MUSIC THERAPY SUPPORT GROUPS FOR FAMILY CAREGIVERS OF
INDIVIDUALS RESIDING IN LONG-TERM CARE FACILITIES: A SURVEY OF
MUSIC THERAPISTS AND INTERVIEWS WITH CURRENT FAMILY CAREGIVERS

A Thesis
by
STEPHEN HENRY WILSON

Submitted to the Graduate School
at Appalachian State University
in partial fulfillment of the requirements for the degree of
MASTER OF MUSIC THERAPY

May 2014
Hayes School of Music

MUSIC THERAPY SUPPORT GROUPS FOR FAMILY CAREGIVERS OF
INDIVIDUALS RESIDING IN LONG-TERM CARE FACILITIES: A SURVEY OF
MUSIC THERAPISTS AND INTERVIEWS WITH CURRENT FAMILY CAREGIVERS

A Thesis
by
STEPHEN HENRY WILSON
May 2014

APPROVED BY:

_____
Christine P. Leist
Chairperson, Thesis Committee


_____
Cathy H. McKinney
Member, Thesis Committee


_____
Lisa J.  Emery
Member, Thesis Committee


_____
William L. Pelto
Dean, Hayes School of Music


_____
Edelma D. Huntley
Dean, Cratis Williams Graduate School

**Abstract**

MUSIC THERAPY SUPPORT GROUPS FOR FAMILY CAREGIVERS OF
INDIVIDUALS RESIDING IN LONG-TERM CARE FACILITIES: A SURVEY OF
MUSIC THERAPISTS AND INTERVIEWS WITH CURRENT FAMILY CAREGIVERS

Stephen Henry Wilson
B.S., State University of New York at Fredonia
B.A., State University of New York at Fredonia
M.M.T., Appalachian State University

Chairperson:  Christine P. Leist

This study examined the use of music therapy as a way to provide support to family caregivers of individuals residing in long-term care facilities. The use of music therapy as a way to support caregivers is not well documented in the current existing literature, especially for caregivers who have transitioned their loved ones into a long-term care facility. This study used a mixed methods design. A survey of current music therapy practice was sent to 139 board-certified music therapists who were currently working with older adults. A total of 31 respondents (response rate of 22%) provided information about their knowledge, confidence, and use of music therapy to support family caregivers. The results indicated that music therapists support the idea but have not implemented support groups in their facilities. Two family caregivers shared their caregiving story to provide information about the needs of caregivers. Both interviewees expressed the need for a support group for this population. The study also included recommendations for future music therapy support groups for family caregivers of individuals residing in long-term care facilities. The results of the study indicate that there is a need for more support for this population.

**Table of Contents**

# List of Tables

**Chapter 1**

**Introduction**

**Overview of Caregiving**

In 2013, roughly 30% of the United States population provided support for at least one family member in a caregiving capacity. This includes care for children, adults, and older adult family members. Often times, this support was without financial compensation, but if it had been it would have equaled approximately $375 billion, which is twice as much as the cost of paid care in the home. Caregivers' ages were reported to range from children under 10 years of age caring for parents to older adults caring for spouses. It was estimated that 1.4 million children cared for parents, while 72% of the population cared for an aged parent, grandparent, or spouse. Approximately 70% of caregivers care for a person over 50 years old. Over 75% of older adults depend on their family and friends as their only source of help for their long-term care needs (Caregiver Action Network, 2014).

Due to the economic decline in 2009, many caregivers reported they were forced to move in with their loved one. Almost 50% of caregivers have said that they have spent most or all of their life savings on their caregiving duties. Despite this economic toll, only 60% of caregivers work part or full time, stating that their caregiving duties often demand all of their time and energy. American businesses have also felt the impact of caregiving, reporting that in 2013 they lost approximately $34 billion due to employees' needs to care for older aged loved ones (Caregiver Action Network, 2014).

1

Despite the stresses of caregiving, caregivers have reported that their role has increased their self-awareness. Over 75% of caregivers reported that they found a sense of identity through their caregiving role. Over 90% of caregivers were proactive about finding support after they adopted this role (Caregiver Action Network, 2014).

**Overview of Caregiving and Neurocognitive Disorder**

One in eight older adults is diagnosed with some form of neurocognitive disorder, which suggests that most caregivers will have cared for a loved one with a neurocognitive disorder. In 2012, more the 15 million Alzheimer's patients' caregivers provided 17.5 billion hours of care, and nearly 15% provided long distance care. The Alzheimer's Association estimated the impact to total more than $215 billion worth of unpaid hours. Most caregivers reported that caregiving causes financial and family relationship strain, and as the demands of their loved one increased, this strain increased as well. More than 60% of caregivers reported the emotional stress of caregiving as high to very high, and 57% reported the physical stress to be not high to somewhat high. Over 70% of caregivers reported relief when their loved ones passed away, which resulted in feelings of guilt and betrayal of loved ones. Due to the emotional and physical toll on caregivers, caregivers had an additional $9.1 billion worth of costs added to their own health care in 2012 (Alzheimer's Association, 2013). While the caregiving experience can yield positives in the form of self-identity and self-awareness, it often leads to insurmountable financial strains. This economic stress often leads to decreased quality of life of the caregiver.

# Definitions of Terms

**Music Therapy**

According to the American Music Therapy Association, music therapy can be 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. Music Therapy is an
> established health profession in which music is used within a therapeutic relationship
> to address physical, emotional, cognitive, and social needs of individuals. Through
> musical involvement in the therapeutic context, clients' abilities are strengthened and
> transferred to other areas of their lives. (American Music Therapy Association, 2013,
> paragraph 1)

**Family Caregiver**

For the purposes of this study, a family caregiver is defined as a person connected to an individual residing in a long-term setting by marriage, genetics, or choice and who cares for that individual's needs, including assistance in the areas of one or more activities of daily living (ADLs), financial management, transportation, administration of medication, making arrangements/scheduling appointments, mediation in the family, and managing behavioral symptoms. The majority of family members in this role have little to no prior education about caring techniques or medical training (Chan et al., 2010), which increases the burden of the actual caregiving situation, as many caregivers report they feel underprepared. Family members provide management for getting through the day, and this is in addition to what they need to do in their own lives, such as caring for their families and providing an income.

In addition to the stress of watching a loved one decline, caregivers face challenges including daily social, financial, emotional, and physical difficulties and uncertainties (Caregiver Action Network, 2014).

**Support Group**

For the purposes of this study, support groups are defined as a group of people who come together on a regular basis to help one another cope with their current situation. Traditionally, counselors or therapists facilitate support groups; however, peer-based support groups also can be effective. In any case, these groups address common questions and concerns of the members, such as information regarding diagnoses or resources in the community. These groups provide an outlet for self-expression and inclusion, which may help to decrease the isolation that the members often experience (Earle, 2006).

**Chapter 2**

**Review of the Literature**

This chapter will outline three important themes found in the literature that support the need for a study of this nature. It will begin with discussion of the needs of caregivers and will continue with music therapy interventions that address the needs and quality of life of caregivers. Then, grief and powerlessness will be discussed including ways music therapy may address these situations. Finally, the chapter will conclude with the statement of the problem and research questions of this study.

**Needs of Caregivers**

The emotional toll taken on family members during times of caregiving can be debilitating. Not only does the family member need to manage financial obligations and make life-altering decisions, but they must also witness their inevitable cognitive and physical decline of their loved ones (Chan et al., 2010). It is clear that a caregiver's quality of life is compromised by the demands of caregiving (Vickrey et al., 2009), and through a review of the literature, many factors that influence these demands have been identified. The five factors discussed in this section are (a) symptoms of depression as a result caregiving, (b) coping strategies, (c) family support, (d) the relationship between the caregiver and the family member with neurocognitive disorder, and, (e) the need for support groups.

Caregivers of people with neurocognitive disorder display a high prevalence rate of diagnosed depression, ranging from 30% to 50% (Saad et al., 1995). Erkkilä et al. (2008) and

Baker, Grocke, and Pachana (2012) both measured the depressive symptoms exhibited by their participants as a means to measure the change experienced over the course of their studies. Baker et al. (2012) also assessed anxiety level of each participant as well as depression as these two emotions tend to be interconnected. Similar to Baker et al. (2012), Erkkilä et al. (2008) found that anxiety was the most prevalent secondary outcome. Uniquely, Erkkilä et al. (2008) also determined the participants' ability to identify and describe their emotions by asking each participant to complete a self-report questionnaire. Saad et al. (1995) found that not only was there a high prevalence of depression among their participants, but also that many of their participants' depression stemmed from having difficulty coping with the reality of their situation. They identified three categories for facilitating coping: (a) management of the situation, (b) management of meaning, and (c) management of stress. The researchers defined management of the situation as being able to effectively protect and assist their family member with their daily needs, as well as manage behavioral symptoms; management of meaning as acceptance of old age, that is part of growing old; and management of stress as the ways the caregiver coped with the stress of caregiving, both positively and negatively. They also found that the caregivers experienced feelings of powerlessness and helplessness, both of which directly related to all three of the identified areas of coping (Saad et al., 1995).

Vickrey et al. (2009) conducted phone interviews with 200 caregivers of family members with neurocognitive disorder to assess the impact of caregiving on quality of life of the caregivers. The researchers assessed 10 areas of the caregivers' lives to determine their quality of life: (a) assistance in instrumental activities of daily living, (b) assistance in activities of daily living, (c) personal time, (d) role limitation due to caregiving, (e) family

involvement, (f) demands of caregiving, (g) worry, (h) caregiver feelings, (i) spirituality and faith, and (j) benefits of caregiving. Those who reported more unmet needs displayed lower scores on the assessment. They also found that isolation from family and friends often occurs while caregiving; for example, 57% of their participants spent over 30 hours per week providing care for their family member, and 42% had been family caregivers for over five years. Over 50% of the caregivers reported that they asked for little to no help caregiving. Due to this isolation, caregivers are more likely to be depressed and anxious (Vickrey et al., 2009). This leads to high stress and feelings of burden by the family member who has neurocognitive disorder. In addition, the family member with neurocognitive disorder often becomes dependent on the caregiver, which leads to grief of the loss of the relationship after the family member has been moved to a long-term care facility. They found that caregivers who participated in social activities as a way to cope experienced the least amount of depressive symptoms and reported the highest quality of life, and those that felt that they had family support also reported a higher quality of life as well (Vickrey et al., 2009).

Takai, Takahashi, Iwamitsu, Oishi, and Miyaoka (2011) investigated the difference between the subjective and objective variables that influence the caregiver's emotional health. The researchers defined the subjective, or "caregiver," variables as the quality of life, level of burnout, anxiety, or depressive symptoms experienced by the caregivers (p. 99) and the objective, or "patient-related," variables as the physical and psychological changes that the person with neurocognitive disorder experienced (p. 100). After giving each participant a series of assessments, they analyzed the data for correlations among the caregivers' quality of life and the variables and found that the quality of life of was more closely reflective of the caregiver variables. They found that if the participant was experiencing high levels of

burnout and depression, they scored lower on the quality of life scale. Further, they found that the severity of neurocognitive disorder was not highly correlated with higher levels of burnout and depression. Rather, the longer lasting and more intense the relationship between the caregiver and family member, the more anxiety and depression feelings reported by the caregiver. This was not the expected outcome of the researchers, nor was it the outcome that had been suggested by other studies (Takai et al., 2011).

Chan et al. (2010) also explored this deep emotional component in a qualitative study by analyzing the responses given during multiple focus groups and discussions. They found five themes: (a) confusion regarding diagnosis, (b) emotional impact, (c) difficulty coping with the care recipient's behavior, (d) demand of care recipient's daily care needs, and (e) conflicts among social roles. The researchers stressed the importance of providing clear, accurate information to families from the moment the diagnosis of neurocognitive disorder has been made. The researchers stated that communicating etiology, support service, training, and prognosis are of the highest importance. The researchers also found that family members felt that it would be helpful for each person diagnosed with neurocognitive disorder to have a person to whom either the person with neurocognitive disorder or family members could turn for answers to questions (Chan et al., 2010).

The relationship between caregiver and family member also was found to be relevant for the family caregivers' ability to see the benefit of caregiving (Vickrey et al., 2009). Baker et al. (2012) examined this in two ways. First, they measured the perceived quality of the relationship between the spouses, and second, they measured the satisfaction of each caregiver with their role in the relationship. They also asked each participant to make diary entries each week based on guided questions designed by the researchers and to partake in a

semi-structured interview following the study. Chan et al. (2010) placed an emphasis on the emotional impact of caregiving when planning the questions for their focus groups. They placed a higher importance on this aspect of caregiving because each participant was an unpaid, informal caregiver of their loved one. They used open-ended questions that investigated four domains: (a) background and contextual factors, (b) stressors, (c) mediators of stressors, and (d) outcomes. Chan et al. also addressed the relationship between caregiver and family member at the same time they measured the impact on the caregiver's health. They found these two factors were interconnected, since the caregiver's mental health directly affected the relationship during caregiving.

As a result of a meta-analysis of the existing support group literature, Chien et al. (2011) found that it was imperative for family members of people with neurocognitive disorder to have an outlet to express their struggles. Of the studies selected, 19 assessed psychological needs, 17 assessed depressive symptoms, 24 assessed burden, and 13 assessed social outcomes of caregiving. They found that the most successful support groups were classified as psychoeducational support groups, where psychological and emotional issues were addressed along with education about neurocognitive disorder. These studies helped establish a social support system to help alleviate the feelings of isolation and provide an outlet for frustration, sadness, and other feelings (Chien et al., 2011). Gräßel, Trilling, Donath, and Luttenberger (2010) also recognized the need for family member support groups; however, before they started the support group process, the researchers sent a questionnaire about the family members' wants and needs from such a support group. They asked participants about the caregiving situation, what kind of support system they felt they had, and what kinds of support they felt their current situation lacked. The researchers also

asked an open-ended question about what they wanted from a support group. From these answers, they determined three categories that needed to be addressed by a support group: (a) structure, (b) process, and (c) quality of results. The participants felt that the most important function a support group could offer is a place to exchange experiences. Knowing that someone else is going through a similar experience could help ease the burden and pain (Gräßel et al., 2010).

The literature suggests that there are several needs of caregivers. Caregivers experience a high prevalence rate of depressive symptoms in comparison to their non-caregiver peers (Saad et al., 1995). They need support with addressing coping skills specifically, balancing their duties of caregiving and their own lives (Vickrey et al., 2009). Most importantly, the emotional impact of caregiving can be devastating (Chan et al., 2010) and caregivers need a place where they can express their emotions (Chien et al., 2011).

**Support Groups for Caregivers**

This section highlights the needs of caregivers identified through research about support groups for caregivers that used musical and nonmusical interventions. The section is separated into three subcategories. It begins with a discussion of the literature that focuses on support groups for caregivers of people with neurocognitive disorder. Next, support groups for caregivers of people who are in palliative care and people who have intellectual disabilities will be discussed. Finally, the ways music has been found to be successful in providing support for caregivers of people with neurocognitive disorder and who are terminally ill will be discussed.

**Support Groups for Caregivers of People with Neurocognitive Disorder**

The burden experienced by caregivers causes long lasting physical and mental damage. Lilly, Robinson, Holtzman, and Bottorff (2012) investigated the effects of burden and burnout and how caregivers moved past it or why they were unable to recover. They gathered information from caregivers in three different categories: (a) caregivers who were unpaid, such as family members or friends who were caregiving because there was nobody else to provide the care; (b) caregivers who volunteered, either family, friends, or professionals; and (c) paid professionals who were caregivers as part of their daily job responsibilities. Despite the diversity in the caregivers' situations, the researchers found each subgroup expressed the same concerns. They shared that they felt like they were taken for granted by every person they knew or came into contact with as a result of their caregiving, for example, family, friends, physicians, and their loved one. Initially, they felt they were recognized and commended for their efforts, but as time went on they were abandoned and often left behind as others moved on with their lives. Even professionals did not make active attempts to return calls or follow up, which the caregivers understood was partially due to caseloads, but when they did they were often met with sarcasm, annoyance, and disinterest. They also felt that they often received inadequate support from professionals, as they felt like they were more knowledgeable but were not treated as knowledgeable. They said they especially met this sort of resistance when trying to find in-home help or making the transition to long-term facilities. Lastly, they felt like it was unrealistic to be expected to find time for their own needs. Many worked full-time jobs in addition to their caregiving demands and estimated that they worked over twice that when caregiving duties were factored into their schedules. They said that this was especially tough because the high demand often

caused them to be unhappy, which caused turmoil in their lives, that in turn caused problems while caregiving. Many were extremely frustrated that no support was offered to them at any step of their journey. Often times, family, friends, and professionals assumed they did not need any support due to their "willingness" to be a caregiver and ability to balance everything. They all expressed that if they had any sort of support system that it would have made everything seem bearable, manageable, and worthwhile.

Support groups provide caregivers with a place to connect to others. This connection is often the only stable and empathic connection that they have during this time of high stress. Earle (2006) shared a review of 12 years of support groups that she had been a part of and found four important themes shared by each group. First, the warmth, openness, sharing, and homogeneity offered by a support group were found to be the key for successfully navigating caregiving for a person with neurocognitive disorder. Second, the caregivers expressed the importance of openness and the welcoming atmosphere for caregivers at every stage of caregiving. It was rewarding for seasoned veterans to provide support to new caregivers, both reassuring them that they could do it and also seeing how far they had come in their process. It was almost cathartic to be able to provide guidance, not even realizing that they were looked up to as role models. Third, the warmth of support groups was important for creating a safe, supportive atmosphere. Members often commented on how surprising it was to just be able to walk in and feel welcome no matter how often they had attended. The sharing of information and experience was invaluable to the members. Hearing that others had gone through similar situations and discovering the ways to reach out for help were essential for helping maintain a positive outlook on the situation. Lastly, the homogeneity of the groups helped tie everything together, as it was easiest to relate to others who came from

similar backgrounds. It also built some natural bridges between people to connect with. They reported that support groups helped to decrease the isolation that caregivers found themselves experiencing. Many caregivers reported that it was nice to have somewhere to go or people to see that were not directly related to the needs of their loved ones. It also provided them a network of friends who understood their situation, as many caregivers experienced that friends seemed to disappear since they were frequently unavailable due to their caregiving demands.

Wang, Chien, and Lee (2012) compared the effects of a mutual support group for family caregivers of people with neurocognitive disorder and the standard support provided by the community, specifically looking for quantitative evidence to support the qualitative literature available. They were interested in discovering a support group's effectiveness on decreasing distress and increasing quality of life of the participants. The control group was provided typical services, such as medical consultation, advice from professionals, information for financial aid or compensation, and access to educational seminars. The experimental group received 90-minute bi-weekly sessions for 24 weeks, where they discussed strategies for coping, shared stories, developed a network of peers, learned about self-care, learned how to improve interpersonal skills, discussed the emotional impact of caregiving, and received information pertaining to their family member's condition. The results were highly positive. Both groups showed similar increases in seeking mental health support from various professionals; however, the experimental group showed a significant decrease in distress and increase in life satisfaction. The caregivers felt that the support group helped validate their emotions. This allowed them to carry the burden of their duties, provide positive support to their loved ones, and find meaning in their efforts for caregiving.

Yoo, Jang, and Choi (2010) found similar results when they analyzed message posts from online support groups. They found that even though the support was not face-to-face, the social support was effective. The researchers categorized the support into either informational or emotional, and in both cases the support paralleled that found in a traditional face-to-face support group. The message posters used poetry, humor, and prayer to support their peers, which were found to be especially helpful with helping caregivers work through the anger and resentment they held towards their situation and loved one. Again, the caregivers expressed that knowing that other people were experiencing situations that were similar helped them cope with their situation, find meaning in their lives, and empower them to continue.

**Support Groups for Caregivers of People with Other Illnesses**

The lack of a support system for caregivers of people living in Botswana inspired Kang'ethe (2011) to conduct interviews with the caregivers to create awareness for the need of support groups. The participants were caregivers for people with AIDS who were terminally ill. The caregivers were interviewed using a semi-structured guide developed by the researcher. Each caregiver shared their individual journey in a narrative style. Kang'ethe found several common themes for the needs expressed by the caregivers. The main focus of each caregiver's story was that it was torturous to provide care alone. They all stated that they felt like they were in a position where they may "sink or float," and many of them were sinking despite their best efforts to persevere. They expressed that if they had any sort of support or place to connect that it would have helped keep their morale high. Many felt the affiliated program was mistreating them, and that they were taken for granted. They expressed the need for advocacy for the work they were doing, not for self-recognition but to

motivate them to keep going. They shared that having a place to connect to others would make the situation seem like it was not an impossible task that they were asked to complete alone. Loved ones put their lives in the hands of their caregivers, and many of the caregivers felt that nobody else truly understood what that meant. A support group would provide them with a place be accepted and surrounded by people who believed in them.

Wei et al. (2011) researched the impact of a support group on caregivers of family members who were diagnosed with intellectual disabilities. The researchers found that the support group was effective in addressing positive changes in two categories: physical–psychological and social support. Physical-psychological changes include depressive symptoms, anxiety, and somatic symptoms. The somatic symptoms included sleep deprivation, hypertension, anxiety, headaches, arthritis, mental stress, exhaustion and allergies. The caregivers were encouraged to share their experiences in as much detail as possible. They later confessed that while it was difficult to express such deep emotions and painful experiences, they also found solace in realizing that their peers were experiencing similar problems. Many of their somatic symptoms began to disappear over the course of the group. They were inspired by their peers and reduced their self-pity and isolation practices. They commented that many other people in their lives did not understand what they were going through and that their friends and family did not make an effort to try to understand. The emotional support that was provided by their peers was stated as the most helpful part of the whole support group.

The increased emphasis for patients to be cared for at home puts more pressure on family members to become caregivers who in turn often feel they have to take on the task with little or no training. Henriksson, Årestedt, Benzein, Ternestedt, and Andershed (2012)

investigated the use of a support group to increase the competence, feelings of preparedness, and rewards of caregiving. The participants took several pretests and posttests to determine the effectiveness of the support group. The participants reported 78% improvement in the area of preparedness to provide care and over 50% improvement in the areas of competence and feeling rewarded by the caregiving experience. The support group appeared to increase the self-confidence of the members, which increased their perceived level of competence, as the caregivers shared that by feeling more confident they felt more competent, prepared, and rewarded. The emotional support provided by the caregivers' peers also helped them work through their family members' impending deaths. Participating in the support group helped assist in this process of anticipatory grief. Lastly, even if information sharing was based on peers' experience and therefore was informal, having a place to share stories and ask for advice was invaluable, rewarding, and empowering.

**Music Therapy Support for Caregivers**

Hammar, Emami, Engström, and Götell (2010) investigated the use of music while caregiving, looking for ways that it improved the caregiving relationship of six caregivers and their loved ones, who were diagnosed with neurocognitive disorder. They chose to specifically address "the morning care situation," as this was deemed the highest stress situation by the caregivers. The caregivers described the usual routine as a struggle to communicate, often ending in violent or aggressive acts by the person with neurocognitive disorder or the caregiver having to physically restrain their loved one for protection. The researchers observed the typical routine and the routine where music was used. The primary form of music that was provided was singing songs. The caregivers reported that when music was used during the morning routine, there was an increased level of awareness, higher

communication, and a deeper connection. They said that there was a general feeling of wellbeing that was shared, but not spoken, by them and their loved ones. They shared that the music created a safe place and a feeling of trust, in addition to enhancing their relationships with their loved ones. Many caregivers shared that it was the closest they had felt in years, which surprised them because the only verbalizing they did was the to inform their loved one of what was happening next.

The adaptability of music to support in a variety of situations is crucial for support groups where wide ranges of emotions are present. The ability of music to support and hold the space no matter what emotions are being experienced makes it a valuable tool for facilitators of any kind of support group. Magill (2008) investigated the use of music to provide support to the caregivers of advanced cancer patients in palliative care. The researcher investigated what the music meant for the seven caregivers and was particularly interested in the music that was chosen "pre-loss" and how its meaning shifted throughout their loved one's dying process. During times of loss and grief, music takes on a deeper, more significant role in providing meaning (Bright, 1996). Music's ability to be reflective, exploratory, and transcendent is essential, and helps give caregivers anticipatory and postdeath support (Magill, 2008). The researcher used a variety of musical interventions, such as (a) listening, (b) lyric improvisation and song writing, (c) precomposed songs, and (d) imagery. These experiences helped the caregivers (a) feel connected to others who were in a similar situation, (b) be empowered to continue caregiving, (c) find hope that there is a peaceful ending, and (d) experience increased overall satisfaction in life. The participants described four powerful themes of the sessions: (a) music is a conduit, or a vehicle, for awakening, support, and engagement; (b) the music "gets inside us" and increases awareness

of dormant feelings; (c) live music is preferred over recorded music because of the increased involvement of the voice; and (d) that music is love, and has the ability to elicit positive emotions during times of great distress and make us feel needed.

O'Callaghan, McDermott, Hudson, and Zalcberg (2013) echoed these findings with their research into the power of music for eight informal caregivers of people who died from cancer. They were interested in the effects of music on people in times of bereavement, specifically investigating the ways that music was able to provide support. They noted that while stress diminishes during these times, sadness, loneliness, and guilt remain present after a loved one has passed on. The ability of music to hold these emotions and allow for emotional expression was invaluable during the caregivers' grieving process. During preliminary screening, the researchers discovered that the participants had all shown a decrease in musical activities after their loved ones had passed away. Each participant had attributed this to the fact that many songs heard on the radio brought back such powerful memories that it was too difficult to listen to more than a song or two before being overwhelmed with these emotions. Songs that held significant meaning during the times their loved ones were dying were almost impossible to listen to. However, through semi-structured interviews, the researchers identified six themes that spoke to the power of music in the caregiver's lives: (a) music reminded the caregivers of how music increased the quality of their loved ones' lives; (b) music connected them to their loved ones after they had died; (c) music improved their mood, energized them to move on, and supported them in times of sadness; (d) music extended the legacy of the loved one; (e) the "preloss" music was instrumental in providing support for the grieving process before and after death due to the stability it provided; and (f) all the caregivers recommended the use of music for every

person who was caregiving. Although the music provided an intensified experience, the caregivers reported that it made it better due to the stability, support, closure, and transcendent experiences that the music offered.

**Music Therapy Interventions to Address Quality of Life**

As indicated earlier, the emotional impact of caregiving is a common focus for support groups. Previous research has reported two musical interventions, improvisation and songwriting, to be effective and flexible ways of facilitating musical and emotional expression.

Baker, Wigram, Stott, and McFerran (2008) explored the use of songwriting in the therapeutic setting as a means of emotional expression and exploration. They distributed a 21-question survey worldwide to gain information on the use of this approach in the various populations that music therapists serve. The majority of clinical songwriting was used with adults with psychiatric or mental health needs. Some of most common goals of songwriting were to (a) enhance quality of life; (b) develop a sense of self; (c) tell the client's story; (d) externalize thoughts, fantasies, and emotions; (e) gain insight or clarification into thoughts and feelings; and/or, (f) experience mastery, develop self-confidence, and enhance self-esteem.

Erkkilä et al. (2008) used improvisation as the primary musical intervention in their study. Music improvisation and verbal processing coupled with the range of emotional depth and expression in the music allowed the group members to explore the many emotions surrounding their situation.

The use of music as a way to find hope, strength, meaning, inspiration, and encouragement can provide caregivers with a unique support system (Magill, 2008). Music

holds the emotional space well and provides a large container for expression (O'Callaghan et al., 2013). The use of song writing and improvisation as methods to approach this work provides the right balance of structure and adaptability to be what is needed in the moment.

**Grief, Powerlessness, and the Role of Music**

Grief can be experienced in many forms, such as crying, sadness, constant thought about the loss, anger, fear, guilt, disappointment, changes in daily routine, loss of interest in normal events, isolation, loss of concentration, or changes in appetite (Bright, 1996). Due to a lack of cultural awareness and the dormant development of many of these symptoms, often times a person is unaware that they are grieving or have not fully grieved a loss they have experienced. Many of these symptoms may lie hidden for years. The manifestations of grief can occur around or during anniversaries, and may include blocked grief, such as a chemical dependency to mask the pain, incorrect perceptions of grief, and possibly most importantly, powerlessness (Bright, 2002).

Powerlessness can be defined as a feeling of loss of control, no control, and/or the inability to regain control over the events in a person's life, and is often associated with the process of grieving. Its manifestation sometimes occurs in a cyclical way, where the grief a person is experiencing leads to feelings of powerlessness, which in turn, result in more grieving (Bright, 1996). This is commonly witnessed during old age, or as a reaction to witnessing someone getting older, as the person feels like they have lost all control over themselves and their lives due to the inability to stop aging. Powerlessness is also experienced while coping with loss, whether it is a loss of a loved one or a loss of one's own abilities. Accepting the reality of the situation, adjusting to the new situation, coping with the pain, and withdrawing physically or emotionally are all situations where a person may feel

like they have lost control, have no control, or cannot regain control of their lives. Death, or watching someone decline or die, not only presents challenges with powerlessness, anger, and fear leading up to or during the process of dying, but also afterward during the process of grieving. Again, the lack of control may lead to feeling powerless to stop (Bright, 1996).

Music provides one crucial and powerful advantage. Specifically, it is able to open up, or provide access to, the feelings we are unaware that we are experiencing but are hidden "below the surface" (Bright, 1996, p. 5) It provides the support, atmosphere, and container for holding the powerful emotions associated with grief, powerlessness, and loss. In particular, song writing and improvisation allow clients the expressive freedom, but still provide structural barriers to explore, experience, and potentially resolve these intense emotions. As music therapists, it is important to recognize the role of music, the therapist, and the client during times of grieving, and the power a phrase, chord, or melody may have (Bright, 2002).

**Statement of the Problem**

The studies described previously address the importance of music therapy for caregivers, yet there are no studies about the impact of family caregiver situations once the loved one has entered a long-term care facility. The investigator used PsycInfo and PubMed databases to search *Journal of Music Therapy*, *Music Therapy Perspectives*, music therapy journals from other countries, journals in psychiatry, social work, and medical journals and found studies that investigated needs of current family caregivers, but found none that addressed needs of family caregivers after the loved one entered a facility. It may be a reasonable assumption that many of the feelings of grief and powerlessness do not diminish

after the family caregiving relationship has changed and an outlet for these feelings is not only suggested, but imperative (Chan et al., 2010).

**Research Questions**

The purpose of this study was to develop recommendations for music therapy support groups for family caregivers of individuals residing in long-term care facilities. The primary research question was: How might a music therapy support group address the emotions and challenges experienced by caregivers of individuals living in a long-term care facility?

Subquestions:

- How does the caregiving experience change when the family member is moved into a skilled nursing facility?

- What challenges do caregivers face as their role shifts?

- What emotions are experienced as their role shifts?

- What is currently being done in music therapy for this population?

**Chapter Three**

**Method**

This chapter will describe how the study was conducted. The chapter describes the respondents, the survey instruments and their development, the study design, the procedures and the data analysis.

**Respondents**

The researcher solicited respondents for the survey via email messages that were sent to 139 board-certified music therapists. To be eligible for the survey, these music therapists were required to be current professional members of the American Music Therapy Association (AMTA) working in one of the following older adult facilities: (a) adult day care, (b) assisted living, (c) geriatric facility – not nursing, (d) geriatric psychiatric unit, and (e) nursing home.

Of the 31 respondents, 30 (97%) were female and one (3%) was male. The respondents' ages ranged from 24-64, with a mean age of 42.2 years old and a median age of 40 years. One respondent did not provide an age. All of the 31 respondents had the credential of Board Certified Music Therapist (MT-BC) and one respondent also had the designation of Neurological Music Therapist (NMT). The respondents had practiced music therapy for 1-35 years with a mean of 12.3 years and a median of 11 years. The number of years of experience ranged from 1-33 years with a mean of 11.3 years and a median of 9.5 years. One respondent did not provide a response, another respondent shared that she had worked in activities for 2

years before working as a music therapist, and another respondent listed that she had worked in long-term care for 2 more years than she had been a music therapist.

A majority of the respondents had a Bachelor's degree in Music Therapy. An additional 15% had an equivalency degree and 15% had a Master's degree. See Table 1 for the results of the educational training of the respondents.

Table 1

*Educational Training of Respondents*

| Type | Frequency | Percentage |
|---|---|---|
| Bachelor's degree in Music Therapy | 20 | 65 |
| Equivalency in Music Therapy | 7 | 23 |
| Master's degree in Music Therapy | 7 | 23 |
| Bachelor's degree in another field | 6 | 19 |
| Master's degree in another field | 4 | 13 |
| Bachelor's degree in Music Education with an emphasis in Music Therapy | 1 | 3 |
| Doctoral degree in another field | 1 | 3 |
| Doctoral degree in Music Therapy | 0 | 0 |

*Note:* Number of responses ($n = 46$) reflects that respondents indicated more than one degree.

The most represented AMTA region was the Great Lakes region. There were no respondents from the Southwestern or International regions. See Table 2 for the membership regions of the respondents.

Table 2

*Membership Regions of Respondents*

| Region | Frequency | Percentage |
|---|---|---|
| Great Lakes | 9 | 29 |
| Mid-Atlantic | 7 | 23 |
| Midwestern | 7 | 23 |
| New England | 3 | 10 |
| Western | 3 | 10 |
| Southeastern | 2 | 6 |
| Southwestern | 0 | 0 |
| International | 0 | 0 |

The majority of respondents worked in skilled nursing and/or memory care. Memory care was divided into two levels because the approaches used vary greatly between the two settings due to the functioning level of the clients. See Table 3 for the settings in which the respondents provide music therapy services.

Table 3

*Settings in Which Music Therapy Services Are Provided*

| Setting | Frequency | Percentage |
|---|---|---|
| Memory care I (early to moderate stage dementia) | 26 | 84 |
| Skilled nursing | 25 | 81 |
| Memory care II (moderate to late stage dementia) | 25 | 81 |
| Assisted living | 18 | 58 |
| Other | 11 | 35 |
| Rehabilitation | 10 | 32 |
| Independent living | 7 | 23 |

*Note:* Number of responses ($n = 122$) reflects that respondents indicated more than one setting.

For the interviews, the researcher solicited interviewees through referral from staff at a long-term care facility in the southeastern United States. Additionally, an email announcement (see Appendix A) was sent to the faculty and staff at a public university in the southeastern United States. Two female caregivers whose family members now reside in a nursing facility volunteered. Additional information will be presented in Chapter 5.

**Instruments**

Due to the lack of preexisting measurement tools, the researcher created the survey used in this study (see Appendix B). The purpose of this survey was to gather demographic

information about the respondent, inquire about his or her knowledge of family caregivers, and discover how he or she uses music to provide support to family caregivers. The survey consisted of 19 questions and was constructed in Google Docs using Google Forms. The survey was sent via email to current professional AMTA members who worked in the settings specified in the previous section.

The survey consisted of four sections. Section one included eight demographic questions; section two included two questions relating to family caregivers; section three had six questions inquiring about the music therapist's use of musical support groups at his or her facility and his or her thoughts on the importance of offering these groups; and, section four provided the respondent with three open-ended questions to share his or her personal thoughts about music therapy support groups for this population.

There were also no preexisting interviews or previously created interview questions for family caregivers of people who reside in long-term care facilities; therefore, the researcher created the interview questions used for the family caregiver interviews (see Appendix C). The interviews were semi-structured, with the researcher preparing 10 open-ended questions. The questions pertained to the family caregiver's role as a full-time caregiver, how that role shifted after facility placement, what his or her emotions were during active caregiving, how these emotions have changed, and how his or her relationship with the loved one has changed throughout this process.

**Procedure**

The survey for the music therapists was sent out via email with a link to the questionnaire and the consent form in the body of the message (see Appendix D). Three email messages were sent: a) the original request with a one-month due date, b) the second,

the reminder with the questionnaire link two weeks from the due date, and c) the third, another reminder one week before the due date. The researcher received IRB approval/exemption from the Institutional Review Board at Appalachian State University prior to sending out the survey (see Appendix E).

The interviews were conducted with two family caregivers whose family members lived in long-term care facilities in North Carolina. The interviewees were invited to participate in the study through a phone call following initial referral from staff. They were given a brief summary of their role in the study, and a meeting time was scheduled. At the meeting, the consent form (see Appendix F) was presented to the participants, and if consent was given, the interview was conducted at that time. The interviews lasted approximately 60 minutes. The researcher asked the participants each question and then asked follow up questions depending upon the answers. The interviews were audio recorded for data analysis purposes.

**Design**

The researcher used a mixed methods approach (Bryman, 2004) to provide a broader picture of the use of music as support for family caregivers of people residing in long-term care facilities. The survey for music therapists provided both quantitative and qualitative data and the interviews with caregivers provided qualitative data. The survey consisted of data relating to the importance, implementation, and barriers for facilitating a music therapy support group at the music therapists' facilities at which they work. The interview responses provided open-ended, qualitative data. In addition, the broader picture of this topic helped clarify many of the needs that family caregivers have, which provided valuable information for the development of a music therapy support group program.

**Data Analysis**

The researcher computed descriptive statistics to analyze the quantitative data gathered from the survey using Google Forms, which is available through Google Docs. The qualitative data were analyzed by categorization. The data were divided into four themes: (a) knowledge of caregiving and support groups, (b) the implementation of support groups at the facilities where the respondents work, (c) the importance of offering support groups to family caregivers, and (d) the barriers/challenges of providing music therapy support to family caregivers. The interview responses were compared to each other and to the survey responses to discover similarities and differences between the two components of the study.

# Chapter 4

## Music Therapy Survey Results

This chapter will report the results of the survey administered to music therapists working with the older adult population. The information will be presented in three sections, which is consistent with the remaining sections of the survey: (a) family caregivers, (b) support groups, and (c) open-ended questions.

### Family Caregivers

Respondents indicated sources of knowledge of caregiving and the amount music therapy support provided to the family members of residents who resided at the respondents' facilities.

The definition of a family caregiver used by the researcher was provided, and then the ways that the respondents have gained insight into the caregiving process were given. The majority of the respondents have gained knowledge through journal articles, books, and in-service trainings. See Table 4 for the ways through which the respondents acquired information about family caregiving.

Table 4

*Ways Through Which Information About Family Caregiving Was Acquired*

| Type | Frequency | Percentage |
|---|---|---|
| Journal articles/books | 19 | 61 |
| In-service at work | 16 | 52 |
| Professional workshop | 14 | 45 |
| Other | 14 | 45 |
| Music therapy undergraduate coursework | 13 | 42 |
| Conference session | 13 | 42 |
| Graduate music therapy coursework | 4 | 13 |
| None | 1 | 3 |

*Note:* Number of responses ($n = 94$) reflects that respondents indicated more than one way information was acquired.

Nearly half of the respondents reported that family caregivers participate in music therapy with their loved ones "Occasionally," and no respondents reported that family caregivers never participated in music therapy with their loved ones. See Table 5 for the frequency of participation of family members in music therapy.

Table 5

*Participation of Family Members in Music Therapy*

| Rating | Frequency | Percentage |
|---|---|---|
| Very Frequently (76 to 100% of sessions) | 1 | 3 |
| Frequently (51 to 75% of sessions) | 6 | 19 |
| Occasionally (26 to 50% of sessions) | 14 | 45 |
| Rarely (1 to 25% of sessions) | 10 | 32 |
| Never (0% of sessions) | 0 | 0 |

**Support Groups**

Of the 31 respondents, 27 (87%) responded that they do not facilitate support groups and 4 (13%) responded that they do. Those who do facilitate support groups facilitate them for family caregivers, staff, and residents. See Table 6 for the populations that are served by support groups at the respondents' facilities.

Table 6

*Populations Served By Support Groups*

| Population | Frequency | Percentage |
|---|---|---|
| I do not facilitate support groups | 27 | 87 |
| Family caregivers | 5 | 16 |
| Staff | 4 | 13 |
| Residents/patients | 4 | 13 |

*Note:* Number of responses (*n* = 40) reflects that respondents indicated more than one population served.

The most common source of knowledge concerning facilitation of support groups was undergraduate coursework. See Table 7 for the ways that the respondents acquired knowledge regarding facilitation of support groups.

Table 7

*Sources of Knowledge Regarding Facilitation of Support Groups*

| Type | Frequency | Percentage |
|---|---|---|
| I do not facilitate support groups | 23 | 74 |
| Music therapy undergraduate coursework | 5 | 16 |
| In-service at work | 5 | 16 |
| Professional workshop | 5 | 16 |
| Journal articles/books | 5 | 16 |
| Participation in a support group | 5 | 16 |
| Conference session | 4 | 13 |
| Other | 4 | 13 |
| Graduate music therapy coursework | 2 | 6 |
| None | 2 | 6 |

*Note:* Number of responses (*n* = 60) reflects that respondents indicated more than one source of knowledge.

When asked which musical experiences the respondents use in their support groups, nearly all respondents who facilitate support groups indicated song writing, music listening, and song discussion. The other interventions were used less frequently. See Table 8 for the music therapy experiences used in a support group.

Table 8

*Music Experiences Used in Support Groups*

| Musical experience | Frequency | Percentage |
|---|---|---|
| I do not facilitate support groups | 23 | 74 |
| Song writing | 8 | 26 |
| Music listening | 8 | 26 |
| Song discussion | 7 | 23 |
| Music improvisation | 6 | 19 |
| Movement to music | 6 | 19 |
| Lyric analysis | 6 | 19 |
| Expressive singing | 5 | 16 |
| Music and imagery | 5 | 16 |
| Other | 2 | 6 |
| None | 0 | 0 |

*Note:* Number of responses (*n* = 76) reflects that respondents indicated more than one type of experience

Respondents were asked to rate their level of agreement with the following statement: "Music therapy should be included as a way to support family caregivers." The most

common responses were "Agree" and "Strongly Agree," making up a combined total of 84% of the responses. See Table 9 for the opinion about inclusion of music therapy as a way to provide support for family caregivers.

Table 9

*Opinion About Inclusion of Music Therapy as Support for Family Caregivers*

| Level of agreement | Frequency | Percentage |
|---|---|---|
| Strongly agree | 13 | 42 |
| Agree | 13 | 42 |
| Neutral | 3 | 10 |
| Disagree | 0 | 0 |
| Strongly disagree | 2 | 6 |

Concerning the level of confidence in facilitating music therapy support groups, 54% of the respondents feel confident and 37% feel neutral about their confidence level. See Table 10 for the level of confidence the respondents have in facilitating music therapy support groups.

Table 10

*Level of Confidence in Facilitating Music Therapy Support Groups*

| Level of confidence | Frequency | Percentage |
|---|---|---|
| Strongly agree | 5 | 17 |
| Agree | 11 | 37 |
| Neutral | 11 | 37 |
| Disagree | 2 | 7 |
| Strongly disagree | 1 | 3 |

*Note:* Number of responses (*n* = 30) reflects that one respondent did not indicate level of confidence.

**Open-Ended Questions**

Through open-ended questions, the respondents were provided with an opportunity to discuss challenges of facilitating support groups, share their opinions about providing support for family caregivers in this way, and cite examples from their work. There were several common themes displayed throughout the responses.

**Barriers or Challenges of Implementing This Type of Group**

This question asked the respondents to provide some feedback regarding the barriers and challenges of facilitating a support group. There were several themes throughout the responses: (a) time restrictions, (b) low motivation by an external source, (c) the decision to start a support group was out of the control of the music therapist, (d) low confidence in the music therapist's skills, (e) financial constraints, and (f) other. The majority of the responses

discussed the time challenges, and the second most frequent response discussed starting a group being out of their control.

**Responses about time restrictions and constraints:**

- Time to hold the group, money to fund the group, location for the group, time for the facilitator to lead the group in an already overbooked schedule.

- Finding a time to accommodate schedules, finding time within own schedule to provide another group

- I have a full caseload of other groups/individual sessions as I work in a 240 bed facility as the only music therapist, but I would like to try to add a caregiver support group in the future once I have an intern.

- I work part time.

- Many of our family caregivers have other obligations during my set work hours during the day. I would need to come in on the evenings or weekends but my schedule does not allow for such right now.

- Our facility does, however, offer support and education to those in the community caring for Lewy Body dementia but they meet at time when I have obligations elsewhere in the workplace and I have not yet been able to collaborate with them.

- Time - I am one person serving 350 residents

**Responses about low motivation of participants and others at the facility**

- Low motivation from family caregivers.

- I work in many facilities, as I work in hospice care. Most of the support I do is in the home, where family members are more often present.

- Lack of understanding about the skills MTs have

- The need for patient care is so great that there is little time to offer groups for family caregivers.

- I work in a skilled nursing facility and currently that isn't a service we offer. I would think it would be something we'd have interest in if asking the families, but no one has tried to get it going.

- Not much support group participation by current family members/care givers.

**Responses about confidence level of the music therapist**

- Not knowing how to initiate a group, market, and finance.

- I don't feel like I have the knowledge-base to adequately facilitate this type of group.

**Responses about logistics being out of the control of the music therapist:**

- Facilitated by another discipline (social services)

- My contact with the facilities at which I conduct music therapy groups is as a contractor - I come in for one hour sessions - I have little or no input into the amount or style of interaction with family members

- Outside the range of my job description and responsibilities

- My current position (activity therapist) doesn't include extensive family contact. I hope to have more opportunities to work with families in my new position of Life Enrichment Director in a long term care and rehabilitation facility starting next month.

- Family Support Groups are facilitated by Social Workers & Behavior Health Specialists.

**Responses about financial challenges:**

- Facilities wanting me to provide this service for free (as some companies do as a marketing/outreach effort)

- Monetary

**Other Responses:**

- I do not routinely facilitate family caregiver support groups but am asked to speak often on the benefits of music therapy for the caregiver as well as their family member.

- There are no barriers

- I've never considered facilitating a support group.

## Thoughts About Incorporating a Music Therapy Group as a Way to Support Family Caregivers

The respondents were asked what their personal thoughts were about providing music therapy support groups for family caregivers. The responses were overwhelmingly positive. There were no negative or impartial answers. The answers were grouped according to two themes; the first group were answers that were supportive of this idea and the second group consisted of answers that suggested resistance from staff or family members.

**Responses with supportive language about this type of group:**

- I see excellent interactions between individuals with dementia and their family members in groups when family are present and I feel like support groups could offer families with some coping, relaxation mechanisms as well as more understanding of their loved one's condition and how it presents itself and how to connect with them in their new reality.

- It would be a great asset to a program to assist caregivers with the physical, spiritual, mental, and emotional demands that they encounter while caring for their loved one.

- Music therapy would be a great way to support the family caregivers as it could be a common experience between patient and caregiver.

- Important to give specific examples of ways that caregivers can use music to improve the quality of life for their family member.

- Whether it is for anxiety, agitation, sleeplessness, motivation to exercise I feel that when speaking to support groups you need to be very specific and give them tools to use.

- I am capable and ready to provide every music therapy intervention listed above in this survey. And, I believe it is an effective tool to support family members/caregivers.

- I think it would certainly be useful for caregivers to have music therapy opportunities to give them a break from their loved one and to interact with people in similar situations. When family members attend resident groups, they are included and given opportunities to have positive interactions with residents and other family members.

- Fabulous idea. It would help relieve stress of caregivers, express emotions that can't be expressed anywhere else, be a shared experience that would reassure caregivers that they are not alone and be a bonding time with others going through the same thing.

- It's important for the caregivers to maintain stress management and health so they can best help the patients...and have a good life too!

- I would consider doing this in a variety of settings, if asked. I have a private client whose spouse/caregiver would benefit from a support group, but she is currently providing the majority of the care at home, and not able to get away except while her spouse is in daycare or seeing a therapist.

- I think that it is a fun way to delve into rather heavy topics. Someone who is less inclined to participate in a verbal discussion may connect to a music therapy experience.

- Drum circles for stress management

**Responses with language about resistance from other staff at the facility:**

- Don't see it as a possibility now. While it clearly addresses the needs of the caregivers it also gives them a practical understanding of the person they are caring for if they too receive MT services OR can facilitate their ability to use music in self care and care for loved one when MT is not present.

- Great idea, and one I had the opportunity to do in a medical MT internship, but not practical in private practice now.

- I think it's an absolutely perfect, logical idea. I don't know why I can't get this to catch on in my area.

- I think it could be very effective. Caregivers are searching for some way to understand what is happening with their loved ones and for something to do other than care for their loved ones.

- Difficult to do in my setting, though could possibly be developed.

- I envision there being resistance from other staff.

**Music Therapy Examples**

Lastly, the respondents were provided with the opportunity to share personal experiences of facilitating support to family caregivers. Here are some examples of the types of music experiences that the respondents have facilitated with family members.

- I've spoken to dementia, Parkinson's, mental health, diabetes support groups on how caregivers can use music in their daily routines of their family member.

- I facilitated one support group at the hospital we are affiliated with, and had mixed responses from the participants. This was a pre-existing group which usually consists solely of participants sharing their personal experiences caring for a loved one with dementia. I was asked to facilitate this as a music therapy support group so as to limit some of the insensitive statements made by group members at times; however, most of the group members came in and immediately began discussing the "horrible" things their loved one had done to them that month, and although I redirected the group with statements such as, "Those are the moments when it's most difficult to remember that your loved one cannot help making those mistakes or acting that way as a result of their disease," this is always what it came back to.

- I also work in hospice, and in that setting I have worked with a client and their caregivers together. This often brings meaningful, resolution-type conversations.

- Parkinson's Support Group - for patients and their caregivers together. Alzheimer's Support Group - for patients and their caregivers together. Breast Cancer Support Group - we have some caregivers come even when the patients can't.

- In a dinner meeting at a nice restaurant, spouses of men with Alzheimer' toned to the sound of crystal wine glasses. They also participated in moving to the "Macarena." These experiences were facilitated by the music therapist but were at the request of the group members

- For my undergraduate research project, I worked with a group of caregivers for those caring for someone with dementia. We did a lyric replacement exercise and discussion around self care, changing the words from the Beatles' "With Love from Me to You" to "With Love from Me to Me." In my training at the Hospice and Palliative Care Music Therapy institutes, I also saw the potential to incorporate art projects or art therapy (if a therapist is available) in the same settings, though I have not had the opportunity to put it together yet.

- I have done 1:2 sessions with an individual and her daughter, doing musical life review and helping them to reconnect with each other when the patient no longer really recognized her daughter. I was very cathartic for the daughter and the patient really enjoyed the session and was happy socializing with her "new friend."

**Chapter 5**

**Interview Results**

This chapter will report the results of two interviews conducted with people who have a loved one with neurocognitive disorder who resides in a long-term care facility. The information will be presented in the following order: (a) responses pertaining to how the caregiving experience changes when the family member is moved into a skilled nursing facility, (b) responses pertaining to the challenges caregivers face as their role shifts, (c) responses pertaining to the emotions experienced by caregivers as their role shifts, (d) benefits of a support group, (e) challenges of a support group, and (f) rewards of caregiving.

The first interviewee, Dolores, is a retired university staff member whose mother resides in a local long-term care facility. Her interview lasted approximately 34 minutes. She shared that her mother has resided in the facility for 3½ years. Previous to moving her mother to the facility, she shared that she had been seeing symptoms for years. Her mother lived next door, so she was not an in-home caregiver, though she stressed that she was at her mother's home everyday and most nights. Dolores reported that she had seen her mother decline for years before she decided to become her direct caregiver.

The second interviewee, Maude, is a university professor who is the primary caretaker and legal representative of her former neighbor who now resides at a local long-term care facility. Her interview lasted approximately 71 minutes. She reported that she had known her neighbor for 7 years prior to becoming her power of attorney and transitioning her

into the nursing home. The former neighbor has resided in the facility for 5 years. Before the transition, she lived next door and was her primary caregiver for several years before her neighbor moved to the facility. She reported that she had made the decision to become her primary caregiver almost immediately after seeing symptoms.

The interviewees were invited to answer ten questions that related to their caretaking journey, as well as share their story in as much detail as they were comfortable. The first seven questions directly related to the three research subquestions and the results of these questions will be categorized by research subquestions. The next two questions did not directly relate to any of the research subquestions, however, they provided the interviewees an opportunity to provide feedback regarding the implementation of support groups. The final question was intended to give the interviewees an opportunity to recognize their strengths and end the interview on a positive note. The questions were presented in a conversational way and the researcher provided therapeutic support throughout the interview to help create a safe place to share their answers. Each interviewee answered all ten questions.

**How does the caregiving experience change when the family member is moved into a skilled nursing facility?**

This question was addressed in several questions in the interview. These included what the interviewee's role was before their family member moved to the facility, the difference between the interviewee's role as an active caregiver and post facility caregiver, and the ways their relationship with the family member had changed since moving to a facility.

Dolores shared that prior to moving her mother to a facility, she was the primary caregiver of her mother. She said that she had some external support from home nurses and from family, friends, and neighbors that were invaluable. During that time she was also working full time, and again, having external resources was crucial to being able to balance working and caregiving.

Maude recalled a story of one night when she and her husband went to her neighbor's house late at night to check on her to find that she was missing. They searched for hours and eventually found her trying to put the chickens away. When they found her she did not see that they were upset; she just thought they had come to visit. Maude shared that this was the moment when she realized something was very wrong. She used words such as, "disconcerting," "terrifying," "scared," and "upsetting." She said, "It was real… I didn't see it coming before then even though we were around each other all the time." She shared that she worried often that her neighbor would continue to make decisions that could put her in danger. She said it was extremely hard to concentrate at work because she was constantly thinking about her neighbor. She saw inconsistency in her behavior as well. For example, one day she was confused and had no self-awareness, and the next day she was "back to normal."

She shared another story about her neighbor trying to drive up the mountain they lived on in the middle of an ice storm. She said her neighbor had never displayed any sort of poor decision making like that in the time that they had known each other. She recalled just how shocked she was that she had not noticed the changes in her neighbor. She said that she realizes now that she was making excuses and rationalizing the behaviors, because she did not want to see that they were real.

Maude also shared that because she was not blood-related family, she experienced some difficulties legally and personally. She said she was met with resistance from her neighbor's children when trying to obtain power of attorney. She said that as this process unfolded, she experienced a lot of anger at her neighbor's family for taking advantage of her decreased mental capacity. She recalled that as her neighbor deteriorated more and more family members showed up to "get things" from her, and then left with no concern about her actual health. As her neighbor and friend, Maude felt that she essentially had no voice to stand up for her neighbor.

**What challenges do caregivers face as their role shifts?**

Dolores shared that some of the challenges currently are getting phone calls that are informing her of events that have happened with her mother. She kept reiterating that she can make sure that her mother has what she needs, but it is so different from direct caregiving because she does not have to be on call 24 hours a day for seven days a week. She said that it is not necessarily easier, but it is different.

Dolores also shared that she and her mother have switched roles. She commented on the regression experienced by her mother, saying that she is like a 2-year-old in a way, and that Dolores is the "momma" now. She also commented on her mother's personality change, saying that she is typically very sweet but occasionally lashes out at others. She said that her mother never would have done that before. She shared examples of her mother confusing her with another person, often her mother or her sister, and expressed that it used to be very painful but she has "gotten used to it." Again, she used the phrase, "It's just the way it is."

Maude shared that the stress is "different stress" now that she is not actively caregiving. She shared that while actively caregiving, she was always worried about the

future, saying that she wondered what she was going to do "next time" and whom she could call for help. She said that now her worry is more "situational" and comes up when something arises that she needs to address. She shared that now she is more reactive where she was previously proactive, and this is completely due to the lack of control that she has over the situation now.

When asked how the relationship has changed, Maude shared that her neighbor has needed to become more dependent upon her. Because she was such an independent woman previously, Maude is worried that her neighbor resents her. She also shared that she is worried that once her neighbor passes away that her neighbor's family will cut her out, and potentially resent her for making the decisions she did. She reiterated her frustrations with all of the legal and logistical red tape that she must go through just to care for this person she loves.

**What emotions are experienced as their role shifts?**

Dolores shared that the emotions she experienced while actively caregiving were up and down. She used words such as, "frustration," "crying," "funny sometimes," and she shared the phrase, "You're better to laugh than to cry." She expressed that her mother would have been horrified if she could have seen the things she did; for example, she shared a story about her mother going outside in the snow barefoot. She said that she had a tough time balancing the everyday tasks and also keeping an eye on her mother to keep her safe. Dolores recalled that her mother wandered and that made things "tough." She said she would go home and cry a lot. She kept returning to using laughter as a substitute for tears when trying to cope with what was happening. When asked if she took on some of the emotions for her

mother, she said she might have. She shared that she experienced a lot of fear and disappointment. She shared that her emotions evolved from frustration to more acceptance.

Dolores shared that as her mother continued to get worse, she realized that she just "couldn't do it anymore." She shared that at the beginning, even though she got frustrated with her mother more, she also had more patience after her mother behaved erratically. She shared that she went to look at the facility to which her mother eventually moved; however, she also was very ill. She shared that she was diagnosed with cancer, and on the day her mother moved she was in the hospital. She could not recall a lot from that time and was unable to comment about her emotional state during this transition. She said that it was too hard to keep track of her own life. During the time that she was making the decision to move her mother, she was deciding whether she should retire. She felt like she could not retire because she did not want to be home with her mother all day. She said that work was like a break from being a caregiver. She shared that she goes to visit her mother frequently at the nursing home, usually every other day. However, she said that caring for her now is very different, because it is so relaxed. She does not have to keep an eye out every minute of every day. She said, "I have time for me and time to do things I want to do." She agreed that she feels relieved by this change in care and especially relieved that she knows her mother is safe.

Maude shared that she experienced a range of emotions as the situation worsened. The primary emotion was sadness for her neighbor, as she seemed to be aware that she was declining, and then sadness for herself because she misses her. She also said that she felt like her sadness had melded with anger in a way.

Maude shared that she experienced a lot of anxiety and confusion about the decision to move her neighbor into a facility. However, she said that she felt like this was the one advantage she had over a related caregiver. She felt that while it was very difficult, she was able to separate herself from her neighbor emotionally and make the best decision for her, not herself. She thought that it must be harder for an adult child due to having more memories and having to "reverse roles" with the parent. She shared that what was most difficult was being blindsided by the medical and financial decisions. She said she felt, and still feels, very underprepared and poorly informed about what she is "supposed" to do in those situations. She shared that she is currently being brought to court due to signing a paper "incorrectly" and misinforming a medical company. Her tone of voice while sharing this conveyed desperation, and she even stated that she wished she had more guidance about these decisions. She even commented that she is a highly educated professor and researcher, yet she feels like an uninformed child when these decisions are placed in front of her. She said, "Now I have to run this gauntlet of mess to get this [person whom I love] taken care of."

**Benefits of a Support Group**

Dolores shared that the benefits of a support group would be having someone to talk to who has been there before. She commented that until you go through this process you could not fully understand what it is like. She commented that many people do not even understand how to interact with her mother. She also expressed that a support group could be helpful by providing resources and information about dementia and providing answers and helpful tips. While discussing some of the challenges, she postulated that it could be a positive experience to have tears and emotional pain brought up and worked through.

Maude shared that it would be really nice to have a place to go talk with other people about their experiences. She shared a story about a friend who is at the beginning stages of this process with her mother and said that it felt "so good" and "uplifting" to be consulted for advice. She said, "It made me feel accomplished." She said that she wished that she had known a "senior member" to look to when she first started and that she wished that she could provide support to more people who are currently facing similar situations. In addition, having a place to share her story would be invaluable; for example, "to just talk" would help. She said that there are support groups "for everything else" and that it is shocking that there are not ones for a situation like she is in currently.

**Challenges of a Support Group**

Dolores shared that time constraints would be the biggest challenge about participating in a support group. She also commented that it could be painful depending upon the emotional state of the participants.

Maude felt that the major challenge is time. She said that a group would need to meet after 5pm or on the weekends, and even those times may be difficult for caregivers with children.

**Rewards of the Experience**

Dolores shared that the biggest reward of this experience has been that she has been able to "give back" the care that her mother provided for her. She said that although it is difficult at times, her mother was always there for her, so the least she could do is return the favor.

Maude shared that it is rewarding to be able to care for someone else. She shared that she keeps doing this because she hopes that someone in her family would do it for her. She

used the phrase, "Paying it forward." She also said that she feels responsible for her neighbor. She also said that she has a naturally caring personality and that she gets self-fulfillment out of caring for her neighbor. She ended by saying that she can help her neighbor and that she "can do this."

**Chapter 6**

**Discussion**

This chapter integrates the findings of the music therapy survey and the information provided by the interviewees. It is intended to explore what is currently being done in music therapy to address the needs of this population by using examples from the literature and the interviewees' responses. It begins with a discussion of each research question, then discusses recommendations made by the researcher, and ends with limitations of the study.

**How does the caregiving experience change when the family member is moved into a skilled nursing facility?**

As both interviewees in this study expressed, the caregiving experience becomes less involved once the family member is moved into a skilled nursing facility. There is less required of them in an immediate way. Both interviewees spoke about this concept, saying that they are in a "second call" role now with their loved ones. They both shared that while it is upsetting to hear that their loved ones have fallen, struck another resident, or have a medical need, it is easier to process and cope with the situation. When they were actively caregiving, they needed to manage the logistics and the emotions, but now they are able to emotionally process what is happening without having to interact as much with doctors, insurance companies, or other professionals. They shared that this role is not without its downsides; for example, they both shared that they are not notified as often or immediately when something happens with their loved one. They also shared that it is hard to hear what their loved ones have done, and it is difficult that they are unable to be with them.

**What challenges do caregivers face as their role shifts?**

It is expected that caregivers face emotional challenges. They are witnessing the decline of a loved one and are powerless to stop it. It is common for caregivers to be the only support system for their loved one, and they are coupled with the demands of their own lives. This can cause insurmountable stress and be a heavy burden to carry (Chan et al., 2010). Existing research also suggests that caregivers' needs extend farther than emotional support. Often times, caregivers are left with decisions that they have not ever faced, especially when they involve financial demands, legal questions, and medical decisions. The challenges that caregivers experience can be separated into two categories: logistical concerns and emotional concerns. Logistical concerns are challenges such as confusion about the diagnosis of neurocognitive disorder, time management, financial demands, legal questions and documents, or medical decisions. Emotional concerns are challenges such as burnout, depression and anxiety, loneliness, grief and powerlessness, and anger. Both interviewees in this study expressed these types of challenges. They shared that while they had family and friends to support them, it often was not enough due to the complicated tasks and decisions with which they were presented. One interviewee shared a story several times about being summoned to court over a decision that she made for her loved one almost four years prior. Both interviewees expressed and conveyed emotions of burnout, anxiety, depression, grief and powerlessness, and anger several times throughout the interviews.

The literature suggests that both categories of concerns can be addressed with a support group. These groups allow for caregivers to have a place to express themselves, connect with others, increase their self-awareness, and receive advice from peers or professionals. While caregivers reported that the most important aspect of a support group is

a place to address emotional concerns, it is important to address logistical concerns as well. They reported that even just hearing what their peers had done was important for their self-confidence and was empowering for the "veteran" caregivers (Henriksson et al., 2012). Several shared that their emotional concerns were fueled by logistical concerns, which in turn caused more emotional concerns (Chan et al., 2010). The process appeared to be iterative. Both interviewees in this study identified the same strengths of a support group as the literature. One interviewee shared a story about an opportunity that she had to be a "veteran" caregiver to a friend who was at the beginning stages of the caregiving process. She expressed that the experience was empowering, as she was able to offer support to her friend and see how much she had accomplished in the same moment. Both interviewees shared that being part of a support group would help ease their burdens and that they would like the opportunity to process what has already happened. They both shared that a place to be supported by peers and share their story would make their journey seem more manageable, which is exactly what the caregivers in the literature shared.

**What emotions are experienced as their role shifts?**

When a person experiences a loss they also experience some form of grief (Bright, 2002). Caregivers experience grief and loss in several ways. The loss of his or her loved ones is a difficult loss to grasp due to the simple fact that they have not physically died, but they are not the same person they once were. The interviewees in this study explained this loss as several different types such as (a) the loss of the person they once knew, (b) the loss of what "might have been," (c) the loss of their loved one as a support system, and (d) the loss of their own lives, which suggests different emotions are present during the role shift. They grieved the loss of who the person was, which was expressed as frustration. They grieved the

loss of what they thought they should have had which was expressed in anger and disappointment. They grieved the loss of their own time and lives, which was expressed in sadness, frustration, and disappointment. They grieved for their loved one and expressed that they felt like they were taking on the emotions, such as embarrassment and shame, that their loved one would surely feel if they knew what was happening to them. Both used phrases such as, "If she could see herself now," and "Thankfully she doesn't know what she's doing." So, caregivers experience grief and go through the grieving process. While it is clear both interviewees experienced the five stages of grief, it is also clear that they experienced the process on a larger scale than initially speculated.

**Denial.** With typical "old age" stereotypes and family members' having busy lives, a family member with neurocognitive disorder often has symptoms that go unnoticed for years. Additionally, a person with neurocognitive disorder often goes to great lengths to hide their confusion, and this is exacerbated by family members who avoid warning signs and find ways to rationalize behaviors (Vickrey et al., 2009). Both interviewees talked about several occasions when they excused symptomatic behavior. Small events such as missed appointments, recalling times and dates wrong, forgetting to pay bills, losing personal items, forgetting names, and erratic behavior were all examples of warning signs that went overlooked. They both shared that they knew something was not right, but it was easier and less painful to credit these mishaps to everything but confusion of their loved one. They often blamed themselves, old age, and others for these mistakes. While they did not use the word "denial" in their interviews, it was clear that they were denying that something was wrong with their loved one.

**Anger.** Caregivers often experience a moment of realization when they realize something is wrong. More often than not, this moment comes during or immediately after a terrifying experience, such as a loved one getting lost outside in the middle of the night or being found by the police far from home. Both interviewees shared these types of experiences. They used words like "blindsided" and "completely unexpected," and "shocked" that their loved one had done what they had done. They were flabbergasted by what they saw and it was almost like they had no idea it was coming. They both shared that initially they were terrified for the safety of their loved one, and then they were furious with themselves for not realizing how bad the situation was in reality. They were angry that they had not kept a closer eye, had rationalized behaviors, and had let their loved one get hurt or put themselves in danger. They did not see it coming. Both interviewees shared that they felt helpless, and as they were recalling the event, they got upset and angry with themselves again in that moment.

**Bargaining.** This phase of the grief process manifests in a unique way for caregivers. Both interviewees shared stories of their own struggle with maintaining control over the situation. Dolores shared that she was so involved in her mother's care that she did not realize that she was sick with cancer. She shared that she strongly considered retiring from her job of 40 years to become a full time caregiver. Maude shared that she found that she was stretching herself too thin among her fulltime job responsibilities, duties to her family, and her caregiving role. She had no time left for herself. She shared that she was missing events and cancelling appointments that were not related to her neighbor's care. These types of situations also are supported by the literature (Vickrey et al., 2009). Many caregivers have shared that they trade personal health and well being for the care of their loved one. The

moment when the caregiver realizes how much they have compromised for their loved one, and they cannot continue to do what they have been doing is a pivotal moment in caregiving. It is easily thought of the end of caregiving; however, this is hardly the case. It is merely a transition to the next part of caregiving.

       **Depression.** Over 75% of caregivers reported that they found a sense of self-identity through their caregiving role (Caregiver Action Network, 2014), which suggests that once they have relinquished their duties of active caregiving, they will feel a loss of identity. This phase typically begins right after the caregiver has moved their family member into a facility, which ironically is when caregivers often have the least amount of support. Emotionally, caregivers experience guilt, frustration, sadness, and anger. Both interviewees shared moments from this time, and it was evident that there was still much that was unresolved. Dolores shared that due to her own cancer she did not take an active role in her mother's transition to nursing care; however, she made several down payments and planned the move. She reported it was almost a blessing that she could not be there because she did not know if she could have handled it emotionally. Maude appeared to be quite distressed over the lack of support she received in the first few months after she had moved her neighbor into a facility. She repeatedly shared the same story about her decisions during this process, and commented that she was pretty frustrated with the way she was treated by her neighbor's family. When she was sharing her story during the interview, she appeared to need to express the pain she was in and appeared liberated when she was done. Often times, caregivers are faced with financial, legal, and medical decisions that are not only difficult to make, but also difficult to understand. Coupled with the emotional stress, the weight of this decision can be unbearable. It is hard to believe that there is not a better support system being offered for this population

considering the amount of stress and pain that they are in, especially immediately after their loved one has moved.

        **Acceptance.** Acceptance comes in many forms for caregivers. Some caregivers do not reach acceptance until their loved ones have passed away (O'Callaghan et al., 2013) and others reach it after their loved ones have been moved into a facility. There seem to be two forms of caregivers with loved ones who reside in a facility: task-oriented and emotional. The first type, a task-oriented caregiver, allows the facility to care for their loved one's medical needs on site, but they maintain their medications, do their laundry, take them to appointments, and keep contact with professionals on their loved one's behalf. They visit semi-regularly, probably a few times a month. The second type, an emotional caregiver, visits regularly, often daily. They bring their loved ones snacks, sit with them during meals, help them participate in activities, and let the facility take care of all the logistical needs in addition to the skilled care they provide. Maude was an example of the first type of caregiver while Dolores was an example of the second type. Dolores seemed to be in this phase of her process as she used language that suggested acceptance with her role and her mother's disease. It was evident that she was sad that her mother was going through what she was, but she was able to talk about it with less emotional charge than Maude.

**What is currently being done in music therapy for this population?**

        As evidenced by the survey results of this study, there is little being done in music therapy for this population. Few respondents have worked with a support group: one through a school project and the other professionally. Many reported that they have done one or two sessions with a resident and their family member, but not with the family member alone. The music therapists responded overwhelmingly positively to the idea of a support group for this

population. Most stated that they are confident about their skills to facilitate a support group. Two music therapists reported that they do not feel that music therapy should be offered to support family caregivers; however, these respondents also reported neutral confidence level. There were several challenges reported. The largest barrier seemed to be time. This was the most common response given from the participants. They cited work schedules and life schedules as the main reason why they could not provide this service. The second barrier was lack of support from the facility where the music therapist worked or their community. Overall, it appeared to be a well-received idea and several respondents even stated that they had never thought about offering such a group; however, there is no existing music therapy research for this particular population to support or refute these findings.

**Recommendations**

Based on the literature review and results of this study, recommendations begin with using music therapy to support family caregivers of residents residing in facilities. One of the most powerful aspects of music is that it takes the client where they are ready to go (Magill, 2008) and helps them make connections to themselves and others (O'Callaghan et al., 2013). Additionally, music is able to hold the emotions that are brought up as a result of the caregiving process and can help the person resolve these emotions in a healthy and supported way (Erkkilä et al., 2008).

It is recommended that the sessions follow a format that allows the clients to bring whatever is present with them on that day to the group to work through with music therapy. One option is an improvisation-based support group that might increase interpersonal and intrapersonal awareness. This will allow the group members to use music to connect to one another and support their peers while also using music to share and process what is

happening in their lives. Additionally, because music is inviting and motivating, it is speculated that music therapy would help the group members form deeper bonds with one another so they can serve as supports during the caregiving journey.

The sessions should address several elements of caregivers' needs that have been identified throughout this study. First, the group should address the diagnosis of neurocognitive disorder and provide members resources for medical, financial, and legal guidance. Both the literature and the interviews showed that there is a lot of confusion about the diagnosis of neurocognitive disorder, specifically etiology and prognosis. Second, many caregivers reported they had little to no time for themselves (Lilly et al., 2012). Therefore, the facilitator should provide the members the opportunity to identify what their own needs are and strategies for self-care. Third, related to self-care, the group should provide its members help with developing coping skills for their situation. Fourth, the group should provide members with opportunities to process their emotions. This could be facilitated in a variety of ways, such as interventions that address fears, loss, or anger. Fifth, the caregivers should be provided with an opportunity to recognize their accomplishments with caregiving. Sixth, the caregivers should be provided with ways to utilize music outside of the support group. The use of music during caregiving activities has been shown to be an effective way to reach loved ones with neurocognitive disorder (Hammar et al., 2010). Last, the group should provide caregivers with a way to honor or remember their loved ones. This may be in the form of a songwriting project or improvising music for their loved one. Caregivers experience feelings of powerlessness, and helping them create a legacy for their loved ones may help them feel more in control of their situation (Saad et al., 1995).

Several of the respondents indicated staff resistance as a primary reason for not having a support group. They shared that leading a support group was outside their duties or finding money to pay for this additional service was impossible. The option to co-lead a support group with the social worker or other staff member could address this issue. Another option may be to include a music therapy support group in the job description of the music therapist. This would provide a way to designate this as the responsibility of the music therapist and if it was part of the music therapist's weekly or bi-weekly duties, the facility would not be responsible for paying an additional cost. Additionally, the music therapist is often seen as a member of the staff that directly interacts with the residents only, which may cause some confusion. The resident's families are just as important to them and should be held in the same regard by the staff. Often, family members are in the facility several times a week and know the staff just as well as their loved ones. It is difficult to see a reason to treat them with any less care and support.

Finally, time was listed as a major challenge by the music therapists and the interviewees. The potential to facilitate a support group during the day or on a weekend would help address this problem. Again, if the music therapist's job description included a music therapy support group for family caregivers, then the music therapist and facility would have the flexibility to hold the group whenever worked best for the caregivers.

**Limitations**

The study has several limitations. One limitation is the small number of respondents for the survey. With only 31 responses, the results are difficult to generalize. Also, the respondents were solicited due to reporting that they work with older adults; however, this category is quite large. According to AMTA, it included the range of adult day care to late

stage neurocognitive disorder care. The range of needs for caregivers in these situations is large, and difficult to quantify without getting responses from caregivers with each specific subpopulation of the older adult population. The specific situations that music therapists work in also limit the reality of even starting a support group. For example, some respondents reported that they work in private practice or hospice, which implies that they are not the music therapists at a single facility. This employment situation would make facilitating a support group difficult. The survey sample was also limited to members of AMTA, excluding all members who are not currently members of the organization. Therefore, the survey results may not represent the all music therapists working with the older adult population. Finally, there were a large number of music therapists of the solicited population who did not respond. Concerning the interviews, although the interviews were intended to provide in-depth accounts of caregivers' experiences, they include data from only two caregivers, which cannot be generalized to the caregiving population.

Another limitation concerns the format of the survey. Three questions all contained the option "I do not facilitate support groups," and if this option were chosen for one question it should have been selected for each one. However, several respondents selected this option for one or two of these questions and then answered the others. Additionally, some respondents who stated that they did not facilitate support groups later provided answers indicative of facilitating support groups. These mistakes in the survey's construction may have caused inaccurate representation of the results.

Finally, there were several questions that provided the survey respondents the "select all that apply" option. While this type of question gives information on all of the options that

apply, it is also a limitation because it provides an unclear picture of what options were most important.

Another limitation is in regards to the interview questions. More background information questions were needed to provide a clearer picture of the caregivers' lives. The questions did not ask about the length of time the caregiver had provided direct care, how long their loved one has resided in a facility, or how long they had been experiencing symptoms. Additionally, it may have been helpful to inquire about family dynamics prior to the loved one experiencing symptoms as the research suggests that the relationship between the caregiver and their loved one plays an intricate role in the caregiving process.

**Conclusions**

This study has provided an overview of the use of music as a way to provide support for family caregivers of people who reside in long-term care facilities. The findings in this study provide data that support the implementation of music therapy as a way to address the needs of this population. While there is little research being done currently, there appears to be interest by current music therapists in learning about and implementing support groups at their facilities.

This study has barely scratched the surface of what is happening in this topic. There is a need for further research to corroborate the findings in this study and to further investigate the consequences of caregiving on family members. The next step for this study would be to implement a pilot support group to help identify what music has to offer to this population.

The findings imply a change in the way society views caregiving and nursing homes. It is a stereotype that family members leave their loved ones and never look back, and while that does happen, there are many family members who are involved in their loved ones'

lives. The symptoms of grief and feelings of powerlessness are very real for family caregivers. It is evident that their emotional burden does not end once their loved one has transitioned into a facility.

This caregiver population is quickly growing as more people are reaching the age when they will need caretakers. Music is a powerful tool for supporting this population. Music is able to help explore and resolve emotions, and the use of music in this context may be more effective than verbal therapy due to the complexity of the emotions experienced by family caregivers.

# References

Alzheimer's Association. (2013). *Alzheimer's facts and figures.* Retrieved from

      http://www.alz.org/alzheimers_disease_facts_and_figures.asp

American Music Therapy Association. (2013). *What is music therapy*? Retrieved from

      http://www.musictherapy.org/about/musictherapy/

Baker, F. A., Grocke, D., & Pachana, N. A. (2012). Connecting through music: A study of a

      spousal caregiver-directed music intervention designed to prolong fulfilling

      relationships in couples where one person has dementia. *Australian Journal of Music*

      *Therapy*, *23*, 4–19.

Baker, F., Wigram, T., Stott, D., & McFerran, K. (2008). Therapeutic songwriting in music

      therapy. *Nordic Journal of Music Therapy*, *17*, 105–123.

Bright, R. (1996). *Grief and powerlessness: Helping people regain control of their lives.*

      Bristol, PA: Jessica Kingsley Publishers.

Bright, R. (2002). *Supportive eclectic music therapy for grief and loss: A practical handbook*

      *for professionals.* St. Louis, MO: MMB Music.

Bryman, A. (2004). *Social research methods* (2nd ed.). New York: Oxford University Press.

Caregiver Action Network. (2014). *Caregiving Statistics*. Retrieved from

      http://caregiveraction.org/statistics/#Caregiving%20Population

Chan, W. C., Ng, C. C., Mok, C. M., Wong, F. F., Pang, S. L., & Chiu, H. K. (2010). Lived

experience of caregivers of persons with dementia in Hong Kong: A qualitative study.

*East Asian Archives of Psychiatry*, *20*, 163–168.

Chien, L., Chu, H., Guo, J., Liao, Y., Chang, L., Chen, C., & Chou, K. (2011). Caregiver

support groups in patients with dementia: A meta-analysis. *International Journal of

Geriatric Psychiatry*, *26,* 1089–1098. doi:10.1002/gps.2660

Earle, S. S. (2006). Reflections on 12 years of Alzheimer's caregiver support groups. *Care

Management Journals, 7,* 135–140.

Erkkilä, J., Gold, C., Fachner, J., Ala-Ruona, E., Punkanen, M., & Vanhala, M. (2008). The

effect of improvisational music therapy on the treatment of depression: Protocol for a

randomised controlled trial. *BioMed Central Psychiatry*, *8*, 50–58. doi: 10.1186/1471-

244x/8/50

Gräßel, E., Trilling, A., Donath, C., & Luttenberger, K. (2010). Support groups for dementia

caregivers: Predictors for utilization and expected quality from a family caregiver's

point of view: A questionnaire survey PART I. *BioMed Central Health Services

Research, 10*, 219–226. doi:10.1186/1472-6963-10-219

Hammar, L. M., Emami, A., Engström, G., & Götell, E. (2010). Finding the key to

communion: Caregivers' experience of 'music therapeutic caregiving' in dementia

care: A qualitative analysis. *Dementia, 10,* 98–111. doi: 10.1177/1471301210392994

Henriksson, A., Årestedt, K., Benzein, E., Ternestedt, B., & Andershed, B. (2012). Effects of

a support group programme for patients with life-threatening illness during ongoing

palliative care. *Palliative Medicine, 27,* 257–264. doi: 10.1177/0269216312446103

Kang'ethe, S. (2011). Evaluating the role of support group structures as vehicles of palliative

    care: Giving productivity in the Kanye care program in Botswana. *Indian Journal of*

    *Palliative Care, 17,* 11–19. doi: 10.4103/0973-1075.78444

Lilly, M. B., Robinson, C. A., Holtzman, S., & Bottorff, J. L. (2012). Can we move beyond

    burden and burnout to support the health and wellness of family caregivers to persons

    with dementia? Evidence from British Columbia, Canada. *Health and Social Care in*

    *the Community, 20,* 101–112. doi: 10.1111/j.1365-2524.2011.01025.x

Magill, L. (2008). The meaning of music: the role of music in palliative care music therapy

    as perceived by bereaved caregivers of advanced cancer patients. *American Journal*

    *of Hospice and Palliative Medicine, 26,* 33–39. doi: 10.1177/1049909108327024

O'Callaghan, C. C., McDermott, F., Hudson, P., & Zalcberg, J. R. (2013). Sound continuing

    bonds with the deceased: The relevance of music, including preloss music therapy,

    for eight bereaved caregivers. *Death Studies, 37,* 101–125. doi:

    10.1080/07481187.2011.617488

Saad, K., Hartman, J., Ballard, C., Kurian, M., Graham, C., & Wilcock, G. (1995). Coping by

    the carers of dementia suffers. *Age and Aging, 24,* 495–498.

Takai, M., Takahashi, M., Iwamitsu, Y., Oishi, S., & Miyaoka, H. (2011). Subjective

    experiences of family caregivers of patients with neurocognitive disorder as

    predictive factors of quality of life. *Psychogeriatrics, 11*, 98–104. doi:10.1111/j.1479-

    8301.2011.00354.x

Vickrey, B. G., Hays, R. D., Maines, M. L., Vassar, S. D., Fitten, J., & Strickland, T. (2009).

    Development and preliminary evaluation of a quality of life measure targeted at

    dementia caregivers. *Health and Quality of Life Outcomes*, 7, 56–67.

doi:10.1186/1477-7525-7-56

Wang, L., Chien, W., & Lee, I. Y. (2012). An experimental study on the effectiveness of a

mutual support group for family caregivers of a relative with dementia in mainland

China. *Contemporary Nurse, 40,* 210–244.

Wei, Y., Chu, H., Chen, C., Hsueh, Y., Chang, Y., Chang, L., & Chou, K. (2011). Support

groups for caregivers of intellectually disabled family members: Effects on physical-

psychological health and social support. *Journal of Clinical Nursing, 21,* 1666–1677.

doi: 10.1111/j.1365-2702.2011.04006.x

Yoo, J., Jang, S., & Choi, T. (2010). Sociocultural determinants of negative emotions among

dementia caregivers in the United States and Korea: A content analysis of online

support groups. *The Howard Journal of Communications, 21,* 1–19. doi:

10.1080/1064617090350119

**Appendices**

**Recruitment Announcement and Response**

**ANNOUNCEMENT FOR FACULTY/STAFF**

MUSIC THERAPY RESEARCH STUDY: Do you have a family member residing in a long-term care facility? Men and women aged 18 and older are needed to participate in a graduate thesis study that aims to develop recommendations for music therapy support groups for family caregivers of individuals residing in long-term care facilities. You are asked to participate in a one time, hour-long interview with the researcher about your caregiving journey. For more information, please contact Stephen Wilson, MT-BC (Music Therapist-Board Certified) at wilsonsh1@appstate.edu or (315) 436-1873. If no answer, please leave a message.

**LETTER FOR PEOPLE WHO HAVE INQUIRED AND ARE ELIGIBLE**

Dear (First Name),

Thank you for your interest in this study. My name is Stephen Wilson. I'm a Board-Certified Music Therapist and currently pursuing a Master of Music Therapy degree at Appalachian State University. This research is part of the requirements of that degree. The purpose of this research is to develop recommendations for music therapy support groups for family caregivers of individuals residing in long-term care facilities. The study was approved by the Institutional Review Board at Appalachian State University on January 24, 2014.

If you decide to participate, you will be asked to participate in a one time, 60-minute interview with the researcher. This interview will consist of 10 open-ended questions that inquire about your caregiving role with your loved one, how that role has shifted after facility placement, your emotions during active caregiving and now, and how your relationship with your loved one has changed throughout this process. The interviews will be audio recorded for data recording purposes and will be conducted in the Music Library in the Broyhill Music Building on the Appalachian State University campus.

If you are interested, please let me know a good time and day to contact you about setting up the interview.

Sincerely,
Stephen

# Appendix B

## Caregiver Support Group Questionnaire

The purpose of this survey is to investigate the implementation of music therapy as a way to provide support to family caregivers of individuals in long-term care.

The survey consists of 19 questions, and should not take more than 10-15 minutes to complete.

If you have any questions regarding the survey, please contact:

Stephen Wilson, Principal Investigator, wilsonsh1@appstate.edu, (315) 436-1873
Christine P. Leist, Faculty Advisor, leistcp@appstate.edu, (828) 262-6663
Or the Institutional Review Board at Appalachian State University at irb@appstate.edu

## Section 1 of 4

Demographic Information

1. What is your gender?

    a) Female

    b) Male

    c) Other

2. What is your age?

    _____

3. What is your music therapy credential or designation?

    a) MT-BC

    b) RMT

    c) ACMT

    d) CMT

    e) Other_____

4. How many years have you been a music therapist practicing in the field?

    _____

5. How many years have you worked specifically with individuals in long-term care?

    _____

6. What levels of education have you completed? (Check all that apply).

    a) Bachelor's degree in Music Therapy

    b) Bachelor's degree in another field

    c) Bachelor's in Music Education with an emphasis in Music Therapy

    d) Equivalency in Music Therapy

    e) Master's degree in Music Therapy

    f) Master's degree in another field (please specify)

    g) Doctoral degree in Music Therapy

    h) Doctoral degree in another field

7. In which AMTA region do you currently practice music therapy?

    a) Great Lakes

    b) Mid-Atlantic

    c) Midwestern

    d) New England

    e) Southeastern

    f) Southwestern

    g) Western

    h) International

8. In what types of settings do you provide music therapy? (Check all that apply.)

    a) Skilled nursing

    b) Memory care I (early to moderate stage dementia)

    c) Memory care II (moderate to late stage dementia)

    d) Assisted living

    e) Independent living

    f) Rehabilitation

    g) Other _____

9. A family caregiver is defined as a person connected to the individual residing in a long-term care setting by marriage, genetics, or choice who cares for that individual's needs, including assistance in the areas of one or more activities of daily living (ADLs), financial management, transportation, administration of medication, making arrangements/scheduling appointments, mediation in the family, and managing behavioral symptoms. The majority of family members in this role have little to no prior education of caring techniques or medical training (Chan et al., 2010).

   In what ways have you gained knowledge and insight into caregiving or caregiver's lifestyle? (Check all that apply).
   a) Music therapy undergraduate coursework
   b) Graduate music therapy coursework
   c) In-service at work
   d) Professional workshop
   e) Journal articles/books
   f) Conference session
   g) Interaction with family caregivers
   h) None
   i) Other (please specify) _____

10. How much do family caregivers participate with their loved ones in your music therapy groups?
   a) Very Frequently (76 to 100% of sessions)
   b) Frequently (51 to 75% of sessions)
   c) Occasionally (26 to 50% of sessions)
   d) Rarely (1 to 25% of sessions)
   e) Never (0% of sessions)

**Section 3 of 4**

Support Groups

11. Support groups are defined as a group of people who come together on a regular basis to help one another accept and cope with their current situation. These groups address common questions and concerns of the members, such as information regarding diagnoses or resources in the community. Additionally, these groups provide an outlet for self-expression and inclusion, which may help to decrease the isolation that the members often experience.

    In your music therapy work, do you facilitate support groups?
    a) Yes
    b) No

12. Who is served by the group? (Check all that apply).
    a) Residents/patients
    b) Family caregivers
    c) Staff
    d) I do not facilitate support groups

13. In what ways have you gained knowledge and insight regarding facilitation of support groups? (Check all that apply).
    a) Music therapy undergraduate coursework
    b) Graduate music therapy coursework
    c) In-service at work, including co-facilitation with colleagues
    d) Professional workshop
    e) Journal articles/books
    f) Conference session
    g) Participating in a support group
    h) None
    i) Other (please specify) _____

j) I do not facilitate support groups

14. What musical experiences have you included in your support groups? (Check all that apply).
    a) Song writing
    b) Music listening
    c) Song discussion
    d) Music and imagery
    e) Music improvisation
    f) Movement to music
    g) Musical games
    h) Lyric analysis
    i) Expressive singing
    j) None
    k) Other _____
    l) I do not facilitate support groups

15. Please rate your level of agreement with the following statement:
    "Music therapy should be included as a way to support family caregivers."
    a) Strongly Disagree
    b) Disagree
    c) Neutral
    d) Agree
    e) Strongly Agree

16. Please rate your level of agreement with the following statement:
    "I feel confident facilitating a music therapy support group for family caregivers."
    a) Strongly Disagree
    b) Disagree
    c) Neutral
    d) Agree

e) Strongly Agree

## Section 4 of 4

Open-Ended Questions

17. If you do not facilitate family caregiver support groups, what are the barriers or challenges of implementing this type of group at your facility?

18. What thoughts do you have about incorporating a music therapy group as a way to support family caregivers?

19. If you wish, please cite an example of your music therapy work with family caregiver support groups.

Thank you for completing the survey!

If you have questions regarding the survey, please contact:

Stephen Wilson, Principal Investigator, wilsonsh1@appstate.edu, (315) 436-1873
Christine P. Leist, Faculty Advisor, leistcp@appstate.edu, (828) 262-6663 or the Institutional
Review Board at Appalachian State University, irb@appstate.edu

## Appendix C

## Interview Questions

1. How long has your family member resided in a facility?

2. What was your role in the care of your family member before he or she moved into the facility?

3. What types of emotions did you experience in that role?

   a. How did those emotions evolve throughout your time in this role?

4. What types of emotions did you experience while making the decision to move your family member into a facility?

   a. What new emotions have emerged as a result of this change?

5. What are the differences between your previous role and now that your family member is now residing in a facility?

6. What are the challenges for your situation now?

7. In what ways has your relationship with your family member changed?

8. What are the benefits of participating in a support group?

9. What are the challenges of participating in a support group?

10. What has been rewarding about your caregiving experience?

**Appendix D**

**Email/Survey Consent Form**

Dear Music Therapist,

As a music therapist who provides services in an older adult setting, you are invited to participate in a survey that concerns your implementation of music therapy as a way to provide support to family caregivers of individuals in long-term care. This survey is part of my thesis research, which I am conducting at Appalachian State University. This study was reviewed and declared exempt from further review by the Institutional Review Board at Appalachian State University on January 24, 2014.

Your contact information is being used with permission from the American Music Therapy Association, but the information you provide will remain completely anonymous. The website (Google Docs) where the survey is located is a secure site, and it neither stores nor tracks your email address, nor does it attach your email address to your responses. The researcher will have no access to email addresses of those who participate or do not participate in the study, and the researcher will not have the ability to link e-mail addresses to responses. The anonymous data will be included in the researcher's master's thesis, and the study may be submitted for publication and presentation at AMTA conferences.

Your participation in completing this survey is voluntary, and there are no consequences if you decline to participate or decide to discontinue participation at any time. No risks are associated with completing this survey, and you will receive no compensation. You will be asked to complete 19 questions regarding the use of music therapy in this capacity; this process should not take more than 10-15 minutes. If you are willing to participate, please continue to access the online survey. By submitting responses to the survey you are consenting to participate. You can choose to respond to all, some, or none of the items.

Please complete the survey by March 6, 2014.

Questions may be directed to:
Stephen Wilson, Principal Investigator, wilsonsh1@appstate.edu, (315) 436-1873
Christine P. Leist, Faculty Advisor, leistcp@appstate.edu, (828) 262-6663
Or the Institutional Review Board at Appalachian State University at irb@appstate.edu

**By continuing to the survey, I acknowledge that I am at least 18 years old, have read the above information, and provide my consent to participate under the terms above.**
Thank you for your participation.
Sincerely,
Stephen Wilson, MT-BC
Principal Investigator
Candidate for Master of Music Therapy degree

# Appendix E

## Email of IRB Approval/Exemption

**To:** Stephen Wilson
CAMPUS MAIL

**From:** IRB Administration **Date:** 1/24/2014 **RE:** Notice of IRB Exemption **Study #:** 14-0168

**Study Title:** Music Therapy Support Groups for Family Caregivers of Individuals Residing in Long-Term Care Facilities: A Survey of Music Therapists and Interviews with Current Family Caregivers

**Exemption Category:** (2) Anonymous Educational Tests; Surveys, Interviews or Observations

This study involves minimal risk and meets the exemption category cited above. In accordance with 45 CFR 6.101(b) and University policy and procedures, the research activities described in the study materials are exempt from further IRB review.

**Study Change**: Proposed changes to the study require further IRB review when the change involves:

an external funding source, the potential for a conflict of interest, a change in location of the research (i.e., country, school system, off site location), the contact information for the Principal Investigator, the addition of non-Appalachian State University faculty, staff, or students to the research team, or the basis for the determination of exemption. Standard Operating Procedure #9 cites examples of changes which affect the basis of the determination of exemption on page 3.

**Investigator Responsibilities**: All individuals engaged in research with human participants are responsible for compliance with University policies and procedures, and IRB determinations. The Principal Investigator (PI), or Faculty Advisor if the PI is a student, is ultimately responsible for ensuring the protection of research participants; conducting sound ethical research that complies with federal regulations, University policy and procedures; and maintaining study records. The PI should review the IRB's list of PI responsibilities.

**To Close the Study:** When research procedures with human participants are completed, please send the Request for Closure of IRB Review form to irb@appstate.edu.

If you have any questions, please contact the Research Protections Office at (828) 262-7981 (Julie) or (828) 262-2692 (Robin).

**INSTITUTIONAL REVIEW BOARD**

Office of Research Protections ASU Box 32068 Boone, NC 28608 828.262.2130

Web site: http://www.orsp.appstate.edu/protections/irb Email: irb@appstate.edu Federalwide Assurance (FWA) #00001076

Best wishes with your research.

**Websites for Information Cited Above**

Note: If the link does not work, please copy and paste into your browser, or visit

https://researchprotections.appstate.edu/human-subjects. 1. Standard Operating Procedure #9:

http://researchprotections.appstate.edu/sites/researchprotections.appstate.edu/files/IRB20SOP 920Exempt%20Review%20Determination.pdf

2. PI responsibilities: http://researchprotections.appstate.edu/sites/researchprotections.appstate.edu/files/PI20Respo nsibilities.pdf 3. IRB forms: http://researchprotections.appstate.edu/human-subjects/irb-forms

CC: Christine Leist, School Of Music

**Appendix F**

**Oral Interview Consent Form**

I agree to participate as an interviewee in the research project, "Music Therapy Support Groups for Family Caregivers of Individuals Residing in Long-Term Care Facilities: A Survey of Music Therapists and Interviews with Current Family Caregivers." The purpose of this research project is to develop recommendations for music therapy support groups for family caregivers of individuals residing in long-term care facilities. The study will be completed by August 1, 2014. I understand that my comments will be audio recorded, transcribed, and used for a Master's thesis and possible publication by Stephen Wilson as partial fulfillment for the Master of Music Therapy program at Appalachian State University. The interview will take place one time for approximately 60 minutes. I understand that there are no foreseeable risks associated with my participation. I also know that this study may benefit the field of music therapy and the needs of caregivers by increasing therapists' understanding of music therapy and caregiver support.

I give Stephen Wilson ownership of the recording and transcript from the interview he conducts with me and understand that the recording and transcript will be kept in the researcher's possession for three years. I understand that information or quotations from the transcript will be published, and my name will not be used without my permission. I understand I will receive no compensation for the interview.
I understand that the interview is voluntary and I can end it at any time without consequence. I also understand that if I have questions about this research project, I can contact Dr. Christine Leist, the Committee Chair, at (828) 262-6663 or leistcp@appstate.edu can also contact Appalachian State University's Office of Research Protections at 828-262-7981 or irb@appstate.edu.

Appalachian State University's Institutional Review Board has determined this study to be exempt from IRB oversight.

☐      I request that my name **not** be used in connection with recordings, transcripts or publications resulting from this interview.

☐      I request that my name **be used** in connection with recordings, transcripts or publications resulting from this interview.

Name of Interviewer_____
Name of Interviewee _____

Signature of Interviewer _____
Signature of Interviewee_____

Date of Interview _____

**Vita**

Stephen Henry Wilson was born in Guatemala City, Guatemala. Shortly after his first birthday, Ron and Kathy Wilson adopted Stephen. He grew up in the Syracuse, NY area and attended State University of New York at Fredonia for his undergraduate studies. He received a Bachelor of Arts in Applied Voice and a minor in Psychology in May 2009 and began his music therapy internship at Bethany Lutheran Village in Dayton, OH in August 2009. Upon completion of the internship, he became a board-certified music therapist and received his Bachelor of Science in Music Therapy in May 2010. He worked with older adults in the Buffalo, NY and San Francisco, CA areas until August 2012 when he began pursuing the Master of Music Therapy degree at Appalachian State University in Boone, NC

After graduating from ASU, Stephen plans to continue working with older adults and would like to start a music therapy internship program. He also plans to continue his training in the Bonny Method of Guided Imagery and Music.