Feasibility of Conducting a Music Therapy Study With Hospice Patients with Dementia & Agitation

By Barbara Reuer, Julie Guy, Ann Sturley, Matt Soskins, Charles R. Lewis

Abstract

This study's purpose was to explore non-pharmacological means for decreasing agitation in hospice patients with late stage dementia administered by caregivers. Subjects in the study were patients on service with San Diego Hospice and the Institute for Palliative Medicine, diagnosed with late stage dementia, as determined by a FAST (Functional Assessment Staging) score of 7, and who were known to become agitated while performing certain tasks (e.g., bathing or eating). A music therapist assessed the subjects using an adaptation of the Music Therapy Assessment (Krout, 2000). The Short Portable Mental Status Questionnaire (SPMSQ) and Blessed Dementia Scale were administered pre- and post-intervention to assess cognitive functioning severity of dementia, respectively. Caregivers were trained to administer the Agitated Behavior Scale (ABS) after performing the stressful task without music (baseline). The music therapist created a CD for each subject based on the following: a) music background/preferences of subject (preferred styles of music, favorite selections or artists), obtained from family/caregiver, and b) subject responses observed during the assessment. Caregivers were instructed to complete the agitated task during the music intervention and immediately following the task completed an ABS evaluation. Out of the 51 patients referred for the study, 11 met inclusion criteria and were consented. Eight subjects completed the study. According to demographic information the majority of subjects were female, had previous music experience, and lived in a skilled nursing facility. The most frequent agitated task was bathing, which caused agitation in 75% of subjects. SPMSQ results indicated all patients had severe cognitive impairment and pre-/post-scores were the same. Pre-music intervention ABS scores were a mean of 23.46 (SD = 5.8), and a mean of 20.69 (SD = 7.1) for post-music intervention. This indicated that subjects became slightly less agitated overall though the effects were not
statistically significant ($t(7) = 1.41, p = 0.2$). Further analysis was unwarranted due to the lack of statistical significance and the small sample size. Two subjects demonstrated decreased agitation levels. Study limitations, implications for further research, and feasibility of research with late stage dementia patients receiving hospice care are discussed by the researchers.

**Introduction**

Caring for patients with dementia who exhibit agitated and aggressive behaviors (e.g., yelling, abusive language, irritability, hitting and/or verbal/physical resistance) is a challenge for doctors, family, staff, and caregivers. These behaviors can be difficult for staff members to manage and can lead to compassion fatigue, burnout, and staff attrition. Agitated behaviors can also indicate a poorer quality of life for patients due to anxiety, distress, and decreased opportunities for quality interactions with others. Grunier, Lapane, Miller, and Mor (2007) estimate that 40% of patients with dementia in nursing homes and special care units in the United States have severe cognitive impairment. Estimates of the prevalence of agitation among patients with dementia in nursing homes vary greatly from as low as 8% to as high as 91% (Lou, 2001; Goddaer & Abraham, 1994). As discussed in Hanser, Butterfield-Whitcomb, Kawata, & Collins (2011) costs of long-term care, the increasing older adult population, and implications for delaying nursing care demonstrate the need for a cost-effective and accessible strategy that can be implemented by caregivers to help manage symptoms of dementia.

Currently there is a paucity of literature regarding use of individualized music intervention for patients with dementia, and only three research studies (Casby & Holm, 1994; Gerdner, 2000; Ragneskog, Asplund, Kihlgren, & Norberg, 2001) have tested the effects of music interventions during peak agitation levels for each individual. Further, each had a small sample size of $N = 3$ (Casby & Holm, 1994), $N = 39$ (Gerdner, 2000) and $N = 4$ (Ragneskog, et al, 2001), limiting generalizability. These studies evaluated the effects of patient-preferred or "individualized" music compared to classical music. Results of all three studies listed above suggested that individualized music helped to decrease agitation and disruptive vocalizations.

There is also a lack of extant research on non-pharmacological interventions (music therapy, aromatherapy, etc.) specifically for individuals with dementia receiving hospice care. A literature review of studies (Kverno, Black, Nolan, & Rabins, 2009) between 1998-2008 found that only 21 (9.8%) of 215 reviewed studies treated neuropsychiatric symptoms of advanced dementia with non-pharmacological strategies. One study (Svansdottir & Snaedal, 2006) showed significantly decreased agitation with live music therapy intervention. Another study (Garland, Beer, Eppingstall, & O'Connor, 2007) also resulted in decreased agitation when preferred pre-recorded music was utilized. Both of these studies showed that patients with advanced dementia did not benefit as much as individuals with mild-to-moderate dementia. Several other studies were shown to successfully decrease agitated behaviors in subjects with dementia. These include a sensory stimulation technique called "Snoezelen" (Baillon et al., 2004), modification of the patient's bathing techniques (Cohen-Mansfield & Parpura-Gill,
2006; Sloane & Hoeffer, 2004), playing tapes of family members' voices (Garland, Beer, Eppingstall, & O'Connor, 2007), and behavioral therapy (DeYoung, Just, & Harrison, 2002).

Group music interventions, such as lunchtime music in a resident dining hall, were shown to decrease agitation in patients with dementia, with an additional benefit of increasing food intake (Ragneskog et al., 2001; Ragneskog, Kihlgren, Karsson, & Norberg, 1996). A case-control study of a group music intervention was shown to significantly decrease agitation ($p < .05$) in patients with dementia when compared to a usual-care group with no music. The music intervention included singing, analysis of song lyrics, playing and making musical instruments (Choi, Lee, Cheong, & Lee, 2009).

Individualized music recordings, or compilations of patient-preferred music, are chosen by trained music therapists over general "calming" or period recordings because they suit the patients' preferences and are potentially more effective. Music preference is shown to be a key element in ensuring the success of music interventions for managing problem behaviors in people with dementia (Sung & Chang, 2005). Individualized music therapy has been shown to decrease interference with certain tasks such as feeding (Gerder, 2000) and bathing (Clark, Lipe & Bilbrey, 1998; Thomas, Heitman, & Alexander, 1997), and to decrease certain behaviors such as repeated vocalizations (Casby & Holm, 1994). In one small study ($N = 4$), only those with less advanced dementia ($n = 2$) had decreased agitation when individualized music was played as compared to a non-music control and a classical music period (Ragneskog, et al., 2001). Individual sessions of music attention reduced wandering behavior in a study by Groene (1993). Listening to 30 minutes of preferred music, chosen by patients' family, significantly reduced symptoms of agitation in five dementia patients during individualized sessions (Gerder & Swanson, 1993). Three reviews of the published studies of individualized music interventions or music therapy conclude that there is evidence supporting its effectiveness, yet they caution that more rigorous studies with larger sample sizes are needed (Lou, 2001; Sung & Chang, 2005; Vink, Birks, Bruinsma & Scholten, 2007).

In a study of 24 patients with late-stage dementia who exhibited agitated behaviors, three different music therapy interventions were researched. Length of participation was compared to singing, movement and drumming tasks. Patients participated longer in drumming and movement than singing. Results suggest that agitated adults with late-stage dementia can respond positively to these structured music interventions (Ebberts, 1994). Another study found that an intergenerational program incorporating music activities with children and adults with dementia decreased levels of agitation in the residents with dementia (Ward, Los Kamp, & Newman, 1996).

The effects of background music on agitated behavior in individuals with dementia have been investigated in several studies. Clair and Bernstein (1994) studied the effects of no music, randomized simulative and sedative background music on agitation behaviors in 28 individuals with severe dementia. Their findings showed no significant decrease in agitated behavior during the three conditions. The researchers suggested that future studies examine individual responses with consistently presented (familiar) music experiences over time utilizing preferred music selections. Ziv, Granot, Hai, Dassa, and Haimov (2007) found that familiar, stimulative background music significantly reduced negative behaviors related to agitation in participants with medium-advanced stage of dementia.
This review of related literature indicated that no studies were present that researched the effects of music interventions on decreasing agitation in late stage dementia patients receiving hospice care. Extant research supports using an individualized subject protocol for treatment based on preferred music; however only a small number of research studies in this have been conducted by a board-certified music therapist and all utilized a small group of subjects (Gibbons, 1977; Hanser, et al., 2011). Relevant literature indicated that there is a need for establishing cost-effective non-pharmacological procedures that can be easily implemented by caregivers. The purpose of the present study was to examine the effect of music intervention (a personalized CD created by a music therapist) on agitation when performing a stressful task in eight late stage dementia patients, receiving hospice services, administered by caregivers.

Methodology

Research Design

This study, approved by San Diego Hospice and the Institute for Palliative Medicine's (SDHIPM) Institutional Review Board, measured agitation levels recorded during each patient's individually identified stressful task at baseline without music, and later, while using the recorded music intervention. This study utilized an AB design (where A=baseline without music, B=experimental condition with music intervention). For a detailed outline of the study refer to Appendix A. Subjects were screened before entering the study to ensure all inclusion criteria (Table 1) were met, and to obtain informed consent from the caregiver. Each patient participated for approximately four weeks. The process included the initial assessment, and two 45-minute family/caregiver trainings on agitation assessment and the music intervention. The family/caregiver then completed three agitation evaluations without the music, and then another three evaluations with the music intervention, all during the performance of the stressful task. The research assistant (board certified music therapist) followed up with family and/or staff caregiver by phone 21-30 days from study completion.
Table 1: Patient Inclusion and Exclusion Criteria

<table>
<thead>
<tr>
<th>Inclusion Criteria</th>
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<tr>
<td>• Patient and caregiver speak English.</td>
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<td>• Patient must have a hospice diagnosis of dementia, with a Functional Assessment</td>
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<td>Staging (FAST) score of at least 7a.</td>
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<td>• Subjects must be 55 years of age or older.</td>
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<td>• Patient must become agitated when performing certain activities of daily living.</td>
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<td>• Legally authorized representative is available to sign consent forms.</td>
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<td>• A family member or other person aware of the patient’s music background and</td>
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<td>other preferences must be available to consult with the music therapist.</td>
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<td>• A caregiver must be willing to participate and carry out the protocol of the</td>
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<td>study.</td>
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<tr>
<th>Exclusion Criteria</th>
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<tbody>
<tr>
<td>• Subjects with an uncorrected hearing impairment are not eligible for this study.</td>
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<tr>
<td>• Subjects cannot be concurrently receiving other complementary therapies from</td>
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<tr>
<td>San Diego Hospice (massage, harp therapy, aromatherapy, etc.) while participating</td>
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<td>in this study.</td>
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Subject Recruitment

Study subjects were SDHIPM patients admitted with a primary diagnosis of dementia. Subjects had a score of 7a-7c on the Functional Assessment Staging (FAST) scale (Reisbert, 1998), indicating late-stage dementia. Stages range from 1, normal adult cognitive ability, to 7, severe dementia. Stage 7 is broken down into six sub-stages (Table 2). The patients’ scores were determined as part of their initial assessment on admission to hospice services. The inclusion criteria are listed above in Table 1.
Table 2: Functional Assessment Staging (FAST)-Stage 7

<table>
<thead>
<tr>
<th>Stage</th>
<th>Characteristics</th>
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<tbody>
<tr>
<td>7a</td>
<td>Speech ability is limited to six words</td>
</tr>
<tr>
<td>7b</td>
<td>Speech ability is limited to one intelligible word per average day</td>
</tr>
<tr>
<td>7c</td>
<td>Ambulatory ability is lost</td>
</tr>
<tr>
<td>7d</td>
<td>Unable to sit up without assists</td>
</tr>
<tr>
<td>7e</td>
<td>Loss of ability to smile</td>
</tr>
<tr>
<td>7f</td>
<td>Loss of ability to hold up head independently</td>
</tr>
</tbody>
</table>

All SDHIM staff members (social workers, doctors, nurses and other members of the interdisciplinary team) were invited to refer potential subjects according to the study's eligibility criteria. The research assistants (board certified music therapists) attended SDHIM interdisciplinary team meetings and distributed flyers to staff mailboxes in order to increase awareness of the study.

Measurements

Four scales of measurement were selected for this study (described below). The Agitated Behavior Scale (ABS) was administered by the caregiver to gauge the patient's degree of agitation while performing the task that most consistently provoked agitation. This was performed before the music condition, to establish a baseline for each subject, and during the music condition. Functional Assessment Stating (FAST) scores were obtained from patient files and hospice staff to determine eligibility for the study. The music therapist scored the patient's level of cognitive functioning with the Blessed Dementia Scale (BDS) and Short Portable Mental Status Questionnaire (SPMSQ) and dementia pre- and post-experiment.

Agitated Behavior Scale (ABS)

The ABS was developed to assess the nature and extent of agitation during the acute phase of recovery from acquired brain injury. Its primary purpose is to allow serial assessment of agitation by treatment professionals who want objective feedback about the course of a patient's agitation. This instrument may be useful with populations other than patients recovering from acquired brain injury (Bogner, 2000). Tabloski, McKinnon-Howe, and Remington (1995) and Corrigan, Bogner, and Tabloski (1996) demonstrated the utility of the ABS for measuring agitation in nursing home residents with progressive dementias, primarily Alzheimer's disease. The ABS has been found to be predictive of change in cognitive status and can differentiate confusion and inattention (Bogner, Corrigan, Bode, & Heinemann, 2000). The ABS consists of 14 items chosen from an original 39-item pool based on inter-rater reliability, ability to differentiate agitation, frequency of occurrence, and retention of factors present in the original item pool.
The ABS is completed following an observation period. The person completing the scale rates whether the behavior described in each of the 14 items was present and if so to what degree: absent (1), slight (2), moderate (3) or severe (4). The total sum of scores is determined where the minimum score is 14 and the maximum score is 56. The higher the score the greater the behavioral problems demonstrated by the patient. The percent of maximal score = (((Total score) − 14) / 42) * 100%.

Functional Assessment Staging (FAST)

Health professionals sometimes discuss dementia in "stages," which refers to how far a person's dementia has progressed. Defining a person's disease stage helps physicians determine the best treatment approach and aids communication between health providers and caregivers. Sometimes the stage is simply referred to as "early dementia", "moderate dementia" or "severe" dementia, but often a more exact stage (1 through 7) is assigned, based on a person's symptoms. Evaluation of changes in functional performance and activities of daily living skills is an essential aspect of the assessment of elderly individuals with chronic illness. Empirical and systematic examination of the functional changes occurring in patients with Alzheimer's dementia (AD) has resulted in the development of an assessment measure termed Functional Assessment Staging (FAST) that allows for the specific evaluation of these changes throughout the entire course of AD. Sclan & Reisberg (1992) examined the FAST in three separate investigations regarding the reliability, validity, and progressive ordinality of FAST. Results indicate that FAST is a reliable and valid assessment technique for evaluating functional deterioration in AD patients throughout the entire course of the illness.

FAST scores are determined from information obtained from a caregiver or other persona knowledgeable of the subject (e.g. nursing home staff). The person completing the scale selects the highest consecutive level of disability. FAST stage 1 is the normal adult with no cognitive decline. FAST stage 2 is the normal older adult with very mild memory loss. In stage 3, early dementia, memory loss becomes apparent to co-workers and family. The patient may not be able to remember names of persons just introduced to them. Persons in stage 4 with mild dementia may have difficulty with finances, counting money, and travel to new locations. Their memory loss increases and knowledge of current and recent events decreases. Moderate dementia, stage 5, while they know who they are and the names of their family and friends, they require more help to survive (e.g. choosing clothing), display increased difficulty with serial subtraction, may not know the date and year or where they live. In stage 6, (moderately severe dementia) the person may begin to forget the names of family members or friends, require more assistance with activities of daily living (bathing, toileting, and eating), and become incontinent. In stage 7 patients have severe dementia characterized by loss of speech and ambulation with progressed loss to the ability to sit up, hold head up or smile. Stages 6 and 7 have sub-stages (a-e and a-f, respectively) to further determine the level of disability (Table 2 lists sub-stages for stage 7).

Blessed Dementia Scale (BDS)

The Blessed Dementia Scale (BDS) is a brief behavioral scale based on the interview of someone who works closely with the patient. Its validity as a screening test was evaluated in 105 demented patients and 123 community residents
The BDS proved to be a sensitive and specific screening test for dementia, especially when items related to personality changes were omitted by constructing a revised BDS (RDS). Both the BDS and the revised BDS (RDS) correlated with the patients' neuropsychological test performance. The BDS also differentiated patients with different degrees of dementia. In the screening of dementia the cut-off point of 4 in the BDS gave a sensitivity of 90% and a specificity of 84%. In the RDS the cut-off point of 1.5 gave a sensitivity of 93% and a specificity of 97%. Behavioral rating scales such as the BDS are valuable in the screening of dementia, especially when combined with cognitive testing. In addition they can be used in the evaluation of the degree of disability and in the planning of social support (Erkinjuntti, Hokkanen, Sulkava, & Palo, 1988).

The BDS takes 15 minutes or less to administer and is a clinical rating scale with 22 items that measure changes in performance of everyday activities (eight items), self-care habits (three items), and changes in personality, interests, and drives (11 items). Ratings are based on information from relatives or friends and concern behavior. The inability to complete the task is scored 1 point and the ability to do the activity is given a 0. Overall scores range from 0 (normal) to 28 (extreme incapacity); a cognitive subscale omits the personality questions (12–22) and has a range from 0 (normal) to 17 (severe dementia).

**Short Portable Mental Status Questionnaire (SPMSQ)**

The SPMSQ is a short, reliable instrument to detect the presence of intellectual impairment and to determine the degree. It is a general mental status questionnaire and has questions that can tend to have an educational, cultural, and age bias. The purpose of the questionnaire is to assess the organic brain deficit in elderly clients. The SPMSQ is a 10-item test, easily administered by any clinician and has been designed, tested, standardized and validated. The standardization and validation procedure included administering the test to 997 elderly persons residing in the community, to 141 elderly persons referred for psychiatric and other health and social problems to a multipurpose clinic, and to 102 elderly persons living in institutions such as nursing homes, homes for the aged, or state mental hospitals (Pfeiffer, 1975). It was found that educational level and race had to be taken into account in scoring individual performance. On the basis of the large community population, standards of performance were established for: 1) intact mental functioning, 2) borderline or mild organic impairment, 3) definite but moderate organic impairment, and 4) severe organic impairment. In the 141 clinic patients, the SPMSQ scores were correlated with the clinical diagnoses. There was a high level of agreement between the clinical diagnosis of organic brain syndrome and the SPMSQ scores that indicated moderate or severe organic impairment (Pfeiffer 1975).

The SPMSQ is quick to administer and score. The patient is asked 10 questions and the number of incorrect responses is totaled. A total of 0-2 errors indicate normal mental functioning, 3-4 errors show mild cognitive impairment, 5-7 errors is moderate cognitive impairment and a total of 8 or more errors indicates severe cognitive impairment. One additional error is allowed in the scoring if a patient has had less than a grade school education. One less error is allowed if the patient has had an education level beyond high school.
Study Procedures

Informed Consent

After the initial screening, 11 qualified subjects, and their responsible parties, met with the investigating team (music therapist and music therapist research assistant) at the subject's home or facility to learn about the study, and sign informed consent. In some cases where the responsible party did not live in the area, consent forms were mailed.

Initial Assessment

On the second visit to each patient's residence (home or facility), a board certified music therapist completed an assessment to score the patient's level of cognitive functioning with the Short Portable Mental Status Questionnaire (SPMSQ) and severity of dementia on the Blessed Dementia Scale (BDS). The initial music therapy assessment was conducted using an adaptation of the *Music Therapy Assessment* (Krout, 2000). The therapist obtained information about the subject from the family or caregiver. This included the subject's physical limitations, communicative responses, physical limitations, stressors, previous music experience and favorite music (see Appendix B). The family members and staff assisted in determining the subject's music background and music preference. The music therapist also assisted in selection of music based on preferred styles, favorite selections and artists. The music therapist then played music CDs (from the subject's personal music collection or as selected by the music therapist's personal collection) and noted the subject's response to various genres, eras, and musical instruments. Noted responses (see Appendix B) included change in the patients' affect (facial expressions), eye contact, verbal and/or nonverbal expression, and participation (active vs. passive).

Material Preparation

Following the music therapy assessment session, the music therapist created a recording of the subjects' preferred music selections for the following session. Preferred music (as was discussed in previous paragraph) was put on a CD to be played for the duration of the agreed-upon task, 10-20 minutes. Specially designed instructional handouts accompanied the recording. See directions included in the handout listed below in the next section.

Protocol Training Session

Within ten days after the baseline music therapy assessment, the music therapist created and gave the CD with instructional handouts to the family or staff. The music therapist explained the procedure with simple directions (listed below) and answered any questions from the caregiver.

Directions:

1. Five to ten minutes prior to the patient's agitated task, turn on the CD.
2. Adjust the volume to a moderate level, loud enough for the patient to hear.
3. Implement your typical routine.
4. Immediately following the patient’s task, turn off the CD player and completed the Agitated Behavior Scale forms as directed during your training.
5. This should be completed three times before the music therapy team returns to collect forms, comments and materials in approximately one week.

The caregiver was also given the following information:

- You and the patient are encouraged to sing along with the music.
- If the music on the CD ends before the task has completed, repeat the CD, stopping the music when the task has ended.
- Please do not listen to the CD at any other times while the study is underway (the CD will remain with the patient following the study and can be used anytime after the study has been completed).
- If the patient becomes agitated while using the CD, follow these steps:
  1. Turn the volume down (if no difference proceed to next step).
  2. Change the song (if no difference go to next step).
  3. Call your music therapy team representative.

**Intervention**

Following the protocol, the CD was played during the previously agreed-upon task. The CD was played during the selected task, beginning five to ten minutes prior to starting the task. The caregiver completed the stressful task with the patient while the recorded music was playing, and the patient and caregiver were encouraged to sing along with the recorded music if they were familiar with the songs. Immediately following the completion of the task, the caregiver completed the ABS. The music therapist called to remind the family/patient caregiver to utilize the CD and to complete the study forms. The music therapist stayed in regular contact with the patient's interdisciplinary team to inform them of visits and to obtain current patient information.

**Final Visit**

The music therapist returned to the patient's residence following the experimental phase to collect pre- and post-test data and to retrieve study materials. Additionally, the music therapist answered any follow-up questions from the family, patient, and/or caregivers, and documented their comments about the study. The patient's caregiver was contacted via phone 21-30 days following the final visit to ascertain if the music was still being used, to answer any remaining questions, and to obtain any anecdotes and comments.
Results

Out of 11 subjects who were consented, eight completed the study (one expired and two withdrew). An additional 40 were referred to the study but did not qualify. The majority of subjects were female (63%), 75% lived in a skilled nursing facility (SNF) and ranged in age from 70 to 93 years in age and 63% had previous music experience (see Table 3). Previous music experience was obtained during the interview with family and caregivers during the Music Therapy Assessment (see Appendix B), subject three played the flute in high school; subject five played the trombone and drums in high school; subject six played the organ; subject 10 sang in church choir and shows; and subject 11 wrote show tunes, sang, and played piano. As shown in Table 3, most (75%) patients had two agitated behaviors (subject 6 had only one behavior and subjects 2 and 5 had three behaviors). The most frequent task causing agitation was bathing (75%). Other tasks causing agitation included dressing/changing, transferring/moving, touching, grooming, and care giver leaving. On the SPMSQ all patients had 8 or more errors on both the pre- and post-test indicating severe cognitive impairment. Scores did not change from pre-to post-test.
As subject experiences varied in the number of trials with and without music, scores on the Agitated Behavior Scale (ABS) were averaged within subjects in order to minimize the effects of individual differences. Group data were next calculated to generate descriptive statistics, as well as to compare means. The mean ABS was 23.46 ($SD = 5.8$) for the subjects prior to the music intervention, and 20.69 ($SD = 7.1$) with the music intervention. In other words, they became slightly less agitated overall.

Comparing ABS scores for the same subjects with and without music yielded no statistically significant effects ($t (7) = 1.41$, $p=0.2$). The level of significance was set at 0.1 and because $0.2 > 0.1$, there were not enough results to show statistical significance. Further analysis of the data was considered, including repeated-measures analyses and regression, however
these were determined unwarranted because the lack of statistical significance within the initial t-test and the overall small sample size.

Of the eight who completed the study, two subjects (1 and 9) demonstrated decreased agitation levels following the music condition. The most notable changes in agitation for subject 1 were decreased impulsive and impatient behavior, low tolerance for pain or frustration; pulling at tubes, restraints, etc.; wandering from treatment area; and restlessness, pacing or excessive movement. Subject 9 actually showed slight increases in sudden change of mood and easily initiated or excessive crying and/or laughter. However this subject showed positive changes in attention span and distraction; was more cooperative, less resistant to care, and less demanding; and was not explosive or displayed unpredictable anger.

Discussion

For a patient with dementia to qualify for hospice services, they must be at a FAST stage of 7. This study's results suggest that the FAST score criterion of 7 was too restrictive. Most of the subjects were no longer able to hum, and had a limited ability to respond to music with physical, observable responses. This result is consistent with results found previously (Gerdner, 2000; Ragneskog, et al., 2001; Svansdottir & Snaedal, 2006).

Songs that were learned in childhood (e.g., folk songs, patriotic, children's music) tend to remain in the memory longer than songs learned later in life, although many childhood songs may not be appropriate for adults due to self-esteem issues (Clair & Memmott, 2008). Also, the ability to sing, and thus to more fully participate in the music experience, may be lost at middle or late stage dementia, though each person's degenerative process is unique (Clair & Memmott, 2008; Clair, 1991; Clair & Bernstein, 1990). It takes time to develop an association between specific music and calmness, relaxation and comfort (Clair, 1996), so future studies may wish to facilitate positive music associations prior to pairing with the agitation-producing task, or to record responses over a longer period of time.

See Table 4 for examples of CD track lists for the two subjects who showed decreased levels of agitation. The family/caregivers for Subject 1 reported preference of "soft, pretty music and easy listening" with Andy Williams being a favorite singer. Subject 9 preferred music of Lawrence Welk and show tunes (e.g. Oklahoma) according to family/caregiver. After reviewing all data, because the subject pool was small (N = 8), it is difficult to conclude as to why the music intervention was effective in decreasing agitation for subjects 1 and 9. No significant differences were noted across subjects' music background. However, perhaps variation in the number of patient preferred music styles and artists impacted subjects' responses.
Table 4: Example CD Music Tracks for Subjects 1 and 9

<table>
<thead>
<tr>
<th>Track Number</th>
<th>Subject 1</th>
<th>Subject 9</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td><em>Evergreen</em> (Theme from “A Star is Born”)</td>
<td>Barbara Streisand, <em>Oh What a Beautiful Morning</em></td>
</tr>
<tr>
<td>2</td>
<td><em>What a Wonderful World</em></td>
<td>Louis Armstrong, <em>Oklahoma</em></td>
</tr>
<tr>
<td>3</td>
<td><em>White Christmas</em></td>
<td>Bing Crosby, <em>Amazing Grace</em></td>
</tr>
<tr>
<td>4</td>
<td><em>Always</em></td>
<td>Ella Fitzgerald, <em>On the Street Where You Live</em></td>
</tr>
<tr>
<td>5</td>
<td><em>Fly Me to the Moon</em></td>
<td>Frank Sinatra, <em>I Could Have Danced all Night</em></td>
</tr>
<tr>
<td>6</td>
<td><em>Strangers in the Night</em></td>
<td>Mel Tormé, <em>What a Friend We Have in Jesus</em></td>
</tr>
<tr>
<td>7</td>
<td><em>The Hawaiian Wedding Song</em></td>
<td>Andy Williams, <em>Satin Doll</em></td>
</tr>
<tr>
<td>8</td>
<td><em>Moon River</em></td>
<td>Andy Williams, <em>Come Rain or Come Shine</em></td>
</tr>
<tr>
<td>9</td>
<td><em>Besame Mucho</em></td>
<td>Pérez Prado, <em>“A” Train</em></td>
</tr>
<tr>
<td>10</td>
<td><em>Somewhere My Love (Laura’s Theme)</em></td>
<td>N/A, <em>Andante Sostenuto</em> (Mendelssohn)</td>
</tr>
<tr>
<td>11</td>
<td><em>I’ve Got the World on a String</em></td>
<td>Frank Sinatra</td>
</tr>
<tr>
<td>12</td>
<td><em>Cool Cool of the Evening</em></td>
<td>Frankie Laine</td>
</tr>
<tr>
<td>13</td>
<td><em>Walkin’ My Baby Back Home</em></td>
<td>Nat King Cole</td>
</tr>
<tr>
<td>14</td>
<td><em>Back in the Saddle Again</em></td>
<td>Gene Autry</td>
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</table>

Encouragingly, while the qualitative data in this study were limited, all patient caregivers and family members gave positive feedback during the post-study interview. Positive changes in patient behavior were noted, including becoming more relaxed and cooperative. One caregiver noted that the patient was more alert with the music, and another noted that a patient was less combative.

Caregivers reported that the forms were easy to use and that the requirements of the study did not take too much time. One caregiver noted the effects on her own behavior in that she reported being a "little more calm because I would go with the rhythm of the music." Self-reported caregiver satisfaction from this study is consistent with Hanser et al. (2011) findings. Due to the inherent challenges of researching late-stage dementia in regards to measuring effects on the subject, future studies with this population would benefit by focusing on caregiver outcomes. Designing a cost-effective, in-home protocol for caregivers to help them manage behaviors while managing their own satisfaction is essential (Hanser et al., 2011).
One family member commented:

The therapists were absolutely wonderful. The day they met Mom and played guitar and sang [during the initial assessment], she lit up. You could see the sparkle in her eye and it gave us such joy. Her caregiver was so tickled. The staff at the facility said it was calming for her. Perhaps, because Mom always had beautiful quiet music in the background in her home and did have favorite songs she’d respond to. (She) even remembered some words at the beginning, this worked for her. The therapists came to her when she was still able to communicate and enjoy at times, familiar sounds/tunes. The caregivers at the facility indicated that it did help with agitation.

Study Limitations and Recommendations

Recruitment

- **Limitations**: The research team experienced difficulty communicating information to hospice staff about the study and to recruit patients. This could be due to the music therapists on the research team were in a private practice agency and did not have access to the hospice computer systems and to staff. Having a designated staff person from the organization is essential not only to assist with disseminating information but to also to access patient information.

- **Recommendations**: It would increase efficiency and consistency for the researchers to meet with a team of staff, rather than individuals, at each residential facility. These staff members could assist the researchers and aid with subject recruitment. Flyers or laminated 3x5 inch cards with study criteria could be prepared to encourage staff to refer patients.

Subjects

- **Limitations**: One of the study challenges was that obtaining referrals took longer than anticipated. Additionally, few patients met all of the criteria and several subjects expired before they could participate in the study. Some patients' agitation was treated with medication so successfully that they no longer qualified for inclusion in the study.

- **Recommendations**: Future studies should consider employing multiple sites and agencies to be able to recruit the necessary number of subjects. Future studies would do better to concentrate on those in earlier stages of dementia, likely eliminating those whose hospice diagnosis is dementia, because they may still able to show music preference eliminating some of the "guess work" in determining subject preference. Alzheimer’s support groups, skilled nursing facilities, and physicians' offices may be more appropriate referral sources instead of or in addition to the hospice setting.

Informed Consent (Family & Caregivers)
• **Limitations**: Coordination of times to meet for signing consents and obtaining information was another obstacle. Some consent forms had to be mailed and then returned by the family before the patient began the study. Many forms were returned missing information and some forms had to be re-signed; because of this some patients could not be enrolled in the study.

• **Recommendations**: If an umbrella consent from a hospice would be available for patients, this would eliminate the need for additional study consent. However, if this process is not possible, a more streamlined process of administering the consent needs to be developed.

**Assessment**

• **Limitations**: The researchers' adaptation of the *Music Therapy Assessment* tool (Krout, 2000) was easy to use and appropriate for this study. However, family members did not always know what music the patient preferred when they were young. Therefore, the therapists had to use their expertise and the extant literature to determine appropriate musical selections.

• **Recommendations**: Researchers may want to interview others to help ascertain music preference including activities staff at the facility, where appropriate. Or as discussed previously, concentrate on those in earlier stages of dementia because they may still able to show music preference.

**Material Preparation**

• **Limitations**: With computer programs (such as *iTunes*), creating a CD of recorded music for the study was relatively easy. However, the challenge was finding recorded music of songs/artists that subjects preferred. Most of these subjects responded best to music from their early 20s (from 1925-1940), which at the time was not readily available on *iTunes*. The benefit to purchasing from an online source was that songs could be purchased individually. A much larger budget would have been necessary to purchase entire CDs or to obtain access to a large library of music.

• **Recommendations**: Include budget for purchasing songs and CDs or obtaining access to recordings at local college and university library music departments to keep costs down.

**Protocol Training Session/Patient Caregivers**

• **Limitations**: Due to financial limitations, it was not feasible to hire trained research assistants to record data during the stressful task (e.g. bathing). As subjects were enrolled over the course of two years, each of the caregivers was trained individually, which made it difficult to standardize the training. In some cases the research assistant had to give instructions on the phone because of scheduling challenges. Lack of standardized training and poor communications resulted in inconsistent data and poor reliability.

• **Recommendations**: For future studies we recommend that the research assistants (ideally music therapists) be hired to record all data instead of caregivers.
Intervention

- **Limitations**: This study did not ask caregivers to document the length of time that the recorded CD of music was utilized. Subsequent researchers are encouraged to take this into consideration. Some caregivers commented that it was difficult to use the CD player in the room where the task was being performed, such as a shower.
- **Recommendations**: In future studies, researchers should help caregivers to troubleshoot where the CD player should be set up and other logistics (eg., extension cords or providing a battery operated CD player).

Follow-Up

- **Limitations**: Obtaining the patient's caregiver's comments 21-30 days following the study was challenging. Caregivers tended to forget specific patient responses and were unable to comment. One caregiver had moved away and did not return phone calls.
- **Recommendations**: Future studies should consider only interviewing caregivers immediately following the study to increase chances of obtaining responses and valuable information.

Research Assistant (Board Certified Music Therapist)

- **Limitations**: As the study was extended in order to recruit the required number of subjects, a need to train additional research assistants resulted. In the original design, one to two research assistants were anticipated but by study completion, five were trained. This became problematic in the consistent collection of data and carry-through of procedures from one research assistant to the next.
- **Recommendations**: Establishing a system for inter-rater reliability procedures would be useful for future studies.

Summary

Implications for this study must be made with caution due to the small sample size and its limitations. While there are many challenges inherent in the implementation of a study of hospice patients with late stage dementia (as defined by a FAST score of 7), this pilot study showed that conducting a study in this setting with this population is possible. Replication of this study is recommended with patients with less advanced dementia, multiple recruitment sites, and a larger sample size. Specifically, a study of the correlation between specific FAST scores and the level of response and benefit is needed. For example, at what FAST stage does a person benefit most, and at what stage do they no longer demonstrate observable benefits from this type of intervention? The comments of nursing home staff, hospice workers, and families during and immediately after music interventions could provide for a rich qualitative study. Another area for further research is the effect of live (with a music therapist) versus recorded music on specific "sundowner" behaviors. Additionally, comparing responses between subjects who were previously musicians, those who were avid music listeners, and those who rarely listened to music is a needed area of research. Further research focused on creating a simple and cost-effective protocol for caregivers to implement with their patient or loved one is essential as seen by trends in the older adult population.
References


Ebberts, A.G. (1994). *A comparison of the effects of movement with music, singing, and drumming on duration of engagement in care home residents who have late stage dementia*. Unpublished manuscript, University of Kansas, Lawrence.


