

DESCRIBING THE SUBTLE FACTORS THAT INFLUENCE MOMENTS OF
INTERACTIVE RESPONSES DURING MUSIC THERAPY SESSIONS FOR PEOPLE
WITH LATE-STAGE ALZHEIMER'S DISEASE AND OTHER RELATED MAJOR
NEUROCOGNITIVE DISORDERS: A MULTIPLE CASE STUDY

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by
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Abstract

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The purpose of this qualitative multiple case study was to describe moments of response and their triggers in individual music therapy sessions for three older adults with late-stage Alzheimer's disease and related major neurocognitive disorders in a long-term care setting. The participants in this study were three women from 87-92 years of age who lived in a local skilled nursing facility, had a diagnosis of late-stage dementia, and were considered to be minimally responsive to environmental cues by staff. Individual music therapy sessions were implemented in each participant's room for approximately 30 minutes twice a week for six weeks. Participant responses were captured through video recording, narrative notes, and coding of dominant awareness state for each session according to the classification of behavior states developed by Wolff (1959). The investigator found that although all the participants showed varying levels of responsiveness, they all responded to session factors in each session including the environment, music, and interaction with the music therapist. The implications of the results are discussed in regards to varying functional, environmental, musical, and emotional awareness of individuals with advanced neurocognitive disorders.

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Chapter One

Introduction

According to the *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.; *DSM-5*; American Psychiatric Association, 2013), Alzheimer's disease is the most common occurrence of major neurocognitive disorders (NCD), since it has been estimated that the prevalence of the disease now varies from 60 to 90 percent of diagnosed NCD. The number of people with the disease is rising as modern improvements to healthcare continue to raise the life expectancy along with the dominance of the aging baby boomer generation. Statistics show that 5.2 million people in America have Alzheimer's disease, and this number is expected to rise to 7.1 million by the year 2025, which is a 40% increase (Alzheimer's Association, 2013).

Alzheimer's disease is the fifth leading cause of death for people over the age of 65; and this year alone, 450,000 are expected to die from it. Many people with Alzheimer's disease reside in long-term care facilities, and 64% of the people who reside in long-term care facilities have some type of NCD. By the age of 80, residents with a major NCD account for 75% of nursing home admissions. The average duration of the disease ranges from four to eight years, but the disease has been known to have duration of up to 20 years. Additionally, the later stage of the disease has been estimated to account for 40% of the duration of the disease. Further research on providing support in connecting with people with NCD is essential for improved healthcare in the future (Alzheimer's Association, 2013).

Overview of Alzheimer's Disease and Related Major Neurocognitive Disorders

The criteria for a diagnosis of a major neurocognitive disorder due to Alzheimer's disease must include a decline of memory and learning functioning as well as a decline in another cognitive domain such as motor ability, perception, or language. These declines must have a subtle onset, and the impairments must gradually proceed without instances of prolonged plateaus. There must also be no other evidence of another neurological condition that could cause a decline in cognitive functioning. If all of the previous criteria are met, then the person may be diagnosed with major NCD due to probable Alzheimer's disease. Another diagnostic factor for probable Alzheimer's disease includes a family history or genetic testing that has shown a gene mutation associated with Alzheimer's disease along with the gradual cognitive decline (American Psychiatric Association, 2013).

While components of the disease, for instance amyloid plaques and tau neurofibrillary tangles in the brain, are still confirmed by an autopsy, genetic testing is available for some genetic mutations linked to the disease such the presenilin 1 gene. Besides having a genetic disposition, an individual is at higher risk for the disease as the age of the person increases. Experiencing a cerebrovascular accident or traumatic brain injury is a risk factor as well (American Psychiatric Association, 2013).

Since major NCD is a progressive disease, those who have reached the later stages have experienced a gradual loss of abilities. People in the moderate stages of major neurocognitive disorder often experience behavioral changes such as agitation, wandering, and depression. As the disease progresses, dysphagia, involuntary movement, and a declining ability to complete activities of daily living like toileting needs and walking often manifests. Due to this limited functioning, many people with advanced major NCD are

limited to staying in their beds and primarily interact with the daily staff who come to check on them. By the end stages of the disease, people “are eventually mute and bedbound” (American Psychiatric Association, 2013, p. 613). In addition, sometimes people with NCD do not respond consistently to verbal stimulation, which may result in the person being labeled as nonresponsive; however, although language is often impacted by the disease, “social cognition tends to be preserved until late in the course of the disease” (American Psychiatric Association, 2013, p. 612). As NCD progresses, a person’s quality of life is a major concern due to declining functioning and lack of independence.

Definitions of Terms

Music Therapy

According to the American Music Therapy Association (AMTA), music therapy is defined as “the clinical and evidence-based use of music interventions to accomplish individualized goals within a therapeutic relationship by a credentialed professional who has completed an approved music therapy program” (2013, paragraph 1). Music therapy is an expressive, creative, complementary form of therapy in which the therapeutic relationship between the client and music therapist plus individualized music interventions are used together to help the client to accomplish a non-musical goal or aim. Music therapy can benefit many individuals, but it is especially effective for people who may have difficulty expressing themselves through verbal therapy. Music therapy is often used with infants, children with disabilities, adults with disabilities, people with mental health concerns, people in hospitalized and hospice care, and older adults (AMTA, 2013). Music therapists are able to promote wellness through a variety of domains ranging from emotional expression, social needs, cognitive goals, physical goals (AMTA, 2013). Music can reach people at an inner

depth that touches emotions, retrieves memories, and encourages active and receptive interaction with the therapist, which is effective for people with major NCD who may no longer be able to remember their past, express their feelings clearly, communicate their needs, or interact with people as they previously could (Tomaino, 2000).

Quality of Life

According to the World Health Organization (WHO), quality of life is defined as one's "individual perceptions of their position in life in context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns" (WHO, 1998, p. 551). This definition is consistent with the WHO's perception of health as more than the nonexistence of illness, but a general state of overall well-being. Quality of life can be difficult to measure since it depends upon the individual's experience, perceptions, and preferences. Assessment of quality of life is often measured by considering multiple domains, including physical, psychological, social, and environmental factors. Physical health includes pain, discomfort, sleep, energy levels, mobility, and functioning capability. The psychological domain includes cognition, emotions, personal beliefs, spiritual beliefs, and self-esteem. Another important factor in quality of life is the social domain, which includes support systems, relationships, and the opportunity to interact with others. Quality of life also is influenced by environmental factors such as the noise levels and appearance of surroundings, sense of freedom and security, and opportunities to acquire new skills or engage in leisure activities (WHO, 1998).

Long-Term Care

For the purposes of this study, long-term care refers to ongoing care that often lasts for years and usually involves people who have a chronic medical condition and/or need help with activities of daily living like bathing, eating, or transportation. Long-term care requires skilled care, services that must be provided or supervised by a medically licensed professional and custodial care, services that do not require a medical license, which includes assisting with activities of daily living. For the purposes of this study, long-term care is provided in a skilled nursing facility. The facility must have a registered nurse present 24 hours a day, a doctor on call 24 hours a day, and be accessible to ambulance transportation to a hospital (Day, 2013, paragraph 11).

Responsive and Nonresponsive

For this study, the definition of responsive is taken from Laureys, Owen, and Schiff (2004), specifically “the evidence of awareness of themselves or their environment, on a reproducible or sustained basis” (p. 539) of purposeful behavior. Such behavior could include a movement, gesture, speech, eye contact, or notable attention to sound or touch. The response could be subtle such as “movements or affective behavior that take place in relation to stimuli in the environment” (Laureys et al., 2004, p. 539). An example of a subtle response would be when a person is observed breathing to the beat of music, which was triggered by stimulation of the music in the environment. In this study, nonresponsive occurs when no visual or auditory response to environmental stimulation is observed in the participant by the researcher even though the person is in a conscious state.

Chapter Two

Review of Related Literature

This chapter will outline three relevant themes supported by the literature, which imply the importance of a qualitative, in-depth case research study for people in long-term care who are diagnosed with late-stage Alzheimer's disease or related major neurocognitive disorder. The first theme will discuss concerns and misconceptions about the quality of care that people with late-stage major NCD receive from long-term care facilities and about how people with late-stage major NCD may exhibit signs of awareness to self and environment. The second theme addressed is how music and multi-sensory experiences can focus the attention of people with late-stage major NCD and improve their environmental awareness. The third theme consists of examples of how music therapy interventions created an emotional connection for the participants and allowed them to express themselves emotionally. The chapter will conclude with the statement of the problem and the resulting research questions.

General Misconceptions

Because there are still many unanswered questions about the process of major neurocognitive disorder, there are often misconceptions about the abilities and experiences of people with major NCD. Many staff members of nursing homes believe their quality of care for residents has improved over the years along with the understanding of interventions for major NCD; however, studies measuring how residents spend their day have shown that nursing homes are about as stimulating as they were 25 years ago (Ice, 2002).

Many facilities may give the impression that their residents stay busy with recreational activities and are provided with opportunities for social interaction throughout the day. Ice (2002) conducted an individual sampling study to observe how residents spent their time in a daily nursing home routine. The researcher observed one out of 27 participants in one nursing home daily in 5 minute intervals for 13 hours while recording in her field notes such variables as location, position, mood, and type of activity. Activities were grouped in the themes of personal care, expressive/social, and passive activities, which included sleeping, waiting, and doing nothing. Residents spent most of their day alone doing nothing. Results indicated that 66% of the day was spent as a passive activity from sleeping in front of a television to waiting in the hallways an hour for meals. Other findings supported inadequate quality of life measures due to residents spending at least 43% of their day in their room, 25% of the day sitting in the hallway, and 70% of the day sitting in a chair. The residents in this study showed a neutral, flat affect during 91% of the day, which may be due to the passive, nonstimulating environment (Ice, 2002). Claire (2010) noted that often facilities do not offer enough activities or chances for people in advanced stages of NCD to be involved in meaningful interactions or to demonstrate the abilities they can still perform. This lack of opportunity and stimulation makes the retention of their present skills even more difficult because they are often not engaged actively during the day.

Along with inadequate daily activities, the palliative care treatment of those with major NCD could be improved as well. Another common misconception is that major NCD is often not viewed as a terminal illness. This results in many residents with advanced major NCD not receiving the same care or attention as a person with a different terminal illness, like cancer for instance (Mitchell, Kiely, & Hamel, 2004). Often staff members do not

recognize advanced major NCD as a terminal illness and treat the disease as if it were a behavioral mental disorder. Mitchell et al. (2004) conducted a minimum data set study comparing the palliative treatment of 1,609 people with advanced major NCD and 883 people with cancer who had died in New York nursing homes. Results showed that out of the 72% of people with major NCD who had passed away in 6 months, only 1% of them were given a 6-month life expectancy. Many residents with major NCD received unnecessary and uncomfortable treatments including feeding tubes, catheters, lab tests, intravenous medications, and restraints that the residents with cancer did not receive. Although the residents with cancer had more instances of hallucinations, the people with major NCD received 25% more antipsychotic medication than those with cancer. Depression was most common among those with major NCD. Additionally, pain was often undetected in people with major NCD, because it most often was misunderstood as agitation. The misconception of major NCD as a mental illness instead of a terminal illness may cost a person their deserved respect, comfort, and dignity at the end of life (Mitchell et al., 2004). Although people with major NCD are considered terminal and low functioning, many still exhibit signs of being aware of their sense of self and their environment, if given the opportunity (Claire, 2010; Tappen, Williams, Fishman, & Touhy, 1999). Major NCD is often perceived as a mental illness because of the progressive decline of cognition, which results in many professionals neglecting the extent of the person's remaining awareness and sense of self. Tappen et al. (1999) conducted a conversational analysis study of 23 residents with mid to late major neurocognitive disorder from two nursing homes. They discovered that most strategies used for their participants focused on reducing behavior disturbances "with little attention to the expression of feeling or ways to call forth the self that may be

hidden behind the disease” (Tappen et al., 1999, p. 124). Staff mostly focused on task oriented objectives for their residents, which may result in low expectations for any kind of interaction or response from those with major NCD. While some people may assume the lack of response from people with major NCD may be a direct result of the disease, other factors from a biopsychosocial framework, which are perceptions, emotions, and social interactions, should be considered when assessing the abilities and well-being of the person (Claire, Rowland, Bruce, Surr, & Downs, 2008). Since people with major NCD often are assumed to have little awareness left, the focus of care is left to only personal care tasks, and other factors, like human expression, are forgotten.

Awareness in Individuals with Major Neurocognitive Disorder

People with major neurocognitive disorder have experienced a decline in functioning abilities, and interventions to stimulate their awareness remain necessary throughout their lives. Without a stimulating environment, people with major NCD may withdraw further and eventually seem nonresponsive to verbal stimuli. Interactions with a person with major NCD should be treated with the possibility of “reciprocal influence” from the person, since the extent of expressed awareness “may not correspond fully with the potential degree of awareness at that level” (Claire, 2010, p. 29). Because this population may become nonresponsive to verbal stimuli, other interventions are needed to inspire the motivation to interact with another person. Music has an aesthetic, receptive quality that can provide the motivation, and music therapy interventions are often multi-sensory to encourage further responses. Music has been shown to increase the awareness level of a person with late major NCD through experimental and case studies (Clair, 1996; Gregory, 2002; Magee, 2005).

Studying the subtle responses of this population to various stimuli is important in order to be able to note how best to stimulate and interact with this population. Kovach and Magliocco (1998) conducted a descriptive exploratory study to describe the behavior and participation of people with late-stage major NCD in various therapeutic activities. Certain questions provided direction for this study, for instance, determining if factors relating to time of day, positive and negative expressions, individual or group differences, and effective activities for stimulation were significant. The study included 23 participants who lived in a late-stage special care unit in a nursing home with the following criteria: a score of ten or less on the Mini-Mental State Examination, a score of 55 or lower on the Functional Behavior Profile, inability to engage in a mid-stage major neurocognitive disorder group, and have the Do Not Resuscitate advanced directive. The participants were observed during a total of 98 therapeutic sessions including pet therapy, music therapy, reminiscing, exercising, cooking, spiritual experiences, and sensory experiences, which included aromatherapy, massage, and touching objects. Participants were placed in various sessions that met their past interests. Results suggested that most responses were subtle and nonverbal, and muscle relaxation was common. Participants would spontaneously participate eight percent of the time without prompting. Verbal cues were the most dominant cuing from the therapists in the study. Active participation would normally last for 10 minutes, and the active participation would decrease as down time between stimulation increased. Kovach and Magliocco (1998) found no significant difference in the time of day of the activities or if the participant was in a group or individual session. Participants were the most active in the sensory and spiritual experiences. This study recommended that multi-sensory experiences provide one of the most effective approaches with this population, which can include music therapy

experiences. Witucki and Twibell (1997) also suggested multi-sensory experiences by finding that interventions including listening to preferred music, massaging hands, or smelling objects such as flowers, cinnamon, and chocolate significantly lowered symptoms of discomfort with people with major NCD. Fidgeting was the most reduced symptom by sensory stimulation (Witucki & Twibell, 1997).

Awareness levels involve different aspects that help to explain further the “potential degrees of awareness” for those with major NCD (Claire, 2010, p. 29). Claire, Rowland, Bruce, Surr, and Downs (2008) conducted a study with a grounded theory model of analyzing awareness levels of people with major NCD. The researchers found that all 80 participants showed some sign of retained awareness by responding in the moment from the one to eight sessions of individual unstructured conversations. Certain contexts influenced the level of expressed awareness, which included events happening in the environment during the session, the client’s previous experience before the session, and the client’s level of engagement. The coded transcriptions of the sessions suggested that the three aspects of scope of time, process, and focus of awareness impacted the overall level of awareness. The authors stated that registering information was the element most often assessed for determining awareness level, but emphasis should also be placed on where the focus of the awareness is placed, specifically attention to the environment, relationships, or the self. Participants in the study focused on certain factors involving personal identity, physical sensations, lack of capabilities, relationship status and roles, and surrounding environmental routines which suggested that people with major NCD may have more awareness of their situation and feelings than often perceived by caregivers (Claire et al., 2008).

Tomaino (2000) recognized the potential that singing or listening to meaningful pre-composed music has for this population, especially recalling the past and being aware of the moment. She conducted case studies on people with dementia focusing on the way music therapy sessions influenced her clients' memories of the past by giving them images, bringing an awareness of the present, and helping them to express their experiences. She also described in some instances how the memories that were brought up affected her clients emotionally.

One of the case studies was about an 80-year old woman named Rose who frequently tried to play her favorite songs on the piano. This led to her recalling how she used to play her mother's piano, and she began to realize how her life had changed; however, she would get confused and incorporate her past life into her present by saying statements such as "Sometimes I get lonely...because I was the only girl in the house... then I stopped doing the little things" (Tomaino, 2000, p. 206). Unlike Rose, in 75-year-old Sadie's experience, the music brought Sadie full awareness of the present, which was evidenced by her statement "I was a very good arts and crafts teacher...yeah, and now I lost everything" (Tomaino, 2000, p. 203–204). This realization of her loss had a powerful effect on Sadie, and it was reported that music from her past helped provide her comfort and process these feelings.

Tomaino (2000) also described Molly, an 87-year-old woman who was able to recall and articulate the past while staying oriented to the questions of the present conversation. Previously, she was only able to state her name, yet her facial expressions showed that she was responding to the music. These facial expressions demonstrated her responsiveness so much that "the feelings and emotions she demonstrated provided a glimpse of who Molly once was" (Tomaino, 2000, p. 200). In one session when the music therapist was playing

Irish songs, Molly started to cry and later stated, “My mother’s home, the kids are there” (Tomaino, 2000, p.201). During another session, she started singing an Irish song, which was rare for her, and informatively told the music therapist that she was from Ireland, County Cook. When the music therapist told Molly’s family later, she found out that this was true and that her chart, which stated she was from England, was wrong. These three case studies have shown different types of awareness from confusing the past and present, being fully aware of the moment, and a continuing developing awareness and ability to articulate it. In all of these cases, the music stimulated the client to reconnect with herself in some way.

Music therapy interventions can provide the opportunity to grab a person’s attention and engage one longer in one’s present environment in a meaningful way. Gregory (2002) conducted a study to observe if sustained active listening was a challenge for people with major NCD. The study compared a therapy group of 12 adults with major NCD, Alzheimer’s disease, and cerebrovascular accident with comparison groups of college students and patient caregivers. Participants in each group listened to excerpts of three patriotic songs with 7 seconds of silence between the excerpts for 3.5 minutes total. During this intervention, participants were told to turn a labeled dial to the song or silence being played as they heard the excerpt change. Results showed that the reaction time in the therapy group was significantly delayed compared to the others, and the participants responded most often to the excerpts of songs rather than periods of silence (Gregory, 2002). This finding suggests that although the reactions were delayed, the music excerpts eventually inspired awareness of the environment from the participants with major NCD and therefore a response to complete the activity by turning the dial. Another aspect of the study measured if active listening experiences could aid in improving sustained attention in the therapy group,

and after the participants completed the initial treatment group, a week later they completed the same treatment group again. During the second treatment session, the group's reaction time to turning the dial had significantly increased, which suggested the possibility of improving the attention and awareness of the present in those with major neurocognitive disorder through musical experiences. Clair (1996) found in her experimental study of providing 15-minute sessions of 5-minute intervals of silence, reading, and singing to 27 individual participants from a nursing home with major NCD that unaccompanied singing interventions and reading interventions significantly increased the alert responses from participants. Music had a higher average of frequency of responses. Alert responses to the interventions included opening eyes, lifting eyebrows, making vocalizations, or moving in response to the stimulus. Participants were slow to respond, but over time, their frequency of responses increased, especially in the music condition. Music interventions not only encourage responses to help people with major NCD interact with their environment, but also improve the frequency and reaction time of their responses in the moment.

Music continues to stimulate people even in the end stages of major NCD when the terminal disease has progressed so far that the person may be in a minimally conscious state. A minimally conscious state exhibits a clear yet limited awareness, and the level of awareness may be measured by one of the following: following a command, gesturing yes or no, a phrase of clear speech, or purposeful movement in response to stimuli (Laureys, Owen, & Schiff, 2004). Laureys et al. (2004) noted that it is difficult to assess the cognitive functioning of minimally conscious person due to their inconsistent responses, small reactions, and easy fatigue. On the other hand, music therapy can be a method to affect those who are minimally conscious emotionally and physiologically. Magee (2005) discussed a

case vignette about one of her clients named Mrs. P. who responded to music therapy interventions while considered in a nonresponsive state. During the music therapy assessment, Mrs. P. showed an awareness of her environment by turning her head and providing direct eye contact to the music therapist as the therapist played the piano. Her breathing rate also increased as the music therapist played a note on each exhalation of Mrs. P.'s breath. Due to the responses to the musical stimuli, Mrs. P.'s assessment of cognitive ability was changed from being nonresponsive to being minimally conscious. During the music therapy assessment, Mrs. P. showed emotional responses by closing her eyes and tightening her face as a guitar was placed in her line of vision. Due to the responses to the musical stimuli, Mrs. P.'s assessment of cognitive ability was changed from being vegetative to being minimally conscious. This change of diagnosis affected how the staff and her family perceived her functioning and changed how they interacted with her. Kerr (2004) found that both heart rate and respiration rate were significantly lowered to receptive music therapy interventions implemented for ten participants under hospice care who were considered nonresponsive. The results from the studies suggested that "patients who are nonresponsive are responsive to music" (Kerr, 2004, p. 21).

Music provides the chance for people who may not be able to express themselves outwardly to prove that they are still aware of themselves, others, and their environment through indicating awareness of the music, showing musical preferences, and interacting with the person performing the music (Claire et al., 2008 & Tomaino, 2000). Music has been shown to increase awareness levels over time during a study (Clair, 1996; Gregory, 2002; Magee, 2005), and music can help aid people in showing their retained consciousness during the final moments of the disease (Kerr, 2004).

Emotional Responses in Individuals with Major Neurocognitive Disorder

Music therapy interventions can reach a person with major neurocognitive disorder in more ways than just improving the person's awareness. Not only does music grab the attention of a wandering mind, but it also evokes the emotion that remains within the person and thereby affects the behavior. Studies have varied in discussion on the capability of people with major NCD to express their emotions. Asplund, Norberg, Adolfsson, and Waxman (1991) stated that emotions could not be interpreted. On the other hand, Magai, Cohen, Gomberg, Malatesta, and Culver (1996) found that basic emotions are not lost in the course of this disease, although the expression of them may decrease. Music can be a form of non-verbal communication for people with major NCD and an emotional outlet for those who have lost so much. Music therapy interventions can provide an interactive, therapeutic relationship with another person through music to validate unspoken needs (Ridder & Aldridge, 2005) and to help caregivers interact with their patients in a more personal way (Gotell, Brown, & Ekman, 2009).

Due to the decline in functioning for those who have late stage dementia, it can often be difficult to assess the affective state of the person. Asplund et al. (1991) addressed this in their quantitative study of the facial expressions of four people who were nonverbal and had late stage dementia. Each participant experienced a pleasant condition, which consisted of rocking, sucking on an object, feeding, supportive touch, and music listening, and each participant experienced the unpleasant condition, which was a stretching contracture routine. During the pilot study, they found that most patients reacted more to the music than to supportive touch. They also noted that participants only winked during the unpleasant condition, which may signify pain. Other than that, the only finding was that the most

observed facial expressions were in the eyelids, lips, and jaw. They concluded that the participants had more than likely lost the ability to portray complex emotion and could only give simple indications of reactions. While the researchers suggested that it may be possible to use facial expressions to interpret the experiences of someone with late stage dementia, they stated that in their study “no interpretation of the emotional meaning of the patients’ reactions could be made” (Asplund et al., 1991, p. 599).

Other quantitative studies have considered other interpretations of emotional expression for this population. Kovach, Weissman, Griffie, Matson, and Muchka (1999) conducted a study on the assessment of pain and discomfort for people with late stage dementia, and although the purpose was to test out a new protocol in assessing discomfort, the researchers addressed that what is perceived as pain may have an affective cause. The researchers stated that the majority of the participants’ discomfort was from nonphysiological causes due to the “difficulty sorting out and negotiating their everyday life activities” (Kovach et al., 1999, p. 413), and they discussed how family and staff alike both have to assess the affective state by their observations of non-verbal cues. The study went on to list that the most frequently displayed behaviors of discomfort included fidgeting, tense body language, repetitive language, and sad facial expressions. Interestingly enough, out of all of the nonpharmacologic interventions of sensory stimulation, busy hand activities, massage, music therapy, and soothing touch, music therapy and massage were implemented most frequently for increasing comfort throughout the implementation of the study. The researchers implied that emotional state and expression were important in determining the comfort level of a person.

There have been other studies that look past analyzing facial expressions and frequent behavior characteristics by describing the quality, ability, and overall situation of the emotion expressed and the quality of interaction with the person to whom they may have expressed the emotion. One common occurrence from Claire et al.'s (2008) grounded theory model of awareness in major NCD consisted of a high focus on the self through a retained sense of emotional awareness. Magai et al. (1996) found that although the frequency of expression may decrease, people with major NCD are still capable of meaningfully expressing their emotions. They discovered that the participants still felt basic emotions and expressed them through facial expressions, tone of voice, and body language. Throughout the varying levels of cognitive ability, the awareness of the measured emotions stayed the same. In major NCD, the only decreased expression of measured emotion was joy and emotions of fear and disgust actually began to increase. Some family members noted that the participant's level of interest also declined over time. Regardless of what emotion was expressed, the participants frequently showed awareness of their emotions, for example, appearing sad when the family member was about to leave (Magai et al., 1996).

Often emotions are expressed within an established relationship, but people with major NCD may find it difficult to maintain or develop a relationship with another due to progressive communication deficits. Nonverbal modes of communication like music can help provide an emotional connection to enable the person with major NCD to interact easier (Tomaino, 2000). Gotell, Brown, and Ekman (2009) conducted an experimental study on caregivers using either silence, recorded music, or singing during their morning care routine with 24 participants with major NCD and found that people with major NCD were more expressive and vocal in a positive way when music was added during the routine. When

background music played, the people with major NCD showed more energy, playfulness, and even at times joked with the caregivers. When caregivers sang to the participants, the participants listened more closely to the caregivers and acted more openly and sincerely in a mutual relationship than they did without the music. This result was similar to the findings in another caregiving study by Magai, Cohen, and Gomberg (2002) where caregivers took a class on emotional validation and sensitivity to nonverbal forms of communication to see how it improved their relationship with residents. After 6 weeks, the group who was trained in emotional validation had the largest increase of positive affect from their residents, whereas the behavioral control group had no change. The study concluded that “even those who are severely deteriorated are sensitive to the emotional communication of others” (Magai et al., 2002, p. 25).

Caregivers and therapists can have an influence on the amount of emotional expression from a person with major NCD through their own interaction of facial affect and body language with the resident. Cevalasco (2010) studied how a therapist’s affect and proximity can affect the affect and participation level in a music therapy session for people with major NCD. She observed seven groups that featured four treatment conditions of combined proximity of the music therapist to the person and affect, affect only, proximity only, and no affect or proximity. Positive affect was defined as eye contact, facial expressions like raising eyebrows, smiling and reflecting participants’ expressions. Results were significant that the most beneficial treatment condition in client participation and positive affect was having combined proximity and affect from the therapist. The author of the study noticed that participants tended to follow changes in the therapist’s affect such as smiling as a response to the therapist smiling at them (Cevalasco, 2010). People with major

NCD can show “reciprocal influence” (Claire, 2010, p. 29) by being receptive to those emotions from others, which in return may positively affect their emotional affect as well.

Similarly, the same idea of “reciprocal influence” can happen to the music therapist as well as the client where the therapist may have an open receptiveness to the client that allows for the therapist to connect with the client on a deep, intuitive, spiritual level. Marom (2004) conducted a qualitative study where she interviewed 10 music therapists, each with over 10 years of clinical work, on their thoughts and personal experiences with spiritual moments in therapy. The music therapists agreed about how important it was to let go of expectations and follow the therapeutic process by following the sense of energy and feelings that the client was portraying.

Ruth, who was one of the participants of the Marom (2004) study, shared a time when she was working with a person with late stage Alzheimer’s who was unresponsive and referred to music therapy for relaxation; however, as Ruth was chanting a melody, her client suddenly became fully engaged by giving Ruth direct, focused eye contact, and they held each other’s hand as the client’s breathing rate decreased. Ruth recalled that she had the feeling that her client was trying to connect with her to tell her that her true self was still present within the old body. She felt like her client’s “entire being was there...it was a soul to soul connection” (Marom, 2004, p. 54). Ruth elaborated on how powerful that moment was for her when she realized that despite the lack of evidence and the state of the person’s disease, she knew intuitively that they had made a connection with each other through their gaze.

This vignette is similar to a finding that Brescia (2005) found during her qualitative study into intuition. She interviewed six music therapists who had at least 7 years of

experience and used improvisation frequently. In discussing clients who are nonverbal, they stressed the importance of relying on intuition because “the only clues we have to inform us are so subtle” (Brescia, 2005, p. 92). The author continued to elaborate that when intuition has occurred effectively, “there’s a certain feeling after you’ve done it, you feel like something new has happened for them and for you” (Brescia, 2005, p. 92).

Ridder (2003) reported six music therapy case studies that described in detail her connections with her clients in an emotional way through the music and in their conversations. The study included six participants with late stage dementia who were referred due to their agitation; each had a total of twenty 30-minute sessions. The participants’ heart rates were monitored during the sessions to compare to the observational data from the sessions. Ridder (2003) highlighted sections of three of the case studies that had emotional relevance.

The first case study was about a man named Mr. B. who often had an empty, yet sad facial expression. Nevertheless, he would smile sometimes. Even though he did not express agreement to be in music therapy sessions, he did not oppose it either. Ridder (2003) questioned if music therapy was beneficial for him, since he did not seem engaged and seemed to live in his own inner world. Mr. B. had severe aphasia, so he did not speak unless it was before or after the last song, or when something motivated him to talk, for example when he said, “Ugh, that’s cold” to the application of heart rate monitor gel. He seemed more attentive when the music therapist was talking to him and remained engaged when the music therapist worked to keep his present attention. Mr. B. often sobbed soundlessly to himself during the session, and the only way the researcher was able to observe this was by his sad facial affect and the way he was breathing. All of his sobbing was done during the

music; therefore, the researcher decided that the music was what was motivating the release of emotion and concluded that music therapy had been beneficial for him.

Mr. A. was another participant where music therapy was considered questionable, since he would rather stay isolated in his room and could get very agitated with the staff. Nevertheless, it was quickly established that music therapy was very effective for him, since he demonstrated laughing, smiling, and even kissing the music therapist's hand. There were a couple of sessions when Mr. A. did not feel well, refused to get out of bed, and often told the music therapist not to waste her time in seeing him like that, as if he were an angry, old gnome. During those days, the music therapist supported him by playing simple songs at his bedside, and she reflected that "it seemed important that the music therapist accepted this part of Mr. A. where he feels bad and depressed" (Ridder, 2003, p. 138).

Ms. E., who also generally participated with positive affect in her individual music therapy sessions, also had times when she was in a bad mood and would clearly express it. To begin with, she was a very social person who desired to have company with her; and at times, she would have depressed thoughts and be irritable. In the only session where she did not participate musically, she stated that the session "isn't fun" and it was "such nonsense." After the music therapist gave Ms. E. space for a couple of minutes for the second time and played a couple more songs, Ms. E.'s affect began to change more positively by offering the music therapist "a present" that was in her hand. From this experience the researcher learned that "if she's in a bad mood, she only accepts hymns" (Ridder, 2003, p. 174). Usually Ms. E. showed compliance with music therapy sessions by actively participating in music making and saying such comments as "that's nice" and "it really works" when talking about the music. All the participants in the case studies were able to express themselves and the

current state of attitude they were in, from Mr. B. who was able to release his feelings of sadness, to Mr. A. and Ms. E. who showed a range of affect by actively participating in sessions with positive energy to reacting to the music when in a bad mood.

Ridder (2003) also discussed the effectiveness of using structured, pre-composed music in her sessions in comparison with using improvisation for the emotional expression of her previously mentioned case studies. For those times when she wished to validate a participant's feeling and hold him or her in the space, she would view the music as a container for the emotion. As she described it, the song would allow for a "common place where both of us are able to resound at an emotional level" (Ridder, 2003, p. 100). Ridder discussed how it is a challenge sometimes to determine when to use the context of the song by singing lyrics or when to just use the tone of the song and vocally improvise it. While vocally improvising the song without lyrics may decrease the pressure for the participant to be able to sing the words along with the therapist, the lyrics can sometimes provide the emotional content or the message in a song. Precomposed songs with lyrics allowed for a familiar, predictable structure that may portray a feeling of security and provide the opportunity for recognition and recalling of the past while staying alert in the present moment. When it came down to the music, the choice of song played was essential since "some songs seem to go in at one ear and out at the other, but other songs seem almost actively to get a grasp on us, touching us deeply" (Ridder, 2003, p. 100).

Musical intervention, whether precomposed or improvised, in combination with a supportive relationship, stimulates positive expression even in those with behavioral disturbances who are hard to control. Ridder and Aldridge (2005) reported a case study to discover if therapeutic singing would meet the psychosocial needs of a woman named Mrs.

F. with advanced frontotemporal major NCD by reducing her wandering and yelling behaviors. During music therapy sessions, Mrs. F. began to reach out socially to the therapist by gripping the therapist's hand, pulling the therapist up off the couch to walk with her, and gently touching the therapist's chin. Therapeutic singing sessions appeared to reach Mrs. F. by validating her at a previously unmet level and thereby increasing her emotional and social interaction. Using therapeutic, caring relationships along with musical interventions allow for an opportunity for people with major NCD to express important emotions.

The literature has suggested that people with late stage major NCD have the potential to perceive and express emotional reactions in different ways and considerations. While some took a quantitative approach by analyzing facial movement (Asplund et al., 1991) or assessing measures of discomfort (Kovach et al., 1999), others took a qualitative look into how the emotions are expressed and what they could mean (Claire et al., 2008; Magai et al., 1996). This qualitative view included how the therapist's and client's presences connect with each other in a meaningful way (Brescia, 2005; Cevasco, 2010; Marom, 2004). Case studies have given rich descriptions of the context in which music has allowed for emotional expression and how it affected the individuals involved (Ridder, 2003).

Statement of the Problem

The studies previously described demonstrate how people with major neurocognitive disorder can be more aware of their surroundings than previously thought, and how music therapy interventions can stimulate their awareness of themselves and their environment which in turn may provide a deeper emotional ability to interact with others; however, many of these studies were quantitative studies that tested the effectiveness of a specific musical intervention rather than focusing on the unique needs of the individual clients themselves.

Some of the qualitative studies did address the stories of progress of individuals with late-stage major NCD receiving music therapy, but the studies reported on the overall progress of certain sessions of the person without detail about whether there were patterns of responses for the individual or what factors may have triggered the successful moments throughout treatment. More research about the subtle factors that influence responses of clarity or purposeful interaction from people with late-stage major NCD during music therapy interventions would be useful for advocating and improving future music therapy clinical experiences for this population. It would be useful to increase the level of engagement with this population to facilitate meaningful interactions for self-expression, to give them support, and to promote self-worth, which could positively affect one's perception of quality of life. Because it could be a challenge to communicate with people with major NCD (American Psychiatric Association, 2013), it was important to explore what motivates those responses that lead to meaningful engagement and self-expression in their environment and interaction with others through an alternative form of communication like music therapy.

Research Questions

The purpose of this study is to describe moments of response and their triggers in individual music therapy sessions for older adults with end-stage Alzheimer's disease and related major neurocognitive disorders in a long-term care setting.

- What is happening environmentally during moments of response?
- What is happening musically during moments of response?
- What is happening in the client-therapist interaction during moments of response?
- Is there a pattern to moments of response during music therapy sessions?
- Is there a pattern to moments of response across music therapy treatment?

Chapter Three

Method

Participants

This researcher sought referrals from the activities director and nursing staff at a local long-term care center to determine which residents might be eligible to participate in the study. The researcher then met briefly with each possible participant to verify eligibility for the study. The participants in this study were three women who lived in a local skilled nursing facility, who fit the inclusion criteria, and whose legally authorized representative gave consent for participation in the study (see Appendix A), permission for sessions to be recorded (see Appendix A), and permission for the researcher to have access to the participant's medical records (see Appendix B). The researcher used pseudonyms when referring to the participants to protect their confidentiality.

Inclusion criteria. Participants had to fulfill all the following criteria for consideration in this study:

- Women or men over the age of 65
- Diagnosis of late stage Alzheimer's Disease or related major neurocognitive disorder
- Resident of the long term care facility
- Minimally responsive to environmental cues

Exclusion criteria. Participants who did not fulfill all of the preceding criteria were not eligible for consideration in this study.

Procedure

For eligible residents, the researcher gave enrollment materials to the activities director to send to each resident's legally authorized representative including a letter of introduction, two copies of the IRB approved consent form (see Appendix A), an authorization for use and disclosure of protected health information form (see Appendix B), a music interests questionnaire (see Appendix C), and a postage paid return envelope. The materials included the researcher's contact information. One copy of the IRB approved consent form, the authorization for use and disclosure of protected health information form, and the music interest questionnaire survey were returned to the researcher.

Each participant received a total of twelve 30-minute sessions. Upon the conclusion of each session, the researcher documented observations with narrative notes from the session as described under data collection and analysis. The researcher also viewed a video recording of each session to supplement the narrative notes.

Music Therapy Intervention. The researcher implemented a variety of music therapy interventions and techniques according to how a participant was responding at the time of the session. The order and choice of intervention was determined by the researcher according to her review of previous studies with this population and her previous clinical experience. The majority of the interventions were receptive music methods, which means that the person participated by listening or relaxing to music. Examples of receptive music-making may include, but are not limited to, song singing or vocal improvisation from the therapist, name identification in a song, entrainment of a song to a participant's breathing, and using music to grasp participants' attention. According to *Gale's Encyclopedia of Medicine* (2008), entrainment is the "patterning of body processes and movements to the

rhythm of music.” The participant was also encouraged to participate actively through active music-making, which included instrument playing, singing songs, vocal improvisation, or verbalizing during a song. The researcher also employed extemporization, which is the technique of improvising in the middle of a familiar song. This could be considered a receptive or active music-making technique according to the participant’s response. The researcher occasionally used recorded big band music during instrument playing interventions to provide a more authentic sound for preferred songs and to give the researcher the opportunity to use hand over hand assistance with the participants. The researcher also used nonmusical techniques as well such as using expressive or gentle touch to connect with a client.

Session Format. The music therapy sessions were conducted according to the responses, needs, and interests of the clients. The music therapist allowed sessions to remain flexible in intervention choice and in the order and duration of interventions presented. Nevertheless, the general structure of the sessions remained generally consistent.

Opening. The research session began as soon as the music therapist entered the room of the participant. If the participant’s eyes were open, the music therapist greeted the participant and introduced herself. If the participant’s eyes were closed, then the music therapist gently touched her hand and said her name. The music therapist set up her computer on a table or bedside tray facing the participant’s bed and began recording after greeting the participant. The music therapist opened any song files of recorded music that she planned to use in the session on her computer. She also set up her guitar and music near the participant. The music therapist noted the general condition of the participant including her facial expression, affect, energy level, posture, and breathing before the music therapy

interventions began. The music therapist assessed the current state of the participant in order to determine appropriate interventions and song choice to implement during the middle of the session. According to the initial level of response from the participant, the music therapy session began with a familiar preferred song, a greeting song, or a song that matched the current affect of the person. The opening ranged from 5 to 15 minutes.

Music experiences. After the music therapist completed the opening of the session, the music therapist used her quick assessment of the participant to determine which approach or musical intervention to implement according to her best discretion and previous clinical experience. The musical experiences were various receptive music therapy interventions, although the participant was occasionally involved in an adapted form of active music-making with assistance from the researcher. Music interventions were chosen from, but not limited to, the previously described interventions, and each session ranged from one to three interventions according to time duration and the energy level of the participant. This phase of the session lasted approximately 10 to 20 minutes.

Closing. When the session was drawing toward a close, the music therapist let the participant know the session was ending before the last intervention was implemented. The therapist played a goodbye-themed song to bring the session to a close. The music therapist noted the current state of the participant according to her affect, facial expression, posture, breathing, and energy level and determined or asked if the participant may needed anything before the therapist left the room. After the music therapist closed the recording program, shut down her computer, and packed up her guitar and music, the therapist said good-bye to the participant before leaving the room. The music therapist left the participant's door open according to the preferences of the facility. The closing lasted from five to ten minutes.

Materials. The music therapist used an acoustic guitar along with a notebook of client preferred songs for older adults to conduct sessions. The music therapist also had various percussion instruments that included, but were not limited to egg shakers, tambourines, hand drums, and adapted mallets that the participant was encouraged to play with assistance. The music therapist used her password-protected laptop computer to record sessions using a web camera software program. She also used her computer's media player program to play big band recordings.

Setting. The music therapy sessions took place in each participant's room at the long-term care facility. If the participant was not in her room, the researcher had the participant transported to her room. This location also allowed for a secure, familiar environment and for privacy for the participant. Residents in long-term care facilities often have semi-private rooms, which means that the participant may have had a roommate present on the other side of the room. The researcher used her best discretion in how to address the roommate in the room from either pulling a privacy curtain around the participant's side of the room or involving the roommate in the session, if the participant would benefit from the social interaction from a peer. Sessions were conducted at the participant's bedside or beside the participant's chair. Trays, wheelchairs, or other materials belonging to the participant were rearranged if the objects blocked direct access to the participant, or if the researcher needed the space to sit. The researcher returned any moved object back to its original location upon conclusion of the session. This researcher was not able to control all environmental factors, especially nursing staff entering the room or noises in the hallway. Nevertheless, the researcher attempted to reduce excess noises by turning down the room's television with the roommate's consent and closing the participant's door.

Study Design

This study utilized a qualitative framework with a case study method. A case study is a “research design strategy based upon empirical investigation” (Aldridge, 2005, p. 11), and it is a method that permits the use of multiple factors including environment, interaction, personality, and personal background to apply and study real life situations. This type of study was useful for this purpose of research because the researcher intended to describe how music therapy reached the inner person still existing within these participants who have declining responsiveness to their everyday environment. This researcher chose case studies as a way to portray the bigger picture of who the participants were and how music therapy sessions gave them the opportunity for a deeper connection with their inner selves and a chance to interact with another. Unlike much of the quantitative research with music therapy and major NCD, a case study “allows for the assessment of individual development and significant incidents in the patient-therapist relationship” (Aldridge, 2005, p. 25), which helped to relay the meaning behind the observed responses. This researcher decided to implement multiple case studies to explore possible patterns of response among the individual participants.

Another component in the design of this research study involved the microanalysis of significant, related responses of the participant to the environment, music, or therapist. A microanalysis in research is defined as “the detailed analysis of a small but relevant amount of data drawn from a single experience from a client” (Wigram & Wosch, 2007, p. 14), and in the case of music therapy, microanalysis research often focuses on incremental changes that occur during the music or during the client-therapist interaction; nevertheless, microanalysis studies are not found often in music therapy literature due to the fact that the

clinicians tend to focus on the overall progress of their clients or on a specific goal response. A microanalysis of what is occurring during significant participant responses helped to discover the triggers and stimulating factors behind the participant's responses, possible subtle moments during the music, and therapist interaction that led to expressive moments.

This researcher intended for the case study design and the microanalysis element to complement each other in providing further insight into the significant responses of the participants. The case study structure provided a subjective overview of the sessions along with summarizing important moments during the course of the study. The microanalysis element to the study provided a detailed analysis of what led to or occurred during certain significant responses that were summarized in the case study, because case studies “offer only limited explanation of how music or verbal material has been systematically analyzed” (Wigram & Wosch, 2007, p. 14). Both types of research describe the significant responses from the participants.

Data Collection and Analysis

Data from each session were recorded by subjective narrative documentation after each session, which was organized afterward in an objective manner into a session chart for a visual and quick reference of each session (see Appendix D). After all research sessions were conducted, the researcher chose the most significant moments of response from the participants to analyze in deeper detail by the use of an analysis form (see Appendix E).

Narrative documentation. The researcher utilized this type of documentation most in her clinical practice, because it allowed for attention to environmental and client details that typical progress notes about goals and progress do not usually include. The narrative is a type of storytelling method that describes what happened during the session and what

meanings could be discovered from the session (Aldridge, 2005). This researcher used narratives to describe the initial state of the client, the client's responses to musical interventions, and the concluding state of the client toward the end of the session. Among the objective descriptions, the therapist also recorded what her subjective impressions and feelings were during the session and how she interpreted the client's responses.

Session chart. The purpose of the session chart was to have an objective method of organizing and sequencing the session to help provide a quick overview of the session. The chart assisted the researcher in summarizing the overall progress of the sessions as well as determining from the events in the sessions which event would be most influential to analyze in further detail. The chart was created as an Excel spreadsheet and included major events of response in the rows and the intervention, song, duration of response, and therapist response in the columns. Another column on this chart included a space for the behavior state of the participant. This researcher used the behavior states developed by Wolff (1959) when observing the behavior of infants, which Belgrave (2009) adapted it for use in her study on expressive and instrumental touch for people with late-stage major NCD. Wolff's (1959) classification of different behavior states are as follows:

- Two sleep states - *Sleep inactive* was described as having closed eyes and regular breathing with little movement. *Sleep active* was closed eyes, rapid eye movement, movement, or facial expression.
- Two indeterminate states - *Drowsy* was described as having open eyes, drooping or closing eyelids, and possible vocalization. *Dazed* was described as having open eyes but not focusing on stimuli.

- Four awake states – The *inactive awake* state consisted of the eyes orienting to objects, but having no purposeful movement. The *active alert* state had purposeful glances from the eyes and purposeful interactive movement. The *active stereotype* state included repetitive, stereotypical movements, and the final awake state is *crying* or *agitation*.

The inclusion of behavioral states helped to code and specify what type of state the participant was in when she responded to the therapist.

Analysis form. The analysis form was used for the microanalysis part of this study. The basis of the analysis form is taken from Ridder's (2005) study on the levels of arousal and communication in music therapy with people with major NCD. The analysis form was used to describe an event such as a participant humming that happened during part of the session or intervention. The first column in the form described what was observed from moment to moment, and the second column was the subjective assessment of what the moment was. The last column was reserved for a reflection about the moment or the possible meaning behind the moment. This allowed for the researcher to view monumental events in the sessions on a step by step basis to understand fully what happened or led to an important connection in the session.

Chapter Four

Results

The purpose of this study was to describe moments of response and their triggers in individual music therapy sessions for older adults with late-stage Alzheimer’s disease and related major neurocognitive disorders in a long-term care setting. The chapter begins with a summary showing each participant’s dominant awareness state in each session (see Table 1). Then the results for each participant are discussed individually.

Table 1. *Dominant Awareness State of the Participants in Each Session*

Session	Lucy	Lindy	Martha
1	Active alert	Active alert	Active alert
2	Sleep inactive	Active alert	Active alert
3	Stereotypical	Active alert	Active alert
4	Sleep active	Sleep inactive	Active alert-Drowsy
5	Stereotypical	Active alert	Active alert
6	Sleep active	Dazed	Active alert
7	Stereotypical	Active alert	Active alert
8	Sleep inactive	Active alert	Active alert
9	Sleep active	Sleep active	Active alert
10	Sleep active	Drowsy	Active alert
11	Sleep active-Alert	Active alert-Drowsy	Sleep active
12	Active alert	Drowsy-Active alert	Drowsy

Participant 1: Lucy

Background information. Lucy is a 92-year-old woman who had diagnoses of severe dementia, depression, type II diabetes, hypertension, and cerebrovascular accident. According to her medical chart, she was sometimes disoriented, confused about her whereabouts, and completely dependent for all activities of daily living. She was a widowed homemaker and received strong support from her family, including a son and daughter. Her religious faith was Christian, and she used to participate occasionally in religious and musical activities at the facility. Her family indicated that she liked a variety of different types of music but preferred Elvis songs. Staff informed the music therapist that Lucy was very social, friendly, and a “jokester.”

Awareness states. Lucy usually had her eyes closed during the majority of the sessions and was in bed with the exception of three sessions when she was in her wheelchair. The music therapist did not observe a difference in awareness levels between being in the bed or wheelchair. She was usually in a sleep active state where her eyes were closed but exhibited facial expressions, movement, or vocalizations. Examples of this sleep active state included raising an eyebrow, moving a hand, or saying “um.” Lucy had a few moments when she was consistently in a sleep inactive state evidenced by her stillness with closed eyes, and she occasionally appeared to be in a drowsy state when she blinked open her eyes and quickly closed them. Throughout three sessions, she frequently exhibited stereotypical behavior, and she was only actively alert throughout the first and last session. Even though Lucy was frequently in a sleep state, she often engaged in some aspect of the music therapy session in subtle ways.

Subtle responses. Although Lucy usually had her eyes closed during most of the sessions, she sometimes opened her eyes for a two seconds, which was coded as a drowsy indeterminate state. Lucy opened her eyes 14 times in response to the music, for example, when she opened her eyes during the bridge of an Elvis song. She also tended to open her eyes briefly when the music therapist changed the lyrics to the music. For instance, she opened her eyes for four seconds when the music therapist created a quick song parody and during the last line of the good-bye song when the therapist sang her name. Lucy also opened her eyes to interaction with the music therapist 11 times, for example, when the music therapist touched her arm or said, “hi” to her in close proximity. Lucy cleared her throat and blinked twice in 5 seconds after the music therapist stated, “You seem to be sleeping.” In her active alert state, Lucy sometimes gazed at what the music therapist mentioned or gestured toward in the room. During the second session, when the music therapist sang, “Look at me if you’re feeling good,” Lucy made eye contact with the music therapist. Whether in a drowsy or active alert state, Lucy most often showed responses during the sessions by opening her eyes for two seconds or gazing at an object.

Lucy still exhibited responses when her eyes remained closed by raising her eyebrows when the music therapist stated something or when the music therapist was singing. She raised her eyebrows a total of nine during music therapy treatment. These responses were coded as a sleep active state because she exhibited facial movement with her eyes closed. For instance, she raised her eyebrows when the music therapist said, “I’m glad to see you” and again when asked, “Was that a good one?” Once during the tenth session, she raised an eyebrow when asked if she were still listening. She also raised her eyebrows when the music therapist was doing a blues style vocal improvisation as a solo in the middle of an Elvis song

and when the music therapist added a melodic embellishment to a lyric in a Christmas hymn. Lucy's facial expression of raising her eyebrows suggested that she was still receptively participating in the session when her eyes were closed.

Even when Lucy was considered to be in a sleep inactive state indicated by her stillness and closed eyes, she still had instances of receptively participating in the session by breathing to the rhythm of the music, which is known as entrainment (Gale Encyclopedia of Medicine, 2008). She would frequently breathe to the rhythm of the majority of the goodbye song or at the end of songs themselves, for example, when she breathed to the last couple of lines in a slow song. Lucy responded most often to entrainment when the music therapist played a few slow waltz songs. Lucy had one instance where she entrained to the music in an active alert state in the treatment process. During that session, Lucy did not feel good as evidenced by her quick shallow breathing and furrowed eyebrows. According to a staff member and her roommate, she had been coughing nonstop that day. As the music therapist played some slow songs in a gentle rhythm, her breathing became deeper and more relaxed. She also did not cough until there was a break in the music. At the end of the session, her face appeared more relaxed, and she made eye contact with the music therapist as the music therapist left the room.

Movements and vocalizations. Across several sessions, Lucy was frequently in a stereotypical behavior state where she displayed repetitive movements like hand tremors or rubbing her wrist. Lucy had repetitive movement in her hands and occasionally her shoulder during the majority of at least one session with her eyes closed. Another common stereotypical behavior for Lucy included the stereotypical vocalization of a repeated syllable. She vocalized what sounded like "sha" repetitively in a stereotypical type manner that would

range from a faint whisper to a strong audible sound. The tone of these vocalizations ranged from sounding tired or not feeling good to an energetic, conversational tone. In the eleventh session, her repetitive vocalizing had the tone of being congested and not feeling good. After the music therapist played a relaxing song, Lucy's repetitive vocalizations began to sound more conversational as her foot started to tap to the beat. During the music, Lucy stopped vocalizing the repetitive syllable, slowed down the tempo of it, or decreased the volume of her vocalizations. For instance, as the music therapist began to improvise vocally to the rhythm of her "sha" vocalizations, her vocalizations became softer. Then the music therapist transitioned into singing the hello song, but she kept the rhythm of Lucy's vocalizations in the strumming of the guitar. By the end of the song, Lucy's repetitive vocalizations had stopped. She often said "sha" three times in a rhythm and then rested a beat before saying the phrase again. On the other hand, while her roommate was playing tambourine to the tapping of Lucy's feet, Lucy's stereotypical vocalizations changed from three short syllables to two short and one long syllable. Lucy frequently had stereotypical movement and vocalizations, which occasionally changed during the music.

Lucy also had moments of movements and vocalization that were not classified as a stereotypical state. These instances of movements or vocalizations were most often observed during a sleep active state when she had eyes closed but exhibited some form of expression. She sometimes gave subtle movements in response to the music therapist commenting on or asking about her alertness. During the eighth session, after the music therapist said that the next song would wake her up, she moved her head to the left and back as if it were a slight shake of the head. She also had moments when she moved her hand in a specific way during the music. During an upbeat, familiar song, Lucy brought her right hand to her left hand

which was up near her chin, and then she moved her mouth eight times and vocalized three sounds. During another song, Lucy raised her right arm completely up in the air and gently brought it down to her side. This moment was the only instance that the music therapist saw her move her arm that way. In session six, she tapped her index finger to the beat of another lively song and kept her eyes open in a dazed state during the song for 36 seconds. She demonstrated purposeful movement when she was actively alert in the first session. The music therapist offered her a small instrument, and she held out her left hand to grasp the shaker. She then made a sound from it once with hand over hand assistance. Not only did Lucy move in ways that were in response to the music therapist or the music, but she also vocalized syllables that were in response to the music therapist and the music as well.

Although Lucy did not have clear speech the majority of the time, she could vocalize certain syllables like “ah” or “um.” Most of these syllables were spoken in a sleep active state after the music therapist asked Lucy a question. When the music therapist offered her soft, relaxing songs, she said “ah” and repeated “ah” again after the music therapist asked if that sounded good. At the end of another session, she said “ah” when the music therapist sang, “Enjoyed this time with you.” Also, she vocalized an “ugh” sound when the music therapist strummed for a while on the unstable dominant V7 chord and stated, “You want me to resolve this don’t you?” in the same session. During the sixth session, she made conversational vocalizations during the last verse of a slower song and stated two repeating syllables after the music therapist stated, “You seem to respond to that song.” Lucy had one moment of clear speech in the first session when she was actively alert. After the music therapist said, “You look good,” she stated what sounded like “I don’t...” and then repeated the syllable “on’t” multiple times.

Similar to her verbalizations, Lucy also vocalized occasionally during the music when she was in a sleep active state. In session nine, Lucy said “ah” in the pitch of the previous note after the music therapist paused after singing a lyric in a Christmas song. Fourteen minutes later in the same session, the music therapist began to hum a slow song to Lucy’s rhythm of breathing, and Lucy hummed four times on the same pitch along with the music therapist. She stopped when the music therapist began singing the lyrics. After that song, the music therapist asked her what she thought, and Lucy vocalized for 7 seconds in clear strong phrasing that was not repetitive. Lucy also vocalized or sang once in an active alert state during the last session. She said, “Ah, ba, ba” during an Elvis ballad in which the music therapist then started singing “yeah, yeah, yeah” from an upbeat song. Then Lucy made eye contact with the music therapist, and they both alternated singing this phrase together for about 30 seconds. Lucy used subtle movements and syllabic vocalizations to express herself in response to the music therapist and the music.

Affect. Lucy also expressed herself affectively through her facial expressions, which were most often observed in her actively alert state. She showed many instances of positive affect during the first session when she was actively alert for the entire 30-minute session. Before the first session, Lucy was sitting in her wheelchair in the hallway with her eyes open. As the music therapist greeted her the first time, Lucy gave her full eye contact. After the music therapist set up the room and came back to get her, Lucy gave the music therapist a full smile with effort that slowly grew from a half grin with effort. She smiled again during the hello song and once more after the music therapist first smiled at her. After a second of her smile, the smile faded into a half grin. She gave a half smile again after a slow hymn and appeared to mouth the words to another slow hymn. After the song, she looked away from

the therapist and appeared to have tears in her eyes. Similarly, her eyes were open and alert the entire 30-minute session in the last session. She seemed to be in an energetic, bright mood evidenced by her half smile as the music therapist greeted her. When the music therapist said good-bye, Lucy raised her arm four inches and waved at the music therapist. Lucy also watched the music therapist leave through the doorway. During the beginning of the second session, she gave a half grin that grew into a full smile when she saw that the music therapist was looking at her. She continued to smile as the first song started and kept her eyes open during the first 5 minutes of the session. The fourth session also began with another half grin until the left side of her face moved upward to a full smile. Although she was often in a drowsy or sleep active state in this session, she expressed affect after a staff member came in the room for a medical test. Lucy kept her eyes closed the entire time the person was working with her even when her face furrowed in discomfort during the procedure. When the music therapist touched her hand afterward and said how she was loved here, she opened her eyes after 5 seconds and gave full meaningful eye contact to the music therapist for 10 seconds before the focus faded from her eyes. Lucy also showed negative affect once during a ballad when she furrowed her eyebrows and breathed a little faster which may have been a lack of preference for the song. Lucy appeared to express her affect and preferences when she was in an actively alert state.

Although Lucy was often classified as being in a sleep active state, she frequently gave subtle responses to many of the music therapist's questions and to her music interventions through facial expressions, spontaneous eye-opening, and movements. The music often changed or stopped her stereotypical behavior, and entrainment appeared to provide relaxation for her on occasion. Lucy had moments of purposeful movement in

response to the beat of the music and the lyrics of the music. Additionally, she had interactive vocalizations and facial expressions with the music therapist during moments of conversation and music improvisation. She expressed her affect through facial expressions, body language, and tone of voice to socially connect with the music therapist in a subtle manner throughout music therapy treatment.

Participant 2: Lindy

Background information. Lindy is an 87-year-old woman who had diagnoses of severe dementia of the Alzheimer's type, osteoarthritis, hypothyroidism, glaucoma, and a frozen shoulder. She was a widow who used to be a licensed practical nurse, and she had a daughter. Her religious faith was Christian. According to her medical chart, she frequently used to attend groups, especially those involving music and church-related functions. She preferred songs by Frank Sinatra. Her family indicated that she sang in her church for many years and used to win dance competitions when she was younger.

Awareness states. Most of the time Lindy was in an actively alert state; however, Lindy's engagement levels often depended on which time of the day the session took place. In the afternoon, she was her in bed and usually not as engaged in the session, even if she was in an alert state to the environment. Even though Lindy was in an actively alert state to what was happening environmentally in the first three sessions, she did not fully engage with the music therapist or the music as often as in sessions five, seven, eight, eleven, and twelve of the treatment process. After the fourth session, the music therapist discovered that Lindy showed the most energy and participation in the morning right before lunch when she was in her wheelchair. She was more likely to be in a dazed or sleep state in the afternoon, for example when she was dazed in the sixth session. The only time Lindy had focus in her eyes

during this session was when the music therapist got in close proximity and asked in her ear how she was feeling. Then she opened her eyes fully and looked at the music therapist for 15 seconds before the focus began to drift away from her eyes again.

Lindy had two sessions where her dominant awareness state changed from one state to another. In the tenth session, she was actively alert for the first 10 minutes. Then, her focus began to fade from her eyes to a dazed type state, and she closed her eyes halfway into the session. When the music therapist touched her gently, she would wake up in a drowsy state, but the focus would only last about 20 seconds before she would close her eyes again. The opposite effect happened during the last session. In the twelfth session, she appeared drowsy at the start with her head drooping often, and she stated that she was “ok” in a tired tone of voice. Her eyes were often unfocused during the session. Toward the end of the session, the music therapist was playing a ballad version of one of her favorite songs when Lindy began to close her eyes and breath deeper. Then the music therapist changed the song into an upbeat bossa nova rhythm at the bridge of the song. As soon as the song ended, she raised her head, smiled, pointed at the music therapist’s notebook, and read the label on its side. Throughout the rest of the session she was in an actively alert state becoming talkative and stating that she was feeling “really good” with an energetic tone at the end of the session.

Responses to environment. Whether she was in an alert or dazed state, Lindy looked at or listened to happenings in her environment. She noticed her surroundings by looking out the window, glancing at her family pictures on the wall near her bed, and reading one or two words from a notebook or lyrics from sheet music in her environment. Four times, the happenings in her room would interrupt what she was saying. In the eighth session, she said, “Well, yeah I can...” and stopped to point to her roommate who was being helped out of bed.

After she pointed to her roommate getting out of bed, Lindy forgot what she was about to say. Lindy often pointed or gestured to what had her interest and also looked at what the music therapist pointed to in her environment.

Most often, staff members and her roommate's activity would gain her attention, especially when staff members would come in to attend to her roommate. Frequently, Lindy would turn her head to the door or the curtain when she heard movement or talking from the other side of the room. During the first session, there were multiple staff members attending to Lindy's roommate, and Lindy spent the majority of the session turning her head to look at the music therapist and to the curtain concealing her roommate for times ranging from 3 to 20 seconds. Occasionally, she would comment on this by asking, "Who's yelling?" when her roommate was groaning while being turned or by saying, "I don't understand" when a staff member was going through clothes in the closet.

The happenings in Lindy's room appeared to influence Lindy's affect as well as attention. During the second session, as the music therapist entered the room, a staff member was trying to convince Lindy to move the blanket away from her face, which resulted in Lindy saying, "No" sternly to the staff member. When the music therapist offered music, she said, "Yeah" in a happy tone, and she slowly lowered the blanket from her face during the first song. Twenty minutes later when her roommate made a loud moan when being turned, Lindy brought the blanket back up to her face again with wide concerned eyes. Throughout the session, Lindy said, "I don't know" frequently in an anxious tone of voice when asked questions like, "How are you feeling?", "What's on your mind?" or even when there was no question, for example when her roommate made a sound. She did give a direct, confident answer of "yeah" when the music therapist offered her more music. When staff kept coming

in and out of the room during the first session, Lindy kept looking over at them with a curious look on her face. As she looked back at the music therapist, she often had a surprised look evidenced by raised eyebrows and an open mouth, which may suggest that Lindy forgot the music therapist was there when focusing on the staff members on the other side of the room. Lindy often noticed what was happening in her environment, which impacted her affect and was frequently distracting to her.

Musical responses. Music often helped to recapture her attention briefly in an alert state when she was distracted by another sound in the environment. Often, the first strum of the guitar or the first sung note of a song directed her glance back at the music therapist. When her attention was distracted during the middle of the song or repeated verses, Lindy usually brought her full attention back to the music therapist through eye contact at the end of the song. She also would look at the therapist when there was a change in the music such as changing the guitar accompaniment from finger picking to strumming or during a fermata at the end of a phrase. For example, in the first session, she looked over and laughed when the music therapist paused on a specific phrase during a rhythmic jazz song. Receptive music also seemed to gain Lindy's attention when she was not in an alert state.

Lindy sometimes receptively responded to the music through entrainment, which tended to occur during a sleep inactive state. In the fourth session, she had her eyes closed the entire session. When the music therapist began quietly playing the guitar, Lindy took a deeper inhaling breath. She frequently breathed to the rhythm of the music in this session during the bridge section of a waltz and of a ballad. During the last phrase of a ballad, she breathed on each note as the music therapist slowed the tempo at the end. In the ninth session, which also took place in the afternoon, she breathed to the rhythm of all three verses

of a ballad with closed eyes, yet she opened her eyes during the bridge section of the song. While Lindy had some instances of receptively responding to the music, she frequently actively participated in the music-making as well.

Lindy responded to the music when in an active alert state by reading a few words of song titles, mouthing lyrics, singing, and playing instruments. Lindy had a moment when she read a word from a song title. In the last session, she read a word from a familiar, older song and watched attentively as the music therapist pointed to each word as the music therapist sang the song. Often, Lindy hummed the melodies with “da dum” vocalizing. When she sang lyrics to a song, it was usually on a short song, and she usually would begin to sing during the second phrase or the end half of the song. Three times Lindy would harmonize a few lines of melody when she sang with the music therapist. Lindy showed that she was able to read certain words, recall lyrics to certain songs, and even sing in harmony with the music therapist to the harmony of the music.

Lindy also participated in the music by playing instruments. She played the tambourine independently while the music therapist held it for her. The music therapist first introduced and modeled how to play the instrument. Then, she encouraged Lindy to feel the top with her fingers. After Lindy was comfortable touching the instrument, the music therapist would again model how to play it and invite Lindy to play along with her. For instance, in the eighth session, the music therapist tapped the tambourine twice, then Lindy tapped twice, and the pattern was repeated one more time before both started playing the instrument together. The music therapist would then sing a song and tap the drum to the melody as well. Lindy would often stop playing as the singing started and sing the song instead. The music therapist noticed once that when the music therapist stopped tapping the

beat and tapped the melody rhythm instead, Lindy started singing the song with her. She also sang and played the drum with the therapist seven times.

Lindy also played the eggshaker five times during the study. She looked at the graphic design on it first, held it up to her ear, and then with encouragement would shake the eggshaker six times in a row. The music therapist played the original recording to big band music during five sessions. During one of the songs in the eighth session, Lindy started to shake the shaker up higher and in bigger movements on a big crescendo climax to the music. She also shook the shaker with emphasis in the song to the triplet rhythm of the horn parts at the end. In the eleventh session, she shook the shaker eight times in the beat of another triplet rhythm in the horn part of another jazz ballad. Lindy was actively involved in the music by mouthing or reading lyrics, singing with the music therapist, and playing instruments to live and recorded music.

Verbalizations. When sessions were held in the mornings, Lindy was also actively engaged in commenting on the music and talking to the music therapist. She said variations of the phrases “Aww, that’s good,” “That’s very nice,” or “That’s cute” after a song. She said those phrases a total of 25 times during the songs as well. These statements occurred in the first 30 seconds of a song or during the bridge transition in a song. In session five, she said, “That’s good” 20 times during the session, and in session eight she said a variation of that phrase 33 times. These statements were said in variety of tone of voice from disinterested, tired, polite, happy, and excited. She said this phrase in response to the questions, “Would you like to hear an upbeat song or a slow song?” and “What comes to mind when you hear this song?” a combined total of four times. She was able to give simple direct answers to questions in session eleven. When asked who a certain song reminded her

of, she stated, “Myself!” with a smile. Then after another song, she responded with, “Everyone” when asked whom she loved. Lindy had five instances where she initiated questions to the music therapist that included asking where the music therapist learned to play guitar and where she went to school. Lindy’s level of focus generally lasted less than 30 seconds when talking about a subject. Nevertheless, she had four instances of sustained focus where she continued referring to or singing a previously mentioned topic or song.

Moments of sustained awareness. During the fifth, seventh, eighth, and tenth sessions, Lindy seemed to connect to a topic during the session by making a statement about a previous conversation or revisiting a song that happened during the opening of the session. The following examples suggest that Lindy had sustained thought and focus on stimuli from the session. For instance, she was able to hold a conversation about the sunshine out her window in the fifth session. Lindy said, “It’s the sky there,” while pointing out the window after the music therapist had mentioned the sunshine out the window eight minutes beforehand and sang a song about the sky 3 minutes previously. Then, after she sang all the words to a song about sunshine, she said, “Ah, does that shine away.” She continued to state, “We always play that where... where the... where the sunshine was” and pointed out the window. As the music therapist asked about playing another song on the tambourine, she said, “Uhhh” in a thinking tone and began to sing the song about sunshine again. She had sunshine on her mind throughout most of the session by talking about it, singing songs about it, and pointing out the window.

During the seventh session, Lindy appeared to focus on the style or source of the music being played in the session more than a conversational topic. The music therapist played the original recording of a big band song to which Lindy gasped and gave an excited

smile. She stated, “Sounds just like it,” as she played the tambourine and sang parts of the melody. Lindy asked, “Do you have it on the?” and “Is it from there?” and stated, “Oh yes!” when the music therapist explained the music was playing from the CD player. After this song, the music therapist mentioned the name Frank Sinatra, and Lindy stated, “Like our guy there?” seven minutes afterward. The music therapist then proceeded to play a big band song sung like Frank Sinatra, and Lindy furrowed her eyebrows and stated, “That really, is that... really that way is it?” After the music therapist played a country song, she smiled and stated, “That’s just like the music.” Lindy seemed to focus on the difference in style between recorded and live music when she was listening to big band songs.

Sometimes it was not so clear whether Lindy was connecting ideas from previous songs or not. During the eighth session, on Valentine’s Day, the music therapist sang a song about love and asked Lindy if she had a sweetheart. She replied, “Oh” and looked from left to right with a puzzled look before saying, “A little bit.” When asked what he was like, she replied, “Well, it’s almost the same way.” The music therapist asked “As the song?” and she stated, “Yes.” Next, after another song about love, she stated, “That was pretty,” and the music therapist agreed. Then she stated in a reflective, serious tone of voice, “Indeed he was.” When the music therapist asked her about this statement, she stated, “That was nice” in her usual happy tone. The music therapist then proceeded to play a love song accompanied by the tambourine, and unlike the previous time, Lindy mouthed the phrases “I’m in love with you” twice and also “keep the love light glowing” once. After the song, the music therapist asked again about her sweetheart, and Lindy replied in a questioning tone “I’m in love with you?” The music therapist confirmed that was part of the song, and Lindy

stated, “Ahh.” While it was clear that Lindy recalled lyrics from the song, it was not as clear if she related the song to her life.

In the last example of sustained awareness, Lindy recalled that the music therapist had visited her 15 minutes earlier. At the beginning of the tenth session, she had not gotten out of bed yet and appeared confused and irritated. She did not say yes to the offer of music and said in a frustrated tone, “Where is the ...where is?” The music therapist told her that she would come back at a better time, and she asked, “Where are you going?” grabbed the music therapist’s hand, and then stated “You better come back.” As the music therapist entered the room 15 minutes later, Lindy was sitting in her armchair, smiling, and said “Oh, you’re back!” excitedly. She was able to remember the music therapist after she was gone for 15 minutes. Lindy showed her ability to sustain focus on a topic through conversation, noticing the difference in music played, and even remembering a visit after 15 elapsed minutes.

Lindy showed active responses during the session by singing, playing instruments, and making comments throughout the sessions. Even though she was generally observed in an active alert state, she was more engaged and energetic in the morning compared to the afternoon. She noticed or indicated the events in her environment, especially staff members coming in to the room and her roommate’s activity, which seemed to at times affect her emotional state. Her verbalizations consisted of a variation of the sentence, “That’s nice” approximately 107 times, but she did have 18 instances when she directly answered a question. Even though she had a short attention span, she had multiple occasions when she maintained a sustained awareness of a topic, which was usually influenced by a song implemented during the session.

Participant 3: Martha

Background information. Martha is an 89-year-old woman who had diagnoses of severe dementia of the Alzheimer's type, depression, hypertension, osteoarthritis, and muscle weakness. She was a widowed housewife with two sons. Her religious faith was Catholic. According to her medical chart, she often did not recognize people and seldom responded during conversations. According to her medical chart, she preferred classical, big band, and pop music.

Awareness states. Martha was active alert for eighty percent of her total sessions by attending to the music or talking to the music therapist. Sometimes she was drowsy during a session, but she was often aware of these moments, for example when she told the music therapist that she was tired. She also had seconds where she would be dazed when she was talking, yet she often mentioned this as well by saying, "Where did my mind go?" She had moments of clear speech and at other times said unclear phrases where she would say an unrecognizable word or repeat a syllable in a word. Martha talked in a soft voice that was hard to hear and understand. The music therapist was uncertain at times whether Martha displayed unclear speech or the music therapist could not hear what she was saying. Martha's speech became more accurate and clear when she was in an alert state as opposed to a drowsy state. Martha often said the start of her sentence clearly and then paused as she had an unfocused look to her eye. In this instance, her focus would drift and other times she would shrug or shake her head and say, "I don't know" or "It doesn't matter."

She responded to questions when she was alert and held a few brief conversations throughout the sessions. She often became more talkative when asking the music therapist questions about the music therapist. For instance, she asked the music therapist twice where

she went to school and where the music therapist got the guitar. Also, she asked the music therapist “Where, where, where, are you going to play?” and said, “I was just wondering...is that yours?” while looking at the guitar. In session nine, she asked, “Do you play for others?” She also showed consideration for the music therapist’s space by asking if the music therapist had enough room to play.

Responses to environment. Martha noticed what was happening in her environment when in an active state. Often when a staff member would open the door and peek in during a session, because she or he was looking for somebody, Martha asked, “Who was that?” and “Did she find her?” She also listened to her roommate’s comments. Her roommate frequently answered the questions that the music therapist had directed to Martha. The music therapist sometimes pulled back the curtain dividing the room and had a conversation with both of them. Martha often looked back and forth from the roommate to the music therapist and often asked the music therapist, “What did she say?” During the tenth session, her roommate was agitated, and it was very distracting to Martha. At the beginning of the session, this agitation seemed to make Martha appear nervous with wide eyes, but towards the end of the session Martha began to appear irritated as she rolled her eyes a couple of times when her roommate said an angry comment. The roommate apologized for her behavior at the end of the session, and Martha asked the music therapist her roommate’s name. Another time, a staff member was attending to the roommate, and Martha grabbed the curtain in an effort to pull it back again to see her roommate. Martha also asked seven times about the things in her room like objects on her tray. She started to pick up her drink off her tray but required assistance five times due to her hand tremors, which were present in three sessions. Martha also showed interest in what was going on outside of her room such as

asking the music therapist to open her door so she could see out into the hallway. She also looked out the window when the window was in her line of vision. During one session, she looked toward the window when it was snowing and stated “Oh, look it really is... really is coming down out there...all that snow, it’s like calm over the world.” Martha was attentive to what was happening in her room and also what was going on outside of her room when she was alert.

Martha also was attentive to the music in the sessions in both active and receptive ways. She mouthed lyrics, sang a few lines, or played an instrument with prompting. She would usually mouth the repetitive words at the beginning or end of a phrase. Martha was willing to play an instrument four times and agreed to with prompting in two instances. The music therapist began introducing an instrument by modeling it first and then encouraging her to just explore the surface of the instrument. In one session, Martha flipped the tambourine over and exclaimed the other side was “shiny.” Another time she stated that she did not expect the tambourine “to feel that way.” When she was in bed, she played the tambourine with a mallet as the music therapist held it out to her because the original angle of playing was challenging for her when she was in bed. When she was in her wheelchair, she was able to play the tambourine with her hand. One time she did not play on the top part, but held on to the side of the tambourine where she played one of the jangles on the side instead. Martha also played the eggshaker independently six times and strummed the guitar with an adaptive pick with hand over hand assistance once. Martha usually played an instrument for no more than 15 seconds before stopping.

Martha seemed to prefer to participate receptively to the music. When the music therapist sang, Martha often closed her eyes during the song and opened them the moment

the song was over. At times she would say, “That was nice” in a genuine tone with a slight smile on her face right after a song. She receptively participated in the music when she was drowsy, which usually led to entrainment of her breathing. On the other hand, the next session had the opposite effect when she was receptively listening to the music. She was drowsy again and stated that she had trouble sleeping and was tired. Her eyes were closed during a majority of the session. Towards the end of the session, after two upbeat songs, she became actively alert by opening her eyes, smiling, and stating, “You are so young” to the music therapist. She continued to say, “This was great. Thank you for coming” as the music therapist was about to leave. Martha appeared to prefer to listen to the music more often, although she also actively participated in the music a total of 23 occurrences.

Moments of emotional expression or preference. Throughout the course of the sessions, Martha expressed her emotions or gave statements influenced by what was on her mind to the music therapist. These concerns ranged from talking about her family and past to her present concerns of living in the facility. Each session was a different emotion or concern than the one before. During the first session, she answered a question with, “Not since I’ve been here” in a depressed tone and stated, “Yeah” when the music therapist asked, “Is it hard for you here?” In the second session, she was sometimes confused by asking the question, “Is your mother up yet” and telling the music therapist to “Watch your step” as she left. Even with her confusion, she was still able to express herself by saying, “Things I don’t understand about people...” in a frustrated tone. She went on to talk unclearly and ended this thought with a shrug of her shoulders and saying, “Whatever will be, will be.”

In session three, she was much more alert than the previous time and held a conversation about her son who visited her almost every other day. When the music therapist

asked about him, she stated, “Somebody said they were here yesterday, they told me...that was sweet...finally today or tomorrow.” When the music therapist asked if Martha looked forward to his visit, she responded, “Oh, yeah, they’ll all come here, you know that, I know well that.” Then in the next session, Martha asked for the music therapist to open the door to her room. The music therapist asked if she liked to watch what was going on in the hall. Martha responded, “Sometimes, but sometimes I like to be alone...I wish I could.” She nodded when the music therapist validated that she wanted time to herself.

When the music therapist entered Martha’s room in the next session, her son had just left sometime within the hour. Martha stated that she was “not good” but did not know why. She continued to say she was feeling “not the best” and talked unclearly in an emotional tone for a couple of sentences while looking away from the music therapist. When the therapist responded, “That’s been on your mind today,” she continued to speak unclearly for another sentence. She gave a small smile when the music therapist introduced a song that is “not for the best of days.” “That’s alright,” Martha stated. The music therapist then asked Martha to listen to the song and tell her what she thought about the song. As the music therapist sang the lyric “smile,” Martha closed her eyes, hummed along to the line “although a tear” and harmonized on the last note of the song. After a silence, she began to speak unclearly again, but the music therapist heard the phrase “means to me...” in the sentence. Then Martha and the music therapist laughed at an occurrence in the hallway. At the end of the session, Martha smiled slowly and said, “We’ll see” with a laugh as the music therapist offered to come back.

In contrast, Martha was beaming with smiles and compliments at the end of session six. During the session, she was alert, but not excitedly engaged. Her happiness and energy

increased by the last song. She said she “enjoyed those young girls coming by” and that the music therapist was “one of the better ones.” Martha continued to say, “Thank you for this.” As the music therapist was leaving, Martha held out both of her arms and raised them one inch as in the shape of a hug. Her smile grew larger as she received a hug from the music therapist. Martha also expressed her feelings at the end of the seventh session as well, although the affect was solemn and sad. As the music therapist was packing up her things, Martha stated, “I don’t like it here.” She continued to speak faintly, and it was unclear to the music therapist what was said except for “home,” but she ended the statement with an audible, “But not that I’m complaining.” Martha nodded when the music therapist just told her it was okay to be honest and did not mean she was complaining.

In the next session, Martha was very talkative, alert, and reminiscing. During the middle of the session, she reminisced about her home by stating that she was born in New York, lived in both the city and the country, and she talked about how she loved her two siblings and how they would get together as a family. During the ninth session, she was very alert again and chose to listen to happy sounding songs over sad songs, which had been answered with “I don’t know.” She also chose a fast song over a slow song. When asked how she was feeling, she stated, “Joy, but I still have” and drifted off in thought. As the therapist stated that she was glad that she felt joy, Martha stated, “I’m glad I’m listening to you” with a smile. Martha expressed herself to the music therapist through a variety of emotions throughout the course of the music therapy sessions.

Martha was generally in an active alert state throughout most of the music therapy sessions, and she was usually able to express what was on her mind to the music therapist even though she had instances of unclear speech at times. While she did participate actively

in the sessions by playing instruments and singing songs occasionally, she appeared to connect affectively to the receptive interventions more by closing her eyes and listening to the lyrics of the songs. The music combined with the conversations from the music therapist appeared to encourage Martha to express emotions that had been on her mind and bring awareness to her feelings about her present living situation, her family, and her hometown.

Chapter Five

Discussion

This chapter will begin with a discussion of the differing levels of responsiveness among the participants and then will present the subtle environmental, musical, and social stimuli that triggered their responses. Emerging social and emotional awareness will also be discussed in addition to addressing the research question of observed patterns during the session. The chapter will conclude with challenges and limitations of the study plus implications for future research.

Differing Levels of Responsiveness

All three participants in this study exhibited signs of aware and affective responses in varying ways throughout the course of the sessions. Although each participant was diagnosed with a late-stage type of dementia and referred to the music therapist by the activities director as being minimally responsive, two of the participants, Lindy and Martha, were more actively responsive in the sessions than originally expected. This situation coincided with the Ice (2002) finding that residents in her nursing home study displayed flat affect for 91% of the day. In the current study, the participants had their eyes closed or did not notice the music therapist until she touched them, said their name, or came in close proximity 72% of the time. At first glance, the participants may seem to be minimally responsive to the environment or to those around them; however, when the participants became alert, they were all involved in the sessions, although with varying levels of physical and communicative abilities. Although each participant in the study was able to play an

instrument, each participant had her own level of ability that required varying assistance. For instance, Lucy sometimes had involuntary movement in her hands almost throughout the entire session, while Martha had hand tremors five times when trying to pick up an object, which the *DSM-5* (2013) stated as one of the symptoms of late-stage major NCD. Lindy was not observed to have hand tremors. This difference was observed when Martha attempted to pick up her drink with a shaking hand, said it was “slippery” and “heavy,” and put it back down. Lindy could pick up her drink and sip from it without effort. When playing an instrument, Lucy was able to move her hand, but could not open her hand to grasp the instrument, while Martha was able to touch the instrument with a soft or shaky grasp. Meanwhile, Lindy was able to play or hold the instrument with a strong grasp and play with dynamics which required control of her hand. To accommodate for the range in physical capabilities, the music therapist used adaptive methods that involved giving Lucy a small instrument with a handle so she would not have to open her hand. Then, she was able to play it one time with hand over hand assistance. Martha would often play an instrument in an adaptive way by playing the tambourine with a mallet or playing just the metal part of the tambourine instead of having to open her hand to play the top. Occasionally, hand over hand assistance was provided to produce a stronger sound she could hear well. Lindy also had hand over hand assistance at times, but it served the purpose of cuing her to maintain attention during the instrument playing.

Similar to their varying physical capabilities, the participants had a range of communicative abilities that presented throughout the sessions. While Lucy was able to vocalize syllables, Lindy was able to say simple comments or sentences, and Martha could hold a brief conversation with a couple of sentences on a topic. Even though Martha

typically used more expressive language than Lindy, Lindy had louder and clearer speech than Martha. Lindy often said the repetitive phrase “that’s nice” in response to questions or statements while Martha usually gave a specific answer to questions. Lucy responded to a few questions with a syllable such as when she stated “ah” when asked if she preferred relaxing songs that day. Although Lindy and Martha had mostly clear speech, they did not always respond to questions or comments posed by the music therapist, which related to the fact that people with major NCD do not consistently respond to verbal stimulation (American Psychiatric Association, 2013), yet all three participants had times when they vocally responded to a question, which suggested that “social cognition tends to be preserved until late in the course of the disease” (American Psychiatric Association, 2013, p. 612).

The differences in the response levels of the participants may vary so much due to the fact that major NCD is a progressive disease where the person’s abilities are gradually affected overtime. Each participant was affected with a different progression even at the same stage of the disease. Since 40% of the duration of the disease is considered to be late-stage (American Psychiatric Association, 2013), this stage left a big gap of time in considering the progression of the disease and possible functioning levels at the onset of the study. Regardless of the participants’ differences in functioning, all the participants were alert and responsive in some way to factors of environment, music, social interaction, and emotional expression.

Environmental Stimuli

The environment was important to consider when describing or observing responses because the environment of their room provided the context and the setting of the sessions. This was useful to describe because their room was considered their home environment, and

it was beneficial to take note of what stimulates them in their everyday routine of living in a facility. Environment played a considerable role in affecting the music therapy sessions and eliciting responses in the participants. Because the sessions were held in their room, the sessions were susceptible to interruptions from staff members, distractions or contributions from roommates, and influences from their surroundings. Staff members often entered the room to check on participants' roommates, bring drinks, or to look for somebody, which distracted Lindy and Martha. Even when Lindy was in a dazed state and not alert to the music therapy session, she would turn her head to the sound of someone entering the room. Often Lindy and Martha wondered who was visiting and what their purpose was when a staff member entered the room. Martha asked, "Who's that?" when a staff member opened the door, and when told the staff member was looking for someone, Martha wanted to know if the staff member found her. In the seventh session, Lindy stated that she did not understand why a staff member was looking through the clothes closet in her room. Occasionally, staff members told the participants the purpose of their visit, but other times they did not mention the intention of entering the participants' room, which in return made Lindy and Martha concerned. The music therapist did not notice a response in Lucy when staff members entered her room; nevertheless, at the beginning of two sessions, Lucy opened her eyes and glanced at the music therapist as she set up for the session, which suggested that Lucy was aware of the music therapist entering the room. All the participants in the study had times when they were alert to a person entering their room, which suggested that the participants noticed who staff were and often wanted to know the reason for why they were visiting.

Roommates were another environmental factor that Lindy and Martha noticed which either distracted from, or contributed to, the session. When Lindy was in the middle of

making a statement, she became distracted by watching her roommate get out of bed and lost her train of thought. Also as Lindy's roommate let out a groan as she was being turned in bed, the sound concerned Lindy so much that it distracted her from the music and caused her to ask, "Who's yelling?" Likewise, Martha was also distracted with concern and eventually what appeared to be annoyance during the session when her roommate was agitated and made inappropriate comments. In a previous session, Martha's roommate joined in a conversation about playing in the snow, which added social stimulation from a peer to the conversation and caused Martha to ask with interest, "What did she say?" Lucy's roommate at times was a distraction to the music therapist since her roommate occasionally talked to the music therapist between songs. Lucy's roommate frequently talked to the music therapist about Lucy's family, how they used to spend time together, or the condition that Lucy was previously in that day, which contributed to helping the music therapist learn more about Lucy. She also provided peer interaction for Lucy by talking to her and playing a tambourine to the rhythm of Lucy's foot tapping. Regardless of whether the roommates interrupted or positively affected the session, the participants responded to their roommates' actions, which showed their retained ability to initiate interaction or concern for their peers.

The surroundings of the session space also occasionally activated the participant's attention. Lindy occasionally noticed objects in her room. For example, she gestured to the doll on the windowsill and glanced at her picture collage on the wall. Lucy gazed at a flower bouquet on her table when the music therapist pointed to it, and Martha asked about her roommate's red blanket. Thus, objects in their room that tended to have a personal touch or added a homelike atmosphere to the room seemed to stand out and activate the participants' attention and help to connect them to their environment. Lindy and Martha's curiosity for

their environment extended to outside their room to the hallway and to the window. Martha suggested that she wanted to know what was going on in the hallway by asking the music therapist to open her door, and Lindy asked, “Can they hear out there?” while looking toward the open door and the hallway. The hallway seemed to be their social connection to the happenings of the facility. Lindy also frequently gazed out the window during sessions and occasionally connected a previously sung song to what she could see outside, for instance, pointing and saying “It’s the sky there” and “Does that shine away?” after songs about the sky and sunshine. Martha seemed motivated to talk about the snow by saying how it looked like “a calm over the world” after the music therapist asked her if she had looked out the window that day. The surroundings in their environment at times provided visual stimulation that helped prompt a purposeful connection to the conversation or the music, which either the participant or the music therapist initiated. The major factors of the environment that influenced the music therapy in either disruptive or contributive ways included staff members entering the room, conversations from the roommates, personal objects in their surroundings, and the environment outside of their room. The participants’ engagement in the environment suggested that they were in some aspect alert and interested or concerned about what was happening in their room.

Musical Stimuli

When the environment began to distract the participant’s attention away from the music therapist, music was often the stimulus that brought the attention back to the music therapist and elicited a response from the participant. For Lindy, either the first sung note or the first strummed guitar chord of the song caused her to turn her head and look at the music therapist in the first three sessions when she was distracted by looking over at her roommate

and staff members. The final cadence of a song also caused Lindy to turn her head and bring her focus back to the music therapist. Magai (2005) found similar findings in her case study with Ms. P. who was believed to be nonresponsive until Ms. P. turned her head toward the source of the music after the first note. Occasionally, when the music therapist speculated that Martha was asleep, she would open her eyes and begin to stir as the final cadence was played. Various changes in the music including the bridge of a song, change in guitar accompaniment, extending a phrase, or adding an unexpected pause in the song often triggered the participants' awareness as well. Lucy frequently opened her eyes during the bridge to a love ballad and opened them for 36 seconds at the start of the bridge to an upbeat pop song. Lindy opened her eyes during the bridge section, which was played twice, during a jazz ballad and kept them closed throughout the rest of the verses. The bridge section consisted of a change in chord progression and melody, and the participants seemed to at times be aware of this change in the pattern of the music.

Changing the guitar accompaniment was also a way to introduce novel stimuli in the session. For example, Lindy often laughed and said, "That's nice" as the music therapist changed from a finger picking to a strumming pattern. Strumming also tended to add energy and stimulate Martha and Lindy to become more alert when they were becoming drowsy. The participants seemed to be aware of the rhythm and flow of the songs. When the music therapist held out a chord longer than usual for effect, Lucy said "ugh" in an irritated tone, which suggested that she may have been waiting for the song to proceed. Also, when the music therapist held out the end of the phrase "anything more" before finishing "I Got Rhythm," Lindy and Martha had instances where they smiled and laughed during the pause in the song. The music therapist discovered that nuances in the music including unexpected

fermatas, change in accompaniments, and specific sections in songs could trigger the attention of the participants and show they were receptively involved with the music.

The dynamics of music also activated alert responses. For example, Lindy appeared to be responsive to dynamic changes in recorded music, which was evidenced by her playing the shaker. She tended to be motivated to play the shaker during the horn line riffs in the big band songs, and she would shake the shaker on the triplet beat the horns were playing. She also raised her hand upward while playing the shaker as the music began to increase in volume, which suggested that she was following the intensity of the music. As the horns stopped playing the riff, she put her hand down and stopped shaking. Gotell et. al (2009) found that caregivers noted an increase in energy and playfulness in the people with dementia when recorded background music was playing, and this finding was relatable to Lindy since she generally smiled, laughed, and was more playful in playing instruments during the recorded music than performed music on the guitar. This may be due to the fact that Lindy preferred big band music, and one person cannot replicate the style and intensity of big band music found in the original recordings. Gotell et al. (2009) also discussed how people with dementia tended to listen more closely to songs that were directly sung to them by caregivers, and Martha appeared to listen more closely to songs sung to her rather than recorded music. She often closed her eyes at the start of songs with relaxed look on her face and opened them with a smile at the end of the song, which suggested that she was relaxing and possibly having a meaningful, personal connection to the song.

While recorded music was a great resource for Lindy, it was important to use live music to be able to manipulate the music as needed, specifically in the case of entrainment. All of the participants in the study became entrained to the music at some point, which was

usually when the participants were drowsy, sleeping, or needed to relax. The music therapist purposely used entrainment to slow down Lucy's rate of breathing, when she was not feeling well in session 11, and she began to breathe more deeply, appeared to relax, and even opened her eyes and gave eye contact to match the music therapist. Entrainment increased relaxation and improved breathing. When entrainment occurred for all the participants, it tended to be toward the second half or end of a song. Also, the bridge either provided entrainment where the rest of the song did not or disrupted entrainment until the verses began again, such as when Martha breathed to the rhythm of the verses of a jazz ballad and did not breathe to the bridge of the song even though the rhythm was consistent. Lindy had a few instances where she breathed on each note during the last phrase of a song, when the music therapist slowed the rhythm down to a close, which was a strategy that Magai (2005) implemented with Ms. P. by playing a note on each exhalation of her breath. Each participant seemed to be more likely to breathe to the rhythm of songs that were in a triplet meter or meter of three with a slow, waltz type feel. For instance, the music therapist noticed that when Lucy was entrained to the majority of songs in session seven, the music therapist was playing a constant stream of slow, relaxing waltz songs. Slow waltz songs appeared to reflect the natural rhythm of the breathing cycle and meet the participants at the pace they were. Entrainment was an important intervention in this study because it suggested that the participants were still engaged with the music during times when they were in a drowsy or sleep state, which supports the statement that "patients who are nonresponsive are responsive to music" (Kerr, 2004, p. 21).

Along with the rhythm of the music, the melody of the music also influenced responses from the participants in the form of rhythm, harmony, and lyrics. Lindy tended to

tap the rhythm of the melody of a song being sung on the tambourine rather than the beat of the song being sung. Also, when the music therapist began to tap the rhythm of the melody instead of the beat of song on the tambourine, Lindy began to sing the song. Lindy and Martha also sang harmony to the melody of songs five times, which showed their retained capacity for knowing the original melody and hearing the melodic relationship between pitches to sing harmony. Lyrics were another factor that added meaning to the melody of songs. Lucy may have been influenced by the lyrics of songs at times like when she raised her hand in the air during a lyric that was about needing a helping hand. She also brought her hands together right under her chin during a religious song from childhood, which could signify having the world in her hands or could have been a symbol of prayer. While such observations cannot be proven, the speculations of these actions in response to lyrics should be considered. All of the participants had times where they would raise an eyebrow or say, “That’s cute” when the music therapist would change up the lyrics to reflect the moment or insert the name of the person in the song. Ridder (2003) discussed the benefits of having lyrics versus vocal improvisation and mentioned that while improvisation decreases the pressure to sing, the lyrics can provide a sense of familiarity and recognition, a message, and deliver emotional content. It appeared that a lack of lyrics did encourage Lucy to sing, for example, when she hummed a few notes as the music therapist hummed a Christmas song, and when they alternated singing a phrase of syllables in the middle of an Elvis rock song; however, lyrics were recognized by all three participants since they all had instances of mouthing words or lines to songs. The subject of the lyrics in familiar songs seemed to hold Lindy’s awareness on the previously mentioned conversation of the sunshine that day or the questions about her sweetheart. Also, the lyrics were at times a source of emotional

validation, for example, when the music therapist sang a song with a comforting yet sad tone when Martha appeared sad. The researcher found it interesting that Martha hummed the line about tears and no other phrase of the song when she did appear tearful. Some songs tend to “get a grasp on us” (Ridder, 2003, p. 100) due to the content of the lyrics. The participants in this study were responsive to many aspects of the music including the stimulus of the sound itself (Magai, 2005), the subtle changes in the performance of the song, the differences between recorded and live music (Gotell, 2009), the importance of rhythm for entrainment to breath (Magai, 2005), and the importance of lyrics in the songs (Ridder, 2005).

Social Interaction with the Music Therapist

Music was not the only stimulus that inspired responses from the participants in this study because many of the alert responses happened during verbal interactions between the participant and the music therapist. The participants had blank stares or closed eyes at the start of a session 72% of the time, but their alertness level often increased with more interaction with the music therapist during the middle or closing of the session. It was confirmed that a person “may not correspond fully with the potential degree of awareness” (Claire, 2010, p. 29). If a person dropped in for a moment to check on the person, he or she more than likely would not be able to witness the full extent of the person’s capability and have a false impression of the person’s functioning ability. Even though Lucy was not able to use clear speech and had her eyes closed approximately 80% of the treatment, the music therapist still talked to her and asked her questions to which Lucy did occasionally respond to by saying “ah” and “umm” in response to questions of having more music or choosing slow, relaxing songs. It was essential to treat each participant regardless of what awareness state they were in with the possibility of reciprocal influence.

As Cevasco (2010) mentioned, close proximity and positive affect from the music therapist also increased the interaction between participant and music therapist. In session six, the only time the music therapist grasped the attention of Lindy was when she got in close proximity to Lindy's face to say hello. Martha sometimes did not realize that the music therapist was in her room until she was in close proximity of Martha. Proximity was also important for interacting with Lucy as well due to implementing gentle touch interventions to grab her attention. The participants tended to reciprocate changes in the therapist's affect by smiling as a response to the therapist smiling at them (Cevasco, 2010), because there were instances when all three participants returned a smile given from the music therapist, especially during the greeting and goodbye part of the session. Lucy even waved in the last session after the music therapist told her goodbye.

Gesturing was another way that the participants and music therapist often interacted with each other to clarify what they were mentioning. Lindy and Martha often pointed to what they noticed or had a question about, for instance, when Martha pointed at the guitar or when Lindy pointed at the words she was reading. All three participants would focus on whatever object the music therapist pointed to as well, which included pictures, items on their tray and home-like objects. Lindy and Martha glanced out the window and commented on the weather after the music therapist gestured to the window and mentioned what it was like outside that day. Lucy looked at her flowers after the music therapist pointed to them. The proximity and reciprocating affect from the therapist increased the interaction with the participants and helped to encourage them to express themselves, which demonstrated their awareness of themselves and the music therapist. Gesturing showed their desire to be understood by providing clarity to what object that were referring to.

Emerging Social and Emotional Awareness

The interactions and conversations the music therapist had with participants revealed moments of clear awareness the participants had of themselves or their immediate experience. Claire et al. (2008) discussed how people with late-stage dementia had moments of awareness when it came to personal identity or the self, the previous experience before the session, and even their level of engagement in her grounded theory model of awareness, which the findings in this study support. Martha showed a retained awareness of herself when she reminisced about being from New York and talked about her siblings and mother when she was growing up. The song about New York may have stimulated this awareness, but it was the conversation with the music therapist that seemed to encourage her further reminiscence and expression of these memories. Tomaino (2000) reported a similar experience when her client Molly recalled that she was from Ireland and talked about her family being from there. Not only did Martha recall moments of her past, but she also had times where she recalled her previous experience before the session. As the music therapist greeted her at the beginning of session nine, she stated that she was just put into bed after they “drenched” her, and Martha did have the appearance of just receiving a shower. Lindy also had a moment when she recalled the previous experience when she stated “Oh, you’re back!” after the music therapist returned to her room after being in there 15 minutes before. Martha even had a few moments when she stated, “I’m tired,” “I’m falling asleep,” or “Where is my mind?” that suggested that she was aware of her current level of engagement or in the case of her mind statement, her declining abilities. Through interaction, Lindy and Martha showed emerging awareness of themselves, their previous experience from minutes before, and even of their current level of engagement in the session.

Participants not only showed awareness of themselves, but also showed politeness and interest to the music therapist within the session during moments of interaction. It appeared that the participants desired to reflect the attention that the music therapist was showing to them back to her. Martha often asked the music therapist if she had enough room when she was setting up her guitar and pulling up a chair in the tight space between the wall and the bed. Both Lindy and Martha asked the music therapist questions about herself including where she learned to play the guitar and where she went to school, which showed their interest in getting to know the music therapist and developing a relationship with her. Lucy had a few instances when she raised her eyebrow or cleared her throat when the music therapist asked if she was listening or sleeping, which may have been Lucy's way of telling the music therapist that she was still actively listening to the music. Clair (1996) noted that alert responses to stimuli included raising eyebrows, opening eyes, and making vocalizations, which Lucy gave to the music therapist's questions when the music therapist asked how Lucy was doing. The participants actively interacted with the music therapist through subtle ways (Clair, 1996) and direct ways which gave the participants opportunity to show their awareness of themselves and the moment (Claire et al., 2008) as well as opportunity to get to know another person.

The opportunities for social interaction between the participant and the music therapist led to moments of emotional expression from all of the participants. This researcher supported the findings of Magai (1996) that people with late-stage major NCD can still express emotions and disagreed that "no interpretation of emotional meaning of patients' reactions could be made" (Asplund et al., 1991, p. 599). In the first and last session, Lucy gave a full smile that suggested a happy affect as the music therapist mentioned having

music. She also had tears in her eyes and a focused look when she mouthed the words to a religious song from childhood in the first session. The reaction of Lucy mouthing the words had emotional meaning evidenced by her tearful eyes, which suggested that the song was meaningful to her and brought up powerful emotions. Body language, facial affect, and tone of voice were non-verbal ways of expressing emotion (Magai, 1996), which Lucy did through her smiles, raised eyebrows, and tone of voice in her vocalizations when she sounded like she was speaking in conversational phrases. Martha expressed her affect through facial expressions and body language, for instance, when she rolled her eyes at her roommate annoying her or the times when she would shrug her shoulders when asked a question she didn't know or want to discuss further. Lindy expressed her affect through tone of voice when she said "that's nice" in emotional variety from excited, approving, and polite to tired and disinterested. In Ridder and Aldridge's (2005) case study of E., the authors described how she frequently stated, "That's nice" to show preference and enjoyment in the songs sung during the session. Kovach (1999) mentioned how comfort and positive affect can increase throughout the session, which was evidenced by Lindy when at the beginning of the session she said she was feeling "ok" in a tired, disengaged voice and by the end of the session stated she was feeling "very good" with energy.

Martha occasionally expressed her emotions to the music therapist and told the music therapist feelings or concerns that had been on her mind, especially about living in the facility. She stated once "not since I've been living here," and said, "Yeah," when asked if it was hard for her to live there, which was an oriented statement to the present moment that was uttered in a session where she stated a couple of confused, unrelated statements. She also brought up the subject again in the seventh session when she stated, "I don't like living

here,” and continued to say an unclear sentence about home. Tomaino (2000) found that music and emotional awareness brought instances of awareness to the present through case studies. For example, Sadie she stated how she had lost everything and how she used to do things that she does not now in Tomaino’s (2000) case study. It appeared in both cases that either their depressed emotion stirred up awareness about their present or that their awareness of declining abilities or change in living arrangement brought up depressed emotions. Magai (1996) observed that people with major NCD showed moments of awareness through emotion expression when participants appeared sad when their family members left. Martha appeared sad and tearful when the music therapist visited her soon after her son left from his visit, and although she may not have been aware of why she was upset, she was aware that she was not feeling good at that moment. Although the music therapist was unable to understand her speech when she was talking, Martha seemed to feel an emotional release and validation through the song played. After the song, her affect appeared to improve evidenced by her smile and occasional laughter throughout the rest of the session, which supported Magai’s (2002) finding that emotional validation increased positive affect when people with major NCD were not in a good mood.

The emotional expression of the participants also suggested the awareness of the interaction or the relationship between the participant and music therapist. Martha frequently expressed her appreciation for the music therapist coming to visit her by saying, “Thank you for this” and even “You’re one of the better ones.” Often this expressive emotion was expressed in a non-verbal way including when Lindy shook the music therapist’s hand, when Martha reached out for a hug, or when Lucy waved goodbye to the music therapist. Ridder and Aldridge (2005) had a similar finding when Ms. F. reached out to the music therapist and

gently touched her chin in an attempt to connect emotionally with the music therapist. The participants expressed their emotions through facial expressions (Clair, 1996), verbal means, and purposeful touch (Ridder & Aldridge, 2005) that suggested their awareness of themselves (Tomaino, 2000) and their desire and ability to connect emotionally with another person (Magai, 1996). The opportunities for emotional expression and validation of emotions would not have been as likely without the interaction between the participant and music therapist, which appeared to show reciprocating influences on the participants (Cevasco, 2010) and increased awareness of self and others (Claire et al., 2008).

Patterns of Participants' Responses

One of the questions posed in this study was if there were any patterns or tendencies of the participants throughout the course of a session. While the music therapist noticed that at times the participants appeared to become more active and alert as the session came to an end, for example in Lindy and Martha's last session when they went from a drowsy state to an alert state, these findings were not consistent. There were a few sessions when the participants appeared to become drowsy as the session progressed and the participants eventually went to sleep. Some sessions showed a change in awareness level, while in other sessions the participant had a consistent awareness state. In looking for subtle tendencies, Lindy and Martha seemed to sing or mouth the words of songs toward the end of the song instead of at the beginning of the song. For ten instances, Lindy or Martha did not sing until the second time a song was repeated, or they would start out mouthing the lyrics and eventually switch to singing by the end of the song. As Clair (1996) noted, the participants' responses were often slow, but as time passed, the responses began to increase. This may be due to the fact that people with major NCD have a delayed reaction time in processing

material, but reaction time can improve with practice (Gregory, 2002) by singing a song again or mouthing a phrase before singing it. Similar to the inconsistencies of participants during the session due to awareness state, the researcher did not discover any patterns of the participants' treatment throughout the sessions. The music therapist noticed that at times that participants would seem to go through stages of having a couple of alert sessions and then a few drowsy sessions or vice versa, but the findings were not consistent enough to draw any major conclusions from them. In this study, the researcher did not notice any major patterns of response that developed consistently during the individual session or throughout the course of treatment.

Although there was no definite evidence of patterns during or throughout the progression of the music therapy sessions, all the participants had instances that suggested direct responses to factors of environment, music, and the social interaction from the music therapist herself even with the varying differences of ability in the three participants. Staff members and sometimes roommates occasionally caused disengagement (Ice, 2002) from the sessions, while roommates, personal objects in the room, and the outside environment including the hallway or the weather outside the window contributed to the session in a conversational manner. Meanwhile, music was often the stimulus that initially grabbed the attention of the participants (Magai, 2005) and even suggested that participants were still responding to the session when they did not appear to be responding (Kerr, 2004). The various factors of the music, such as subtle changes in performance, recorded music versus live music (Gotell et al. 2009), rhythm, and lyrics (Ridder, 2003) influenced the participants' level of energy and alertness (Gotell et al. 2009), emotional expression (Ridder, 2003), and even breathing pace (Magai, 2005). The interactions between the music therapist and the

participants provided further enhancement of the participants' awareness levels by providing the opportunity for social stimulation and reciprocating influences (Cevasco, 2010; Claire, 2010), which resulted in the expression of awareness of one's past (Tomaino, 2000), previous experience before the session, and level of engagement (Claire et al., 2008) along with emotional expression (Magai, 1996) of concerns (Tomaino, 2000) and gestures of appreciation (Ridder & Aldridge, 2005). People with major NCD who may appear to be minimally responsive to stimuli in their environment must be considered as having "potential degrees of awareness" (Claire, 2010, p. 29) that can be exhibited through involvement in the environment, through meaningful interactions with another person, and through an engaging, expressive stimulus like music. Music therapy sessions provided all of those qualities and opportunities for purposefully engaging people with major NCD by providing them the opportunity for a better quality of life through facilitating meaningful interactions to promote their well-being and self-worth by motivating means of music interventions.

Challenges of the Study

The unpredictable nature, inconsistencies, and differences of the participants posed many challenges in this study. Each session was an opportunity for engaging a participant in more detail or in a different way than previously. One of the main challenges was interpreting the responses of Lucy and analyzing whether a movement was a response motivated by a factor in the music therapy session or just a random occurrence. Most of the time her responses were inconsistent, subtle, and done with her eyes closed, so the music therapist could not assess her level of focus in her eyes. The music therapist found her system for categorizing awareness states to be inapplicable for interpreting many of Lucy's responses because having one's eyes closed was considered a type of sleep state. Lucy

usually had her eyes closed, yet she could not be considered in a sleep state when she was still actively responding to the music therapist at times through vocalizations or facial affect. Also, when the participants seemed to be in a sleep or dazed state, they still were able to respond to the music through entrainment. This was confusing to code, because they were responsive to the rhythm of the music even though they were not coded as having an alert state. People who can be minimally responsive to their environment are hard to assess due to their small reactions, inconsistent responses, and easy fatigue (Laureys et al., 2004).

Kovach and Magliocco (1998) found similar results in their study on participation levels of people with late-stage major NCD in that the participants spontaneously responded in a subtle way. They also recommended only 10 minutes of activity because the participants did seem to fatigue easily and stated that the time of day had no significant factor in the participation levels. While some of Lucy's responses were subtle and spontaneous, most of the participants' responses were directly related to what was going on in the session. The researcher would also argue to conduct sessions longer than 10 minutes with this population to provide more time for the participant to adapt and get acclimated to the experience. The opening of the music therapy sessions from introducing oneself, offering music, setting up, and checking in with the participant often took 10 minutes on its own. If nothing else, the extra time provided more opportunity for spontaneous and subtle interaction if the participant were not as engaged. All of the participants in this study had a session in which they were alert for the entire 30 minute session without showing signs of fatigue, which suggested that 30 minutes was not overwhelming for them to be engaged actively. Time of day was a significant factor for Lindy, which the researcher did not discover until her fifth session. In the afternoon, she barely talked and often did not make eye contact with the music therapist

if she were awake; but in the morning, she was alert, talkative, and energetic the majority of the session. This tendency was not uncommon due to sundowning, which according to Bliwise, Carroll, Lee, Nekich, and Dement (1993) is a phenomenon that occurs in older adults with NCD where they show sleep disturbances or agitated behavior in the late afternoon as the sun begins to set. Scheduling the sessions at the right time of day when participants were most alert was another challenge of this study. The differences in findings between this study and Kovach and Magliocco (1998) may be due to the fact that the experiences in Kovach and Magliocco's (1998) study were activities instead of music therapy which meets the person at their level of energy and engages them according to their needs. The activities were also conducted in groups as well, whereas the music therapy sessions in this study were individual sessions, which may impact the focus level and directness of the responses.

Because Lindy and Martha were often more interactive and verbal than the music therapist first expected, the research questions in the study seemed too broad to cover all of the aspects of their responses. Because the researcher was expecting spontaneous, subtle, and minimal responses from the participants, she wanted to include all the possibilities of potential ways to respond in the music therapy sessions from her previous experience of working with people who were not as responsive as the participants in this study. In hindsight, the music therapist could have narrowed the focus of the study to a specific topic of noting the musical responses, the content of emotional expressions, or how the environment affected the sessions. The researcher would also recommend meeting the potential participants of the study more than once before enrollment in the study and at different times of the day to get more of an idea of their average functioning level.

Limitations and Implications for Future Research

Although research can be challenging and unpredictable with this population, investigations into their level of awareness and interventions that stimulate their interest are important to discover in order to improve their quality of life and provide opportunities for social interaction. Limitations for this study included the broad range of measured responses, the differences in functioning abilities of the participants, the small number of participants, and the fact that they were all seen by a music therapist who was also serving as the researcher, which may have affected the outcome of some of the results in the sessions. For future studies with this population, the music therapist would recommend extending the number of sessions and investigating whether people with major NCD have different phases where they experience alternating a few alert sessions with a few drowsy sessions. Another study to consider would be investigating how people with major NCD respond to the lyrics in songs or how they respond to entrainment even when they seem to be minimally responsive.

The findings from this research have many implications for future consideration in the field of music therapy as well as in the overall treatment of people who are considered “minimally responsive” with late stage major NCD. The subtle responses of facial expressions, movement, and breathing described in this case study could lead to an improved assessment of client response for this population. The study also addressed how varying musical elements can elicit affective responses from this population, which could improve music therapists’ skill of implementing music for this population. Both improved assessment and improved music implementation would lead to better therapeutic outcomes, which would also increase music therapy referrals for people who may have originally been considered “minimally responsive.” Not only do people with late stage major NCD need more

stimulation in their day (Ice, 2002), but according to the findings of this study as compared to previous literature (Kovach & Magliocco, 1998), they may not have enough time to be engaged fully in the activities that they may be offered. Each participant in this study had at least two sessions in which she was fully engaged for 30 minutes, which suggested that participants were not fatigued after 10 minutes. Because many of the responses increased towards the end of the session (Clair, 1996), there would have been fewer recorded responses if the sessions lasted only ten minutes. The extra time allowed for more opportunity of expression the participant could use or not according to their energy level; therefore, another implication of this research is to increase the amount of time spent with people with NCD to compensate for their delayed reactions (Clair, 1996) and increasing responses over time (Gregory, 2002). One of the most important implications is to recognize that although a person may appear minimally responsive, the person may be more aware than expected and should be treated with that possibility in mind.

Similar to Claire's (2010) findings, all the participants in this study were more alert to their environment and interaction with others than originally perceived. The environment provided the context of the session, as well as a glimpse into their everyday lives for the music therapist, and often influenced the focus or affect of the participants. The social interaction factor between the participant and the music therapy in the music therapy sessions seemed to inspire the participants to become more responsive and comfortable expressing themselves. This study described multiple examples of people with NCD responding to a personal connection with another person, for instance, Martha sharing her emotional concerns, Lindy talking and singing with the music therapist, and Lucy giving subtle hints that she was still listening to the therapist. Music was an equally important factor because it

was the music that often gained their attention when talking could not do so. It was music that provided, in Martha's case, the emotional container for validating her feelings, or in Lucy's case, provided relaxation when she was not feeling well. Music was the means of actively interacting with Lindy during those times when her conversation consisted only of the line, "That's nice." Music, along with the presence of the music therapist for social interaction, was the intervention that reached out to the participants with major NCD and provided them with a way to express themselves and connect with another person. While people often focus on the declining abilities of a person with major NCD, it is essential to continue to recognize the retained abilities of the person and provide the opportunity, through music therapy, for the person to continue to interact with their world.

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Appendix A

Consent to Participate in Research

Describing the Factors that Influence Moments of Interactive Responses during Individual Music Therapy Sessions for people with Late-Stage Dementia: A Multiple Case Study

Principal Investigator: Carey Barwick, MT-BC

Graduate Student

Department: Hayes School of Music

Contact Information:

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Faculty Advisor: Christine Pollard Leist, PhD, MT-BC

Assistant Professor of Music

Department: Hayes School of Music

Contact Information:

828-262-6663

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This research is not funded.

What is the purpose of this research?

Your family member has been invited to participate in a research study that describes moments of response from people with late-stage dementia or Alzheimer's disease during music therapy sessions. Music therapy is a creative, alternative form of therapy that uses a therapeutic relationship and music interventions to accomplish a goal. Music therapy can benefit anyone, but it especially reaches people who may have difficulty expressing themselves. Previous studies have suggested that people with late-stage dementia may be more aware of their surroundings than previously thought, and music therapy interventions may stimulate their awareness of themselves and their environment. By conducting this study, we hope to describe what happens when people with late-stage dementia respond to the music or their environment during a music therapy session and see if there any patterns of responses during the music therapy sessions. The researcher will present the results of this study in the form of a thesis paper and in educational presentations.

Why is my family member being invited to take part in this research?

Your family member is being invited to take part in this study because he or she is over the age of 65 and has been diagnosed with late-stage Alzheimer's disease or a related dementia. Your family member must also be a current resident of Glenbridge Health and Rehabilitation. Another reason your family member is being invited is because he or she is minimally

responsive to social interaction or his or her surrounding environment. If you are interested in your family member's inclusion in this study, he or she will be one of four participants in this study.

What will my family member be asked to do?

If your family member participates, he or she will receive two individual music therapy sessions each week for a total of six weeks. Each session will last an average of 30 minutes. These sessions will take place in your family member's room. The session day and time for each participant will be determined through the activities director.

The music therapist, who is the researcher, will complete a variety of music therapy interventions according to how the individual is responding at the time of the session. The order and choice of intervention will be determined by the researcher according to her academic study and previous clinical experience. Some of the interventions will be passive for the participant such as listening or relaxing to music. The participant may be encouraged to actively participate as well through instrument playing, singing songs, or verbalizing during a song. The therapist may use gentle touch such as holding a hand or stroking an arm to interact with the participant. While the participant will be encouraged to participate in the previously stated interventions, the participant is not expected or required to respond to the music therapy interventions.

In order to best document your family member's responses to music therapy, it would be helpful to have a video and/or audio recording of each session. The investigator will view these recordings after sessions and may use brief excerpts at professional conferences and meetings. Your family member's full name would never be disclosed on the recordings or at the conferences and meetings.

What will I be asked to do?

In order to sign these forms, you must be the individual's court-appointed legal guardian, health care power of attorney, durable power of attorney, or if no guardian/power of attorney, you must be the individual's spouse or majority of the individual's reasonably available adult children.

In order for the researcher/music therapist to offer the best music therapy experience to your family member, the researcher will need to review your family member's medical chart to access information about diagnoses, social history, information about cognitive abilities, information about communication abilities, current medications, and confirmation of legally authorized representative status. A HIPAA authorization form is included with this consent form.

If you meet the requirements to be the individual's legally authorized representative and wish for your family member to participate in this research, please complete and sign one copy of this Consent to Participate in Research form, the Authorization for Use and Disclosure of Protected Health Information form, and the Music Interests Questionnaire. Please return the

three forms in the enclosed envelope. Please keep one copy of the Consent to Participate in Research form for your records.

What are possible harms or discomforts that my family member might experience during the research?

To the best of our knowledge, the risk of discomfort or harm from participating in this study is no more than the risk that your family member experiences during his or her usual routine at the facility. Due to the nature of music to inspire emotions, a song may bring up strong emotions or associations for the participant, in which case the researcher will use her clinical experience to best support the participant. The participant may also rest or wish to rest during a music therapy session, and the therapist will provide interventions to match the energy level of the participant. Breach of confidentiality is an additional risk of this study.

Are there any reasons my family member might be taken out of the research?

Your family member may be taken out of this research if he or she no longer resides at that facility during the six weeks of the study. Your family member may also be taken out of the study if you no longer wish for him or her to take part in the study.

What are possible benefits of this research?

There may be no direct benefit for your family member participating in this research. However, there are many potential benefits that could include but are not limited to the following:

- Improved mood
- Increased relaxation
- Decreased anxiety
- Opportunities for social interaction
- Improved communication
- Increased awareness to environment

The information gained from this study may describe a deeper level of awareness than originally thought for people with late-stage dementia. This possible finding may educate caregivers, nursing facility staff, and music therapists on how to best interact and care for people with late-stage dementia.

Will I be paid for taking part in the research?

You or your family member will not be paid for taking part in this research study. Your family member will receive the individual music therapy sessions for free.

What will it cost me to take part in this research?

It will not cost you, your family member, or Glenbridge Health and Rehabilitation any money to be a part of this research study.

How will you keep my family member's private information confidential?

We cannot guarantee absolute privacy, but we will keep personal identifying information confidential to the best of our ability. Any public use of the data will be stripped of identifiable factors linking your family member to the study such as changing names and omitting personal details when discussing the findings of the study with others. Notes collected from the sessions will be kept on a password protected computer on a secure drive away from others use. Data will only be reviewed by this researcher and her faculty advisor. Information about you or your family member will be kept private to the fullest extent of the law. However if there is known or strongly suspected elder abuse, the investigators are required to notify appropriate authorities. The results of the study will be presented for a thesis defense, but identifying information will be omitted for any presentation of findings.

Whom can I contact if I have a question?

The people conducting this study will be available to answer any questions concerning this research, now or in the future. You may contact Carey Barwick, MT-BC at 843-267-9503 or barwickca@appstate.edu. If you have questions about your rights as someone taking part in research, contact the Appalachian Institutional Review Board Administrator at 828-262-2130 (days), through email at irb@appstate.edu or at Appalachian State University, Office of Research and Sponsored Programs, IRB Administrator, Boone, NC 28608.

Does my family member have to participate?

No, the participation of your family member is voluntary according to his or her best interests as determined by you. You have the right to withdraw your family member from this study at any time for any reason. There will be no penalties or consequences for your family member if you decide that this study is not for him or her. You or your family member will not lose any benefits or rights he or she usually has if he or she does not participate in the study.

This research project has been approved on _____(date) by the Institutional Review Board (IRB) at Appalachian State University. This approval will expire on [Expiration Date] unless the IRB renews the approval of this research.

I have decided I want to take part in this research. What should I do now?

If you have read this form, had the opportunity to ask questions about the research, received satisfactory answers, and want your family member to participate, then sign both copies of

the consent form, the HIPAA authorization form, and complete the music interest questionnaire. Keep one copy of the consent form for your records and return the other consent form, the HIPAA authorization form, and questionnaire in the enclosed postage-paid envelope.

I agree to allow the researcher to obtain a copy of the court order, health care power of attorney, or durable power of attorney documentation from Glenbridge and maintain it with research records.

Yes _____ No _____ Initials _____

I agree to allow video recording of my family member's music therapy sessions for educational purposes.

Yes _____ No _____ Initials _____

I agree to allow audio recording of my family member's music therapy sessions for educational purposes.

Yes _____ No _____ Initials _____

Glenbridge Resident's Name (PRINT)

Legally Authorized Representative Name (PRINT) Signature

Preferred Phone Number Date

Appendix B

Authorization for Use and Disclosure of Protected Health Information

This form implements the requirements for client authorization to use and disclose health information protected by the federal health privacy law (45 C.F.R. parts 160, 164), the federal drug and alcohol confidentiality law (42CFR, part 2) and state confidentiality law governing mental health, developmental disabilities, and substance abuse services (GS 122C)

Resident Name: _____ Date of Birth: _____

I hereby authorize Glenbridge Health and Rehabilitation to disclose protected health information to Carey Barwick. This disclosure is limited to the following information: diagnoses, social history, information about cognitive abilities, information about communication abilities, current medications, and confirmation of legally authorized representative status.

The Purpose of Disclosure is so the researcher may better understand the needs and characteristics of the resident in order to provide music therapy sessions in the context of the study titled, *Describing the factors that influence moments of interactive responses during individual music therapy sessions for people with late-stage dementia: A multiple case study*. This information will be held in confidence and not further disclosed, except in de-identified descriptions of study participants.

EXPIRATION AND REVOCATION

I understand that, with certain exceptions, I have the right to revoke this authorization at any time. [If I want to revoke this authorization, I must do so in writing.] If not revoked earlier, this authorization expires automatically upon May 1, 2013.

NOTICE OF VOLUNTARINESS

I understand that I may refuse to sign this authorization form. A readable photocopy or fax of this authorization shall have the same force and effect as this original.

SIGNATURES

Signature of Legally Authorized Representative:

Date: _____

Specify Relationship to Resident and Print Name in Full:

Appendix C

Music Interests Questionnaire

Name of Resident: _____

In order to offer individualized music therapy services for your loved one, I would like to find out about his or her musical interests and background. Please complete this one-page questionnaire and return it with the consent form in the postage-paid return envelope.

Sincerely,

Carey Barwick, MT-BC

1. Did your loved one play a musical instrument? Yes No
 - a. If yes, what instrument? _____
2. Did your loved one like to sing? Yes No
3. Does your loved one have a song he/she really enjoyed? Yes No
 - a. If yes, what song? _____
4. Please indicate with a check the types of music your loved one enjoys. Listing artists/groups would be really helpful.
 Big Band. Artists /groups: _____
 Bluegrass. Artists / groups: _____
 Blues. Artists / groups: _____
 Classical. Artists / groups: _____
 Classic Rock (60's / 70's). Artists / groups: _____
 Country. Artists / groups: _____
 Folk. Artists / groups: _____
 Gospel. Artists / groups: _____
 Religious. Artists / groups: _____
 Other. _____
5. Is there any other information you would like to share regarding your loved one's musical involvement? (Feel free to use the back of the page, if needed).

Appendix E

Analysis Form

Event	Subjective Assessment	Reflection on Event

Vita

Carey Ann Barwick was born in Washington, NC, to Gary and Diane Barwick. She graduated from Socastee High School in Surfside Beach, South Carolina, in June 2006. The following autumn, she entered Coastal Carolina University in Conway, SC, where she graduated Magna Cum Laude with a Bachelor of Arts degree in music in 2010. She was a recipient of the Outstanding Student Achievement Award in Music. In August 2010, she entered the equivalency/master's program for music therapy at Appalachian State University in Boone, NC. She completed a music therapy internship with Four Seasons Hospice in December 2012. After her internship, she became a board-certified music therapist in January 2013 and returned to Appalachian State University to complete her Master of Music Therapy degree with a focus on older adults with major neurocognitive disorder. Carey is a member of the American Music Therapy Association. Following graduation, Carey plans to pursue a career as a music therapist working with older adults.