indirect costs such as productivity losses due to caregivers missed work or agitation, stress, and depression of families” (p. 179). While several countries, including Australia, France, South Korea, the United Kingdom, and the United States have developed national plans, others, such as Japan, Mexico, and Peru, are working on it (Wortmann, 2013). However, the concept of a national dementia policy is relatively new, and there is only modest experience on effective metrics. Moreover, no real evaluation has been done on the efficacy of these national plans (Wortmann, 2013).

In the United States, Medicare is the federal health insurance program for 54 million people, ages 65 and over, and for people with permanent disabilities. Medicare pays for most hospital and physician visits, prescription drugs, and other post-acute services, and it plays the most significant economic factor in America’s health care system. According to Centers for Medicare & Medicaid Services (CMS), in 2013, Medicare spending accounted for 14% of the federal budget (Centers for Medicare & Medicaid Services [CMS], 2014). Medicare benefit payments totaled $583 billion in 2013; roughly 25% of this was for hospital inpatient services, 12% for physician services, and 11% for the Part D drug benefits (CMS, 2014). Medicare data reveal that in 2013, the total Medicare expenditures for Part D medications were nearly $50 billion (CMS, 2014). From a public policy perspective, reductions in medication usage, alone, could provide dramatic economic relief.

**Medication interventions.** There are limited medication interventions for Alzheimer’s disease and related dementias. In fact, the only Food and Drug
Administration drugs approved over the past 30 years have been cholinesterase inhibitors (ChE-Is) and Memantine, and none have been approved since 2003 (Schneider et al., 2014). ChE-Is are the most popular drug because they inhibit the enzymes that break down neurotransmitters in the brain. The brand and generic names of the four most popular ChE-Is are: Cognex (Tacrine), Aricept (Donepezil), Exelon (Rivastigmine), and Razadyne (Galantamine). Memantine is also approved for the symptomatic treatment of moderate to severe Alzheimer’s disease. Zec and Burkett (2008) noted that, “It inhibits neurotoxic overstimulation of glutamatergic neurons by blocking excess amounts of the neurotransmitter glutamate” (p. 427). While the medications have shown clinical efficacy in treating symptoms of the disease, none prevent or stop the progression of the disease (Alzheimer’s Study Group, 2009).

Although pharmacological interventions are ordinarily used to control the associated symptoms and behavioral problems, the potential unwanted side effects, such as medication interactions and increased frequency of injury from falls, justify the pursuit of alternative therapeutic interventions (Spiro, 2010; Walter et al., 2007). Discovery and development of treatments for Alzheimer’s disease and related dementias have been propelled by an enormous clinical need and a potentially huge world market and thus, pharmaceutical development in this area has become a major political, academic, and industrial effort. However, the challenges and difficulties of developing new drugs frames the care and treatment possibilities in a broader perspective to which complementary and alternative interventions have greater meaning (Spiro, 2010; Takeda et al., 2012). Schneider et al. (2014) suggested that, “Despite considerable advances in knowledge of the pathogenesis of Alzheimer’s disease and in medicinal chemistry, no
practical treatments have been introduced over the past quarter of a century” (p. 252). The limited efficacy of drug therapy and the plasticity of the human brain are the two main reasons that explain a growing interest in non-pharmacological interventions (Takeda et al., 2012).

**Non-pharmacological interventions.** According to Hattori, Hattori, Hokao, Mizushima, & Mase (2011), “The well-balanced administration of drug and non-pharmacological therapies is a matter of basic importance in the therapeutic strategy for Alzheimer’s disease” (p. 431). There is a wide variety of these non-pharmacological therapies for Alzheimer’s disease and related dementias. Although not adequately studied, some include cognitive stimulation, reminiscence therapy, massage therapy, aromatherapy, humor therapy, doll therapy, exercise, and music therapy. Regardless of the type, they are typically low cost, enjoyable, can be implemented without difficulty, and have no side effects (Flood & Scharer, 2006; Hulme, Wright, Crocker, Oluboyede, & House, 2010; Jimbo, Kimura, Taniguchi, Inoue, & Urakami, 2009; Moyle et al., 2012; Vasionytė & Madison, 2012).

One of the interventions is cognitive stimulation, which involves reviewing current events, drawing, word associations, discussion of hobbies, and planning daily activities. Another intervention is reminiscence, which involves stimulating memories of the past by looking at personal photos and newspaper clippings, and discussing the past. In reminiscence therapy, a group approach typically attempts to trigger personal and shared memory with photographs, recordings, and artifacts (Woods et al., 2009). Although the use of photography, books, film, and music have been a regular feature of both cognitive stimulation and reminiscence therapy, advances in technology enable
senior care and service professionals to use technology and reminiscence tools, together, in ways that are easy to use and accessible for people with dementia. Pringle and Sommerville (2013) noted, “Multimedia technology affords the seamless inclusion of text, photographs, graphics, sound and film recordings, as well as the ability to link the various items together in a dynamic and flexible way” (p. 35).

Other interventions have been successful as well. Massage therapy can induce comfort and reduce agitation, and potentially eliminate the need for chemical or physical restraints (Moyle et al., 2012). Aromatherapy is thought to reduce agitated behaviors; lemon and lavender, in particular, are most commonly used at nighttime, however the underlying effects are not fully known (Jimbo et al., 2009; Raetz, 2013). Research involving humor therapy suggests that humor can provide an additional therapeutic tool in late-life depression or Alzheimer’s disease (Walter et al., 2007). The use of therapeutic dolls as a reminiscence tool can provide sensory stimulation, enhance communication, and facilitate memory retrieval (James, Mackenzie, & Mukaetova-Ladinska, 2006; Mitchell & Templeton, 2014).

Exercise has a positive influence on wandering, aggression, and agitation. Other physical activities, such as dance, drama, music, and movement activities, provide opportunities for people with dementia to engage in pleasurable activities that support creative self-expression and enhance communication with others (Rylatt, 2012). While many of these and other interventions are popular, there is not enough evidence to recommend any consistently, and they have not been studied well enough to provide clear conclusions as to their effectiveness.
In their 2007 literature review of non-pharmacological approaches for dementia, Hulme et al. (2010) found evidence that alternative approaches should be explored. In a search of seven databases using the terms: dementia/Alzheimer’s and non-drug therapies, the search yielded 33 reviews written in or after 2001. The majority of the studies were based in community residential settings and were characterized as weak or small in sample size. Still, three interventions were found to be effective: music therapy, hand massage, and physical activity (Hulme et al., 2010). In particular, the authors found that playing preferred music can reduce agitation, and during bath times, it can reduce occurrences of aggression. Also, group music activities, both active and passive, were found to reduce wandering. However, according to Hulme et al. (2010) “Even for these interventions the evidence is mixed or limited. For example, within music or music therapy methodological limitations were highlighted that included weak study designs and small sample numbers” (p. 761).

McLaren, LaMantia, and Callahan (2013) completed a systematic literature review to identify controlled clinical trials, reporting the impact of non-pharmacologic interventions on any measure of functional impairment or disability among community-dwelling dementia patients. Of the clinical trials published that met their inclusion criteria, 18 study interventions fell into three different groups: occupational therapy, exercise, and other. The literature provided clinical trial evidence that non-pharmacologic interventions could delay progression of functional impairment or disability among community-dwelling dementia patients and provide a rationale for larger and longer-term studies to determine if these interventions are sufficiently potent to delay institutionalization.
The power of music. People working in senior care and service environments know, intuitively and anecdotally, the power of music, as it is popular and generally offered as part of a therapeutic environment in nursing homes, assisted living facilities, and adult day centers. Throughout history, music is omnipresent in all cultures and has the ability to elicit emotions in listeners, regardless of age (El Haj, Postal, & Allain, 2012). Because music is often based on cultural experiences, music appeals to diverse groups of people regardless of language, economics, religion, or education. In cultures around the world, music is associated with numerous life events, including religious gatherings, social occasions, concerts, graduations, weddings, and funerals (McCaffrey & Locsin, 2002). It is a socially acceptable form of self-expression and, in fact, oftentimes it encourages social interaction (Murrock & Higgins, 2009).

Music is the art of organizing tones in a coherent sequence so as to produce a unified and continuous composition (American Heritage Dictionary, 1982). Based on five key elements, including rhythm, melody, pitch, harmony, and interval, music produces psychological responses within a person, when it passes through the part of the brain that processes music—the auditory cortex of the brain (Murrock & Higgins, 2009). According to Murrock and Higgins (2009), “This processing occurs in the limbic system, which is known as the centre of emotions, sensations, and feelings” (p. 2252).

There are numerous types of music programs and many have been studied (Vasionytė & Madison, 2012). Active music therapy can be defined as a combination of more than one musical technique that includes the active involvement of the participants, such as playing musical instruments, singing, song writing, or dancing, where both patients and therapists participate in music making (Vasionytė & Madison, 2012). While
receptive (passive) music implies patients are listening to either recorded or live music, no activity is required other than listening, as music is selected by someone besides the patient or according to the listeners’ preferences (Lancioni et al., 2013; Vasionytė & Madison, 2012). Ambient or background music is also used to modify clinical environments in a cost-effective way (Nair et al., 2013). In institutional settings, such as skilled nursing facilities and assisted living and adult day services environments, music is commonly delivered to groups as a form of recreation with relatively untapped potential for making significant therapeutic contributions to those with memory impairments (Lin et al., 2010).

Music is popular for seniors with Alzheimer’s disease and related dementias because it typically involves passive listening (individualized or within a group). This type of programming is not always considered clinical music therapy, which is an established health profession in which there is a clinical evidence-based use of music to accomplish individualized goals within a therapeutic relationship by a board-certified music therapist. The music therapist uses a variety of interventions, including singing, instrumental playing, and music listening with discussion, to facilitate outcomes that are measurable and transferable to other parts of patients’ lives, in an effort to make contributions to the patients’ highest practicable physical, social, emotional, and cognitive functions (American Music Therapy Association, 2017).

Music discovered during one’s life holds a special power to capture and re-create an experience and emotional memory in the listener’s mind, long after it has faded from conscious memory (Benveniste et al., 2014; Campbell & Doman, 2012). According to Campbell and Doman (2012), “Because the prefrontal cortex is among the last brain
regions to atrophy, music can often still assist in connecting with people, even in advanced stages of cognitive illness” (p. 179). According to Woods et al. (2009):

One factor in its popularity is that [music] works with early memories, which are often intact for people with dementia, thus drawing on the person’s preserved abilities, rather than emphasizing the person’s impairments. However, its popularity has not led to a corresponding body of evidence on its effects. (p. 2)

When individualized music programming is used as a care intervention, and a patient’s past music interests, social, and cultural background are taken into account, the benefits from the effects of music can be improved (Sung, Chang, & Lee, 2010). Even when verbal abilities become poor, such as in the late stages of dementia, the ability to respond to music, such as humming or playing instruments, tends to remain (Vasionytė & Madison, 2012). Regardless of the type, the use of music in institutional settings can render extraneous noise that is more familiar for the patient; thus, a connection can be made with pleasant memories from the past, creating a positive emotional state in the present (Sherratt, Thornton, & Hatton, 2004).

**Problem Statement**

It is clear that non-pharmacological programming may improve quality of life, thus the issue should be factored into academic and policymaking conversations as we plan for the care and services of our world’s aging population. However, according to Nair et al. (2013), “Problems with available studies include small numbers of subjects, inadequate descriptions of study participants, imprecise data collection methods, high attrition rates, and insufficient statistical analysis” (p. 48). Most cultural arts programming involves participation and interpersonal interaction with others, thus
enhancing social engagement. Also, because of the natural appeal of music and the arts, programming has an engaging and sustaining quality, unlike many of life’s general activities. With respect to quality of life, seniors who participate in cultural arts programming experience an improvement in their quality of life, and that socialization plays an important role (Cohen, 2006). In many cases, sense of control and exceeding one’s expectations plays an important role in continuing an activity. According to Cohen (2006) “The repeated success of the various participants profoundly affected their motivation and desire to continue; they consistently reported high self-esteem and mood as [their involvement] continued” (p. 728).

In spite of decades of clinical research and pharmacological advances, there is nothing currently available that can stop or reverse the effects of this disease, and there is still a significant amount of unknowns about the disease’s etiology and clinical manifestations (Alzheimer’s Study Group, 2009; Kolanowski et al., 2010). According to Menchola and Weiss (2015), “While identifying and treating medical causes contributing to dementia such as infection pain, and environmental issues, non-pharmacologic treatments are generally preferred for behavioral problems and should be considered prior to drug therapy” (p. 15). However, most specific non-pharmacologic therapies have not been robustly studied in randomized controlled trials. Raetz, (2013) emphasized the importance of addressing specific behavioral symptoms and setting realistic expectations.

While there has been progress, one solution to the problem is continued exploration into the non-pharmacological strategies for treating Alzheimer’s disease and related dementias. As an intervention, individualized music programming is relatively inexpensive and requires only minimal training for staff or family members (Hulme et al.,
Music also holds an almost exclusive and privileged position in scholarly brain research compared to other forms of art (Thaut, 2005). “The effects of music on brain development have suggested a possible clinically useful effect in the care of patients suffering from neurodegenerative diseases” (Nair et al., 2013, p. 48). The intervention is versatile and can be implemented in a variety of settings including for those living in community settings. Although the use of music is popular, and senior care and service providers support the idea that it has beneficial effects, there are very few studies in the assisted-living environment, which is the first level of institutional-based care in New York. According to Sung et al. (2010), “When socially and culturally specific music is offered sensitively to the individual, the acceptance and benefits from the effects of music can be improved” (p. 1062). Building on previous work, this study attempts to address the problem by creating a unique experimental condition using individualized music programming and an Alzheimer’s disease and related dementia-specific quality of life measurement instrument.

**Research Questions**

While non-pharmacological interventions, such as individualized music programming for treatment of Alzheimer’s disease and related dementias, is an emerging topic with potential significance to the field of senior care and services, it needs further study. In addition, a disorder-specific instrument of measurement is required to evaluate such an intervention. The intervention also needs to be applicable across various care settings, and most importantly, because those with cognitive impairments are limited in their ability to provide feedback, the instrument needs to be administered to those who are most knowledgeable of the day-to-day activities and behaviors—their caregivers.
Music has the ability to elicit emotions deep in listeners, regardless of age. In fact, music enhances autobiographical recall by promoting positive emotional memories (El Haj et al., 2012; Spiro, 2010). Yet, all seniors do not have the same lifetime musical experiences or level of interest. Therefore, the understanding of one’s relationship to music prior to cognitive impairment also needs to be studied for possible correlations to any influences on quality of life. According to Spiro (2010), “A number of characteristics set musicians apart from untrained individuals related to practice and memory of movement, patterning and auditory material – aspects that are particularly important for dementia” (p. 896). To this end, the following two research questions guided this quantitative study:

1. From the perspectives of caregivers, are there significant health-related, quality-of-life effects on seniors diagnosed with Alzheimer’s disease, or a related dementia, as a result of individualized music programming?

2. Is there a correlation between the importance of music in a senior’s life and any health-related effects of individualized music programming?

**Theoretical Rationale**

While there has been much research in the area of dementia and the efficacy of non-pharmacological interventions over the past 10 years, Eccles (2006) argued that a theoretical approach to research, “informs the development and delivery of interventions, guides their evaluation, and allows exploration of potential causal mechanisms” (p. 2). This is not always easy because music-intervention studies focus on treatment efficacy rather than on theoretical frameworks, by typically exploring individual mechanisms and variables to better understand how music produces its effects (Sherratt et al., 2004). In
other words, according to Sherratt et al. (2004), “the theoretical framework and philosophy are more implicit” (p. 9).

The philosophical worldview most commonly influencing the approach to the clinical and health science field of research is that of the post positivist (Eccles, 2006). This is a traditional form of research, and it is sometimes called the scientific method, or conducting scientific research. While one cannot be positive about the claims of knowledge of human behavior, within post positivism, by using measurement and careful observation, quantitative researchers argue there is an objective reality (Creswell, 2014). Despite an increased focus on theory, it can sometimes be difficult to identify explicit theories used in the research (Carpiano & Daley, 2005). Thus, developing metrics to study the behaviors of individuals is central to this theoretical framework, and the use of individualized music programming as a non-pharmacological intervention for Alzheimer’s disease and related dementias is no exception.

**Midrange theories.** Upon a review of the literature, a frequently referenced midrange model that suggests environmental modifications for managing the behaviors of those with cognitive impairment is the progressively lowered stress threshold (PLST) model (Hall & Buckwalter, 1987). The PLST model proposes that when individual stressors accumulate, such as fatigue, noise, requests from others, and untreated medical conditions, the person’s stress level rises. According to the PLST model, those with cognitive impairment have a lowered stress threshold and, therefore, they are less able to manage stress and process external stimuli. Sung, Lee, Li, and Watson (2012) suggested, “The inability to process external stimuli may cause a progressive decline in their stress threshold level and a heightened potential for anxiety and agitated behaviors” (p. 625).
The PLST model hypothesizes that by controlling the factors that lead to increased stress levels, the person will exhibit less agitation and more functional behaviors. For example, using familiar and predictable music, a link can be made to pleasant memories from the past, creating a positive emotional state for persons in the present (Sherratt et al., 2004).

Sung et al. (2012) hypothesized that on the basis of the PLST model, Gerdner (2010) proposed a theory of individualized music interventions for agitation (IMIA) to explain the effects of individualized music on agitation in people with dementia. The IMIA theory proposes that music, matched with personal preferences, provides an opportunity for the patient to connect with the past, and that the familiarity of music from one’s past will, in turn, assist in the recall of memories based on intact remote memory and memory of music in those with dementia (Sung et al., 2012). Suzuki, Kanamori, Nagasawa, Tokiko, and Takayuki (2007) also utilized Gerdner’s (2010) IMIA model. They noted that when connecting with the past, “The recall of past memories will produce a soothing effect, which should prevent or reduce agitation as the person’s stress level is prevented from reaching and exceeding the threshold” (Suzuki et al., 2007, p. 12). However, according to Suzuki et al., the relationship between stress and behavioral problems has not been proven, and there are no studies that describe the relationship between stress and behavioral symptoms among dementia patients.

Kolanowski et al. (2010) studied culture change in nursing homes including non-pharmacological interventions for behavioral and psychological symptoms of dementia. In their study, the researchers found that even when attempting to facilitate a sense of autonomy and preserved identity, a caregiver’s overarching goal is often to have a calm resident in a controlled environment (Kolanowski et al., 2010). Therefore, moving from
managing behaviors to an understanding of these behaviors, the PLST model was congruent with the concept of culture change in the environment (Kolanowski et al., 2010).

Culture change supports the creation of environments where both seniors and caregivers are able to express choice and practice self-determination in meaningful ways at every level of daily life. The vulnerability framework which focuses on interactive effects of the characteristics of a vulnerable person (state) and the physical, social, and cultural context in which that person exists (space) and the flow of (time) emerges as a strong theoretical fit for many institutional senior care and services studies. In this framework, for Kolanowski et al. (2010), the three elements interacted in a dynamic fashion, yet the concept of time posed the most significant barrier to the use of non-pharmacological interventions. As caregiver time was limited, practical priorities in the institutional environment often focused on the highest operational needs. Without the manifestation of care demands, such as verbal outbursts or at-risk activities or challenges to the orderly operation of the environment, it was difficult for caregivers to make enough time to add extracurricular activities. Simply put, time is a dimension of a caregivers’ ability to apply individualized resident-centered care and services (Kolanowski et al., 2010).

Micro-theories. Several micro-theories sought to understand behavioral problems and which interventions produce positive outcomes for those with Alzheimer’s disease and related dementias. Lawton’s (1982) person-environment fit (PEF) theory suggests that individuals with lower competence (e.g., seniors with cognitive impairment) are more sensitive to the demands of their environment (Sung et al., 2012). According to
Sung et al. (2012), “If environmental demands are too strong for the level of competence, maladaptive behavior will occur. Lawton’s (1982) theory suggests that supporting the remaining abilities and modifying the environment can facilitate person-environment fit for older adults with dementia” (p. 625). With the PEF theory, autonomy and independence are particularly important because a person with dementia may attribute personal failures or deficits to the environment.

Behavioral symptoms, such as agitation and passivity, are common with Alzheimer’s disease and related dementias, and meeting individual preferences may improve the effects (Kolanowski et al., 2010). According to Kolanowski et al. (2010) and the need-driven dementia-compromised behavior (NDB) model (Algase, Beck, & Kolanowski, 1996), when one demonstrates behaviors, such as agitation and passivity, it is a symptom of an unmet need. “Failure to understand the need communicated by the behavior may lead to inappropriate and ineffective treatment” (Kolanowski, 2010, p. 1032). Kolanowski et al. also described the five-factor model (FFM) (Costa & McCrae, 1990), and unlike the NDB (Algase et al., 1996) model, FFM theory offers an alternative framework for assessment as the domains of extraversion and openness help define personality and are associated with preference for leisure activities (Kolanowski et al., 2010).

One theory that attempts to explain how music might affect human psychological response is the theory of music, mood, and movement (MMM) (Murrock & Higgens, 2009). It proposes that music produces the psychological response of an altered mood, leading to improved health outcomes (Murrock & Higgens, 2009). Chan, Wong, Onishi, and Thayala (2012) studied depression in older adults and believed that while
conventional pharmacological methods might result in adverse issues of impairment and dependence, listening to music, which is non-invasive, simple, and inexpensive, might offer relief.

In their 2012 study, Chan et al. performed a randomized controlled study whereby participants listened to their choice of music for 30 minutes per week for 8 weeks. Depression scores based on the Geriatric Depression Scale (GDS-15) (Sheikh & Yesavage, 1986) were used as measurement. Results indicated that there was a statistically significant reduction in depression levels found in the music group compared with the non-music group. Chan et al. (2012) noted, “Therefore, our findings support the MMM model that music stimuli exert an emotionally meaningful effect on human health by engaging specific brain functions” (p. 781). The study utilized selected music chosen by the participants, each music session lasted for 30 minutes, once per week for 8 weeks. The findings contributed to knowledge about the effects of music used as an intervention to relieve depression in older adults.

And finally, Kitwood’s (1997) theory of personhood was incorporated in a study by Sherratt et al. (2004), where music listening with the focus on social interaction and the behavioral responses of people with dementia were monitored. This theory attempts to integrate neurological findings with social psychological principles and theories of interpersonal processes and moves away from the traditional medical view of Alzheimer’s disease and related dementias. The theory has a number of advantages over other micro-theories. According to Sherratt et al. (2004), “The PLST model focuses largely on anxious/agitated behaviors. What is less clear is how it accounts for individual engagement and participation processes that do not involve aggression or agitation”
In the theory of personhood, maintaining a sense of personhood involves providing a high standard of care by finding positive and meaningful ways in which to interact with the person with dementia. Simply put, listening to music has the potential to maintain one’s personhood, even in those with severe cognitive impairment. A key reason is language abilities, which may have deteriorated, are not necessarily required (Sherratt et al., 2004).

**Statement of Purpose**

The purpose of this study was to explore the effects of individualized music programming and its relationship to quality of life, in people with Alzheimer’s disease and related dementias, by building on previous research and creating a unique experimental condition. In this case, an Alzheimer’s disease and related dementia-specific quality of life measurement instrument in the assisted living environment was used. Drawing comparisons with previous research, however, is challenging as there are limited studies in this area.

While this study focuses on health-related quality of life, it also highlights the most-valued resource in the field of senior care and services—the front-line caregiving staff. It is the caregivers who have the greatest understanding of the challenges and difficulties of managing through the behavioral disturbances of dementia and the stress it creates for both the patients and the caregivers. Given the physical and emotional consequences of care giving, as well as the inherent challenges of recruitment already within the field, studies of this type warrant even greater attention from senior care and service administrators, regulators, researchers, and policy makers.
This country is faced with the economic challenge of providing for the millions of people with some form of dementia, notwithstanding the changing demographics and the many millions more who will be affected. Enabling one to live as independently and in the least restrictive environment for as long as possible, averting the need for other more-costly and potentially harmful interventions such, as pharmacological or other restrictive interventions, is significant, particularly because there is no cure (Alzheimer’s Association, 2015; Vasionytė & Madison, 2012). Many with cognitive impairments, who are otherwise healthy enough to stay at home, require only minimal daily care such as food delivery and help with personal hygiene. Homecare services, as an example, cost less than the cost of assisted living and roughly half as much as a nursing home admission and almost three times less than a stay at the hospital (Benveniste et al., 2014). There are clear implications for programming, senior care and service administration, public policy, and additional research. Therefore, establishing evidence for a cost-effective, non-pharmacological treatment will make an important contribution to the field.

**Potential Significance of the Study**

In spite of ongoing attempts to develop pharmacological treatments, there is nothing currently available that can stop or reverse the effects of Alzheimer’s disease and related dementias (Alzheimer’s Study Group, 2009; Kolanowski et al., 2010; Solomon et al., 2014). This study is significant as the prevalence of the disease and resulting economic impact will continue to grow as the world’s population ages. To complicate matters, based on current demographic trends, the senior care and services workforce is
currently unable to meet demands as the baby boom generation enters the senior care and service continuum (Alzheimer’s Study Group, 2009).

Determining whether there are quality of life improvements as a result of an intervention has become increasingly relevant as senior care and service providers, patients, and families have alternatives. While the payers (both government and commercial) attempt to determine which alternatives are both beneficial and cost-effective, according to Black, Rabins, and Casper, (2009):

The issue has become increasingly salient as clinicians, patients and their families are faced with choices among alternative treatments or therapies that have varying benefits and risks, and as payers and policy makers, in the current climate of health care reform, seek to determine which alternatives are more cost-effective.

(p. 4)

All stakeholders must envision a national healthcare system with a workforce to accommodate future needs including the evolution of technological advances with the potential to reduce cost and improve services. All available intervention options, particularly those that are relatively inexpensive and require only minimal training, need to be explored and promulgated. Basic assistive technologies must become commonplace as there are opportunities for significant economic savings. However, any new methods of care and service, or the improvement of existing methods, need to be assessed with adequate quality of life measures (Ettema, Dröes, de Lange, Mellenbergh, & Ribbe, 2005). The literature shows promising results using non-pharmacological approaches such as music to improve quality of life for those with cognitive impairments (Lee, Chan & Mok, 2010; Spiro, 2010); however, with methodological challenges in
relation to sample size, demographic characteristics, study setting, outcome measures, failure to randomize, and standardization, this study may have the potential to significantly refine the research.

**Definition of Terms**

The following definitions of key terms are used in this study.

*Activities of Daily Living (ADL)* – self-care pursuits/interests/actions of an individual that are routinely used by health professionals as a measurement of the functional status of a person.

*Agitation* – when someone becomes nervous and difficult to control because of worry or fear.

*Assisted Living* – an entity that provides or arranges for housing, on-site monitoring, and personal care services and/or home care services, in a home-like setting for five or more adult residents, who are unrelated to the assisted living provider. The services include daily food service, 24-hour on-site monitoring, case management services, and the development of an individualized service plan for each resident.

*Alzheimer’s Disease* – a health condition that is common among older people that results in the gradual loss of memory, speech, movement, and the ability to think clearly.

*Alzheimer’s Disease-Related Quality of Life (ADRLQ)* – a multidimensional assessment instrument developed to meet the needs of researchers and clinicians, which can be used in evaluating therapeutic interventions toward health-related quality of life issues for Alzheimer’s disease or related dementia patients.
Amyloid – insoluble fibrous protein aggregates sharing specific structural traits that are associated with the pathology of neurodegenerative disorders including Alzheimer’s disease.

Amyloid-Beta – the main component of the plaques or abnormal clusters of chemically “sticky” proteins that build up between nerve cells that are found in the brains of those with Alzheimer’s disease.

Apolipoprotein E (APOE) – a gene providing instructions for making a protein that combines with fats in the body to form molecules that are responsible for packaging cholesterol and other fats and carrying them through the bloodstream.

Autobiographical – an account of a writer’s life, either written by the writer or documented by another person of the speaker/author’s life.

Barthel’s Index of Activities of Daily Living – used to measure performance of the self-care pursuits/interests/actions of an individual, and it is used in more than 16 major diagnostic conditions.

Biomarker – a measurable substance in the body whose presence is indicative of some phenomenon such as a disease.

Cholinesterase Inhibitors (ChE-Is) – a drug used to treat the cognitive symptoms of Alzheimer’s disease and related dementias that inhibits the acetylcholinesterase enzyme from breaking down acetylcholine, thereby increasing both the level and duration of the action of the neurotransmitter acetylcholine.

Cohen-Mansfield Agitation Inventory (CMAI) – used to assess the frequency of manifestations of agitated behaviors in elderly individuals in the nursing home environment. Although originally developed for research purposes, it has also been used
for clinical purposes, such as deciding whether withdrawal of psychotropic medication resulted in an increase in agitation.

*Cognitive* – mental abilities and processes related to knowledge, attention, memory and working memory, judgment and evaluation, reasoning, problem-solving and decision making, comprehension, and production of language.

*Culture Change* – also known as person-centered care or resident-directed care that transforms the long-term care medical model to one that nurtures the human spirit as well as meeting medical needs.

*Degenerative* – progressive, often irreversible deterioration and loss of function in the organs or tissues.

*Dementia* – a disease or condition that exists especially among older people and that results in the gradual loss of mental abilities, such as the ability to think, reason, and remember.

*Diurnal Rhythm Disturbance* – interferences in the sleep-wake cycle, which is known as sun-downing.

*Dysphoria* – a profound state of unease or dissatisfaction, and it may accompany depression, anxiety, or agitation.

*Etiology* – the study of causation or origination.

*Five Factor Model (FFM)* – micro theory with domains of extraversion and openness defining personality style of interests that are associated with preference for leisure activities.
Geriatric Depression Scale (GDS) – a screening for symptoms of unhappiness, melancholy, sorrow, despondency, low spirits, etc., in older adults. The long form consists of 30 questions, and the more commonly used short form has 15 questions.

Global Deterioration Scale (GDS) – provides caregivers with an overview of the stages of cognitive function for those with some form of degenerative dementia.

Home Health Aide (HHA) – individuals who are the primary caregivers of activities of daily living in the assisted living environments. They are licensed and regulated by the New York State Department of Health (DOH), and they are required to complete a minimum of 95 hours of training within a 60-day window, including 65 hours of didactic training – lecture (45 hours), return demonstration (20 hours), and 30 hours of supervised clinical experience.

Hypothesis – a provisional conjecture or tentative assumption about the causes or relation between phenomena.

Impaired – damaged or weakened.

Individualized Music Intervention for Agitation (IMIA) – a mid-range theory that proposes music, matched with personal preferences, provides an opportunity for those with dementia to connect with the past, and that the familiarity of music from one’s past will, in turn, assist in the recall of memories based on intact memories.

Life Review Index (LRI-R) – measures an individual’s fulfillment in their living, situation, or existence.

Life Satisfaction Index A (LSI-A) – a self-reporting instrument to measure an individual’s personal fulfillment or contentment, especially with one’s social relationships, occupation, maturation, or aging. A total of five rating scales are used.
Limbic System – a complex set of brain structures under the cerebrum, supporting a variety of functions including emotion, behavior, and long-term memory.

Medicare – a government service in the US for people who are 65 years and older that pays for their medical treatment.

Mini-Mental State Examination (MMSE) – also known as the Folstein test, it is a sensitive and reliable questionnaire that is used extensively in clinical and research settings to measure cognitive impairment. It is commonly used in medicine and allied health to screen for dementia.

Music, Mood, and Movement (MMM) – a micro theory proposing that melodic tunes produce the psychological responses of an altered state of mind or particular feeling leading to improved health outcomes.

Myoclonus – a brief, involuntary twitching of a muscle or a group of muscles.

Need-Driven Dementia-Compromised Behavior (NDB) – a micro theory that suggests that when an individual demonstrates dementia behaviors, such as agitation and passivity, they are symptoms of an unmet need.

Neocortex – the largest part of the cerebral cortex in mammals concerned with sight and hearing, and is regarded as the most recently evolved part of the brain, which is composed of complex, layered tissue, and it is the site of most of the higher brain functions.

Neurocognitive Disorder (due to Alzheimer’s disease) – an individual shows a decline in understanding from a previous level of performance in one or more domains of higher cortical functioning, such as learning and memory, complex attention, executive function, language, perceptual-motor, and social understanding or cues.
Neurodegeneration – the umbrella term for the progressive loss of structure or function of nerve cells in the brain, including death of such nerve cells. Alzheimer’s disease is a neurodegenerative disease.

Neuropsychiatric – the branch of medicine dealing with mental or emotional disturbances or diseases involving brain function.

Neuropsychiatric Inventory (NPI) – an outcome behavior instrument used in many pharmacologic intervention studies. The information is typically obtained from a caregiver who is familiar with the patient’s behavior.

Part D – also called the Medicare prescription drug benefit, it is a U.S. federal-government program to subsidize the costs of prescription drugs and prescription drug insurance premiums for Medicare beneficiaries.

Pathologenesis – the development of morbid conditions or of a disease. More specifically, it involves the cellular events and reactions and other pathologic mechanisms occurring in the development of disease.

Perioperative – the time period describing the duration of a patient’s surgical procedure.

Personhood – the belief in a non-material soul that remains intact underneath all the neurological losses that result from dementia.

Pharmacological – relating to the science of drugs, including their composition, treatment, uses, and effects.

Pittsburgh Sleep Quality Index (PSQI) – an instrument used to measure the condition and patterns of sleep in adults.
Plasticity – the ability of the brain and central nervous system to acquire alternative pathways for sensory perception as a result of experience.

Postoperative – the period of time after a surgical procedure.

Progressively Lowered Stress Threshold (PLST) – a mid-range theory that proposes that those with cognitive impairment caused by dementia have a decreased ability to handle mental or emotional pressures. Those individuals with dementia are less able to manage stress and process external stimuli.

Psychotropic – of or relating to a chemical substance that changes brain function and results in alterations in perception, mood, or consciousness.

Psychometric – data that has been collected on a test to determine how well it measures the intended construct of interest.

Psychometrics – the science of measuring mental capacities and processes.

Purpose in Life Test (PIL) – measures the levels of meaning and purpose in an individual’s existence.

Rating Anxiety in Dementia (RAID) – a clinical research instrument used for assessing worry, nervousness, or unease, in dementia sufferers.

Reminiscence – to talk or write about past experiences that an individual remembers.

Reminiscence Bump – the tendency for older adults to have a disproportionate or increased autobiographical recollection of events that occurred during their adolescence and early adulthood.

Renarcissization – to improve dementia patients’ self-image.
**Short Index of Self-Actualization (SI)** – a test that measures the degree of and an individual’s realization or fulfillment of potentialities that are considered a drive or need in that individual.

**Tangles** – when protein in the brain called, tau, collapse into twisted strands that destroy a vital cell transport system.

**Vascular Dementia** – a common form of dementia caused by an impaired supply of blood to the brain, such as may be caused by a series of minor strokes.

**Vulnerability Framework** – a mid-range theory that is focused on the interactive effects of the characteristics, over time, of an individual who is susceptible to emotional attack or harm in the context in which the individual exists.

**Chapter Summary**

In recent years, the knowledge that has been gained with respect to the care and treatments available to families and caregivers of those with Alzheimer’s disease and related dementias has the potential to enrich care practices greatly, and the knowledge will also help to reveal new understandings of the therapeutic possibilities related to quality of life. While quality of life is a core value of the culture-change movement (the creation of both long- and short-term living environments as well as community-based settings where both seniors and caregivers are able to express choice and practice self-determination in meaningful ways) within our nation’s senior care and service providers environments, empirical aspects of the movement have yet to grow at the same pace as the population. New methods of care and service, or the improvement of existing methods, need to be assessed with adequate quality-of-life measures (Ettema et al., 2005).
Helping seniors to maintain their sense of identity, while struggling with the complications of a failing memory, should be the prime objective. This study, grounded in Kitwood’s (1997) theory of personhood, aspires to the highest standard of cultural arts programming through individualized music as a meaningful way for individuals with cognitive impairment to re-live an experience and an emotional memory long after it has faded from their conscious mind. As Kitwood (1997) suggested:

To have an identity is to know who one is; it involves maintaining a sense of continuity with the past, and some kind of consistency across the course of present life. Identity involves having a “narrative” – a story to tell about oneself and one’s life. To some extent, identity is conferred by others, as they respond to a person and convey subtle messages about how that person is perceived. (p. 20)

As quality of life will become an increasingly important outcome measure, particularly in institutional environments, such as assisted living, a stronger evidence base is needed.

In Chapter 2 the literature review and theoretical framework are provided. Chapter 3 describes the research context, research participants, data collection instruments, data collection procedures, the process for data analysis, and the dissemination and disposition of the data. Chapter 4 presents a detailed analysis of the data analysis and findings, and Chapter 5 discusses the implications of the findings, limitations of the research, and recommendations for future research and best practice.
Chapter 2: A Review of the Literature

Introduction

A review of empirical literature helps to establish what has been done in the field of senior care and services, Alzheimer’s disease and related dementia care, cultural arts programming, and ultimately, the use of individualized music programming as a non-pharmacological approach to improved quality of life. It places the research in the historical context of the field, enhances the vocabulary on the subject, and enables the ability to articulate relevant variables (Boote & Beile, 2005). The literature also presents the possibilities of what still needs to be done. The following two research questions framed the literature review and guided this quantitative study:

1. From the perspectives of caregivers, are there significant health-related, quality-of-life effects on seniors diagnosed with Alzheimer’s disease, or a related dementia, as a result of individualized music programming?

2. Is there a correlation between the importance of music in a senior’s life and any health-related effects of individualized music programming?

Given the research questions, there were two hypotheses tested in this study. Hypothesis 1 was that caregivers would notice significant improvements in the health-related, quality of life of seniors diagnosed with Alzheimer’s disease, or a related dementia, after providing individualized music programming. Hypothesis 2 was that there would be a significant positive correlation between the degree of music
involvement and the health-related, quality-of-life improvements as a result of individualized music programming.

**Review of the Literature**

This literature review begins with the initial landmark study in the field of cultural arts, aging, and wellness, and it follows a progression of more recent national and international studies and their advancement of the topic. Alzheimer’s disease and related dementias and the concept of quality of life emerges within the literature, as well as the challenges of assessment, given these diseases multidimensional subjectivity, notwithstanding the assessment of those who are unaware of their impairments and disabilities, are without capacity, and perhaps, most importantly, who have lost the ability to verbalize their feelings about their quality of life. The literature review also highlights emerging studies related to the use of several non-pharmacological interventions for the millions suffering from the effects of Alzheimer’s disease and related dementias.

**Historical Context**

At the turn of the last century, senior care and services and the arts had very little national public policy support. While the Social Security Act of 1935 provided federal programs and justification for service to older Americans, Blanchard (2006) asserted:

Perhaps the biggest contribution came in the form of legislation that acknowledged the importance of the arts and other nonprofit organizations in American society by exempting them from the federal income tax and by creating tax deductions for charitable gifts. (p. 51)

From a federal policy-making perspective, the concept of improving health outcomes changed the modern infrastructure for research and advocacy when, in 1975,
the National Institute on Aging appointed its first director. That same year, the National Institute of Mental Health established a research center on aging. At the turn of the 21st century, The National Center for Creative Aging was established to foster an understanding of the link between creative expression and health aging, as well as to unite research, practice, and inform policy (Patterson & Perlstein, 2011).

**Initial Landmark Study**

In 2001, the landmark creativity and aging study, conducted by Cohen et al. (2006) measured the impact of professionally conducted, community-based cultural arts programs on the general health of seniors aged 65 and older. The majority of the cultural arts programming in the study involved participation and interpersonal interaction with others, thus enhancing social engagement. Because of the natural appeal of the arts, cultural arts programming has an engaging and sustaining quality, unlike many of life’s general activities. In many cases, sense of control and exceeding one’s expectations plays an important role. The study proved that seniors who participated in some form of cultural arts programming experienced an improvement in their quality of life and that socialization played an important role in the programming. Cohen et al. (2006) reported, “The repeated success of the various participants profoundly affected their motivation and desire to continue; they consistently reported high self-esteem and mood as their involvement continued” (p. 728).

The Cohen et al. (2006) study was the first of its kind, as no previous study had measured physical health, health utilization, mental health, and social functioning of seniors involved in diverse participatory art programs that were conducted by professional artists. Conducted at three locations, the cultural arts programs were diverse
and participatory. Each of the three sites had at least 100 seniors participating in the study, and the average age of the participants was 80, with a range between 65 years and 103 years. Compared to a control group, at the 1-year follow-up investigation, those who participated in the arts programs reported better health, fewer doctor visits, less medication usage, fewer falls, and had more positive responses on mental health measures.

**Recent Studies on Cultural Arts, Aging, and Wellness**

Robertson (2005) investigated how creative activities have a positive impact in the lives of seniors by helping individuals with the challenges of aging, providing meaning in life, and guarding against loneliness. Participants in Robertson’s study completed Debats’s revised form of the Life Review Index (LRI-R) created by Battista and Almond (1973), which measures meaning in life. According to Robertson (2005), “Creative works provide a retrospective of participants’ lives, enabling them to achieve wholeness” (p. iii). Robertson (2005) asserted a direct positive impact of creativity on “ultimate tasks of later life” (p. 118) such as developing wisdom, achieving unity and wholeness, and facing death. Robertson utilized a primarily qualitative approach; however, three quantitative aspects, including a participant-information questionnaire, the LRI-R, and the Short Index of Self-Actualization (SI) instrument (Jones & Crandall, 1986) measured self-actualization.

Flood and Scharer (2006) examined the relationships between functional performance, creativity, and successful aging, using the Roy (1989) adaptation model which, “is a guide for understanding successful aging that incorporates dimensions of aging such as physical, mental, spiritual, and existential being, approached subjectively
by the aging individual” (p. 941). The 2006 study used a pretest-posttest design with a control group. Functional performance mechanisms, demographical information, and group interventions were the independent variables. The Life Satisfaction Index A (LSI-A) (Neugarten, Havighurst, & Tobin, 1961) and the Purpose in Life Test (PIL) (Crumbaugh & Maholick, 1964) were used as measures of successful aging. There were no significant differences found between the control group and the intervention group.

Roden (2007) explored the experiences of seniors over 70 years who employed creativity in dealing with age-related losses defined as death of a spouse, eyesight, dexterity, and the effects of a stroke. Roden studied individuals who reported life-long involvement with the arts. The study was qualitative through face-to-face unstructured interviews with narrative gerontology as a contextual framework whereby narrative was a metaphor of life history as it pertains to theory, research, and practice. The limitations of Roden’s (2007) study and recommendations for future research were notable as questions emerged relating to gender differences, economic and cultural differences, and the experiences of those who take up creativity later in life.

In their study of cognitive stimulation therapy, Spector, Gardner, & Orrell (2011) investigated whether improvements found in clinical trials were also noted by people with dementia, their caregivers, and the group facilitators in their everyday lives. There were 14 group therapy sessions, all were group activities drawing on implicit learning and person-centered care. They recruited 38 participants from community dwellings in London, UK, and all therapy sessions were run in day-care settings. Qualitative interviews and focus groups were conducted with people attending cognitive stimulation therapy sessions along with their caregivers and the groups’ facilitators. As a result, the
overall experience was seen as being emotionally positive, relaxing, and most of the participants reported some cognitive benefits. However, limitations included the inherent difficulty of asking people with memory problems to remember, in some detail, the experiences of the cognitive stimulation therapy sessions.

Polenick and Flora (2012) studied the effects of social praise on seniors in residential care facilities (e.g., nursing homes and assisted living) where the researchers believed older adults were offered few opportunities for creativity. Inclusion criteria required that participants did not have a diagnosis of dementia, were able to provide usual responses for conventional household objects, and they were able to provide appropriate unusual uses for more common objects. The results showed that repeated social praise increased subsequent creativity in this setting.

In a study of seniors participating in a creative dance workshop, Thornberg, Lindquist, and Josephsson (2012) identified two emerging themes: awareness of the connection between body and mind, and how participation in the program led to personal growth. While an increase in physical activity through dance had a positive effect on psychological well-being and reduced mortality rates, “being involved in serious leisure activities and cultural and creative occupations promotes successful aging in aspects such as enhanced adaptation, personal growth, social interaction, mental and psychological well-being and even survival” (Thornberg et al., 2012, p. 71). The study was qualitative, using open-ended interview questions, and data were analyzed using an interpretative narrative method. This study added to the discussion that the concept of participating in creative and cultural activities has a positive influence on health.
Narne et al. (2013) investigated two non-pharmacological interventions for residents with Alzheimer’s disease, or a related dementia, in a nursing home in France. The researchers compared the effects of music versus cooking in the emotional, cognitive, functional, and behavioral domains of participants as well as their professional caregiver distress. There were 48 patients who were randomly assigned to either the music or cooking group. The interventions were scheduled for 1 hour, twice a week, for 4 weeks. For the music intervention, music was played on a CD player with material from the 1950s to the 1980s. Participants listened to the music and were asked to accompany the tracks by singing or by using percussion instruments. The same playlist was used in the same order for each music session. During the cooking sessions, participants made a different recipe for each session, and a game about ingredients was played, and collectively, the participants prepared a given recipe. The Cohen-Mansfield Agitation Inventory (1991) measured agitation. The participants’ emotional state was determined by assessing discourse content, emotional facial expressions, and mood, using the severe impairment battery test (Hugonot-Diener et al., 2003). The participants’ mood also was assessed using the state-trait anxiety inventory for adults (Spielbelger, 1983). Caregiver distress was measured using the Neuropsychiatric Inventory, which was adapted for professional caregivers. Analysis revealed that both the music and cooking interventions led to positive changes in emotional state, and they decreased the participants’ behavioral disorders as well as reduced caregiver stress. No cognitive benefits were seen in the participants. The results did not demonstrate a specific benefit on any of the tested variables, but the study suggested the efficacy of two pleasant, non-pharmacological treatments in patients with moderate to severe dementia.
Kumar et al. (2014) studied occupational therapy programs and their effect on quality of life in seniors with dementia. Prior to selection, the diagnosis of dementia was established by a physician and confirmed with the Mini Mental State Examination (MMSE) (Folstein, Folstein, & McHugh, 1975) and the Clinical Dementia Rating Scale (Morris, 1993). Participants were randomly assigned to experimental and control groups. The experimental group received an occupational therapy regimen along with medical treatment, while the control group received only medical treatment during the same time period. Participants were assessed at baseline and post intervention using the World Health Organization Quality of Life assessment (The WHOQOL Group, 1998). The intervention, including a total of 10 treatment sessions of 70 minutes was implemented for 5 weeks. Each session contained the following interventions: relaxation, physical exercises, and personal activities, such as personal care and household tasks; cognitive exercises, including dual-task activity, such as writing or drawing while listening to music; and recreational activities including games, story-telling, and singing. The occupational therapy program improved the short-term physical performance and psychological well-being domain of quality of life of the participants in the study (Kumar et al., 2014).

**International Studies**

With the unprecedented aging population, international studies regarding aging, wellness, and cultural arts have advanced a collective knowledge base. According to Hattori et al. (2010), art therapy has been reported to be effective for alleviating psychiatric symptoms of Alzheimer’s disease and related dementias. In the Hattori et al. (2010) outpatient study, Alzheimer’s disease patients in Japan were selected for group art
therapy sessions, lasting 12 weeks and consisting of the coloring of abstract patterns. Patients were studied pre- and post-intervention, and the patients’ mental functions, such as mood and vitality, behavioral impairment, quality of life, and activities of daily living, were evaluated using the Geriatric Depression Scale (Sheikh & Yesavage, 1986) and the Apathy Scale (Marin, Biedrzycki, & Firinciogullari, 1991). The effects of the art therapy on the Alzheimer’s patients in this study focused on the patients’ cognitive function, vitality, and behavior. The burden on caregivers was also evaluated. Comparison of evaluation before and after each therapy revealed significant improvement in the Apathy Scale for those who participated in the art therapy interventions.

In Portugal, Lima and Castro (2011) studied how emotional recognition of music changes as a function of aging. In this study, there was evidence of age-related changes in how emotions were recognized in faces, voices, and music; and the authors sought to examine how emotion recognition changes as we age. There was evidence that seniors had more difficulty than younger adults in recognizing the negative emotions of fear and sadness in music as opposed to happy, peaceful emotions. According to Lima and Castro (2011), “It is therefore possible that the age-related changes in motivation towards positive input and the bias to positivity, which appear to be linked with changes in brain function, underlie the pattern of results reported here” (p. 596).

Seniors who are socially active are less likely to show signs of physical decline (Eun-Kyoung, Yoon, Lee, Yoon, & Chang, 2012). According to Eun-Kyoung et al. (2012), “In addition, older adults who participate in social activities or groups seem to experience benefits similar to those of physical activity” (p. 475). Eun-Kyoung et al. (2012) developed the Body-Mind-Spirit (BMS) program involving educational sessions
on basic health promotion as part of an evidenced-based practice model. In their study, educational sessions were implemented at senior centers in South Korea and provided a comprehensive review of how BMS interactions impact lifestyle with the overall goal to improve the quality of life by adapting to life changes.

In Taiwan, Lee (2013) examined the motivations for seniors to engage in music, who were still active in the community, with particular attention to their experiences and preferences. Lee’s (2013) qualitative study used interpretative phenomenological analysis and focused on identifying the differences between female and male seniors who sought to achieve the goals they had set for themselves. According to Lee (2013), “For males, musical experiences become a source of lifelong learning support and social recognition; it appears to be more crucial to the male social life than it is to the female” (p. 84). The results indicated historical-cultural lifestyle factors as male participants had more independent leisure time compared to female participants who had more family and home responsibilities. The study found that “music contributes to the psychological and physical health and that making and listening to music can enhance body, mind and spiritual harmony” (Lee, 2013, p. 89).

Also in Taiwan, alternative cultural arts interventions in nursing homes included visual arts and group music interventions, inter alia. Chang, Lu, Lin, and Chen (2013) investigated the effect of a visual art-based environment on nursing home residents’ satisfaction with their living environment. Lin et al. (2010) studied the effectiveness of group music intervention against agitated behavior in seniors with forms of dementia. Chang et al. (2013) implemented a study with a pretest and posttest that included 33 participants with an average age of 79 years. It was believed that local art could evoke
both memories and emotional experiences and reminiscence as a natural process of thinking or telling about one’s past experiences. In the semi-structured interviews, the participants said that they were more active and that the new visual art-based scenes stimulated their old memories and gave them opportunities to explain the local culture to their visitors and younger family members such as their grandchildren. The study confirmed that human dignity, the meaning of life, and the cultivation of aesthetics are important to the institutionalized elderly.

Lin et al. (2010) used an experimental pretest-posttest randomized design with a control group to study music’s effect on agitation in patients with dementia. The experimental group received a total of 12, 30-minute group music intervention sessions, conducted twice a week for 6 consecutive weeks. Although the research included participants’ fondness for music, the frequency and type of music-related activities in which they were involved, as well as their preference in music genres before their cognitive impairments, the study did not factor this data into its analysis. Their study used the CMAI (1991) and other scales, and they revealed that group music intervention is effective in alleviating agitated behaviors in patients with dementia. In both the physically aggressive and non-aggressive behaviors, there were statistically significant decreases.

In Mumbai, Pandya (2014) examined the interface between aging, art, and well-being through participants in arts programs. The author suggested that art can be a useful therapeutic and social instrument for planning interventions with older adults. Pandya noted, “Art oriented interventions provide scope for activity engagement, self-enhancement and promoting an overall sense of well-being among older adults” (Pandya,

In Switzerland, Walter et al. (2007) evaluated humor therapy in patients with late-life depression as well as patients with Alzheimer’s disease. Study participants were aged 65 years or older and were diagnosed with either Alzheimer’s disease or a major depressive disorder. There were 10 patients in each group (Alzheimer’s disease and depression), and they underwent humor therapy once every 2 weeks for 60 minutes, in addition to their standard psychopharmacologic protocol. A moderator acted as the stimulant for humor by smiling and laughing, while reading funny stories with an aim to trigger the patients’ reactions by way of personal associations with what they just heard or observed. For evaluation of depressive mood, the Geriatric Depression Scale (GDS) was used. As a measure of subjective global quality of life, the Anamnestic Comparative Self-Assessment Scale was used, which is a 10-stage anchor scale for global assessment of present quality of life, defined in terms of the best time versus the worst time in life. Although there was no significant effect of humor therapy comparing with standard therapy on quality of life in either of the study groups, the findings suggest that humor therapy can provide an additional positive therapeutic tool, particularly in depressed patients (Walter et al., 2007).

Quality of Life Research

In 1997, the World Health Organization defined quality of life as “The individual’s perception of their position in life in the context of the culture and value system in which they live, and in relation to their goals, expectations, standards and
concerns” (p. 1). This is a broad and complex concept that includes physical health, psychological health, independence, social relationships, personal beliefs, and one’s relationship to their environment (World Health Organization, 1997). From a health-related perspective, quality of life is intended to capture the effects of health or illness on other aspects of life that most people value (Black et al., 2009). Quality of life is the central purpose of health care, and it is an essential outcome of treatment effectiveness (Ettema et al., 2005). However, the concept of quality of life is difficult to define, is multidimensional, and is subjective. This subjectivity is even more difficult to quantify for seniors with cognitive impairments, as many are unaware of their disabilities, and they have lost the ability to verbalize their feelings and the capacity to assess their own personal health and status (Black et al., 2009; Terada et al., 2002).

Critics may maintain that a concept like quality of life cannot be measured because its nature is unclear. Measures vary considerably in scale, content, and methods of data collection. On the other hand, many researchers, including Rabins, Kasper, Kleinman, Black, and Patrick (1999), Ettema et al. (2005), and Terada et al. (2002) agreed that progress had been made and there is a general consensus on some fundamental issues regarding quality of life. While some authors conclude that self-reporting is the only viable option in assessing quality of life, others consider proxy reports to provide valid data as well. For example, Ettema et al. (2005) suggested, “In the field of dementia, self-reporting in many cases is not possible, as the dementia affects the cognitive abilities, raising doubts about persons with dementia being valid and reliable informants on their life quality” (p. 676). What is clear is that in the past decade, quality
Quality of life is a core value of the culture-change movement (supporting the creation of both long- and short-term living environments as well as community-based settings where both seniors and caregivers are able to express choice and practice self-determination in meaningful ways at every level of daily life) within senior care and service environments. Kolanowski et al. (2010) sought to provide a stronger evidence base for culture change in nursing homes, focusing on the barriers to the implementation of non-pharmacological interventions for treating the behavioral and psychological symptoms of dementia. Their qualitative study utilized a focus group methodology and captured discussions with nursing, recreational therapy, and medical staff in six nursing homes located in Pennsylvania and North Carolina. Four broad themes were identified: the changing landscape, resident behaviors, reaching out to the person with dementia, and the educational needs of staff. The concept of time emerged as a barrier to the use of non-pharmacological interventions, and the findings indicate a need for implementation of staffing patterns that allow staff the time to make a difference in the care of residents with dementia. Moreover, the findings also stress a need for the development of educational programs that promote staff understanding versus control, and the need for the design of research studies that answer questions about the influence of time on the selection of interventions for behavioral and psychological symptoms of dementia.

According to Rabins et al. (1999), “Health-related quality of life measures, whether generic or not, have a shared objective: to provide information about the effects of treatment beyond the traditional focus on mortality and clinical indicators” (p. 34). In
2002, Terada et al. determined that the unique characteristics of dementia lead to
differences in the importance and definition of specific quality-of-life domains, and for
this reason, the authors determined that a disease-specific, health-related quality-of-life
questionnaire was necessary. This was particularly true in Japan where no questionnaire
had been developed, and it was unclear whether the concept of quality of life in dementia
is trans-culturally universal or not (Terada et al., 2002). While many questionnaires have
been developed to assess cognitive function and activities of daily living, the authors
placed the emphasis on social interactions and psychological well-being. In developing
their instrument, Terada et al. (2002) used information obtained from caregiver
interviews, expert opinion, and comprehensive reviews of the literature. The final
questionnaire consisted of 31 items grouped into six response sets, each with its own
scale. The questionnaires were completed by members of the nursing staff or family, and
all raters had daily contact with the patients in the study. Of the 300 participants who
were selected from several geriatric health service facilities and adult day health centers
in Okayama, Japan and Hyogo, Japan, 264 participants with cognitive impairments were
rated. Reliability was good to excellent, and validity was established (Terada et al.,
2002).

Quality-of-life assessment instruments specifically for Alzheimer’s disease and
related dementias are preferable to generic instruments because they are specific to the
aspects that are associated with dementia (Gräske, Fischer, Kuhlmeier, & Wolf-
Ostermann, 2012). In the study conducted by Gräske et al. (2012), the researchers
suggested that self-ratings were to be considered the best way to evaluate quality of life,
and discrepancies between self-ratings and staff-ratings were underrepresented. The aim
of their study was to identify characteristics of people with cognitive impairments that improve the probability of completing a self-rating quality of life instrument, to establish a level of agreement between self-rating and caregiver-rated findings and to identify influencing factors. The study generated new findings concerning a better understanding of quality-of-life measurements, and while there was a suggestion regarding the usefulness of self-ratings whenever possible, if proxy-ratings are to be used, according to the researchers they should be performed by the direct-care nursing staff (Gräske, 2012).

Deudon et al. (2009) evaluated the effectiveness of a staff education intervention to manage behavioral and psychological symptoms of dementia in 306 seniors within 16 nursing homes in France. The nursing homes were randomly allocated to an intervention group or a control group. An 8-week staff education and training program was conducted for the intervention group. Training consisted of practical advice on how to deal with behaviors, such as agitation, aggression, and delusions, as well as interactive sessions in which trainers provided constructive feedback for the caregivers. The main outcome measures were the CMAI (Cohen-Mansfield, 1991). Assessments were done at baseline and at the end of the intervention period and 12 weeks after the conclusion of the study. As a result, there was a significant decrease in the CMAI scores in the intervention group but not in the control group.

In the study by Gräske et al. (2012), results indicate that research focusing on measurement of quality of life in dementia care and services are not yet exhaustive, and there is a lack of agreement between self-ratings and staff ratings. The Gräske et al. (2012) study had implications for further research as the findings created the discussion as to whether an overall score from several quality-of-life domains can be a sufficient
A critical discussion concerning quality of life is still ongoing, but it is generally accepted that quality of life is a multidimensional concept” (p. 825).

Hoe, Katona, Orrell, and Livingston (2007) sought to compare quality-of-life differences between family caregiver observations and the patients, themselves, in an effort to compare views and identify determinants. While the authors recognized that one’s subjective ratings on quality of life is optimal, observational proxy ratings by family or professional caregivers are more useful and reliable in dementia environments. Therefore, in this study, the Quality of Life in Alzheimer’s Disease (QOL-AD) (Logsdon, Gibbons, McCurry, & Teri, 1999) was completed by both patients and family caregivers. The 13-item assessment includes physical health, energy, mood, living situation, memory, family, marriage, friends, self as a whole, ability to do chores, ability to do things for fun, money, and life as a whole (Hoe et al., 2007). While quality of life ratings between those made by the proxies and those directly from the patients were highly correlated, there were differences between the family caregivers and the patients, as the caregivers rated the patients with higher quality of life if the patient had fewer depressive symptoms, less irritability, and less apathy. Fewer depressive symptoms, living at home vs. an in-patient environment and taking AChEI-inhibitors predicted higher patient quality of life ratings. The authors were guarded when substituting caregiver proxy ratings for self-ratings.

Trigg, Watts, Jones, and Tod (2011) explored the predictors of quality-of-life ratings in a sample of people with mild dementia. The participants ($N = 69$) and their caregivers were recruited from a memory clinic setting. The Bath Assessment of
Subjective Quality of Life in Dementia (BASQID) (Trigg, Skevington, & Jones, 2007) measures subjective quality of life information direct from people with mild to moderate dementia. The Alzheimer’s Disease Related Quality of Life (ADRQL) (Rabins et al., 1999) is a measure of health-related, quality-of-life measure that is administered to a caregiver. Regression analyses indicate that the strongest predictor of quality of life ratings from persons with dementia was their awareness of memory function, such that lower awareness was associated with higher quality of life ratings. Proxy ratings of activity performance and enjoyment of activity were also found to be significant predictors. The study found a weak association between the BASQID patient ratings and ADRQL proxy ratings. However, the researchers found that discrepancies between patient and proxy quality-of-life ratings do not necessarily occur because of patient unreliability, but may, instead, reflect the application of distinct modes of quality of life assessment that emphasize very different outcomes.

**Music Therapy Research**

There are numerous types of music therapy programs and many have been studied in institutional settings such as in skilled nursing facilities, assisted living, and adult day services environments. Music can enhance autobiographical recall by promoting positive emotional memories (El Haj et al., 2012; Spiro, 2010). According to Murrock and Higgins (2009), “Music alters mood, leading to the improved health outcomes of decreased anxiety, depression, agitation, pain, altered physiological responses, and improved social interaction” (p. 2252). Music evokes opportunities for retrieving autobiographical memories and those associated with strong emotions such that the
The music encountered during one’s late adolescence and early adulthood have the greatest nostalgic impact on individuals throughout their lives (Krumhansl & Zupnick, 2013; Powell, 2016). This phase of life is when there are many first experiences, which are nostalgic, still vivid, and are often times linked to self-identity. In addition, life events that occur during these years such as graduation, marriage, or birth of a child, contribute to life’s personal goals, attitudes and beliefs, amplifying this phase of life. This phenomenon is known as the reminiscence bump, which is the tendency for older adults to have a disproportionate or increased autobiographical recollection of events that occurred during their late adolescence and early adulthood (Krumhansl & Zupnick, 2013).

In 2012, El Haj et al. investigated the relationship between emotion and music-evoked autobiographical memories in patients with early stage Alzheimer’s disease. The study used semi-structured interview questions that probed memories over the course of three key life periods including childhood, early adult life, and recent life. The results suggest a significant improvement of autobiographical recall for individuals with Alzheimer’s disease in the study. Twelve patients with Alzheimer’s disease and 12 healthy seniors were studied. A major finding was that autobiographical recall of mild Alzheimer’s disease patients improved after listening to their chosen music. The patients expressed reduced anxiety and their responses also contained fewer negative emotional words. El Haj et al. (2010) suggested, “It seems to have reinstalled positive emotional memories [autobiographical recall] that were related to goal achievement in participants’
lives and may also reduce negative emotional memories that are associated with personal failures” (p. 38).

In 2013, Lancioni et al. studied the use of music as a therapeutic intervention for seniors in the moderate stages of Alzheimer’s disease. Ten songs were available for each patient and were recommended by the patients or the patients’ families after a brief preference screening procedure. Patients received three to seven sessions per day. The MMSE (Folstein et al., 1997) was used as an assessment instrument as well as daily observations of the patients. This study was the first to include an active (patient self-regulated) management of music stimulation. The results of the study indicate that the use of music stimulation was successful in increasing indices of positive participation of patients. Moreover, the results indicate that patients in the severe or lower moderate state of the disease can benefit from music stimulation and, more importantly, can benefit by managing the use of this stimulation on their own, through assistive technology.

In their clinical study, Fukui, Arai, and Toyoshima (2012) focused on the side effects of hormone replacement therapy in its prevention and treatment for Alzheimer’s disease; these include risk of adverse reactions such as cancers and heart diseases. An alternative to hormone replacement, music therapy, is as effective as hormone replacement therapy with no risks of harmful reactions. Fukui et al. (2012) noted that, “Moreover, the study found that music therapy can serve as an effective prophylaxis of Alzheimer’s disease for the healthy elderly” (p. 4). The population studied comprised six patients with an established diagnosis of Alzheimer’s disease with a mean age of 81.8 years. Music sessions were 1 hour per day, and lasted 1 month.
Cooke et al. (2010) sought to investigate the effects on agitation and anxiety that result from the participation in facilitated singing and reading. Their design was randomized with both music and reading control groups. According to the authors, the advantages of this methodology were that it ensured a good level of equivalence among the participants who were exposed to the two treatments; no participant was denied a potentially beneficial treatment, and it allowed for an examination of effects over a 6-month period (Cooke et al., 2010). Participants in the study were from long-term care facilities in Queensland, Australia and were assessed using the CMAI (Cohen-Mansfield, 1991) and the Rating Anxiety in Dementia scale (RAID) (Shankar, Walker, Frost, & Orrell, 1999). While participation in the music programming did not significantly affect agitation and anxiety in those studied, both the music and reading group activities increased participants’ verbalization. According to the authors, future studies would benefit from in-depth participant assessments prior to study commencement, helping to moderate interventions at times when assessed symptoms are most prevalent.

Hammar, Emami, Engstrom, and Götell (2011) studied how people with dementia and their caregivers express verbal and nonverbal communication during morning care situations, with and without music as a therapeutic-caregiving intervention. Findings revealed that during the time periods without music, caregivers led the morning care with verbal instructions and body movements, and they seldom invited the patient to communicate or participate in getting dressed. Patterns in responses to caregivers’ instructions included both active and compliant responses and reactions that were resistant, aggressive, confused, and disruptive (Hammar et al., 2011). The study was conducted in two nursing homes in Sweden, and 12 patients participated in the study.
The MMSE (Folstein et al., 1975) was used to assess dementia levels. Caregivers participating in the study were trained in music therapeutic caregiving, which included theories about music and health, as well as body movements to accompany singing and learning songs from a patient’s childhood. The authors concluded that musical therapeutic caregiving could be a way for dementia patients and their caregivers to successfully interact and cooperate during caregiving situations, as it seemed to evoke enhanced communication for both parties.

In 2011, Boulay, Benveniste, Boespflug, Jouvelot, and Regaud used active music therapy concepts with MINWii, a music therapy game designed for the geriatric population, mixing music therapy and cognitive stimulation with video game technologies. MINWii is a simple music therapy tool usable by untrained caregivers. Its objective is to improve ones’ self-image in an effort to reduce behavioral symptoms, which are important factors influencing institutionalization. With MINWii, participants in the study used Wiimotes (wireless remote-control devices) to improvise or play predefined songs on a virtual keyboard. Overall, participants were very satisfied with the game and expressed a desire to repeat the experience (Boulay et al., 2011). Weekly sessions were attended by seven participants in a long-term care facility in Paris, and the study measured efficacy indicators such as number of errors, time to complete each task, number of verbal interventions provided by the moderator, and satisfaction indicators. The experience fostered positive interaction with caregivers and elicited powerful reminiscence, even with the most severely impaired patients. The study justified future research to assess the lasting effects of playing MINWii on both quality of life and cognitive impairment in dementia patients.
Van de Winckel, Feys, De Weerdt, and Dom (2004) studied the effect of daily music-based seated dance sessions on both cognition and behavior in women with Alzheimer’s disease and related dementias. The controlled study took place in Belgium, and subjects in the study were diagnosed using the MMSE (Folstein et al., 1975). Participants in the study had to be able to respond to verbal or visual commands, be able to mimic the movement of the therapist, and have the ability to hear the music. Medication regimes remained unchanged throughout the experiment. Participants were randomly assigned to either an exercise group or to a control group. Treatments were carried out over a period of 3 months, and music sessions were organized daily for 30 minutes. Exercises focused on upper- and lower-body strengthening, as well as balance, trunk movements, and flexibility. Participants were tested three times: at the beginning of the experimental period, after 6 weeks, and after 3 months. Van de Winckel et al. (2004) noted, “Most patients used a wheelchair or required assistance with transfers, due to impaired balance, immobility, contractures or muscle atrophy. However, all could move their limbs voluntarily and demonstrated at least a minimal range of motion” (p. 255). The study demonstrated that daily music-based dance sessions led to significantly higher scores on the MMSE (Folstein et al., 1975) and were considered clinically relevant (Van de Winckel et al., 2004). The key component in the treatment described in the study was combining music with exercise. The authors hypothesized that “music enhances arousal, and combined with exercise, motivates the patient to be even more active and alert to the present” (Van de Winckel et al., 2004, p. 258).

Chang, Huang, Lin, and Lin (2010) conducted a study to establish the effect of a music program during lunchtime on problem behaviors among institutionalized older
residents with Alzheimer’s disease or related dementias. The 8-week quasi-experimental design incorporated music during lunch times in weeks 2, 4, 6, and 8. Baseline measurements were taken with Barthel’s Index of Activities of Daily Living (Collin, Wade, Davies, & Horne, 1988), MMSE (Folstein et al, 1975), and the CMAI (Cohen-Mansfield, 1991). The results show that the weekly CMAI scores appeared to rise and fall depending on whether or not music was played during that particular week. The data imply that the lower scores were influenced by the experience of the music playing during the previous week, suggesting that the music program had a delayed effect on the participants. The study concluded that the music program improved problem behavior in dementia patients, which may be attributable to the calmer environment and feelings of happiness and relaxation that reduce symptoms of anxiety and agitation. Chang et al. (2010) noted, “Furthermore, based on the opinion of nurse aides, the music program seemed to save time during meals, but this result was unexpected and anecdotal; therefore, future research needs to log and track any such change fully” (p. 947).

In 2010, Sung et al. evaluated preferred music listening interventions for reducing anxiety in older adults with Alzheimer’s disease and related dementias in nursing homes in Taiwan. Received 30 minutes of music listening based on personal preferences, 29 participants used the Assessment of Personal Music Preference survey (Gerdner, Hartsock, & Buchwalter, 2000). The music intervention was delivered by trained nursing staff in the mid-afternoon, twice a week for 6 weeks, while 23 participants in a control group only received standard programming with no music. Anxiety was measured by RAID (Shankar et al., 1999) at baseline and week 6. Results indicate that the elders who received the preferred music listening had a significantly lower anxiety score at 6 weeks.
compared with those who received no music. Sung et al. (2010) concluded, “Preferred music listening had a positive impact by reducing the level of anxiety in older adults with dementia” (p. 1056). The study found that the importance of music in life was positively related to the reduction of anxiety.

Raglio et al. (2010) undertook a randomized controlled trial to assess whether a music therapy program based on monthly cycles of sessions was effective in reducing behavioral disturbances in severely demented patients living in several nursing homes in Italy. In their study, participants were randomly assigned to experimental or control groups. Baseline multidimensional assessment included demographics, MMSE (Folstein, 1975), Barthel Index, and the Neuropsychiatry Inventory (Cummings et al., 1994). The experimental group received three cycles of 12 music therapy sessions each, three times each week, and the sessions lasted 30 minutes. The analysis showed that delusions, agitation, and apathy significantly improved in the experimental group and not in the control group.

As sleep may be negatively affected by the aging process (Lai & Good, 2005), several studies have focused on the effects of music as a non-pharmacological method of improving the quality of sleep in older adults. Therefore, this randomized controlled study in Taiwan, using the Pittsburgh Sleep Quality Index (PSQI) (Buysse, Reynolds, Monk, Berman, & Kupfer, 1989), and the Epworth Sleepiness Scale (Johns, 1991), included seniors aged 60 to 83 years, who had difficulty sleeping. The participants listened to their choice of six, 45-minute sedative music tapes at bedtime for 3 weeks. Sleep quality was measured before the study and at 3 weekly post-tests. As a result of the study, it was determined that music resulted in significantly better sleep quality in the
experimental group. Lai and Good (2005) stated, “The findings provide evidence for the use of soothing music as an empirically-based intervention for sleep in older people” (p. 134). Lai and Good (2004) went on to state,

Our findings contribute to knowledge about the effectiveness of soft slow music used as therapy on sleep quality in community-dwelling older people. Music is pleasant and safe and can be used therapeutically for insomnia in older people. The intervention is quick and easy to learn, is low cost, and could be used readily by nurses. (p. 142)

In addition to sleep quality, maintaining sufficient caloric intake among nursing home residents with Alzheimer’s disease and related dementias, particularly those who are at risk for weight loss, is a difficult challenge for health care professionals (Thomas & Smith, 2009). Inadequate caloric consumption is often exasperated by an environment that creates stress and agitation, as agitated behaviors during meals tend to lead to reduced food and fluid intake, leading to weight loss and malnutrition.

Thomas and Smith (2009) studied the effect of music on caloric consumption among nursing home residents with dementia where music was used as a cuing mechanism. In a licensed nursing home in Michigan, 12 residents were studied in a dementia unit. The subjects were rated as middle-stage dementia on the GDS for assessment of primary degenerative dementia. Data were collected during lunch, and the study was conducted over two menu cycles (i.e., 8 weeks). The study examined whether music played during meals reduced agitation and would result in increased caloric consumption. The results indicate that the subjects consumed 20% more calories when
familiar background music was played, compared to an eating environment without music.

Lee et al. (2010) studied music as an intervention on the quality of life of seniors in community dwellings in Hong Kong. According to Lee et al. (2010), “Listening to music, as a vehicle for feeling, can facilitate the non-verbal expression of emotion, reaching people’s inner feelings without being threatening, and it can be a tool for emotional catharsis” (p. 2677). The randomized and controlled trial was conducted in a community center with a total of 66 people aged 65 to 90 years. Demographic information and history of musical preference data were collected prior to the intervention. Version 2.0 of the SF-36 (explained below) was used to measure functional health status. According to the Lee et al. (2010):

SF-36 is a generic measure, as opposed to one that targets a specific age, disease or treatment group. It has proved useful in surveys of general and specific populations, comparing the relative burdens of diseases and in differentiating the health benefits produced by a wide range of different treatments. (p. 2680)

In the music group, a 30-minute music intervention was instituted for a total of 4 weeks, and as a result of the study, quality of life improved weekly in the music group, indicating a cumulative dose effect, and a statistically significantly better quality of life was found over time compared to that of the control group. In this study, the researchers concluded, “Being engaged in music activities can help a person to connect with their life experiences and with other people, and be more stimulated” (Lee et al., 2010, p. 2010).

Thompson, Moulin, Hayre, and Jones (2005) investigated the effect of listening to an excerpt of Vivaldi’s Four Seasons on category fluency (generating items from
categories) in healthy seniors and in those with Alzheimer’s disease, where 32 participants were recruited for the study. Vivaldi was chosen because previous studies showed it to have the largest effect on cognitive performance. The researchers reported a positive effect of the music on category fluency, with performance in the music condition exceeding performance without music in both the health older adult control participants and the Alzheimer’s disease patients. The authors concluded that music enhances attentional processes, and that this can also be demonstrated in patients with Alzheimer’s disease. However, improvements were not as dramatic as to bring the Alzheimer’s group into normal limits of cognitive performance.

Ridder, Stige, Qvale, and Gold (2013), studied individualized music on agitation in persons with moderate to severe dementia living in nursing homes and to explored its effect on psychotropic medication and quality of life. Outcome measures include agitation, quality of life, and medication utilization. The study showed that 6 weeks of music therapy reduced agitation disruptiveness and prevented medication increases. Outcomes were measured with the CMAI (Cohen-Mansfield et al., 1991) and the Alzheimer’s Disease-Related Quality of Life (Black et al., 2009; Rabins et al., 1999) instrument. The study protocol allowed for a person-centered approach, where the music therapist carried out the intervention, which was adjusted to the needs of the participant. Going forward, the authors recommended music therapy as a valid treatment of agitation and as a possibility to reduce psychotropic medication as well as to prevent caregiver burnout.
Chapter Summary

A thorough and sophisticated understanding of one’s field of study is only the beginning of the ability to conduct research that will advance the collective understanding of the research topic (Boote & Beile, 2005). Therefore, in planning a study of this type, understanding the philosophical worldview assumptions brought to the study, the research design related to this worldview, and the specific methods or procedures of research that translate the approach into practice will lead to a better evaluation of the theoretically-informed intervention (Eccles, 2006).

As a result of this literature review, it is clear that over the past 10 years (2007-2017), there has been much research in the area of senior care and services, Alzheimer’s disease and related dementias, and the many non-pharmacological interventions, yet there are still opportunities for additional knowledge. Many alternative therapies have desirable outcomes, are observed by caregivers, and thus they should be accessible to measurement. Gaps exist with respect to methodologies including sample size, demographic characteristics, study setting, outcome measures, randomization, and standardization of the music therapy interventions. However, it is the gaps in the research that are encouraging and create the emergence of research possibilities, particularly for those interested in the use of music as an intervention for care and treatment of Alzheimer’s disease and related dementias.

The complexity of studying non-pharmacological alternatives for seniors diagnosed with Alzheimer’s disease and related dementias is acknowledged because the challenges of self-reporting quality of life are impracticable for many (Rabins et al., 1999). The literature also informs researchers of the ease of incorporating music into
treatment practice, as it is widely available, safe, inexpensive, non-controversial, and has minimal ethical, legal, or cultural objections (Lee et al., 2010; Vasionytė & Madison, 2012). Considering these and the broad range of positive outcomes reported, a natural progression is to build on the previous research and create a unique experimental condition. Specifically, use a music intervention, hereafter known as *individualized music programming*, and measure outcomes with an Alzheimer’s disease and related dementia-specific quality of life assessment instrument in a research context known as assisted living, which is the first level of in-patient residential services for this population.
Chapter 3: Research Design Methodology

Introduction

This chapter describes the research context, research participants, data collection instruments, data collection procedures, the process for data analysis, and the dissemination and disposition of the data. Chapter 2 revealed gaps and limitations in the literature, and it is these opportunities that were evaluated in order to strengthen the study’s design and the applied methodology. The purpose of this study was to seek answers to answer the following research questions:

1. From the perspectives of caregivers, are there significant health-related, quality-of-life effects on seniors diagnosed with Alzheimer’s disease, or a related dementia, as a result of individualized music programming?

2. Is there a correlation between the importance of music in a senior’s life and any health-related effects of individualized music programming?

While there are many approved drug therapies for Alzheimer’s disease and related dementias already on the market, and new drug therapies continue to undergo clinical trials, these drugs treat only symptoms of the disease, because there is nothing currently available that can cure or reverse the effects of Alzheimer’s disease and related dementias (Alzheimer’s Study Group, 2009; Kolanowski et al., 2010; Solomon et al., 2014). Menchola and Weiss (2015) put forward that “while identifying and treating medical causes contributing to dementia such as infection, pain, and environmental issues, non-
pharmacologic treatments are generally preferred for behavioral problems and should be considered prior to drug therapy” (p. 15).

Despite the decades of research, there is still a significant number of unknowns about the etiology and clinical manifestations of Alzheimer’s disease and related dementias (Kolanowski et al., 2010). In fact, most non-pharmacologic therapies have not been robustly studied in randomized controlled trials, and while a series of smaller studies have been evaluated in systematic reviews, Raetz (2013) emphasized the importance of addressing specific behavioral symptoms and setting realistic expectations.

One such intervention is the use of music, which can be a powerful catalyst for the reflection of memories, emotions, and images that evoke experiences associated with the musical stimuli (Suzuki et al., 2004). Throughout history, music is present in all cultures and has the ability to elicit emotions in listeners, regardless of age. In fact, music enhances autobiographical recall by promoting positive emotional memories (El Haj et al., 2012). Seniors, in particular, appear to benefit from the therapeutic effects of music, which may be related to the well-established links between music and emotions (Eells, 2014). With Alzheimer’s disease and related dementias, behavioral and psychological symptoms are often rooted in communication difficulties. Combining language and music offers a greater chance of activating those intact neurological pathways in patients rather than using language alone (Hammar et al., 2011).

Research Context

The 6-week study was conducted in a discrete memory care unit in an assisted living environment in Westchester County, New York. The research site is within a Continuing Care Retirement Community (CCRC) licensed by the state of New York,
which includes independent living, skilled nursing and assisted living, has a $42 million dollar annual operating budget, and employs 450 people. The assisted living memory care unit is marketed as a discrete unit dedicated to those diagnosed with Alzheimer’s disease or related dementias, and it is located within the main building on the facilities campus. The unit features private rooms with private baths, a community kitchen, a great room with fireplace and entertainment center, a creative arts center, and a sunroom. There are many cultural arts opportunities factored into the calendar for socialization, artistic and musical expression, cooking, and gardening. The design of the unit is secure with 24/7 staff, all of whom have added training in patient behaviors associated with cognitive impairment.

The residents in this study setting were not chronically dependent on others for their basic activities of daily living. However, nursing care, basic supervision, cultural arts, social activities, and medication management were provided. The environment was secure, with restricted egress to prevent the potential of wandering or unaccompanied elopement. Site considerations included a review of the existing programming to ensure the study did not pose a conflict as well as a review of the public survey findings and corresponding plans of correction to ensure the setting was suitable from a staffing, management, and orderly operation perspective.

Assisted living environments are the first level of state-regulated congregate living for those living with a form of Alzheimer’s disease and related dementias. In New York, the term assisted living was a term-of-art within the long-term care service delivery continuum, and until 2008, it had no controlling state regulations. Assisted living implies very positive connotations, considering its inherent promise of independence and the very
direct emphasis on living. It is not surprising that the concept of living within an assisted living environment may be far more preferable to consumers than the perceived alternative of admission to a nursing facility. However, the cost of care in this environment is beyond what many families can afford, and there are very few assisted living options in this region that are not privately paid. In other words, most assisted living facilities are not part of Medicaid’s safety net for those without insurance or who can no longer pay for care and services privately. This research site however had a unique all-inclusive private-pay fee structure. Table 3.1 provides a schedule of the 8-week study including two baseline assessments prior to the introduction of the 6 weeks of individualized music programming that served as the independent variable.

Table 3.1

<table>
<thead>
<tr>
<th>Activity</th>
<th>Week</th>
</tr>
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<tbody>
<tr>
<td>Baseline 1 Assessment</td>
<td>—</td>
</tr>
<tr>
<td>Baseline 2 Assessment</td>
<td>2</td>
</tr>
<tr>
<td>Music 1 Assessment</td>
<td>4</td>
</tr>
<tr>
<td>Music 2 Assessment</td>
<td>6</td>
</tr>
<tr>
<td>Music 3 Assessment</td>
<td>8</td>
</tr>
</tbody>
</table>

Research Participants

Selection criteria. The selection criteria included resident participants who had been diagnosed with Alzheimer’s disease or related dementias and who were classified as having moderate to severe cognitive declines as defined by the Global Deterioration Scale (GDS). The GDS is an instrument used for assessment of primary degenerative
dementia, developed by Reisberg, Ferris, de Leon, and Crook (1982). GDS is divided into seven different stages. Within the GDS, each stage is numbered (1-7), given a short title, followed by a brief listing of the characteristics for that stage. Stages 1-3 are the pre-dementia stages. Stages 4-7 are the dementia stages, and beginning in Stage 5, an individual can no longer survive without assistance.

There were 13 resident participants in the study. The participants’ families were informed of the study both verbally and in writing (Appendix A), as were their primary physician and interdisciplinary care team. Those who were legally responsible for the participants’ medical decisions were required to sign a written informed consent form prior (Appendix B) to the study. All the resident participants met the following representative sample inclusion criteria:

1. Living in the discrete memory care unit within an assisted living environment.
2. Diagnosis of Alzheimer’s disease or related dementias.
3. Sixty (60) years of age or older.
4. Sufficient hearing to experience music presented using an MP3 player with headphones.
5. Information of personal music preference from either the resident or family member.
6. Approval from primary care physician and interdisciplinary care team.
7. A signed informed consent form.

The participants were excluded for the following reasons:

1. Did not receive approval from primary physician or consent from responsible party.
2. Inability to participate in the interventions.

Family members of the resident participants were engaged beyond the informed consent process because they were presumed to have knowledge of the participants’ musical history, and at least one family member per participant was asked to complete a short survey (Appendix C) concerning the music they believed their loved one would prefer.

**Instruments Used in Data Collection**

**Alzheimer’s disease-related quality of life.** According to Gräske et al. (2012), “Generally, dementia-specific quality of life instruments are preferable to generic instruments, because they focus on aspects which are associated with dementia” (p. 1). Therefore, this study used the Alzheimer’s Disease Related Quality of Life (ADRQL) (Black et al., 2009; Rabins et al., 1999) research instrument throughout the study. The ADRQL instrument was developed to meet the needs of researchers and clinicians for a disorder-specific measure of health-related quality of life for use in evaluating therapeutic interventions across various care settings and stages of the disease. It is a behavior-based assessment instrument, administered to a person closely involved in caring for a patient, which incorporates important characteristics of daily life. Cognitive and physical functioning are not incorporated in the instrument (Missotten et al., 2008). According to Black et al. (2009), “As such, the ADRQL may be used as an outcome measure in determining the efficacy and effectiveness of behavioral interventions, environmental settings and drug treatments” (p. 1).

There are five domain subscales within the ADRQL assessment: social interaction, awareness of self, feelings and mood, enjoyment of activities, and response to
surroundings. Social interaction relates to interactions with other people, including family members, friends, and even professional caregivers, in some observable way through gestures, talking, or facial expression. Awareness of self is the perception of personhood, including family relationships, community friendships, as well as relationships rooted in a former career. Feelings and mood include spoken statements, expressions, or gestures indicating how a person feels. Enjoyment of activities takes into account participation in and enjoyment of cultural arts and hobbies. Response to surroundings is related to how a person responds to the environment in observable ways, such as through physical gestures and verbal communication (Black et al., 2009).

The ADRQL assessment has 40 questions, each with a scale value that represents the weight when scoring and it is scored based on scale values that are assigned to each item. The sum of all responses that reflect good quality of life translates to the maximum total scale value. A scale value (rounded to two decimal places) is assigned for each response that reflects good quality of life while a value of zero is assigned to responses that do not reflect good quality of life. For each individual statement, raw scores range from zero to 13.75. Maximum scale values for the domain subscales range from 42.01 (response to surroundings) to 147.7 (social interaction). Because each ADRQL domain subscale includes both positively-worded and negatively-worded items, responses that reflect good quality of life were indicated by an agree response, and other good quality of life was indicated by a disagree response. Scores can be calculated for the overall ADRQL and for each of the five domain subscales. In every case, a higher score reflects a higher quality of life. A total maximum overall score derived from the sum of all
responses, which reflects a good quality of life is 472.98. Table 3.2 includes sample questions from each of the five ADRQL domain subscales.

**Table 3.2**

*ADRQL Domains and Example Questions*

<table>
<thead>
<tr>
<th>ADRQL Domain Subscales</th>
<th>Example Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social Interaction (SI)</td>
<td>He/She smiles or laughs when around other people?</td>
</tr>
<tr>
<td></td>
<td>He/She does not pay attention to the presence of others?</td>
</tr>
<tr>
<td></td>
<td>He/She can be comforted or reassured by others?</td>
</tr>
<tr>
<td>Awareness of Surroundings (AS)</td>
<td>He/She does not respond to his/her own name?</td>
</tr>
<tr>
<td></td>
<td>He/She talks with people on the telephone?</td>
</tr>
<tr>
<td></td>
<td>He/She does not express beliefs or attitudes once had?</td>
</tr>
<tr>
<td>Feelings and Mood (FM)</td>
<td>He/She throws, hits, kicks, or bangs objects?</td>
</tr>
<tr>
<td></td>
<td>He/She is irritable or easily angered?</td>
</tr>
<tr>
<td></td>
<td>He/She appears to be content or satisfied?</td>
</tr>
<tr>
<td>Enjoyment of Activities (EA)</td>
<td>He/She enjoys doing activities alone?</td>
</tr>
<tr>
<td></td>
<td>He/She does not take part in activities once enjoyed?</td>
</tr>
<tr>
<td></td>
<td>He/She dozes off or does nothing most of the time?</td>
</tr>
<tr>
<td>Responding to Surroundings (RS)</td>
<td>He/She talks about feeling unsafe?</td>
</tr>
<tr>
<td></td>
<td>He/She is upset or unsettled?</td>
</tr>
<tr>
<td></td>
<td>He/She talks about wanting to leave or go home?</td>
</tr>
</tbody>
</table>

In 2009, validity and reliability of the ADRQL were assessed in a sample consisting of participants in three residential settings: community (146), assisted living (134), and nursing home (89). According to Black et al. (2009):

The ADRQL exhibits good item internal consistency (67.5% of items met .40 standard); high correlation of items to hypothesized scales (85% of items met criteria for four of five subscales and the overall instrument); a good range of scores (21.6 to 100 for total sample revised instrument); very low missing data;
and internal-consistency reliability coefficients exceeding the minimum reliability standard for group comparisons (.86 for total scores; range of .56 to .83 for subscales). (p. 1)

Key considerations used in selecting this instrument were its disorder-specific design, validity, reliability, the time required, and both ease of completion and scoring. Most importantly, because those with cognitive impairments are limited in their ability to express quality-of-life feedback, the instrument was created for caregivers who are most knowledgeable of the day-to-day activities and behaviors of the participants, particularly in an in-patient setting, and who are well suited to observe any changes day to day. Both the professional staff (those positions requiring a college degree and state-required licensure) and home health aide (HHA) caregivers were included in this study. Multiple assessors during multiple shifts were used to control for validity and fidelity.

HHA caregivers played an essential role in the study setting. Their duties included assistance with dressing, grooming, bathing, and other personal care such as toileting, serving and assisting with meals, light housekeeping, cultural arts assistance, maintaining records, and reporting changes, accordingly, to professional staff. HHAs are certified by the state of New York with an annual verification. A minimum of 95 hours of training is required, and all HHAs must complete their training within a 60-day window of receiving their certification, including 65 hours of didactic training, which includes lectures (45 hours), return demonstration (20 hours), and 30 hours of supervised clinical experience. In addition to verification of certification, the Department of Health monitors HHA employers by annual unannounced surveys, which assesses compliance with state and federal standards. To become certified as an HHA in New York, and
individual can receive training through the university system, an HHA program, or a certified HHA agency. The DOH and New York’s Education Department (jointly) are the only agencies that can approve HHA training programs. As long as an HHA is employed by an HHA employer, their certificate remains valid. However, the employer is responsible for providing supervision and 12 hours of in-service training per year. If an HHA is not working, the certification lapses 2 years from the date that the person last worked.

Assessment of personal music preference (family version). The level of importance of music in a senior’s life may have an impact on any quality of life correlations as a result of the individualized music intervention (Sung et al., 2010). Therefore, Research Question 2 used data gathered through guided interviews with resident participants and, if appropriate, their families, in an effort to understand the participants’ relationship to music over the course of their lifetime and prior to any cognitive impairment. The Assessment of Personal Music Preference (APMP) (Gerdner et al., 2000) was designed for the purpose of obtaining detailed information regarding personal music preference and to identify the importance of music in a person’s life, and it served as the interview guide. According to Gerdner (2010):

It is theorized that the presentation of carefully selected music, based on personal preference, will provide an opportunity to stimulate remote memory. This changes the focus of attention and provides an interpretable stimulus, overriding stimuli in the environment that is meaningless or confusing. (p. 8)

Although resident participants were interviewed to the degree practicable, if a participant was unable to provide information due to cognitive impairment, it was the
family members who provided feedback through the APMP. There were nine questions of various types, including Likert response scale questions, Guttman scaled questions, and several open-ended questions. Notes were taken during each interview but the interviews were not recorded. Sample questions included:

1. How important a role did music play in the participant’s life?
2. Did the participant play a musical instrument?
3. Please identify specific artists/performers that the participant enjoyed.

**Procedures for Data Collection and Analysis**

The participating residents and their powers of attorney for health care were informed of the study both verbally and in writing, as well as the participant’s primary physician and interdisciplinary care team. Prior to the study, an introductory meeting was held for the staff, the participants, their powers of attorney for health care, and the family members. Once the residents and their powers of attorney for health care agreed to participate, a signed written consent was obtained. As the study involved human subjects, a full review application was submitted to, and approved by (Appendix D), the Institutional Review Board (IRB) at St. John Fisher College.

The study also required approval from the executive administration of the participating assisted living facility, including executing a Health Insurance Portability and Accountability Act (HIPAA) business-partner agreement (Appendix E).

Demographic data was collected from the resident participants’ records including age, gender, race, religion, education level, marital status, length of residency, medical diagnosis, and medications. Initials were used to protect the resident participants’ and their families’ privacy and to maintain confidentiality throughout the study. All
information, interview documents, and notes were stored in a secure location. The research procedures were explained in writing, in advance including ethical considerations, residents’ rights, and any possible adverse effects that may result from the study. The following occurred prior to initiating the research study:

1. Host site approval (Appendix F)

2. IRB approval

3. Information packets were mailed to power of attorney for health care decisions that contained:
   a. An introductory letter stating the purpose of the study, the time required, potential risks and disclosure of resident’s rights
   b. An informed consent form authorizing participation in the research study
   c. Alzheimer’s Disease Related Quality of Life instrument

Obtaining informed consent from the resident participants’ powers of attorney for healthcare was a modification to the informed consent form. It should be noted that modifications are permitted when a study involves no more than minimal risk. The modification does not adversely affect the subjects, it was not practical to carry out the research without modifying consent, and the appropriate information was provided to participants (Code of Federal Regulations 45 CFR 46 § 116(d) 1-4, 2009). In this study, all of these requirements were met. Simply put, obtaining informed consent directly from the participants was not practical due to their cognitive impairments. Modifications are also permitted when a study involves no more than minimal risk and what the participants
will do would not require their written consent if it was done outside of research (Code of Federal Regulations 45 CFR 46 §117(c) 2, 2009). In this study, however, listening to music for 30 minutes is an activity that, outside of research, did not require informed consent. However, the participant assent was obtained and those who were not interested in participating were not included in the study.

**Testing effect.** To control for testing effect and internal validity, ADRQL assessments were scored two times at 2-week intervals prior to the individualized music intervention, then they were scored at 2-week intervals during the music intervention, and again at the end of the study.

**Individualized music programming.** With information provided by the APMP, each resident participant in the study was given a designated MP3 device with a personalized playlist music library provided by this researcher. Creating the personalized playlist for each participant required three pieces of equipment: (a) a personal computer, (b) an entry-level MP3 player, and (c) headphones. For purposes of this study, the goal was to obtain 10 to 15 artists and between 80-100 music selections per participant. This researcher’s iTunes account served as the master library for all the music selected in the study.

The participants listened to their individualized music as a group activity for 30 minutes, three times a week, for 6 weeks at approximately 2:00 p.m. on Mondays, Wednesdays, and Fridays. The music was introduced to the participants by this researcher using the MP3 players provided. The MP3 players were easy to operate with volume adjustments, with the ability to play, pause, and shuffle the music. During the listening sessions, caution was taken to ensure that the volume was set at an appropriate
level and that it was loud enough for the participants to hear. The participants were also monitored by direct-care staff during the music intervention to assess tolerance to headphones given that their use may have been unfamiliar, discomforting, or confusing.

During each listening session, the resident participants were invited to participate, either in the main gathering lounge or in their preferred setting. During each session, the resident participants were monitored by this researcher as well as direct-care staff, and descriptive field notes were recorded as well as reflective information was logged immediately following the listening session. If a resident participant was not interested or did not agree to a particular listening session, they were not included but were invited at the next listening session. Some sessions were missed due to medical appointments, hospitalizations, family visits, and hair appointments. Missed sessions were controlled within the statistical analysis.

**Data Analysis**

The study was a quantitative design. Research question 1 asked, “From the perspectives of caregivers, are there significant health-related, quality-of-life effects on seniors diagnosed with Alzheimer’s disease, or a related dementia, as a result of individualized music programming?” Responses from the ADRQL were analyzed using the Statistical Package for the Social Sciences (SPSS) software for Windows, Version 23 (2015). Descriptive statistics were used to describe demographic characteristics and musical history data. A within-subject, repeated-measures multivariate analysis of variance (ANOVA) tested quality of life measures at baseline and during the study. Pearson correlations were used for the importance of music and age. The Kruskal-Wallis Test within SPSS was used for the type of dementia. The independent variable was
individualized music programming, and the dependent variable used the ADRQL. Baseline data was captured at 4 and 2 weeks prior to the music intervention. This design protected against threats to internal validity, and it strengthened the study. The advantage of this methodology is that the error variance was reduced by using the same participants, therefore creating more power in the statistical analysis.

Research question 2 asked, “Is there a correlation between the importance of music in a senior’s life and any health-related effects of individualized music programming?” The APMP survey provided data through guided interviews in an effort to understand the participants’ relationship to the music over the course of their lifetime and its relationship to any quality of life changes as a result of the independent variable.

**Dissemination.** To protect privacy and confidentiality, no obvious identifying information about the facility was used in this study, and the data will remain confidential. For practical purposes, it was necessary to identify the resident participants on the APMP and the ADRQL. However, when the data was entered into the digital dataset, names were removed and replaced with initials. Initials were also used on the listening session tracking forms.

**Disposition of data.** Each ADRQL assessment was coded by date, by staff assessor, and by resident participant. All data collected, including field notes, will remain confidential for a minimum of 5 years. The results of this research, however, are public and may be quoted in professional journals and meetings, but all study participant information will only be reported as a group and not individually.
Chapter Summary

The purpose of this study was to investigate the effects of individualized music programming in patients with Alzheimer’s disease and related dementias, using the caregiver’s perspective on the health-related aspects of quality of life in a discrete memory care unit within an assisted living environment. According to the literature, many issues, including behavioral problems, cognitive decline, poor social interaction, and other functional problems, have been improved using music (El Haj et al., 2012; Flood & Scharer, 2006; Lai & Good, 2004; Lee et al., 2010; Murrock & Higgins, 2009). The form of music intervention used in this study was relatively easy to implement programmatically, low cost, and without side effects (Flood & Scharer, 2006; Hulme et al., 2010; Jimbo et al., 2009; Moyle et al., 2012; Vasionytė & Madison, 2012).

The two research hypotheses tested in this study were: (a) caregivers will notice significant improvements in the quality of life of seniors diagnosed with Alzheimer’s disease or related dementias who lived in a discrete memory care unit within an assisted living environment after 6 weeks of individualized music programming, and (b) there will be a significant positive correlation between the degree of music involvement (e.g., higher importance of music, played an instrument, or enjoyed singing) and quality of life improvements as a result of 6 weeks of individualized music programming. This chapter provided an overview of the study, including the research questions, methodology, design and intervention, a description of those participating in the study, and the tools used for data collection. In addition, a step-by-step description of the procedures for obtaining the data, as well as how the data was analyzed, was included.
Chapter 4: Results

Introduction

The purpose of this study was to understand how individualized music programming can be a cost-effective, non-pharmacological therapeutic protocol for improving the health-related quality of life in seniors diagnosed with Alzheimer’s disease or related dementias. The participants in this study were part of a convenience sample, living in a discrete memory care unit within a licensed assisted living environment. As representatives of this study’s target population, they met practical criteria including accessibility to this researcher, availability at specified times, and a willingness to participate. The assumption associated with this sample is that the population was homogeneous. That is, there would be no difference in the results obtained from a random sample or one gathered in some other inaccessible part of the population. This chapter presents a compendium of the analysis, such as the study sample’s inclusion criteria, testing effect, demographics, followed by hypothesis testing.

Research Questions

The two research questions and hypotheses tested in this quantitative research study were as follows:

1. From the perspectives of caregivers, are there significant health-related, quality-of-life effects on seniors diagnosed with Alzheimer’s disease, or a related dementia, as a result of individualized music programming?
Hypothesis 1: Caregivers will notice significant improvements in the health-related quality-of-life of seniors diagnosed with Alzheimer’s disease or related dementia as a result of 6 weeks of individualized music programming.

2. Is there a correlation between the importance of music in a senior’s life and any health-related effects of individualized music programming?

Hypothesis 2: There will be a significant positive correlation between the degree of music involvement (e.g., higher importance of music, played an instrument, or enjoyed singing) and quality-of-life improvements as a result of 6 weeks of individualized music programming.

Data Analysis and Findings

The inclusion criteria were three categories of participants: the residents living in the discrete memory care unit, the resident’s families having both power of attorney for health care decisions and knowledge of the resident’s musical history prior to any cognitive impairment, and the staff working in the environment, both professional and HHA caregivers. While there were 13 residents living in the environment, all of whom provided consent and musical preference information, only 11 assented to participate in the study. All study participants (residents, staff, and families) met the representative sample inclusion criteria presented in Table 4.1.

A baseline assessment may introduce a testing effect in which changes in what is being measured are the result of the process of measurement itself, most often with people giving a more socially desirable answer the second time a test is administered (Singleton & Straits, 2005). To protect against this threat to internal validity, this study used two baseline measures prior to the initiation of the independent variable
The two baseline scores were compared as a way of assessing whether there was a testing effect. The difference in scoring the overall quality of life between the two baseline ADRQL mean scores was not significant, indicating that there was no testing effect. Therefore, going forward, the first baseline measure was used in the analysis.

Table 4.1

Inclusion Criteria for Study Participants (Residents, Professional & HHA Caregiver Staff, Families)

<table>
<thead>
<tr>
<th>Study Participants</th>
<th>Inclusion Criteria</th>
</tr>
</thead>
</table>
| Residents          | Diagnosis of Alzheimer’s disease or related dementia  
60 years of age or older  
Sufficient hearing to experience music with headphones  
Information of personal music preference from family  
Approval from primary care physician  
A signed consent form |
| Staff              | Paid staff employed by the assisted living facility  
Employed for at least one month |
| Families           | Relative of participant, power of attorney for health care  
Familiar with music preference of participant  
Aged 18 or over |

Demographic characteristics of the resident participants include age, gender, length of stay, education, history of mental health issues, type of dementia, indication of a prescribed medication related to Alzheimer’s disease or related dementias, and cognitive impairment as measured by the GDS. The staff participant demographics include college
degree, professional licensure or certification, age, and tenure. Music preferences and the
importance of music in the lives of the resident participants prior to any cognitive
impairment was captured by the APMP. To assess health-related quality of life, the
ADRQL used the perspectives of the staff because they were closely involved in the daily
lives of the resident participants in this setting. For each of the ADRQL assessment
periods, the total overall average score was captured as well as the mean scores for each
of the five domain subscales within the ADRQL. A repeated-measures ANOVA tested
for change over the course of the study, and scores were calculated for each resident
participant from baseline to final assessment.

**Participant demographics.** Demographic characteristics of the resident
participants are presented in Table 4.2. They were disproportionately female (90%), all
were White, and five (45%) had college degrees. Medical record information indicated
that 18% had a history of mental health issues. Additionally, eight (73%) were
prescribed medications consistent with FDA-approved drugs for the symptomatic
treatment of Alzheimer’s disease or related dementias, including Memantine and various
ChE-IIs, such as Cognex (Tacrine), Aricept (Donepezil), Exelon (Rivastigmine), and
Razadyne (Galantamine).

Table 4.3 provides additional resident participant demographic characteristics
including age and length of stay in the study setting. The ages ranged from 76 to 93
years with an average age of 86 years. Length of stay was measured in months and
varied from 1 to 55 months. The average length of stay of the resident participants was
34 months.
Table 4.2

Demographics of Resident Participants \( (N = 11, \text{no missing data}) \)

<table>
<thead>
<tr>
<th>Variable</th>
<th>( N )</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>10</td>
<td>90.91</td>
</tr>
<tr>
<td>Male</td>
<td>1</td>
<td>9.09</td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>11</td>
<td>100.00</td>
</tr>
<tr>
<td>College Degree</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>5</td>
<td>45.45</td>
</tr>
<tr>
<td>No</td>
<td>6</td>
<td>54.55</td>
</tr>
<tr>
<td>History of Mental Health Issues</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>2</td>
<td>18.18</td>
</tr>
<tr>
<td>No</td>
<td>9</td>
<td>81.82</td>
</tr>
<tr>
<td>Alzheimer’s Disease Medication</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>8</td>
<td>72.73</td>
</tr>
<tr>
<td>No</td>
<td>3</td>
<td>27.27</td>
</tr>
</tbody>
</table>

Table 4.3

Additional Characteristics of Resident Participants \( (N = 11, \text{no missing data}) \)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Range</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>76-93</td>
<td>86.45</td>
<td>5.03</td>
</tr>
<tr>
<td>Length of Stay (months)</td>
<td>1-55</td>
<td>86.45</td>
<td>17.93</td>
</tr>
</tbody>
</table>

Cognitive impairment levels were captured by the GDS and are presented in Table 4.4. All 11 resident participants scored within Stages 4-7, which are defined as the dementia stages (Reisberg et al., 1982). One resident participant was rated at Stage 4 while six of the 11 (55%) were rated at or above the severe cognitive decline level.
Table 4.4

*Cognitive Impairment Level of Resident Participants (N = 11, no missing data)*

<table>
<thead>
<tr>
<th>Global Deterioration Scale (GDS)</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stage 4 – Moderate Cognitive Decline</td>
<td>1</td>
<td>9.09</td>
</tr>
<tr>
<td>Stage 5 – Moderately Severe Cognitive Decline</td>
<td>4</td>
<td>36.36</td>
</tr>
<tr>
<td>Stage 6 – Severe Cognitive Decline</td>
<td>3</td>
<td>27.27</td>
</tr>
<tr>
<td>Stage 7 – Very Severe Cognitive Decline</td>
<td>3</td>
<td>27.27</td>
</tr>
</tbody>
</table>

*Note.* The GDS, developed by Reisberg et al. (1982), provides an overview of the stages of cognitive impairment. Stages 1-3 are the pre-dementia stages. Stages 4-7 are the dementia stages. Beginning in Stage 5, an individual can no longer survive without assistance.

While Alzheimer’s disease is the most common cause of dementia, there are other causes, thus disease pathology was a variable tested in this study. Table 4.5 provides an overview of the resident participants’ dementia condition using the DSM-5 (APA, 2013). Although vascular dementia is the second-most common type, accounting for approximately 10% of the cases, only one resident participant in the study was diagnosed with vascular dementia alone. Mixed dementia (i.e., Alzheimer’s disease combined with vascular dementia) is more common than previously recognized with about half of those in the study sample having pathologic evidence of more than one cause of dementia (Schneider et al., 2009). In this sample, 45% of the resident participants could be characterized as having mixed dementia. Alzheimer’s disease, alone, was indicated for five of the 11 participants in the study.
Table 4.5

*DSM-5 Diagnosis of Resident Participants (N = 11, no missing data)*

<table>
<thead>
<tr>
<th>DSM-5</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alzheimer’s disease</td>
<td>5</td>
<td>45.45</td>
</tr>
<tr>
<td>Vascular dementia</td>
<td>1</td>
<td>9.09</td>
</tr>
<tr>
<td>Mixed dementia</td>
<td>5</td>
<td>45.45</td>
</tr>
</tbody>
</table>

*Note.* DSM-5 guides physicians in determining if an individual has dementia and, if so, the condition causing dementia. Alzheimer’s disease is the most common cause of dementia. Vascular dementia is the second most common type, accounting for approximately 10% of the cases, and it commonly occurs from blood vessel blockage, post-stroke, or because of brain injuries (Bandyopadhyay et al., 2014). Mixed dementia (Alzheimer’s disease combined with vascular dementia) is more common than previously recognized with about half of those with dementia having pathologic evidence of more than once cause of dementia (Schneider et al., 2009).

Staff demographic characteristics are presented in Table 4.6. There was a total of eight staff members who participated in the ADRQL assessments: two were professional staff (27%), and six (72%) were HHA caregiver staff. All of the staff participants were female.

Table 4.6

*Demographics of all Staff Participants (N = 8, no missing data)*

<table>
<thead>
<tr>
<th>Variable</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>8</td>
<td>100.00</td>
</tr>
<tr>
<td>College Degree/Licensure</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>2</td>
<td>27.30</td>
</tr>
<tr>
<td>No</td>
<td>6</td>
<td>72.70</td>
</tr>
</tbody>
</table>

*Note.* All staff participants include two professional staff and six HHA caregivers.
The ADRQL assessment instrument is behavior based and was administered to a person closely involved in caring for the person with Alzheimer’s disease or a related dementia, as it incorporates important characteristics of daily life beyond activities of daily living such as social interaction, response to surroundings, and mood (Black et al., 2009; Rabins et al., 1999). According to Black et al. (2009), “A formal caregiver is one who provides paid care on a regular basis to the person with Alzheimer’s disease or related dementia in either a home setting, an assisted living facility or a nursing home” (p. 21). In this study setting, these caregivers represented a diverse group based on their education, certification, and the type of care they provided. The level of training varied from that of a certified aide to a licensed practical nurse (with or without a bachelor’s degree) or other formal caregivers such as in the case of a recreational therapist. While level of training may have influenced the ease of which a caregiver responded to the questions, all practical staff were included in the assessments. However, it is the HHA caregiver staff who were most knowledgeable of the day-to-day activities and behaviors of the residents. Thus, additional analysis, including demographics and most importantly the ADRQL assessments, were bifurcated to allow for analysis of only the HHA staff perspectives. Table 4.7 provides additional staff demographics including age and tenure. The average age of the HHA caregivers was 46 years, 4 years older than that of the total staff. Tenure was measured in months with an average of 23 months for all staff and 29 months for the HHA caregivers.
<table>
<thead>
<tr>
<th>Variable</th>
<th>Range</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>26-55</td>
<td>41.88</td>
<td>12.04</td>
</tr>
<tr>
<td>HHA caregivers only</td>
<td>26-55</td>
<td>46.17</td>
<td>10.62</td>
</tr>
<tr>
<td>Tenure (months)</td>
<td>4-33</td>
<td>22.80</td>
<td>14.40</td>
</tr>
<tr>
<td>HHA caregivers only</td>
<td>9-33</td>
<td>29.00</td>
<td>9.79</td>
</tr>
</tbody>
</table>

*Note.* All staff participants include two professional staff and six HHA caregivers.

**Research question 1.** *From the perspectives of caregivers, are there significant health-related quality of life effects on seniors diagnosed with Alzheimer’s disease, or a related dementia, as a result of individualized music programming?* The hypothesis was that caregivers would notice significant improvements in the health-related quality of life for the seniors diagnosed with Alzheimer’s disease, or a related dementia, after 6 weeks of individualized music programming.

This was a challenging hypothesis to test because people with Alzheimer’s disease and dementias are unaware of their impairments and disabilities, and some have lost the ability to communicate. The cognitive impairments, alone, present several unique challenges not the least of which is the fact that persons with the disease cannot participate in a quality-of-life evaluation. Thus, the ADRQL assessment instrument used in this study was designed to capture many non-verbal forms of communication such as body language, gestures, interaction with others, facial expression, and participation in various social activities.
Within the ADRQL assessment, there are five domain subscales. Social interaction (SI) includes questions related to interactions with other people including family members, friends, and staff. Awareness of self (AS) are observable perceptions of family relationships, community friendships, as well as relationships rooted in a former career. Feelings and mood (FM) include spoken statements, or expressions or gestures indicating how a person feels. Enjoyment of activities (EA) takes into account participation in and enjoyment of cultural arts and hobbies. Response to surroundings (RS) relates to how a person responds to the environment through verbal communication and body language or physical gestures (Black et al., 2009).

**Repeated-measures ANOVA.** Table 4.8 provides an overview of the ADRQL means and standard deviation scores for all eight staff participants in the study. Change scores were calculated by subtracting the baseline scores from the third (final) music assessment score. While the pattern was such that the overall scores increased from baseline to the first assessment, 80.45 to 84.05, there was a decrease to 79.97 at the second assessment and then an increase to 82.03 at the final assessment. A repeated-measures ANOVA tested for change over time, from baseline through the final assessment. The repeated-measures ANOVA revealed weak evidence against the null hypothesis (no relationship to the individualized music programming intervention), as $p$ (evidence against the null hypothesis) = .199 using $\alpha$ (significance level) = .05. Thus, the null hypothesis was not rejected, and significant health-related quality of life improvements as a result of the programming could not be concluded. However, two of the eight staff participants were professionals, and their interactions with the resident participants were sporadic or administrative in nature.
Table 4.8

*Overall Quality of Life Means (and standard deviations) Ratings for all Staff (N = 8)*

<table>
<thead>
<tr>
<th>Assessment</th>
<th>Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Baseline</td>
<td>80.45 (9.71)</td>
</tr>
<tr>
<td>Music 1 Assessment</td>
<td>84.05 (4.10)</td>
</tr>
<tr>
<td>Music 2 Assessment</td>
<td>79.97 (5.97)</td>
</tr>
<tr>
<td>Music 3 Assessment</td>
<td>82.03 (8.55)</td>
</tr>
</tbody>
</table>

*Note.* All staff participants include two professional staff and six HHA caregivers.

This study sought to answer questions of the effects on health-related quality of life through a caregiver’s perspective. As such, those directly responsible for the care and service of the residents living in the study setting and those who had direct and constant observation of participants were the HHA caregiver staff. Therefore, a repeated-measures ANOVA using only on the HHA caregiver ratings was used to test for change over time from the baseline mean through the third (final) music assessment scores. As Table 4.9 illustrates, the baseline mean scores were lower than the final assessment scores for the overall ADRQL as well as each of the five ADRQL domain subscales. For overall quality of life, the SI, AS, and EA scores, the means increased from the baseline to the first assessment, decreased at the second assessment, and then increased again at the third assessment, resulting in a final average mean score that was higher than the baseline score. For FM and RS, the means steadily increased from baseline to the final assessment.
Table 4.9

ADRQL and Subscale Means (and standard deviations) HHA Caregivers Only (N = 6)

<table>
<thead>
<tr>
<th>Scale</th>
<th>Baseline Assessment</th>
<th>Music 1 Assessment</th>
<th>Music 2 Assessment</th>
<th>Music 3 Assessment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall (mean, SD)</td>
<td>80.42 (10.22)</td>
<td>86.23 (6.11)</td>
<td>80.23 (6.26)</td>
<td>87.45 (7.55)</td>
</tr>
<tr>
<td>SI</td>
<td>89.67 (9.19)</td>
<td>90.64 (5.26)</td>
<td>83.14 (7.99)</td>
<td>92.44 (5.77)</td>
</tr>
<tr>
<td>AS</td>
<td>61.91 (28.37)</td>
<td>71.42 (22.31)</td>
<td>52.98 (19.17)</td>
<td>66.54 (23.90)</td>
</tr>
<tr>
<td>FM</td>
<td>85.16 (10.68)</td>
<td>90.49 (8.95)</td>
<td>90.74 (6.54)</td>
<td>93.71 (7.81)</td>
</tr>
<tr>
<td>EA</td>
<td>67.69 (18.61)</td>
<td>84.77 (11.43)</td>
<td>80.66 (12.32)</td>
<td>85.51 (18.72)</td>
</tr>
<tr>
<td>RS</td>
<td>71.19 (19.57)</td>
<td>91.88 (11.93)</td>
<td>96.67 (5.90)</td>
<td>98.92 (3.39)</td>
</tr>
</tbody>
</table>

Note. Social Interaction (SI), Awareness of Surroundings (AS), Feelings and Mood (FM), Enjoyment of Activities (EA), Response to Surroundings (RS).

To determine if the changes in means were statistically significant, a series of repeated-measures ANOVAs were conducted. As reported in Table 4.10, the test for change in overall ADRQL was statistically significant, $F = 9.54, p = .000, \eta^2 = .52$. The pattern was similar because the repeated-measures ANOVA revealed evidence to reject the null hypothesis (no relationship to the individualized music programming intervention), as $p = .000$ using $\alpha = .05$. Simply put, the change was such that the resident participants demonstrated significantly higher overall quality of life according to the HHA caregivers following the music intervention than at the baseline. In addition, a repeated-measures ANOVA was completed for each of the five ADRQL domain subscales to identify which specific domains changed and to what degree. The same was true for all five of the ADRQL domain subscales. SI: $F = 8.68, p = .000, \eta^2 = .49$; AS: $F = 9.99, p = .000, \eta^2 = .49$; FM: $F = 5.68, p = .004, \eta^2 = .39$; EA: $F = 5.38, p = .005, \eta^2 = .
.38; and RS: $F = 11.99$, $p = .000$, $\eta^2 = .57$. The results were significant and supported the efficacy of using individualized music programming for improving the health-related quality of life for seniors in the assisted living environment.

Table 4.10

*Repeated-Measures ANOVAs, HHA Caregivers Only (N = 6)*

<table>
<thead>
<tr>
<th>Scale</th>
<th>$F$</th>
<th>$p$</th>
<th>$\eta^2$</th>
</tr>
</thead>
<tbody>
<tr>
<td>ADRQL Overall</td>
<td>9.54</td>
<td>.000</td>
<td>.52</td>
</tr>
<tr>
<td>SI</td>
<td>8.68</td>
<td>.000</td>
<td>.49</td>
</tr>
<tr>
<td>AS</td>
<td>9.99</td>
<td>.000</td>
<td>.53</td>
</tr>
<tr>
<td>FM</td>
<td>5.68</td>
<td>.004</td>
<td>.39</td>
</tr>
<tr>
<td>EA</td>
<td>5.35</td>
<td>.005</td>
<td>.37</td>
</tr>
<tr>
<td>RS</td>
<td>11.99</td>
<td>.000</td>
<td>.57</td>
</tr>
</tbody>
</table>

*Note.* Social Interaction (SI), Awareness of Surroundings (AS), Feelings and Mood (FM), Enjoyment of Activities (EA), Response to Surroundings (RS).

**Strength of the effect.** Statistical significance, as determined by a $p$ value less than .05, indicates that the difference between the means is unlikely to occur if the null hypothesis is true (Gamst, Meyers, & Guarino, 2008; Urdan, 2010). However, the $p$ value is not able to indicate how strong of an effect the independent variable (e.g., individualized music programming) has on the dependent variable (e.g., quality of life as measured by ADRQL). Therefore, to interpret effect strength it is necessary to use a measure of effect size. Reporting effect sizes facilitates the interpretation of the substantive, as opposed to only the statistical significance of this research result.
In this analysis, eta-squared was used as the measure of effect size ($\eta^2$), which indicates what percentage of the variability in overall quality of life and each of the five ADRQL domain means can be attributed to the introduction of the individualized music programming. The eta-squared ranges from 0 to 1, and interpreting eta-squared depends on the context of the research (Gamst et al., 2008). Although what a researcher interprets to be a weak, moderate, or strong effect can vary: common thresholds of eta-squared values of .09 or less are considered weak, values of .10-.21 are considered moderate, and values of .22 or higher are considered strong (Gamst et al., 2008). By these standards, the effect sizes found in this study were very strong. The strongest were for subscales RS ($\eta^2 = .57$) and overall quality of life ($\eta^2 = .52$). The weakest effects, although still strong, were for subscales FM ($\eta^2 = .39$) and EA ($\eta^2 = .37$).

**Research question 2.** Is there a correlation between the importance of music in a senior’s life as reported by close family members prior to any cognitive impairment and any health-related effects of individualized music programming? The hypothesis is that there would be a significant positive relationship between the degree of music involvement and quality-of-life improvements and that those with a lifelong involvement in music prior to cognitive impairment will show greater effects as a result of 6 weeks of individualized music programming.

To this end, the APMP was used to obtain information regarding the resident participants’ personal music preference as well as to identify the importance of music in their lives prior to any cognitive impairment. In this study, only two resident participants provided APMP input. However, when a participant was unable to provide information due to cognitive impairment, it was the family members who provided the information.
In terms of music selections, it was clear that resident participants enjoyed music from the 1940s and 1950s, which is consistent with the literature regarding the music encountered during one’s late adolescence and early adulthood having the greatest nostalgic impact on individuals throughout their lives (Koelsch, 2012; Krumhansl & Zupnick, 2013; Powell, 2016). This reminiscence bump of phase of life is when there are many first experiences that are nostalgic, still vivid, and are often linked to self-identity, and it is the time period when older adults tend to have disproportionate autobiographical references (Krumhansl & Zupnick, 2013). That said, it was no surprise that the big-band swing artists, such as Benny Goodman and Glenn Miller, were popular among the participants’ playlists. Jazz was also well liked, including artists such as Ella Fitzgerald, Billie Holiday, Louis Armstrong, and Nat King Cole. Other favored music of the 1940s and early 1950s included songs by Tony Bennett, Rosemary Clooney, Dean Martin, Bing Crosby, Perry Como, Connie Francis, and Frank Sinatra. Bobby Darin was also a frequent choice for the resident participants because he performed in a range of musical genres. Broadway musicals from the 1940s and 1950s were common among participants including several by Rodgers and Hammerstein, such as “Oklahoma,” “Carousel,” “South Pacific,” and “The Sound of Music.” There were resident participant playlists that included classical music such as Vivaldi, Mozart, Haydn, and Beethoven. Other unique music selections included French Christmas carols and the Dorsey Brothers. A few playlists did include some of the early pioneers of rock n’ roll such as Elvis Presley and Chuck Berry.

Music importance, as captured by the APMP, included singing enjoyment and the playing of musical instruments, and they are presented in Table 4.11. Music was rated as
moderately important or very important for eight of the resident participants (73%). Of the 11 participants, 64% (7) did not play instruments and seven (64%) enjoyed singing.

Table 4.11

*Importance of Music (N = 11, no missing data)*

<table>
<thead>
<tr>
<th>Variable</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Music Importance</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very Important</td>
<td>5</td>
<td>45.45</td>
</tr>
<tr>
<td>Moderately Important</td>
<td>3</td>
<td>27.27</td>
</tr>
<tr>
<td>Slightly Important</td>
<td>2</td>
<td>18.18</td>
</tr>
<tr>
<td>Not Important</td>
<td>1</td>
<td>9.09</td>
</tr>
<tr>
<td><strong>Played an Instrument</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>4</td>
<td>36.36</td>
</tr>
<tr>
<td>No</td>
<td>7</td>
<td>63.63</td>
</tr>
<tr>
<td><strong>Enjoyed Singing</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>7</td>
<td>63.63</td>
</tr>
<tr>
<td>No</td>
<td>4</td>
<td>36.36</td>
</tr>
</tbody>
</table>

*Note:* Resident participants’ importance of music (importance, played instrument, enjoyed singing) prior to cognitive impairment. In this study, only two residents provided APMP input, the rest were provided by close family members.

**The importance of music correlation.** Research Question 2 addressed the relationship between the importance of music prior to cognitive impairment and any health-related effects on quality of life as a result of individualized music programming. Thus, change scores were correlated with three variables: the importance of music, history of singing, and history of playing an instrument. As a result of Pearson correlations, there was no correlation found between the importance of music and changes in overall quality of life or any of the five ADRQL domain subscales ($r = -.09$, \(r = -.09\), \(r = -.09\), \(r = -.09\), \(r = -.09\), \(r = -.09\)).
Thus, there was no evidence to reject the null hypothesis (no relationship to the importance of music and changes in quality of life).

Additional analyses. In addition to the two research questions, change scores were used to determine if the resident participants’ age and type of dementia was correlated with greater change. For participant age, the Pearson correlations found that age and changes in overall quality of life were not correlated \((r = -0.079, p = .828)\). Therefore, resident age was not a factor in this study. To test if dementia type (Alzheimer’s, vascular, or mixed) was related to change scores, the Kruskal-Wallis Test was used. No significant differences were found \((p = .982)\). Therefore, dementia type was not a factor.

Finally, the number of music-listening sessions attended was tested against change scores in an effort to determine if the number of listening sessions correlated with overall quality of life or any of the ADRQL domain subscales. There was a total of 18 listening sessions during the study as outlined in Table 4.12. Several of the participants attended all 18 listening sessions, and the average number of sessions attended was 15.72. The fewest number of sessions attended was 13.

Table 4.12

<table>
<thead>
<tr>
<th>Number</th>
<th>Music Listening Sessions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lowest</td>
<td>13</td>
</tr>
<tr>
<td>Highest</td>
<td>18</td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>15.72 (1.90)</td>
</tr>
</tbody>
</table>

Change scores were correlated with the total number of music listening sessions attended, and there was no correlation found between number of listening sessions,
overall quality of life, or any of the five ADRQL domain subscales \( r = -.299, p = .401 \).

It should be noted that there was relatively little variability in the number of listening sessions attended (13-18).

**Chapter Summary**

The world is faced with the social and economic challenges of providing for millions of people with Alzheimer’s disease and related dementias. Thus, establishing evidence for a cost-effective, non-pharmacological therapeutic intervention, such as individualized music programming, can make an important contribution to the field of senior care and services, particularly as quality of life emerges as an outcome measure in institutional environments. Using quantitative analysis, this study explains the findings related to the following research questions:

**Research question 1.** *From the perspectives of caregivers, are there significant health-related quality of life effects on seniors diagnosed with Alzheimer’s disease, or a related dementia, as a result of individualized music programming?* When using assessments by all staff members, the data revealed that using a repeated-measures ANOVA, the effects of individualized music programming resulted in an increase in quality of life from baseline through final assessment, although not significant at the .05 \( \alpha \). However, when using the assessments of only the HHA caregivers, there were significant, positive changes in overall quality of life as well as in each of the five ADRQL domain subscales. The results were significant at the .05 \( \alpha \) and support the efficacy of the individualized music programming for improving the health-related quality of life for seniors in the assisted living environment.
Research question 2. Is there a correlation between the importance of music in a senior’s life and any health-related effects of individualized music programming? The study took into consideration the importance of music prior to cognitive impairment and its correlation to any health-related quality-of-life effects. As a result, there was no correlation between the importance of music and changes in overall quality of life or any of the five ADRQL domain subscales, indicating that individualized music programming worked in similar ways, regardless of the importance of music prior to cognitive impairment.

In recent years, the knowledge gained with respect to the care and treatments available to both the families and the caregivers of seniors with Alzheimer’s disease and related dementias has the potential to enrich care practices and introduce new understandings of the therapeutic possibilities. This study supports using music as a cost-effective, non-pharmacological therapeutic tool to help seniors maintain their highest practicable quality of life while burdened with the complications of a failing memory. Chapter 5 reviews the findings of this study, including the study limitations, reflection on the research process, and expository implications for senior care and service providers in an effort to improve care and services, inspire additional research, and potentially influence legislation.
Chapter 5: Discussion

Introduction

Alzheimer’s disease and related dementias are a progressive and increasingly common neurodegenerative disease disorder. Behavioral disturbances, including wandering, aggression, psychosis, and apathy are among the most disabling symptoms of the disease, and create limitations, particularly in institutional environments. Such disease symptoms do not always respond well to medications, so alternative and supplemental interventions are of great interest. This study demonstrates that individualized music programming is an intervention with proven effects on quality of life, is relatively inexpensive, is easy to administer, and has little capacity to do harm. While its efficacy in the field of senior care and services needs further investigation, studies, such as this, suggest a role for individualized music programming as part of a comprehensive plan to improve the quality of the lives served. The intervention is versatile and can be implemented in a variety of settings including those in the community. The purpose of this study was to create a unique experimental condition and build on the previous research using individualized music programming and an Alzheimer’s-disease and related dementia-specific quality of life measurement instrument in an assisted living environment.

There were two hypotheses tested. Hypothesis 1 was that caregivers will notice significant improvements in the health-related quality of life of seniors diagnosed with Alzheimer’s disease or related dementias who live in a discrete memory care unit in an
assisted living environment after 6 weeks of individualized music programming.

Hypothesis 2 stated that there would be a significant positive correlation between the
degree of music involvement (e.g., higher importance of music, played an instrument, or
enjoyed singing) and quality of life improvements for those tested, as a result of 6 weeks
of individualized music programming, compared to resident participants who were less
involved in music. The ADRQL assessment instrument incorporated important
characteristics of daily life beyond activities of daily living such as social interaction,
response to surroundings, and mood and was used to test the first hypothesis. The APMP
was used to obtain information regarding participants’ personal music preference as well
as to identify the importance of music in their lives prior to any cognitive impairments,
and it was used to test hypothesis two.

When using the ADRQL assessments by all eight staff-member participants, the
data revealed that the effects of 6 weeks of individualized music programming resulted in
an increase in quality of life, although it was not significant. Simply put, the collective
staff (professional and direct caregivers) did not observe statistically significant
improvements over the baseline. However, when using the assessments of only the six
HHA caregivers, a series of repeated-measures ANOVAs found that there were
significant, positive changes in overall quality of life as well as in each of the five
ADRQL domains that make up the quality-of-life assessment. As direct caregivers, the
HHAs observed significant improvements over the baseline, and the results support the
efficacy of this intervention.

This study sought to answer questions of the effects on health-related quality of
life through a caregiver’s perspective. It therefore is reasonable that observations by the
HHA caregivers were unique because they are able to witness many more non-verbal forms of communication exhibited by the participant with cognitive impairments such as body language, gestures, and facial expressions (Black et al., 2009). This may also include observable perceptions of how a participant felt, their relationships within the environment as well as with those within their community. Perhaps more importantly, the HHA caregivers were not independent of the residents’ activities of daily-living, personal-care needs on any given day.

While professional staff offer a clinical perspective, in this setting, the HHA caregivers have a greater understanding of the residents given that they have much more direct and profound contact and may be able to discern subtle, nuanced, behaviors more accurately than the professional staff (Makai, Beckebans, van Exel, & Brouwer, 2014). Also, it should be noted that in this study the HHA caregivers had known the residents for a much longer time than the professional staff (the average tenure for HHAs was 29 months versus only 4.5 months for the professional staff). One other staff demographic should be noted: the average age of the HHA caregivers was 4 years older than the professional staff in this study. Notwithstanding the issue of staff tenure, it seems likely that the discrepancy between the ratings occurred simply because there existed two very distinct relationships of assessment, which may have, in turn, produced different outcomes. Also, there was the potential for a caregiver’s own health or stressors to affect his or her evaluation of the perceptions of the residents’ quality of life (Black et al., 2009; Rabins et al., 1999). However, the findings of this study cannot correlate an influence of staff participant age or health. Regardless, the findings warrant a greater focus of
attention to direct-care employees from senior-care and service administrators in this care setting and others.

Regarding the evaluation of the importance of music prior to cognitive impairment and its correlation to any quality-of-life effects, the data shows that the correlation between importance of music and the quality-of-life change scores indicated no relationship. Does this indicate that the individualized music programming worked in similar ways, regardless of the importance of music or that there was no relationship to importance of music? There is an argument against the hypothesis that relationship to music is important because the results show that the participants’ relationship to music was not an explanatory factor. However, according to the literature, a key variable contributing to the effectiveness of individualized music programming is the ability to assess and identify personally meaningful music selections for seniors (Gerdner, 2010; Ridder et al., 2013; Sung et al., 2010; Thomas & Smith, 2009). In this study, the individualized playlist development was not robust. Simply put, either the findings suggest that the changes in quality of life were influenced by a different set of factors than those tested, or the study’s limitations affected the outcome.

Comparison to previous research was difficult, as there were limited studies on the importance of music and no studies examining the effect of importance of music with improvement in quality of life after individualized music programming in assisted living. According to Spiro (2010), “A number of characteristics set musicians apart from untrained individuals related to practice and memory of movement, patterning and auditory material – aspects that are particularly important for dementia (p. 896). As a result of this study, however, the question of one’s relationship to music needs to be
studied for a deeper understanding of relatedness to the influences of music on this study population.

**Implications of Findings**

There are several implications inherent in the findings of this study. First, the type of programming that was used fits well within the practical application of statute-driven minimum standards for recreation/activities/cultural arts in regulated entities (i.e., nursing homes, assisted living, and adult day services). For example, in New York’s nursing homes, each facility “shall provide for an ongoing program of activities designed to meet, in accordance with the comprehensive resident assessment, the interests and the physical, mental and psychosocial well-being of each resident” (NY. Stat. Ch. 10 § 415.5 Part 5 Quality of life (f) Activities, 1998, p. 10,204). The intent is to support residents in their choice of activities and that the programming in facilities meets the interests and supports the physical, mental, and psychosocial well-being of each resident.

In New York’s assisted living program, operators are “responsible for the provision or arrangement of resident services, which shall include, at a minimum, housing, 24 hour on-site monitoring, daily food service, case management services, development of an individualized service plan, personal care and/or home care services” (NY. Stat. Ch. 10 § 4662 Part 10011001.1 Resident Services (k) Individualized Service Plan, 2008, p. 41). In the special-needs environment within an assisted living program (such as Alzheimer’s and related dementia care environment used in this study), operators shall “provide frequent individual and group activities which are geared towards individuals with special needs and which are meaningful to the residents. This programming shall be based on initial and on-going, historical and current, interests,
assessments, and observations” (NY. Stat. Ch. 10 § 4662 Part 10011001.1 Resident Services (k) Individualized Service Plan, 2008, p. 52). The individualized music programming used in this study fits well within the minimum standards required for this environment. In New York’s adult day services environments, operators must:

- Ensure that activities are [an] integral part of the program, are age appropriate, and reflect the registrants’ individual interests and cultural backgrounds; ensure that activities are designed to enhance registrant participation in the program, home life and the community; involve appropriate volunteers and volunteer groups in the program, unless prohibited by law; provide sufficient equipment and supplies for the operation of the activity program; provide or arrange for transportation to and from community events and outings; and ensure that activities are included as part of each registrant’s care plan. (NY. Stat. Ch. 10 § 425.14 Part 14 Activities (a-f) Adult Day Health Care, 2014, p. 10,282)

As a non-pharmacological intervention, individualized music programming is relatively easy to implement, even in a community-based setting such as in adult day services.

Further, state surveyors’ interpretive guidelines for these regulated entities require that facilities identify each resident’s interests and needs, and the facility must involve the resident in ongoing programs that are designed to appeal to his or her interests. These include, but are not limited to, programming that promotes self-esteem, pleasure, comfort, education, creativity, success, and independence. To this end, best-practice expectations should include a variety of music options including individualized music programming. For those with hearing impairments, use of amplifiers or headphones, decreased background noise, adapted TV (closed captioning, magnified screen,
earphones) should be considered. For those who prefer to stay in her/his own room, there can be access to the technology of interest (computer, DVD, handheld video games, preferred radio programs/stations, audio books). Individual and group music offerings must fit residents’ taste and era, and/or contemporary group activities, including the opportunity to play musical instruments, and for those from diverse ethnic or cultural backgrounds, there should be special events that include music and/or opportunities to share information, including the music of their culture with others.

More outcome metrics, particularly in assisted living, must be developed. The current infrastructure needs to facilitate the development and collection of dementia-related, quality-of-care and service measures, including quality-of-life metrics to be applied across care settings and disease stages. Outcome data will enable the transition away from reimbursement based on fee-for-service models and toward reimbursement based on outcomes, which is arguably difficult in today’s assisted living settings. However, once established, these metrics could drive the delivery of better care to where evidence-based outcomes are known.

The data suggest some specific recommendations for practical applications of senior care and service providers. Music is an integral part of cultural arts programming, and the findings of this study provide a basis for an expectation that individualized music programming can become commonplace in regulated environments. Most in-patient settings are required to have recreation space, recreation calendars, and many facilities employ various forms of music in their cultural arts programming; yet, music is most often not individualized, and personal music preferences are not always considered. Staff training in this regard is essential (Chang et al., 2010; Kolanowski et al., 2010; Lai &
Good, 2005; Ridder et al., 2013; Thomas & Smith, 2009). The most beneficial responses of listening to music are elicited when seniors listen to music that is familiar and meaningful to them. Therefore, staff member’s familiarity with music selection is very important for producing optimal resident outcomes (Lee, 2013).

Although turning on an MP3 player, CD, or video requires very little effort, caregivers (both family and staff) have limited experience with therapeutic music interventions. In addition, in institutional environments, caregivers often have considerably high turnover rates and experience greater mental and physical stress, complicating the environmental challenges. Adding individualized music programming can potentially reduce caregiver stressors. The programming could help to steady the environments by reducing resident agitation, quelling disruptions, and enabling caregivers to complete tasks within their time constraints. Simply put, the quality of the resident-caregiver interaction could be improved.

Finally, the most obvious implication as a result of this study is that it verifies that this type of programming is cost effective. The MP3 devices had four gigabytes of memory, could hold up to 100 songs, had 25 hours of battery life, and were purchased new for approximately $35.00 each. In addition, while most standard MP3 players come with earbuds, a much more comfortable set of headphones, such as those used in this study can be purchased new for approximately $15.00. Therefore, for a typical memory care unit (12-15 residents) the cost of the devices should not exceed $750.00. This does not include the cost of the music, which was nominal.
Limitations

The findings of this study support previous research on the positive effects of music on patients with Alzheimer’s disease or related dementias (Boulay et al., 2011; Chang et al., 2010; Cooke et al., 2010; El Haj et al., 2012; Fukui et al., 2012; Hammar et al., 2011; Lancioni et al., 2013; Lee et al., 2010; Raglio et al., 2010; Ridder et al., 2013; Sung et al., 2010; Thomas & Smith, 2009; Van de Winckel et al., 2004), and they provide promise to those afflicted with the disease, their families, caregivers, and senior care and service providers of all types. There were, however, limitations, most importantly the small convenience sample ($N = 11$). While there was consideration of increasing the total sample size, it was not feasible given practical, economic, and time constraints. The obvious disadvantage of this sample is that it is likely to be biased or have outliers, and one should be guarded that the data be taken to be representative and avoid making any formal inductive inferences. Also, while some of the demographics are representative of an assisted living environment, resident participants in this study were disproportionately female (90%) and all were White.

The ADRQL assessment instrument had its limitations, as it does not include measures of physical functioning and cognitive functioning, although both are important components (Rabins et al., 1999). However, excluding physical functioning and cognitive functioning as domains in the ADRQL was intentional, and it allowed for hypothesis testing regarding the relationship between the changes in quality of life and changes in physical and cognitive functioning. Another reason for excluding cognitive and physical functioning is the strong likelihood that these would dominate the
assessment of quality of life in Alzheimer’s and related dementia patients and render the instrument less sensitive to changes in other domains.

Finally, while this study used individualized music programming, the issue of music preference and the approach to obtaining music preference was a limitation because a positive correlation was expected between the degree of significance that music held in a person’s life prior to the onset of cognitive impairment and the intervention. According to the literature (Ridder et al., 2013; Sung et al., 2010; Thomas & Smith, 2009,) a key factor contributing to the effectiveness of an intervention such as this was the ability to assess and identify individually meaningful music selections; yet, in many cases, the music preference input in this study was not always strong. Preferences were captured by this researcher for each participant by either interviewing the participant or his or her family members and with input from the facility’s full-time music therapist. Where possible, specific songs were identified, but the majority of the families had difficulty identifying specific artists and specific song titles. Based at times on limited information, in the end, this researcher chose some of the listening material. Music preference is very personal and inaccurate assumptions of music type a resident may enjoy could have a negative impact on the efficacy of the intervention (Gerdner, 2010).

**Reflections on the Research**

After the final assessment, a 6-month process check with the professional staff who participated in the study yielded interesting feedback. It was pleasing to hear that the individualized music programming continued subsequent to the completion of the study, albeit once weekly versus three times per week. However, it was disappointing that the one new admission to the unit did not have an APMP assessment and no
individualized playlist was made available. Reflecting on the process, the staff emphasized that the listening sessions provided a calm environment, the residents enjoyed the programming, and from a cultural arts perspective, the study was successful. Subsequent to the completion of the study, there were no comments or questions from families, although one family requested the MP3 device for their family member while recovering in the rehabilitation unit after an acute hospital stay. It was also shared that the nursing home on the campus plans to implement an individualized music program and that the program was grant funded.

**Staff reflection.** While the ADRQL instrument was designed to easily assess observations of various aspects of quality of life of those who provide the direct care to people with Alzheimer’s disease and related dementias, the assessments themselves took much longer to administer than anticipated. For some staff members, the assessments were effortless, but for others it was much more time consuming. Questions often needed to be repeated, and several staff required reminders that the responses needed were *agree* or *disagree* and not *yes* or *no* or *true*. Several caregivers needed to be reminded that the statements described a resident’s behavior at any time *in the last 2 weeks*. In addition, the negatively phrased items were often confusing, and an extra effort was needed to help the staff to understand their responses and to ensure they were recorded accurately.

In this researcher’s subjective view, the staff appreciated the opportunity to be part of something meaningful, and they responded with sincerity—not with responses that they thought were the correct answers or answers leading to a successful study. In terms of outcome data, although the patterns were similar, it was surprising that there would be enough of a variance using just the HHA caregiver perspective to make a
A statistically significant difference in the data. Perhaps there could be modifications to the ADRQL instrument to reflect professional (licensed, college educated) versus non-professional caregivers.

It should be noted that the third-shift (night) staff, those typically working 11:00 p.m. to 7:00 a.m., for a variety of practical reasons, were not included in the study. There was nothing in the literature regarding the importance of capturing this cohort. Also, their exclusion was rationalized by determining that the staff working this shift did not interact with the residents in the same way as the day caregivers, thus making their involvement irrelevant. In hindsight, assessments from staff working the third shift may have been informative.

**Family reflection.** All of the resident participants’ families participated in the study. Without hesitation, the families valued the importance of music in their family members’ lives and in the potential positive effects on their quality of life—either through personal experience, anecdotal observations with their loved ones, or in an inherent belief in the power of music. The families were terrific to work with, responsive, and they made every effort (however, at times limited) to provide as much information on music preferences as possible.

**Resident reflection.** For this senior care and service administrator, the study was a joy. After the first week, the residents verbally expressed enjoyment and appreciation at one time or another during each of the music sessions. It should be noted that during the listening sessions, the residents were, at times, particularly interested in what the other participants were listening to, the deduction being that residents in this environment
were so accustomed to participating in music listening programming as a group, it was puzzling to have their own personalized music playlist.

**Recommendations**

Until the disease is experienced personally, not enough Americans recognize the devastating impact that Alzheimer’s disease and related dementias have on individuals, and their families; and even fewer understand the broader impact on the nation in the decades to come. Therefore, while this country debates the nation’s most pressing reform imperative, the President and Congress need to declare the issue of Alzheimer’s disease and related dementias a healthcare-reform imperative, as it is currently estimated that the United States will spend $20 trillion through Medicare and Medicaid appropriations by 2050 (Alzheimer’s Study Group, 2009). As the current funding levels are low relative to the national burden attributable to the disease, Congress needs to increase funding to all applicable agencies, and stakeholders must envision a national healthcare system with a highly skilled workforce to accommodate the future needs. Those individuals already working in the system should receive relevant training and increased healthcare appropriations at state and federal levels to sponsor additional certification requirements with incentives and, most certainly, support training of cost-effective, evidence-based, low-tech tools such as was used in this study.

Just as government has a role in healthcare delivery, it has a role in the evolution of technological advances in healthcare reforms. An increase in appropriations would encourage the development of new, breakthrough technologies or, at a minimum, the furthering application of existing technology, such as the MP3 devices used in this study, and smartphone applications and internet-based support tools must become commonplace.
in senior-care and services environments because they have the potential to reduce cost and improve services. These tools will continue to evolve, but the next generation of seniors will have an expectation that such tools will be commonplace.

An investment in neurologic music therapy research will help to further the therapeutic application of music to cognitive, sensory, and motor dysfunctions. The field, which is subdivided according to type/credential of expertise as well as by the perspective of the practitioners (i.e., neurologists, music therapists, and musicians), collectively need to apply the influence of music to study functional changes and treatment techniques need to be standardized and evidence-based.

In addition, there should be more emphasis placed on research because it is the keystone for new therapies and alternative care models. Stakeholders must find ways to attract and develop scientific and medical researchers who will dedicate their careers to understanding Alzheimer’s and related dementias and to ultimately cure the disease. Researchers and senior care and services providers should be encouraged to collaborate, build on existing capabilities, and create a national network of information exchange that will foster the systemic integration of research, whether it involves clinical investigations, the practical delivery of care and services, or simply an exchange of best-practice information.

Also, senior care and service administrators must pay attention to the sound of institutional environments. Much of the environments consists of hard surfaces designed for durability and disinfecting, with alarms and paging systems used frequently, and staff become desensitized. Minimizing excess alarms to the degree practicable is the first step in creating an improved soundscape. Patient healing experiences must include
harmonious, peaceful sound experiences. The point is not to hide the reality of the environment but, rather, to create an improved healthy sound atmosphere for residents and the caregivers who work there.

While the study had its delimitations to which generalizations can be made, more rigorous studies into the interaction effects of confounding variables, such as medication correlations, one’s living environment, type and severity of dementia, education levels, and other socioeconomic factors, will need to be addressed. In addition, qualitative research in subsequent studies should include interviews with resident participants, staff, and families. While the findings of this study have implications for further research in a variety of senior-care and service environments, future studies should address the following:

1. Increase the resident sample size (e.g., diversity, geographic locations, and so on).
2. Replicate the study with a control group.
3. Include populations in alternative environments such as those living at home, in nursing homes, and in adult day centers.
4. Include staff assessments from those working from 11:00 p.m. to 7:00 a.m.
5. Increase staff sample size to compare data between shifts.

As a final recommendation, healthy individuals should create personal digital content that can be stored with advanced directive information. With the assistance of family or friends, questions to inspire playlist material beyond those used in this study are:

- What five pop artists do you love most?
• What are your favorite albums/CDs?
• What were your 10 favorite songs in high school?
• What were the best concerts you ever attended?
• Which musicals or films had the best music?
• What are your favorite music videos?

The process will be pleasurable and facilitate a lifespan music review in the event of cognitive or other health-related change.

Conclusion

In the United States and around the world, senior-care and services providers use evidence-based guidelines to determine if interventions improve outcomes. Effective non-pharmacological approaches to care, in an effort to improve quality of life for those with Alzheimer’s disease and related dementias are essential, particularly given the increasing prevalence of the disease as well as the negative consequences of the many behavioral problems. The results of the study provide more evidence that alternative non-pharmacological approaches to care should be a tool in a senior-care and service provider’s portfolio. The study also confirmed that studies regarding quality of life for those with Alzheimer’s disease and related dementia are not yet exhaustive, have not been sufficiently investigated, and need additional attention.

This study builds on previous research by having created a unique experimental condition, using individualized music programming, and an Alzheimer’s disease and related dementia-specific quality-of-life measurement instrument in the assisted living environment. The two research hypotheses tested were: (a) individualized music programming for seniors with Alzheimer’s disease and related dementias who live in a
discrete memory care unit in an assisted living environment will, according to their
caregivers, result in observable improvements in quality of life, and (b) those participants
who were more involved in music prior to cognitive impairment (e.g., higher importance
of music, played an instrument or enjoyed singing) will show greater correlation as a
result of the individualized music programming than participants who were less involved
in music.

The 6-week quantitative study was conducted with residents and staff of a discrete
unit in an assisted living environment that was the first level of state-regulated congregate
living for those with cognitive impairment. To assess health-related quality of life, the
Alzheimer’s Disease Related Quality of Life instrument was used to gain the perspective
of caregivers as they were closely involved in the daily lives of participants in this setting
(Black et al., 2009; Rabins et al., 1999). Individualized music preferences and the
importance of music in the lives of the residents was captured by the Assessment of
Personal Music Preference (Gerdner et al., 2000).

The data revealed that the effects of 6 weeks of individualized music
programming resulted in an increase in quality of life from baseline through final
assessment. Further, when only using the assessments of the home health aide staff, a
series of repeated-measures analysis of variance found that there were significant
improvements in quality of life, supporting the efficacy of this intervention in the assisted
living environment. The data also show that the correlation between importance of music
and the quality of life scores has no relationship, indicating that the intervention works in
similar ways, regardless of the importance of music to the participant prior to cognitive
impairment.
There is a long list of non-pharmacological therapies currently in practice for seniors with Alzheimer’s disease and related dementias, including a variety of music therapy approaches, and this study shows promising results in the use of individualized music programming. However, with methodological challenges and limitations in relation to sample size, and demographic characteristics, further research is needed to avail senior-care and service providers with the knowledge of viable alternatives.

As one of the oldest and most-accepted modes for expressing ourselves, music is biologically ingrained, elicits emotional responses, and stimulates memories (Thaut, 2005). According to Sacks (2010):

The aim of music therapy in people with dementia . . . seeks to address the emotions, cognitive powers, thoughts and memories, the surviving self of the patient, to stimulate these and bring them to the fore. It aims to enrich and enlarge existence, to give freedom, stability, organization and focus. (pp. 372-373)

Finally, as a concept central to senior-care and service providers, quality of life is dynamic, it exists everywhere on the care and service continuum, it varies for each person depending on their life circumstances, and it exists independently from illness and disease. According to the literature, many studies have quantified the positive effects of various forms of music programming for those with cognitive impairments, such as agitation, anxiety, food intake, sleep, pain, and even quality of life, which is this study’s primary contribution to the field (Boulay et al., 2011; Chang et al., 2010; Cooke et al., 2010; El Haj et al., 2012; Fukui et al., 2012; Hammar et al., 2011; Lancioni et al., 2013; Lee, 2013; Lee et al., 2010; Raglio et al., 2010; Ridder et al., 2013; Sung et al., 2010;
Thomas & Smith, 2009; Van de Winckel et al., 2004). Although progress has been made toward building a body of evidence in recent years, it is still only the beginning of a collective understanding of the relationship between music and its therapeutic effect on those with Alzheimer’s disease and related dementias.
References


randomized controlled trial. *Journal of Alzheimer’s Disease, 38*(2), 359-369. doi:10.3233/JAD-130893


Appendix A

Study Request Letter to Family Member

DAVID J. GENTNER

(Date)

(Name)

(Address)

Dear ____________________, (Family Member, Primary MD, Interdisciplinary Care Team)

My name is David Gentner and I am an Ed.D. student at Saint John Fisher College in Rochester, NY. I am doing research to determine what effects, if any individualized music therapy programming has on health-related quality of life for assisted living residents with Alzheimer’s disease or a similar type of dementia. I am also interested in the importance of music in your family member’s life and how this potentially relates aspects of the data.

If you would like your family member to participate in this study, included in this mailing is an informed consent form to be signed by individuals with legal power of attorney for health care decisions. Also attached is an Assessment of Personal Music Preference, which will help create a music playlist that is unique to your family member.

It is my hope that you are supportive of this study, both for your family member’s enjoyment of participating in an individualized music therapy program and for the future of Alzheimer’s disease and related dementia research. If you have any questions about the material or any aspect of the study, please contact me at ________________.

Warmest regards,

David J. Gentner
Appendix B

Assisted Living Residence-Resident Rights and

Informed Consent Form

Every resident’s participation in assisted living shall be voluntary, and prospective residents shall be provided with sufficient information regarding the residence to make an informed choice regarding participation and acceptance of services;

Every resident’s civil and religious liberties, including the right to independent personal decisions and knowledge of available choices, shall not be infringed;

Every resident shall have the right to have private communications and consultations with his or her physician, attorney, and any other person;

Every resident, resident’s representative and resident’s legal representative, if any, shall have the right to present grievances on behalf of himself or herself or others, to the residence’s staff, administrator or assisted living operator, to governmental officials, to long term care ombudsmen or to any other person without fear of reprisal, and to join with other residents or individuals within or outside of the residence to work for improvements in resident care;

Every resident shall have the right to manage his or her own financial affairs;

Every resident shall have the right to have privacy in treatment and in caring for personal needs;

Every resident shall have the right to confidentiality in the treatment of personal, social, financial and medical records, and security in storing personal possessions;

Every resident shall have the right to receive courteous, fair and respectful care and treatment and a written statement of the services provided by the residence, including those required to be offered on an as-needed basis;

Every resident shall have the right to receive or to send personal mail or any other correspondence without interception or interference by the operator or any person affiliated therewith;

Every resident shall have the right not to be coerced or required to perform the work of staff members or contractual work;
Every resident shall have the right to have security for any personal possessions if stored by operator;

Every resident shall have the right to receive adequate and appropriate assistance with activities of daily living, to be fully informed of their medical condition and proposed treatment, unless medically contraindicated, and to refuse medication, treatment or services after being fully informed of the consequences of such actions, provided that an operator shall not be held liable or penalized for complying with the refusal of such medication, treatment or services by a resident who has been fully informed of the consequences of such refusal;

Every resident and visitor shall have the responsibility to obey all reasonable regulations of the residence and to respect the personal rights and private property of the other residents;

Every resident shall have the right to include their signed and witnessed version of the events leading to an accident or incident involving such resident in any report of such accident or incident;

Every resident shall have the right to receive visits from family members and other adults of the resident’s choosing without interference from the assisted living residence; and

a) Every resident shall have the right to written notice of any fee increase not less than forty-five days prior to the proposed effective date of the fee increase, provided however, providing additional services to a resident in accordance with section 461-c(2) of the Social Services Law, shall not be considered a fee increase pursuant to this paragraph in the following situations:

b) if a resident, resident representative or legal representative agrees in writing to a specific rate or fee increase, through an amendment of the residency agreement, due to the resident’s need for additional care, services or supplies, the operator may increase such rate upon less than forty-five days written notice;

c) if the operator provides additional care, services or supplies upon the written order of the resident’s primary physician, the operator may, through an amendment to the residency agreement, increase such rate upon less than forty-five days written notice; or

d) in the event of an emergency which affects the resident, the operator may assess additional charges for the benefit of the resident as are reasonable and necessary for services, materials, equipment and food supplies during such emergency.

Every resident of an assisted living residence that is also certified to provide enhanced assisted living and/or special needs assisted living shall have a right to
be informed by the operator, by a conspicuous posting in the residence, on at least a monthly basis, of the then-current vacancies available, if any, under the operator’s enhanced and/or special needs assisted living programs.

Informed Consent for Participation in the Research

Purpose
I understand that the purpose of this research is to investigate the use of individualized music as an intervention for improved quality of life for persons in assisted living with Alzheimer’s disease or related dementia.

Participants
I understand that the person for whom I have legal power of attorney for health care decisions has been asked to participate because they have been diagnosed with Alzheimer’s disease or related dementia.

Procedure
I understand the researcher will ask several questions of the participant, the legal power of attorney for health care decisions and close family members to determine the significance of music prior to the participant’s memory impairment as well as information regarding the participant’s musical preference. Once an individualized playlist is obtained it will be delivered via MP3 player with headphones while in a group setting. Each music intervention session will last approximately 30 minutes or longer if the participant wishes to continue and per facility programming. This music therapy session will be scheduled at least three times per week in the afternoon hours between midday meal and evening meal, on three separate days (planning Monday, Wednesday and Friday), for a total of six weeks.

The Alzheimer’s Disease Related Quality of Life (ADRQL) (Black, Rabins, & Kasper, 2009; Rabins, Kasper, Kleinman, Black, & Patrick, 1999) research instrument will be used to assess quantitative health-related quality of life indicators of participants in this study. ADRQL was developed to meet the needs of researchers and clinicians for a disorder-specific measure of health-related quality of life for use in evaluating therapeutic interventions for persons with Alzheimer’s disease and other types of dementia across various care settings and various stages of the disease. Caregivers (staff) will complete the ADRQL for each participant in the study. The instrument is designed for staff to assess participants at two week intervals. Therefore, there will be three assessments during the music intervention, one every two weeks. In total there are five assessments. The ADRQL is completed by staff individually and will be administered at the end of their shift. Administration of the facility has agreed to provide staff support to ensure there is adequate time to complete the assessments.

Risks
I understand that there are minimal risks associated with participation in this study. If a participant appears to be disinterested or uncomfortable at any time, their participation in
the research will be terminated immediately. If a participant wishes to continue beyond
the formal programming session, staff will enable participant to continue.

**Benefits**  
I understand that the participants may not benefit directly from participating in the
study beyond the enjoyment experienced through listening to their own
individualized music programming. The results of this study, however, may yield
useful information to assist caregivers and family members of people with
Alzheimer’s disease and related dementia, thus the results may lead to improved
quality of life and quality of care. Participation in the study will not influence the
care and services provided. Also, this study will be conducted without cost and
without compensation.

**Confidentiality**  
Demographic data will be collected from each participant’s records regarding age,
gender, race, religion, education level, marital status, length of residency, medical
diagnosis, and medications. I understand that the findings of this study will be
completely confidential. In addition, confidentiality will be protected in that no
identifying information will be included on any records collected during this
study. All information will be kept in a secure location and destroyed after five
years.

**Right to Refuse or Withdraw**  
I understand that I may refuse to allow the person for whom I have power of
attorney for health care decisions to participate or withdraw them from the study
at any time during the study. Furthermore, withdrawal from the study may occur
if the participant chooses not to participate.

**Questions**  
I have been informed that if I have any questions, I am free to ask them. I
understand that if I have any additional questions, I may contact the researcher at
_________________, ______________, ____________, _______________ at
_________________. The dissertation chair for this study is ________________ and
can be reached at ________________________, ______________,  
__________________, ______________, _______________.

**Signature**  
My signature below indicates that I agree to allow the person for whom I have
power of attorney for health care decisions to participate in this research study
and that I have read this form, understand it, and have retained a copy.

_________________________   ________________  
Signature of power of attorney for health care  Date

_________________________   ________________  
Signature of Researcher     Date
Appendix C

Assessment of Music Preference (Family Version)

©Gerdner, Hartsock, & Buckwalter, (2000)

Music is often a very important part of people's lives. Please complete the questionnaire based on your knowledge of the patient's personal music preference.

Before illness, how important a role did music play in the patient's life?

1. Very Important ______
2. Moderately Important ______
3. Slightly Important ______
4. Not Important ______

Does/did the patient play a musical instrument? If yes, please specify (examples: piano, guitar).

Does/did the patient enjoy singing?
If yes, please specify (examples: around-the-house, church choir).

Does/did the patient enjoy dancing?
If yes, please specify (examples: attended dance lessons, participated in dance contests)

The following is a list of different types of music. Please indicate the patient's three (3) most favorite types with 1 being the most favorite, 2 the next, and 3 the third favorite.

1. Country and Western ______
2. Classical ______
3. Spiritual/Religious ______
4. Big Band/Swing ______
5. Folk ______
6. Blues ______
7. Jazz ______
8. Rock and Roll ______
9. Easy Listening ______
10. Cultural or Ethnic Specific ______
    (examples: Czech polkas, Ravi Shankar Indian sitar)
11. Other ______
Please put a check (✔) beside the most correct choice to the following questions.

What form does the patient's favorite music take?

1. Vocal
2. Instrumental
3. Both

Please identify specific songs/selections that make the patient feel happy.

Please identify specific artist(s)/performer(s) that the patient enjoyed listening to the most.

Please identify specific albums, audio-cassette tapes, or compact discs contained in the patient's personal music library.
Appendix D

St. John Fisher College IRB Approval Letter

October 3, 2016

File No: 3605-072116-10

David Gentner
St. John Fisher College

Dear Mr. Gentner:

Thank you for submitting your research proposal to the Institutional Review Board.

I am pleased to inform you that the Board has approved your Full Review project, “Music & Dementia: Effects of Individualized Music Therapy on Quality of Life in Elders Living in Assisted Living Environments”. The Board considers your project adequate to protect the rights and welfare of human subjects as well as meeting the standards for informed consent.

As principal investigator, you are responsible for promptly reporting (in writing), through your department head, the following:

- The location where the signed consent forms will be kept on file for a period of three years.
- Progress reports of the research will be sent to the Board annually. If the research is not concluded within a year’s time, you will need to petition the Board for a one-year renewal.
- Any injuries to human subjects.
- Any unanticipated problems that involve risks to the human research subjects or others.
- Changes in a research activity.
- Changes in research during the period for which the Board approval has already been given shall not be initiated by research investigators without the Board review and approval, except where necessary to eliminate apparent immediate hazards to the subject. In such occurrences, the Board is to be notified as soon as possible.

Following federal guidelines, research related records should be maintained in a secure area for three years following the completion of the project at which time they may be destroyed.
On behalf of the Board, I wish you success with your research project.

Should you have any questions about this process or your responsibilities, please contact me at irb@sjfc.edu.

Sincerely,

Eileen Lynd-Balta, Ph.D.
Chair, Institutional Review Board

ELB: jdr
Appendix E

HIPPA Business Partner Agreement

BUSINESS ASSOCIATE AGREEMENT

This Agreement is executed on the __________ day of ______, 20__ between ______________ INC ("COVERED ENTITY"), and ______________ ("BUSINESS ASSOCIATE").

Whereas the Covered Entity and Business Associate are parties to an underlying agreement ("Services Agreement") pursuant to which Business Associate provides certain services to Covered Entity, which services include or require the creation and receipt of Protected Health Information ("PHI") by Business Associate from or on behalf of Covered Entity;

Whereas the Covered Entity will make available to the Business Associate certain PHI to enable performance of the Services Agreement;

Whereas the purpose of this Agreement is to comply with the Federal Health Insurance Portability and Accountability Act of 1996, Pub. L. No. 104-291, as amended by the Health Information Technology for Economic and Clinical Health Act, Title XIII of the American Recovery and Reinvestment Act of 2009 ("HITECH Act"), and related regulations promulgated by the Secretary of Health and Human Services (collectively, "HIPAA"); and

Whereas the Covered Entity and the Business Associate are required by law to enter into this Agreement;

Now, Therefore, the Covered Entity and Business Associate agree to be bound by the following terms and conditions:

ARTICLE I. DEFINITIONS

The following capitalized terms used in this Agreement shall have the same meaning as those terms in the Regulations (defined below): Breach, Business Associate, Data Aggregation, Designated Record Set, Disclosure, Health Care Operations, Individual, Minimum Necessary, Notice of Privacy Practices, Required by Law, Secretary, Security Incident, Subcontractor, Unsecured Protected Health Information, and Use. Terms used, but not otherwise defined, in this Agreement shall have the same meaning as those terms in the Privacy and Security Rule, including 45 CFR 160.103 and 164.501.
A. Business Associate shall generally have the same meaning as the term "business associate" as defined in 45 CFR 160.103, and in reference to the party to this agreement, shall mean __________.

B. Breach Notification Rule shall mean the standards for Notification in the Case of Breach of Unsecured Protected Health Information at 45 CFR part 160 and part 164.

C. Covered Entity shall generally have the same meaning as the term "covered entity" as defined in 45 CFR 160.103, and in reference to the party to this agreement, shall mean The Osborn/Osborn Home Care.

D. Electronic Protected Health Information shall have the same meaning as the term "electronic protected health information" as defined in 45 CFR 160.103, limited to the information that Business Associate creates, receives, maintains, or transmits from or on behalf of Covered Entity.

E. Privacy Rule shall mean the Standards for Privacy of Individually Identifiable Health Information at 45 CFR part 160 and part 164.

F. PHI shall have the same meaning as the term "protected health information" as defined in 45 CFR 160.103, limited to the Information created or received by Business Associate from, or on behalf of, Covered Entity. PHI shall include Electronic Protected Health Information.

G. Regulations shall mean the regulations promulgated by the Secretary under HIPAA, as they may be amended from time to time, including but not limited to the Privacy Rule, the Security Rule and the Breach Notification Rule.


I. Services Agreement shall mean any present or future agreements, either written or oral, between Covered Entity and Business Associate under which Business Associate provides services to Covered Entity which involve the use or disclosure of PHI.

**ARTICLE II - OBLIGATIONS AND ACTIVITIES OF BUSINESS ASSOCIATE**

A. In its use and disclosure of PHI, Business Associate agrees to comply with HIPAA and the Regulations, and applicable State laws, rules and regulations. Without limiting the foregoing, Business Associate agrees to not use or disclose PHI other than as permitted or required by this Agreement or as required by Law.

B. Business Associate agrees to use appropriate safeguards, and comply with Subpart C of 45 CFR Part 164 with respect to Electronic Protected Health Information, to prevent use or disclosure of PHI, other than as provided for by this Agreement. Without limiting the foregoing, Business Associate will implement administrative, physical, and technical safeguards that reasonably and appropriately protect the confidentiality, integrity, and availability of PHI as required by the Security Rule.

C. Business Associate agrees to ensure that any subcontractors that create, receive, maintain, or transmit PHI on behalf of Business Associate agree to the same.
restrictions, conditions, and requirements that apply to Business Associate with respect to such information, in accordance with this Agreement and 45 CFR 164.502(e)(1)(i) and 164.308(b)(2), if applicable. Without limiting the foregoing, Business Associate otherwise agrees to obtain assurances from any agent, subcontractor, or third party to whom it provides PHI, that such third party agrees to the same restrictions and conditions that apply to Business Associate (i) through this Agreement, and (ii) directly to Business Associate pursuant to the Regulations.

D. Business Associate agrees to report to Covered Entity any use or disclosure of PHI not provided for by this Agreement of which it becomes aware, including Breaches of Unsecured Protected Health Information as required at 45 CFR 164.410, and any Security Incident of which it becomes aware.

E. Business Associate agrees to mitigate, to the extent practicable, any harmful effect that is known to Business Associate of a use or disclosure of PHI by Business Associate in violation of the requirement of this Agreement.

F. To the extent that Business Associate possesses or maintains PHI in a Designated Record Set (as such term is defined in 45 CFR 164.501), Business Associate agrees to make available PHI in such Designated Record Set to Covered Entity as necessary to satisfy Covered Entity's obligations under 45 CFR 164.524, as determined by Covered Entity, and in the time and manner designated by Covered Entity.

G. To the extent that Business Associate possesses or maintains PHI in a Designated Record Set, Business Associate agrees to make any amendment(s) to PHI in such Designated Record Set as directed or agreed to by Covered Entity pursuant to 45 CFR 164.526, or take other measures as necessary to satisfy Covered Entity's obligations under 45 CFR 164.526, as determined by Covered Entity and in the time and manner designated by Covered Entity.

H. Business Associate agrees to make its internal practices, books and records available to Covered Entity, or to the Secretary, in a time and manner designated by the Covered Entity or the Secretary, for purposes of determining compliance with the Regulations.

I. Business Associate agrees to maintain and make available the information required to provide an accounting of disclosures to Covered Entity as necessary to satisfy Covered Entity's obligations under 45 CFR 164.528, as determined by Covered Entity and in the time and manner designated by Covered Entity.

J. To the extent Business Associate carries out one or more of Covered Entity's obligations under the Privacy Rule, Business Associate agrees to comply with the requirements of the Privacy Rule that apply to Covered Entity in the performance of such obligation(s).
ARTICLE III - PERMITTED USES AND DISCLOSURES BY BUSINESS ASSOCIATE

A. Business Associate may only use or disclose PHI as necessary to perform functions, activities, or services for, or on behalf of, Covered Entity as specified in the Services Agreement. Business Associate is not authorized to use PHI to de-identify the information in accordance with 45 CFR 164.514(a)-(c), unless Business Associate is specifically required to de-identify PHI in the Services Agreement or is authorized to do so in writing by Covered Entity. If so permitted or required, Business Associate will de-identify the information, and use and disclose the de-identified information, in the manner specified in the Services Agreement or as otherwise authorized by Covered Entity.

B. Business Associate may use or disclose PHI as Required By Law.

C. Business Associate agrees to make uses and disclosures and requests for PHI consistent with Covered Entity's minimum necessary policies and procedures.

D. Business Associate may not use or disclose PHI in a manner that would violate the Privacy Rule if done by Covered Entity, except for the following specific uses and disclosures:

1. Business Associate may use PHI for the proper management and administration of Business Associate or to carry out the legal responsibilities of Business Associate.

2. Business Associate may disclose PHI for the proper management and administration of Business Associate or to carry out the legal responsibilities of Business Associate, provided the disclosures are Required By Law, or Business Associate obtains reasonable assurances from the person to whom the information is disclosed that the information will remain confidential and used or further disclosed only as Required By Law or for the purposes for which it was disclosed to the person, and the person notifies the Business Associate of any instances of which it is aware in which the confidentiality of the information has been breached.

ARTICLE IV - OBLIGATIONS OF COVERED ENTITY

A. Provisions for Covered Entity to Inform Business Associate of Privacy Practices and Restrictions:

1. If requested by Business Associate, Covered Entity shall provide Business Associate with the Notice of Privacy Practices that Covered Entity produces, in accordance with 45 CFR 164.520, as well as any changes to such notice.

2. Covered Entity shall provide Business Associate with any changes in, or revocation of, permission by an individual to use or disclose PHI, if such changes affect Business Associate's permitted or required uses and disclosures.

3. Covered Entity shall notify Business Associate of any restriction to the use or disclosure of PHI that Covered Entity has agreed to in accordance with 45 CFR
ARTICLE V - BREACH NOTIFICATION

A. Business Associate shall promptly report to Covered Entity any Breach of Unsecured Protected Health Information of which Business Associate becomes aware, without unreasonable delay and in no case later than sixty (60) days after discovery of the breach. At the same time as Business Associate notifies Covered Entity of a breach or promptly thereafter, Business Associate shall collect and provide to Covered Entity such information as may be required to comply with the Breach Notification Rule including such information set forth in 45 CFR 164.404, 164.406 and 164.410, but in no case shall Business Associate delay notifying Covered Entity of a Breach of Unsecured Protected Health Information where such information is not immediately available. Such information shall include, at a minimum:
1. The nature of the unauthorized use or disclosure.
2. The type of PHI used or disclosed.
3. The individual who made the unauthorized use or received the unauthorized disclosure.
4. What Business Associate has done or shall do to mitigate any deleterious effect of the Breach.
5. What corrective action Business Associate has taken or shall take to prevent future similar Breaches, and
6. Such other information, including a written report, as reasonably requested by Covered Entity.

B. If requested by Covered Entity, Business Associate shall provide the notifications required by the Breach Notification Rule as if Business Associate were the Covered Entity to which such Breach related, and in such time and manner as is necessary for such a covered entity to comply with the Breach Notification Rule, provided that Business Associate shall, prior to making any such notification, obtain Covered Entity's written consent to the form and content of such notification prior to distribution to any individual, the media or the Secretary.

ARTICLE VI - TERM AND TERMINATION

A. Term. The Term of this Agreement shall be effective as of the date of this Agreement, and shall
terminate on the date of the termination of the Service Agreement or the date Covered Entity terminates for cause as authorized in Section (B) of this Article VI, whichever is sooner.

B. Termination for Cause. Business Associate acknowledges and agrees to the termination of this Agreement and the Services Agreement by Covered Entity, if Covered Entity determines Business Associate has violated a material term of the Agreement and Business Associate has not cured the breach or ended the violation within the time specified by Covered Entity.

C. Obligations of Business Associate Upon Termination. Upon termination of this Agreement for any reason, Business Associate, with respect to PHI received from Covered Entity, or created, maintained, or received by Business Associate on behalf of Covered Entity, shall:

1. Retain only that PHI which is necessary for Business Associate to continue its proper management and administration or to carry out its legal responsibilities.

2. Return to Covered Entity (or, if agreed to by Covered Entity, destroy or transmit to another business associate of Covered Entity) the remaining PHI that Business Associate still maintains in any form.

3. Continue to use appropriate safeguards and comply with Subpart C of 45 CFR Part 164 with respect to Electronic Protected Health Information to prevent use or disclosure of the PHI, other than as provided for in this Article VI, for as long as Business Associate retains the PHI.

4. Not use or disclose the PHI retained by Business Associate other than for the purposes for which such PHI was retained as allowed herein and subject to the same conditions set out at Section D of Article II above which applied prior to termination.

5. Return to Covered Entity (or, if agreed to by Covered Entity, destroy or transmit to another business associate of Covered Entity) the PHI retained by Business Associate when it is no longer needed by Business Associate for its proper management and administration or to carry out its legal responsibilities; and

6. Obtain and return to Covered Entity, or ensure the destruction of, PHI created, received, or maintained by Business Associate's subcontractors.

D. Survival. The obligations of Business Associate under Section C of this Article VI shall survive the termination of this Agreement.

ARTICLE VII - MISCELLANEOUS

A. Regulatory References. A reference in this Agreement to a section in the Regulations means the section as in effect or as amended, and for which compliance is required.

B. Amendment. The parties agree to take such action, as is necessary, to amend this Agreement from time to time, as is necessary, for the parties to comply with the requirements of HIPAA and the Regulations.
C. Interpretation. Any ambiguity in this Agreement shall be resolved in favor of a meaning that permits the parties to comply with HIPAA and the Regulations.

D. Indemnification. Business Associate agrees to indemnify, defend and hold Unumines Covered Entity and its respective directors, officers, employees, subcontractors, and agents from and against all claims, actions, damages, losses, liabilities, fines, penalties, costs or expenses (including, without limitation, reasonable attorney’s fees) suffered by Covered Entity arising from or in connection with any breach (including but not limited to a breach of Unsecured Protected Health Information) by Business Associate of its obligations pursuant to this Agreement.

E. No Waiver. No waiver of a breach of any provision of this Agreement shall be construed to be a waiver of any breach of any other provision of this Agreement or of any such succeeding breach of the same provision. No delay in action with regard to any breach of any provision of this Agreement shall be construed to be a waiver of such breach.

F. Governing Law. Except as provided in Article VII, Section C above, it is agreed that this Agreement will be governed by, construed and enforced in accordance with the laws of the State of New York, without reference to choice of law principles.

G. Notices. Any notice to be given under this Agreement to a party will be made via U.S. Mail, commercial courier or hand delivery to such party at its address given below, and/or via facsimile to the facsimile telephone number listed below, or to such other address or facsimile number as will hereafter be specified by notice from the party. Any such notice will be deemed given when so delivered to or received at the proper address.

If to Business Associate, to:

Attn: [Signature]
Fax: [Fax Number]

If to Covered Entity, to:

H. Miscellaneous. The terms of this Agreement are hereby incorporated into the Services Agreement. In the event of a conflict between the terms of this Agreement and the terms of the Services Agreement, the terms of this Agreement shall prevail. The terms of the Services Agreement which are not modified by this Agreement shall remain in full force and effect in
accordance with the terms thereof. The Services Agreement together with this Agreement constitutes the entire agreement between the parties with respect to the subject matter contained herein. This Agreement may be executed in counterparts, each of which when taken together shall constitute one original.

IN WITNESS WHEREOF, the parties have executed this Agreement as of the date set forth above:

[Signature]
Name: [Business Associate Name]
Title: [Business Associate Title]

[Signature]
Name: Matt Anderson
Title: President & Chief Executive Officer
Appendix F

Approval from Host Site

June 27, 2016

To whom it may concern:

The __________ is a not-for-profit retirement community located on a 56 acre campus in __________, New York. We offer a full continuum of care, including 188 independent living units, 105 rental independent and assisted living units, 84 skilled nursing beds, 13 units of memory care, outpatient rehabilitation and a licensed home care agency.

Within the assisted living environment, the Memory Care provides the highest-quality senior living experience and is licensed by New York State. Our caring professional staff and family-style living ensure a safe, positive environment for older adults with Alzheimer’s or another form of dementia. This includes a variety of dementia-specific cultural arts programming.

With regards to Mr. Gentner’s study, our organization understands the data collection procedures as well as the approach to confidentiality regarding the dissemination and disposition of data. Also, prior to the study our professional staff will work with the residents and their families on all issues leading to informed consent.

As a senior service provider, we appreciate the variety of non-pharmacological intervention therapies for Alzheimer’s disease and related forms of dementia including Mr. Gentner’s approach using individualized music therapy and we look forward to bringing these benefits to our residents in an effort to improve their quality of life.

If you have any question please don’t hesitate to contact my office at __________.

Matthew Anderson
President & CEO
Appendix G

Alzheimer Disease Related Quality of Life (ADRQL)

Alzheimer Disease Related Quality of Life™ (ADRQL™)

Instruction: Read the following instructions aloud to the respondent.

Quality of life means how someone feels about different areas of his or her life. To find out about quality of life, people are usually asked to answer questions about themselves. Because of the effects of dementia, it is hard to ask people with this illness questions about their own lives. Instead, this questionnaire has been developed so that it can be answered by someone who spends time with and cares for a person with dementia.

There are several areas that make up a person’s quality of life. I will briefly describe each area and then I will read statements about these. As I read each statement, please think about Mr./Ms. _________ and whether the statement describes him/her over the last 2 weeks. If you agree that the statement describes Mr./Ms. _________ over the last 2 weeks, please answer “Agree.” If you disagree, because the statement does not describe Mr./Ms. _________ over the last 2 weeks, please answer “Disagree.”

Let me give you an example. I might read the statement, “He/She does not respond to his/her own name.” If this statement describes Mr./Ms. _________ over the last 2 weeks, you should say “Agree.” If the statement, “He/She does not respond to his/her own name,” does not describe him/her in the last 2 weeks, you should answer “Disagree.” Do you have any questions?

Instruction: Please respond to any questions and finish reading these instructions aloud.

I am going to begin the questionnaire now. Please tell me if you want me to speak louder, slow down, repeat a statement or stop so you can think about a statement. Also let me know if you want me to review your instructions.

Instruction: Read aloud the introductory statements and each item exactly as they are written in sections A-E below. Place an X in one box to the right of each item in the correct response column.

<table>
<thead>
<tr>
<th>Item</th>
<th>Statement</th>
<th>Agree</th>
<th>Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>A1</td>
<td>He/She smiles or laughs when around other people.</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>A2</td>
<td>He/She does not say anything to the presence of others.</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>A3</td>
<td>He/She will stay around other people.</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>A4</td>
<td>He/She seeks contact with others by greeting people or joining in conversations.</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>A5</td>
<td>He/She talks with people.</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>A6</td>
<td>He/She teaches or allows tasks such as household, hugs, kisses, pets.</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>A7</td>
<td>He/She can be comforted or reassured by other.</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>A8</td>
<td>He/She reacts with pleasure to pets or small children.</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>A9</td>
<td>He/She smiles or laughs or is cheerful.</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>A10</td>
<td>He/She shows delight.</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>A11</td>
<td>He/She shows a sense of humor.</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>A12</td>
<td>He/She lists quietly and appears to enjoy the activity of others even though he/she is not actively participating.</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Item</th>
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<th>Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>B1</td>
<td>He/She talks about or still does things related to his/her previous work or daily activities.</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>B2</td>
<td>He/She is aware of his/her place in the family such as being a husband/wife, parent, or grandparent.</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>B3</td>
<td>He/She makes or indicates choices in routine daily activities such as what to wear, what to eat, or where to sit.</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>B4</td>
<td>He/She shows interest in events, places or habits from their past such as old friends, former residences, church or prayer.</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>B5</td>
<td>He/She does not respond to his/her own name.</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>B6</td>
<td>He/She does not express feelings or attitudes that he/she always had.</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>B7</td>
<td>He/She talks with people on the telephone.</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>B8</td>
<td>He/She gets enjoyment from or is satisfied by his/her possessions or belongings.</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>
3. These statements are about different types of behavior in the last 2 weeks. After each statement, please answer “Agree” if the statement describes M/m/M’s behavior in the last 2 weeks or answer “Disagree” if it does not.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Agree</th>
<th>Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>He/She squeezes, holds or pulls his/her hands.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>He/She throws, hits, kicks or bangs objects</td>
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<td></td>
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<tr>
<td>He/She calls out or yells or curses or makes accusations</td>
<td></td>
<td></td>
</tr>
<tr>
<td>He/She locks or barricades himself/herself in his/her room, house, apartment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>He/She is irritable or easily angered</td>
<td></td>
<td></td>
</tr>
<tr>
<td>He/She cries, whines, or howls</td>
<td></td>
<td></td>
</tr>
<tr>
<td>He/She is restless and wound up, or repeats actions such as rocking, pacing, or banging against walls</td>
<td></td>
<td></td>
</tr>
<tr>
<td>He/She resists help in different ways such as with dressing, eating, or bathing, or by refusing to move</td>
<td></td>
<td></td>
</tr>
<tr>
<td>He/She appears to be content or satisfied</td>
<td></td>
<td></td>
</tr>
<tr>
<td>He/She becomes sad or angry when approached by another person</td>
<td></td>
<td></td>
</tr>
<tr>
<td>He/She pushes, kicks, or hits people</td>
<td></td>
<td></td>
</tr>
<tr>
<td>He/She is upset or unsatisfied in his/her living environment</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

4. These statements are about usual activities in the last 2 weeks. After each statement, please answer “Agree” if the statement describes M/m/M’s behavior in the last 2 weeks or answer “Disagree” if it does not.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Agree</th>
<th>Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>He/She enjoys doing activities alone such as listening to music or watching TV</td>
<td></td>
<td></td>
</tr>
<tr>
<td>He/She does not take part in activities he/she used to enjoy, even when encouraged to take part</td>
<td></td>
<td></td>
</tr>
<tr>
<td>He/She shows no signs of pleasure or enjoyment when taking part in leisure activities or recreation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>He/She does off or does nothing most of the time</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

5. The last statements are about behavior in a person’s living environment. After each statement, please answer “Agree” if the statement describes M/m/M’s behavior in the last 2 weeks or answer “Disagree” if it does not.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Agree</th>
<th>Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>He/She talks about feeling unsafe or says his/her belongings are not safe</td>
<td></td>
<td></td>
</tr>
<tr>
<td>He/She is upset or unsettled when in places other than where he/she lives</td>
<td></td>
<td></td>
</tr>
<tr>
<td>He/She talks about wanting to leave or go home</td>
<td></td>
<td></td>
</tr>
<tr>
<td>He/She says he/she wants to die</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

That concludes the questionnaire. Thank you very much for your help.

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Address requests for the licensed use of the ADQL to:
DEMeasure, 402 Carolina Road Towson, MD 21204

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