The Effect of Music Therapy on End-of-Life Patients' Quality of Life, Emotional State, and Family Satisfaction as Measured by Self-Report

Judy T. Nguyen
THE FLORIDA STATE UNIVERSITY
SCHOOL OF MUSIC

THE EFFECT OF MUSIC THERAPY ON END-OF-LIFE PATIENTS’ QUALITY OF LIFE, EMOTIONAL STATE, AND FAMILY SATISFACTION AS MEASURED BY SELF-REPORT

By

JUDY T. NGUYEN

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The members of the committee approve the thesis of Judy T. Nguyen defended on

Jayne M. Standley
Professor Directing Thesis

Clifford K. Madsen
Committee Member

Dianne G. Gregory
Committee Member

The Office of Graduate Studies has verified and approved the above mentioned
committee members.
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ABSTRACT

The purpose of this study was to examine the quality of life, anxiety level, and the family satisfaction of patients’ during their end of life experience within a medical setting. Any patient admitted to Tallahassee Memorial HealthCare that met the criteria of End of Life intervention, as determined by the medical personnel, was considered as a potential subject. The End of Life celebration included any or all of the activities listed: a “song” written about the patient and family, live music as a sing along, patient preferred music to reminisce, and counseling to bring closure for the patient and family. The experimental and control groups were randomly assigned. The experimental group (N=10), received two sessions of music therapy. The first music therapy session was, used to gather family and patient information and also included, singing patient preferred music, seeking information about patient’s favorite song and preference, and assessing patient and family levels of coping. The second music therapy session for the experimental group was the end of life celebration that ended with patient and family providing self-report data on the Visual Analog Scale (VAS) (see Appendix B), Hospice Quality of Life Index (see Appendix D) questionnaire, and the Family Satisfaction Survey (see Appendix C). The control group (N=10), agreed to participate in the study but received no music therapy services. However, each control subject completed the Hospice Quality of Life Index- Revised (see Appendix D) questionnaire and a self-report using a Visual Analog Scale (VAS) (see Appendix B) that measured anxiety levels. There was no change in the usual procedure of hospital care for those subjects. The self-report questionnaire from the Visual Analog Scale, (VAS) showed significantly lower anxiety scores for the experimental subjects then for the control subjects. The Family Satisfaction Survey filled out only by the experimental subjects, also showed a 97% satisfaction of music therapy and its uses in the medical setting. There were no significant differences between groups for quality of life measure.
CHAPTER 1

INTRODUCTION AND LITERATURE REVIEW

Medicine and Music

Introduction

During the years of 1809 and 1899 the medical music therapy articles appeared mostly in medical journals, accessible to physicians and other medical staff. The use of music within these articles advocated music therapy treatment as part of a holistic or an alternative approach to healing. Through Davis’ (1987) compilation of music therapy research throughout the 19th century the music therapy community and others have been able to use this information as a model for future research or a springboard to launch new ideas for the medical community.

Review of Literature

The documentations of Khan (1983) show the ancient cultural pairing of music and medicine to protect against diseases and illness. Songs and chants along with whistles, drums, rattles, gongs, and flutes were used to increase vitality in patients. The ancient Greeks believed music to be the language of the gods, given to humans so they could access the mystical realms and retrieve the vital knowledge of health and healing.
They honored Apollo as the god of music and medicine, recognizing the important connection between these two areas of life (Tame, 1984).

Through the development of man and his culture, innovative methods of healing appeared conducive to the time period of technology and knowledge. The contemporary western and eastern traditions engaged in scientific documentation and research to investigate changes and processes (Winn & Walker, 1996).

In 1978 Munro and Mount observed that music therapy could be an important tool for “improving the quality of life” of hospice patients. They reported success in using singing sessions, a variety of instruments, and stereo recordings to help reduce stress and withdrawal and assist in the relief of intractable pain.

In 1985 Locsin studied the effects of music on postoperative pain of gynecologic and obstetric patients to determine the effect on pain and anxiety. In another study music and relaxation techniques during gynecological procedures, cryosurgery, colposcopy, and punch biopsy of the cervix, were compared to the same medical procedures without music (Davis, 1992). Subjects not receiving the music intervention exhibited higher pulse rates, respiratory rates, behavioral observations of overt pain, and self-reports of pain and anxiety overall throughout the procedures, although differences were not significant. During the punch biopsy procedure only, subjects receiving music intervention had significantly lower respiratory rates and overt pain scores.

The accounts of research in medical music therapy are growing. In Standley’s (1986) meta-analysis of medical/dental procedures using music, data demonstrated that patients’ benefits were highly positive. Therefore, a conclusion could be made that use of music is an effective asset to a medical procedure.

In Maranto’s (1996) research in music and medicine, she reported multiple uses of music within a medical setting. The article pinpoints specific procedures and techniques using music to decrease some of the problematic issues for the patient. For example, a cardiac catheterization for children used: songwriting, singing, tapes of own music, activities, and tapes of familiar activities. All of these were shown to decrease behavioral measurements of anxiety and need for sedation. Robb, Nichols, Rutan, Bishop, & Parker (1995), were able to implement the use of music in a preoperative medical setting to reduce anxiety. There results show that those receiving Music Assisted
Relaxation (MAR), experienced a significant decrease in anxiety. Music paired with deep diaphragmatic breathing, showed a decrease of the experimental group’s heart rate, though no significant difference was shown.

Bailey in 1983 found that cancer patients who listen to live performances of songs were less tense and anxious and experienced a more positive mood and more vigor than patients who listened to recordings of the same songs. She argued that the human voice, human body, and guitar music could diminish the patients’ feelings of isolation and, a consequence the music is able to provide beneficial changes in their mood. This study was a review of 465 cancer patients who received music therapy.

The research of Clark, McCorkle & Williams (1981), was loosely based upon the French obstetrician Lamaze, whose childbirth technique is well-known. The functions of music therapy during this childbirth procedure included: attention focusing, distraction, music conditioned for relaxation stimulus, and music as a structured breathing aid. With each contraction late in labor that the patient endured, the tempo, intensity, and energy of the music was increased. The music also acted as a tool for the mothers to synchronize their breathing.

Thompson, Arnold, and Murray (1990), discuss the use of music therapists in a medical setting. Within this setting music therapy is included in physical rehabilitation and is proving valid as a successful treatment approach. This particular article addresses the need for an assessment tool for the Cerebrovascular Accident Patient, (CVA). Cognition is one of the first priorities in the initial states of assessment and is a vital part of the completion of a stroke rehabilitation program. The use of Rhythmic Auditory Stimulation (RAS) to increase gait independence was demonstrated by Hurt, Rice, McIntosh, & Thaut, 1998). The music functioned as a cue to assist those suffering Traumatic Brain Injury. Faster step rate, stride length and timing of gait movement resulted.

The use of music and Alzheimer’s patients was examined to aid in the memory in 1991 by Prickett and Moore. The researchers found that patients were able to recall the words to songs better than spoken words. They also discovered that these patients were more capable of learning a new song than they were capable of recalling new spoken material. Those who endure pain have major negative effects on their daily living.
Those music therapists working in medical settings that encounter patients with pain must have techniques to decrease or manage pain. Colwell’s (1997) study used music as a cue for relaxation to reduce anxiety and therefore decrease severity of pain and as a distracter to redirect focus of attention. Her data showed that ratings of pain perception decreased 47 to 38.

Wolfe (1978) demonstrated that music therapy (music paired with exercises) was also effective in decreasing chronic pain of pain clinic patients as measured by their verbal complaints. To promote relaxation, progressive muscle relaxation involves contracting and relaxing muscle groups in a sequential order to release tension. Stress and anxiety can contribute to physical and psychological problems; thus, can have an adverse effect on pain management.

From the research of (Bunt & Marston-Wyld, 1995) there is evidence that music therapy and counseling have similarities. Based on the results of a short evaluative study at an internationally known center far cancer care, music therapy appeared to share some common qualities with counseling. Used together the unique strengths, similarities and differences of both disciplines could be harnessed and integrated in complementary therapeutic strategies. When used in the context of a medical setting in a cancer unit, the counselor was able to see the same qualities in client-centered therapy as in music therapy. The music therapist was able to participate in active listening, focusing, challenging and keeping boundaries. The study also documented the use of simultaneous music therapy and counseling with those who have difficulty in verbal expression.

The effectiveness and the use of music therapy with premature infants resulted in many studies. Cassidy and Standley’s (1995), results show that music is not contraindicated in the first week of life for babies with low birth weight. In fact the music had noticeable effect on oxygen saturation levels, heart rate, and respiratory rate. Standley (1998) was able to confirm the benefits of lullaby singing and multimodal stimulation on premature infants in neonatal intensive care. With the use of music and multimodal stimulation, both female and male infants significantly benefited with increased weight and fewer days to discharge. Both female and male infants were able to tolerance stimulation and showed marked and steady increase across stimulation intervals, with females’ tolerance increasing more rapidly then males.
PALLIATIVE CARE

The word “palliative” comes from the Middle English and Late Latin word “palliate” which means to reduce the violence or disease and to moderate the intensity of death (Morehead, 1995). This 15th century word reflects the type of care that requires the modern equivalent of “comfort care” methods. The aims for palliative care are to attain the best possible quality of life for the patients and their families, to facilitate adjustment to the many losses they will face, and to achieve a dignified death with minimal distress in the patient’s place of choice.

The foundation of quality end-of-life care is effective communication. This emphasis does not diminish the importance of medical care such as adequate pain control or treatment of symptoms at the end of life. Rather, good communication skills are important because they will facilitate and improve all other aspects of care (Glaser, 2000). Palliative care emphasizes the use of aggressive care that focuses on comfort, dignity, and quality of life, life closure, and patient/family choice. As a patient advocate, the interdisciplinary team works together to prevent and anticipate the negative effects of physical symptoms, to decrease suffering, and to help patients and families develop coping skills (Egan and Labyak, 2001).

The palliative care movement is a fast growing specialty for doctors and nurses. The hospice movement has paved the way for the adaptation of palliative care methods within the healthcare realm. This method of care is seen as an effective and central routine in the hospital and the community (Faull & Woof, 2002).

Dr. Kubler-Ross (1969), an innovative psychiatrist has led us to understanding the concerns of patients experiencing the imminent reality of death. In the dying process the need for the treatment of symptoms while providing comfort is an important factor. End-of-Life does not simply mean old age or the end of a normal cycle of life, but it also implies the approach of death. Field and Cassel (1997) agree that the focus on the
amount of days or weeks of imminent death is not as true to the meaning of end-of-life as the quality of care the dying person is able to receive during that time.

Caring for the dying during the phase of their end-of-life falls into two realms: the spiritual and practical. For some, the occurrence of death can bring about exploration for the meaning of life, peace, and the increase of hopefulness and security. The search for meaning or spiritual comfort in the face of death is often guided by religious and philosophical beliefs. The role of spiritual care is the principle task for religious advisors or hospital chaplains (Speck, 1993). However, the staff members: doctors, nurses, therapists, and volunteers interact daily to create a comforting environment in all possible ways.

The practical service of the palliative care teams meet the needs of the patient that do not directly deal with the emotional, spiritual, or psychosocial treatment of the patient. The healthcare team deals with the arrangement of home health care services, routine errands, coping with visitors and family, juggling work schedules, personal care issues, and physical accessibility inside and outside of the home. The “family” including close friends, neighbors and community friends, assists with meals, transportation, home repairs, shopping, and cleaning (Field and Cassel, 1997).

In Bauby’s memoirs, The Diving Bell and the Butterfly, the accounts of his dying days are scripted out sometimes as fantasies and other times like the mundane reflection of his everyday life filled with decreasing pleasure day by day. From “Bathtime”, an excerpt (1997):

Rarely do I feel my condition so cruelly as when I am recalling such pleasures. Luckily I have no time for gloomy thoughts. Already they are wheeling me back, to my room, on a gurney as comfortable as a bed of nails. Like the bath, my old clothes could easily bring back poignant, painful memories. But I see in the clothing a symbol of continuing life. A proof that I still want to be myself. If I must drool, I may as well drool on cashmere. p.15-17

As a clinician, one must always remember the importance of the patient’s quality of life and the implications of a decreased quality of life. Palliative care pursues the quality of life issue in patients who face terminal conditions. This type of treatment focuses on the relief of symptoms (Frager, 1996). In addition to alleviating pain and other physical symptoms, physicians provide access to therapies that are likely to
improve the person’s quality of life. Such therapies include: education, grief and family counseling, peer support, music therapy, or spiritual support (Fagen, 1982).

Hospice is a program of care provided across a variety of settings, based in the assumption that dying is the end of the normal life cycle. As those who are dying enter into the final stages of life, hospice is able to provide palliative medical and supportive services, compassion, and care with the goals of comfort and quality of life (Egan and Labyak, 2001). It is important that staff understand that this part of life may be improved by adhering to patients wants and wishes to increase quality of life and enhance their dignity and integrity.

Osterlund, & Beirne, P, (2001) discuss the many different complementary or alternative medicine service, which can be provided, including: guided imagery, reflexology, acupuncture, massage, music therapy, art therapy, aromatherapy, biofeedback, and meditation. Through the exploration of counseling and music therapy, specific outcomes can provide enhancement of the patient’s quality of life with the complementary use of counseling and music therapy. There has been confirmation, through documentation, that the capacity of music therapy and the ability that the music has to access and express emotions is very direct and occurs in an immediate way (Bunt & Marston-Wyld, 1995).

Bright (2002) discusses personal reflection as a music therapist working within grief and loss. With the dying process, there are many situations of change that the dying person is living through, as is the music therapist working closely with the patient. The work requires a broad basis of understanding provide appropriate help for patients as they cope with their sadness, fear, anger, and pain. A music therapy professional is able to provide many musical provisions for the dying patient and their family. The use of live relaxation music by the bedside is a possibility. A music therapist also gives consultation for music selection for the patient’s funeral; live music to distract from pain and anxiety; reminiscing, songwriting, music listening activities and/or guided imagery and relaxation techniques paired with music.

O’Callaghan (1996) addresses the use of palliative care and music therapy, stating that it may offer a “safe” environment that provides opportunities for people to connect with and express their feelings at their own chosen pace. It cultivates supportive
interactions between the patients and their loved ones and enables patients to maintain some degree of physical well-being. Music as a stimulus for life-review and reminiscence is suggested to assist in memory improvement and a means for patients to recognize meaning within their life experiences. Music therapy also offers increased opportunities to communicate with brain impaired palliative care patients. Music therapists use a wide variety of techniques in their endeavors to enhance the quality of life of the palliative care patients and to ease the suffering of their loved ones.

Whittall (1989) indicates that music therapy may promote relaxation and pain relief in palliative care patients. A graphical analysis of 17 patients’ perceived pain relief, physical comfort, relaxation, and contentment scores, after listening to recorded music, pointed to the effectiveness of music. Curtis (1986) similarly found a decrease in heart and respiration rates among eight palliative care patients receiving music therapy interventions including guided imagery, deep breathing, and progressive relaxation exercises. The study also demonstrated that music therapy reduced these patients’ levels of anxiety.

Wylie & Blom (1986) explain the uses music, relaxation process, guided imagery, and patient responses to imagery used with hospice patients. Two hospice patients were subjects in individual case studies. A variety of music was used with each subject; both preferred selections and unfamiliar music. Music and guided imagery were used to help facilitate pain control, and help patients reminisce about their lives. This procedure also provided each with opportunities to control some aspect of their life, to be creative, and to temporarily feel safe and secure. Music therapy with these techniques was shown to increase the quality of life for patients.

Vanderark, Newman & Bell (1983), examined the effects of a music participation program on selected concerns and attitudes of 20 elderly residents of a nursing home. They were compared to 23 residents of another nursing home who received no music program. This study was designed to determine the effect of a music participation program on the self-concept, life satisfaction, quality of life, self-concept in music, and attitudes toward music of elderly residents. Satisfaction, music attitude, and music self-concept were found to be significantly improved after participation in musical activities.
The experimenters suggested that these positive affects of music participation may benefit end of life patient’s quality of life and life satisfaction.

West (1994) suggests a variety of music therapy techniques and methods that may be useful for music therapy interventions for the dying patient. The therapist should select interventions with which he or she has skill and confidence and which are appropriate for the issues or tasks facing the patient. Possible techniques include: song selection by the patient or family, song writing, recorded music selection, and listening, either in session or independently, relaxation with music or nature sounds, music and imagery for relaxation or pain management, instrumental music playing or improvisation with patient (as able) or family, live instrumental music for active or passive listening, music with other creative arts media such as art or writing, music background selection for video or audio taped message from the dying to loved ones, music planning for patient’s funeral or memorial service and/or the use of guided imagery.

In Krout’s (2000) research about the applications of music therapy within the realm of hospice work, he described 23 experimental studies. His work in palliative care relates to pain, anxiety, and the needs of patients who are hospitalized with cancer. From Krout’s eighty-eight case studies, a variety of patient goals were addressed: expression of feelings (n=72), relaxation (n=58), anxiety reduction (n=46), pain management (n=36), insight (n=35), and communication (n=27). The most frequently reported music therapy techniques included: music listening (n=42), improvisation (n=26), singing (n=26), songwriting (n=26), music playing (n=21), and song choice (n=19).

From Hilliard’s (2003) research focusing of a patient’s quality of life with the use of music therapy, he found that the results of his research support the use of music therapy in a hospice and palliative care model. For the experimental subjects in the music therapy group, quality of life scores after the initial music therapy session were significantly higher then those who received only routine hospice services. Those results not only scored higher after the initial music therapy session, but increased further following the second music therapy session. The results of the experimental group who received music were recorded as being higher then the control group throughout the experiment. These data demonstrate the use of music therapy’s importance in creating and increasing the quality of life initially and increase quality of life even more over time.
SONGWRITING IN MUSIC THERAPY

The use of songwriting is a creative way to accomplish goals within a music therapy session. The artistic use of melodies and inventive lyrics create an outlet to express emotions. The innovative applications of songwriting can occur in many populations including: psychiatric, educational, and medical. Songwriting can also be used as an assessment tool within all of these populations. With changes in method and therapeutic focus, songwriting can also be beneficial for populations with reading and written language difficulties, including bilingual or academically disadvantaged students, the learning disabled, and the hearing impaired (Gfeller, 1987).

Schmidt (1983) discusses the use of songwriting tools from a highly structured style to a less structured style of songwriting. Various levels of structure should be provided for group members depending upon their expressive skills, level of music sophistication, and emotional content of their subject matter. This research advocates the use of songwriting as a creative act that has many healing qualities. Through the act of writing songs, clients participate in the actual creation of their own music, thus becoming involved in a musical act in a very intimate way.

Songwriting in Psychiatric Music Therapy

The act of songwriting is a very popular musical activity with the adolescent psychiatric inpatient. The use of inherent symbolism in songs, their lyrics, and their musical elements can provide the adolescent with a medium for self-expression. Winnicott (1971) has been able to assist the adolescent in coping with anxiety and
working through important personal issues. Songs can make powerful statements that neither words nor music, alone, can.

Ficken (1976) used the technique of “successive approximation” to encourage lyric writing. Patients in this study who seemed threatened by songwriting activities were asked to substitute their original lyrics for pre-existing song lyrics. Their exploration of individual and group feelings through songwriting activities was found to facilitate group cohesiveness. Ficken (1976) suggests the use of songwriting within psychiatric settings is a common occurrence where the array of songs that are available do not relay the patient’s current emotional expressions. The therapeutic technique of songwriting remedies this problem. Songwriting techniques used in music therapy are used as a tool to assist emotional expression and social interaction. Ficken also suggests that songwriting may aid interaction and emotional expression, and encourage socially acceptable behavior in the group process. Combining these ideals from Yalom (1995) within a therapeutic structure that is safe and non-judgmental, music therapy sessions can include the use of songwriting to aid the development of group cohesiveness and willingness to share common problems (Plach, 1980).

Cordobes (1997) and Apprey and Apprey (1975) suggest that symptoms of depression can be addressed through group music therapy with the use of songwriting as a way to facilitate recovery of repressed material. They also suggest that songwriting will be more effective as therapy if done in a group where discussion of different aspects of the lyrics and choices of musical settings can be encouraged. In one study, Clendenon-Wallen (1991) used songwriting as a tool to help improve self-esteem. She designed songwriting activities to increase appropriate expression of anger; to explore personal boundaries, trust, and sexuality; and to develop problem-solving skills. As 11 survivors of sexual abuse, these participants gained musical and compositional skills, they were able to express themselves more fully, and they discovered their creativity, thus improving their self-esteem.

Songwriting has also been used as an assessment tool. Goldstein (1990) developed a songwriting assessment to determine hopelessness in psychiatric inpatients. These fill-in-the-blank verses were adapted from the 20 “true/false” questions of the Beck Hopelessness Scale and revised into 10 test-song verses. This study suggested that such a
songwriting assessment format could aid in choosing clinical interventions, measuring patient progress and attitudes toward the future, as well as gauging client change over time.

**Songwriting in Non-Psychiatric Populations**

While Ortman (1984) recommends songwriting for a non-psychiatric population, the physically disabled, she advocates this technique for psychosocial objectives, specifically self-expression and developing self-mastery. Within a group setting, the experience of writing a song can aid in developing relationships to peers, addressing current relevant issues and symptoms faced by the patient, and expressing emotions and levels of hopelessness (Edgerton, 1990; Ficken 1976; Goldstein, 1990). In addition, studies demonstrate that motivated patients show better adherence to medical regimens (Chesney & Folkman, 1994).

Edgerton (1990) described a technique consisting of analyzing the lyrics and music from existing songs, finding a new theme, writing new lyrics and composing new music with adolescents who are emotionally disturbed. Another method used with young adults having substance abuse problems consisted of writing completely new words to existing songs or partially changing the lyrics according to the fill-in-the-blank procedure (Freed, 1987). Both approaches gave the patients an opportunity to enhance self-esteem, self-expression and group socialization.

Edgerton (1990) artistically incorporates the use songwriting to facilitate self-expression. While working with a group of 12 emotionally impaired male adolescents, Edgerton developed a Creative Group Songwriting technique that provided a success-oriented activity for group members. As the adolescents participated in such activities data showed that their self-esteem and group cohesiveness improved. Songwriting was reported to be effective with a Traumatically Brain Injured (TBI) female survivor of a car accident as well (Glassman, 1991). Using lyric substitution, the client began to express her thoughts and feelings. As her therapy continued, she also created original lyrics. In this study, songwriting became not only an avenue for self-expression but also a means of organizing thought processes and changing thinking patterns.
In reviewing specific procedures of songwriting, lyric writing is found to be the most frequently emphasized component. The overall music composition is usually of peripheral importance to the procedures. Freed (1987) offers a successive approximation process in lyric writing and discusses effectiveness of both this process and lyric analysis. Schmidt (1983) and Ficken (1976) describe techniques used to promote lyric writing skills and suggest some approaches to creating musical settings and melodies. Murphy (1983) also addresses the process of developing a general framework for a musical accompaniment to lyrics. Plach (1980) describes his method, which consists of individuals randomly placing notes on a staff and selecting a title for the group composition.

In palliative care, music therapy offers a safe environment where patients have the opportunities to connect with and express their feelings at their own chosen pace. It cultivates supportive interactions between the patients and their loved ones and enables patients to maintain some degree of physical well-being. Song writing in palliative care has been shown to facilitate communication among family members (Salmon, 1993; Slivka & Bailey, 1986), portray patients’ feelings (Bruscia, 1991; Magill-Leverault, 1993), images, dreams, and fantasies (Magill-Leverault, 1993), and, presented as gifts, create a lasting musical memory (Bruscia, 1991), or memento (Porchet-Munro, 1993). In O’Callaghan’s analysis of 64 song lyrics composed by his 39 palliative care patients, specific topics appeared; most of the songs (87%) were used by patients to express important messages.

It has been argued that song writing in music therapy may alleviate some of the physical, social, emotional or spiritual needs of some palliative care patients (O’Callaghan, 1996). O’Callaghan (1996) reports that the major themes of those composed songs included patients’ reflections upon aspects about themselves (66%); patients’ compliments to other people (50%); and memories (45%). Other recurring themes were reflections upon patients’ significant others (31%), self-expression of adversity (25%), imagery (17%) and prayers (11%). In half of the songs patients complimented other people, including staff, other patients, and friends, about their personal qualities and their impact upon the patients’ lives. Such lyrics would be important for patients’ relatives to hear to aid in their bereavement. Having the
opportunity to compliment other people was possibly important to patients’ self-esteem and sense of purpose.

Forty-five percent of the song lyrics also included the patients’ memories. Various music therapists have mentioned the value of a life review process for palliative care patients and this study revealed that song writing could promote a life review. In 31% of the songs patients reflected upon relationships with the significant others in their lives, including pets, suggesting that many patients with end stage illnesses reflect upon their meaning for others and other people’s meaning for them. Again this finding demonstrates that song writing can promote the life review process. In 25% of the songs patients expressed adverse experiences resulting from their illnesses. Such expressions of adversity indicate that song writing can aid in the supportive counseling of palliative care patients, as it is a medium through which they can ventilate their losses and other difficulties. The imagery theme was found in 17% of the songs. The expression of this theme through song writing suggests that song writing offers patients an opportunity to find some refuge from the current situation. Eleven per cent of the songs included prayers, the final theme, supporting the notion that some palliative care patients for spiritual expression or reflection can use song writing.

O’Callaghan (1997) discusses in length the therapeutic opportunities associated with music. The experimenter found that the following six items are therapeutic opportunities associated with music when using songwriting in a palliative care setting:

1. Song writing offers patients opportunities to express creatively through both the words and the music.
2. Song writing may be less threatening than other forms of creative writing.
3. Song writing offers varied opportunities to promote physical and social well-being.
4. Song writing allows people to make creative choices that encompass both musical and verbal dimensions. Expanded opportunities for making choices are especially important for people experiencing a diminishing sense of control over their bodies and lives.
5. Song writing may offer opportunities for counseling. Creating music for the lyrics can encourage further reflections and provide opportunities to discuss whatever feelings are evoked.

6. Helping patients to create new lyrics for well-known music (O’Callaghan, 1994; Salmon, 1993; Slivka & Bailey, 1986) may encourage their expression of thoughts and feelings. The melodic energy of well-known songs often stimulates creative lyric writing and offers patients instantaneous satisfaction as they can immediately sing the lyrics to themselves.

These six therapeutic opportunities derived from O’Callaghan’s research have shown its value during the process of songwriting with palliative care patients and their families. Though O’Callaghan listed ten therapeutic opportunities, the researcher found the six listed above displayed most closely the general use of songwriting in the hospital’s palliative care setting.

The use of music therapy in an innovative manner could possibly facilitate and ameliorate psychosocial aspects of dying. It is theorized that the specific use of music in an end of life celebration would be possible by modeling a life review framework. The purpose of this study is to determine whether songwriting technique known as a song parody may provide benefits for the patient and their family.
CHAPTER TWO

METHOD

Subjects

All of the subjects (N=20) were selected from the Tallahassee Memorial HealthCare admissions. These subjects all met end of life criteria, as determined by the medical personnel. These criteria included two or more of the following: no CRT defined as no cardiac resynchronization therapy (formerly defined as DNR= do not resuscitate), prognosis poor or grave, terminal illness and comfort care measures only prescribed. The subjects in both groups ranged in ages from 28 years old to 97 years old, with an average age of 64.5 years old. The mean age of the control group was 78.4 years old while the mean age of the experimental group was 58.8 years old. In the control group there were seven male subjects and three females. In the experimental group there were three male subjects and seven female subjects. Those patients participating in this study, upon admission were diagnosed most frequently with Congestive Heart Failure (N=4), Chronic Renal Failure (N=2), and different types of Cancer (N=8) with other diagnoses including: Syncope and Collapse, Septicemia NOS, Multi-Cranial Nerve Palsy, Hypertension, Intestinal Obstruction, and Respiratory Abnormalities. Table 1 provides subject demographics including diagnosis, age, and sex, also identifies control/experimental group status.
Table 1 Subject Demographics

<table>
<thead>
<tr>
<th>Experimental/Control</th>
<th>Male/Female</th>
<th>Age</th>
<th>Diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Experimental #1</td>
<td>Female</td>
<td>83 yrs.</td>
<td>Congestive Heart Failure</td>
</tr>
<tr>
<td>Experimental #2</td>
<td>Male</td>
<td>49 yrs.</td>
<td>Chronic Renal Failure</td>
</tr>
<tr>
<td>Experimental #3</td>
<td>Female</td>
<td>34 yrs.</td>
<td>Subcutaneous Histoplasmosis</td>
</tr>
<tr>
<td>Experimental #4</td>
<td>Female</td>
<td>39 yrs.</td>
<td>Malignant Brain/Spine Melanoma</td>
</tr>
<tr>
<td>Control #5</td>
<td>Male</td>
<td>97 yrs.</td>
<td>Syncope and Collapse</td>
</tr>
<tr>
<td>Control #6</td>
<td>Male</td>
<td>56 yrs.</td>
<td>Leukemia NOS w/o Remission</td>
</tr>
<tr>
<td>Control #7</td>
<td>Male</td>
<td>69 yrs.</td>
<td>Cancer</td>
</tr>
<tr>
<td>Experimental #8</td>
<td>Male</td>
<td>44 yrs.</td>
<td>Cancer</td>
</tr>
<tr>
<td>Experimental #9</td>
<td>Female</td>
<td>56 yrs.</td>
<td>Septicemia NOS</td>
</tr>
<tr>
<td>Control #10</td>
<td>Male</td>
<td>67 yrs.</td>
<td>Lymphomas NEC</td>
</tr>
<tr>
<td>Control #11</td>
<td>Female</td>
<td>86 yrs.</td>
<td>Respiratory Abnormalities</td>
</tr>
<tr>
<td>Experimental #12</td>
<td>Female</td>
<td>82 yrs.</td>
<td>Congestive Heart Failure</td>
</tr>
<tr>
<td>Control #13</td>
<td>Female</td>
<td>28 yrs.</td>
<td>Leukemia NOS w/o Remission</td>
</tr>
<tr>
<td>Control #14</td>
<td>Male</td>
<td>67 yrs.</td>
<td>Cancer</td>
</tr>
<tr>
<td>Control #15</td>
<td>Female</td>
<td>78 yrs.</td>
<td>Congestive Heart Failure</td>
</tr>
<tr>
<td>Experimental #16</td>
<td>Female</td>
<td>79 yrs.</td>
<td>Chronic Renal Failure</td>
</tr>
<tr>
<td>Control #17</td>
<td>Male</td>
<td>68 yrs.</td>
<td>Multi-Cranial Nerve Palsy</td>
</tr>
<tr>
<td>Experimental #18</td>
<td>Male</td>
<td>83 yrs.</td>
<td>Hypertension</td>
</tr>
<tr>
<td>Control #19</td>
<td>Male</td>
<td>86 yrs.</td>
<td>Congestive Heart Failure</td>
</tr>
<tr>
<td>Experimental #20</td>
<td>Female</td>
<td>39 yrs.</td>
<td>Intestinal Obstruction</td>
</tr>
</tbody>
</table>

**Design**

The design included control and experimental groups with post-test data collection only. The independent variable was the music therapy intervention. The dependent variables were quality of life, emotional state, and family satisfaction.

**Music Therapy Intervention**

Music therapy referrals are made according to set policy and procedures at the Tallahassee Memorial HealthCare facility and come from the patient care conference, interdisciplinary staff meeting, or through individual staff. The experimenter used these existing procedures and relied on the medical staff to identify end of life patients. A
social functional assessment tool was designed to trigger indicators that met the medical personnel’s definition of end of life. The compilation of these triggers for the social functional assessment tool came from the palliative care committee whose purpose was to design an assessment tool for patients that met the palliative care standard. The participating patient met the criteria for the end of life celebration by possessing two more of the following characteristics: no CRT, prognosis poor or grave, terminal illness, and comfort care measures only.

The subjects were randomly assigned to either control or experimental conditions. The experimental group (N=10) received two music therapy sessions. The initial session consisted of an interview which informed the experimenter of the patient’s music preference, family history, and life anecdotes to be used as lyrics for the end of life celebration, and to arrange the date and time of the celebration with the family. During the initial session the experimenter was also able to assess the overall abilities of participation from the patient.

At the second session, the music therapist returned at the agreed upon time and date with a personalized song for the patient and his/her family. The experimenter compiled the family history and stories into lyrics from the initial interview creating a song parody, using preferred music agreed upon by the patient, and or family. The experimenter was able to provide the patient and family with copies of the personalized song lyrics on embellished paper. Prior to the celebration session, the music therapist had instructed the family to bring mementos of the patient that could include pictures, books, favorite dolls, pillow, or quilts to enhance celebration of the patients’ life.

For the celebration, patients and family engaged in one or more of the following activities: singing patient’s preferred music, using mementos to reminisce, using live music to reminisce, verbalizing to the family members or to the patient sentimental words, humor, discussing ways to cope with the current situation, and discussing positive highlights about the life the family had shared thus far. (See Appendix E for specific sessions.) After the celebration, the family members and patient, if possible, would answer a Family Satisfaction survey (see Appendix C), a Visual Analog Scale (VAS) (see Appendix B) that measured anxiety levels, and the Hospice Quality of Life Index (see Appendix D).
The no-contact control group (N=10), did not receive any music and consented only to participating in the study. The control patients answered the Hospice Quality of Life Index (see Appendix D) and filled out a patient self-report survey that measured the patient’s anxiety levels using a Visual Analog Scale (VAS) (see Appendix B). There was no change in the procedure of care of these control patients.

Materials

Equipment used during this study included a Yamaha CG-201S guitar and various songbooks including The Ultimate Country Fake Book, The United Methodist Hymnal, Baptist Hymnal, Songs of Zion, Gospel’s Greatest, Motown Anthology, and Jump, Jive, Wail, and Swing. All session took place in the patient’s hospital room.
CHAPTER THREE

RESULTS

This study employed the use of three measurement tools used to collect data for subjects. The Visual Analog Scale, (VAS), Family Satisfaction Survey, and Hospice Quality of Life Index- Revised, (HQOL-R), were used as a post-test only for both control and experimental groups. Data on the Family Satisfaction Survey for each experimental subject’s individual points and totals are in Appendix F.

The experimenter implemented the Mann Whitney U two-tailed (Madsen & Moore, 1978) test to determine statistical differences in emotional states using the Visual Analog Scale (VAS), between the control and experimental groups. A U score of 15 for the control group and 85 for the experimental group was obtained and indicated a significant difference between the two groups (n1=10, n2=10, α=.05, critical U=23), since the smaller U (15) was smaller than the critical U (23). The experimental subjects had significantly lowered levels of anxiety.

The Mann Whitney U two-tailed test, the experimenter discovered no statistical differences in the quality of life state of palliative care patients within the medical setting. The U score of 77 for the control group and 28 for the experimental group indicated no significant difference between these two groups (n1= 10, n2= 10, α=.05, critical U= 23), since the smaller U (28) was larger then the critical U (23).
Table 2 Results for Visual Analog Scale

<table>
<thead>
<tr>
<th>Experimental Subjects</th>
<th>Mean Score</th>
<th>Control Subjects</th>
<th>Mean Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxious</td>
<td>37.8</td>
<td>Anxious</td>
<td>49.0</td>
</tr>
<tr>
<td>Dissatisfied</td>
<td>31.0</td>
<td>Dissatisfied</td>
<td>21.44</td>
</tr>
<tr>
<td>Sad</td>
<td>18.4</td>
<td>Sad</td>
<td>51.0</td>
</tr>
<tr>
<td>Stress</td>
<td>14.4</td>
<td>Stress</td>
<td>63.3</td>
</tr>
<tr>
<td>Hopelessness</td>
<td>5.8</td>
<td>Hopelessness</td>
<td>35.8</td>
</tr>
<tr>
<td>Discomfort</td>
<td>11.1</td>
<td>Discomfort</td>
<td>52.1</td>
</tr>
<tr>
<td>Pain</td>
<td>23.5</td>
<td>Pain</td>
<td>42.9</td>
</tr>
</tbody>
</table>

The researcher relied on the Mann Whitney U two-tailed (Madsen & Moore, 1978) test to further determine any statistical differences between each of the Hospice Quality of Life-Revised (HQOL-R) subscales. The categories include: 1) Psycho-physiological well-being, 2) Functional well-being, and 3) Spiritual/Social well-being. The first subscale of Psycho-physiological well-being resulted with a U score of 26 for the experimental group and a U score of 74 indicated no significant difference between these two groups (n1= 10, n2= 10, α= .05, critical U of 23).

The second subscale of Functional well-being resulted in a U score of 31.5 for the experimental group and a U score of 48.5 for the control group indicated no significant difference between these two groups (n1=10, n2= 10, α= .05, critical U of 23). The third subscale of Spiritual well-being resulted in a U score of 27.5 for the experimental group and a U score of 72.5 indicating no significant difference between these two groups (n1= 10, n2= 10, α= .05, critical U of 23). Table 3 reflects Hospice Quality of Life Index-Revised results. See Appendix F to view the Hospice Quality of Life Index-Revised raw scores. The maximum accumulation of points equals 290 points.

Table 3 Hospice Quality of Life Index-Revised Results

<table>
<thead>
<tr>
<th></th>
<th>Sub-scale 1</th>
<th>Sub-scale 2</th>
<th>Sub-scale 3</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Psycho-physiological</td>
<td>Functional</td>
<td>Spiritual/Social</td>
<td></td>
</tr>
<tr>
<td>Experimental Subjects</td>
<td>55.1</td>
<td>90.1</td>
<td>65.5</td>
<td>70.2</td>
</tr>
<tr>
<td>Control Subject</td>
<td>38.3</td>
<td>77.1</td>
<td>55.9</td>
<td>57.1</td>
</tr>
</tbody>
</table>
Each individual subject could have totaled a maximum score of 70 points on the Family Satisfaction Survey. The total score for each question was also found for the entire experimental group, the maximum possible score = 100 points. The minimum individual score from the Family Satisfaction Survey was 54 points, which equals 77.14% family satisfaction. The maximum individual score was 70 points, which equals 100% family satisfaction. Three out of ten experimental subjects rated the following questions with the score of 5 points: 1) I believe music therapy with an end of life celebration has or will bring closure for my loved one, 2) The medical staff meets the need of my loved one, and 3) The medical staff provides support for my loved one and me. The mean Family Satisfaction Survey scored for the experimental group was 88.7% as shown on Table 5.

Table 4 represents the mean score for each of the seven questions from the experimental subjects. The total scores ranged from 7.8 points to 9.7 points. The lowest mean score, 7.8 points, is linked to the question pertaining to the medical staff meeting the needs of the family’s loved one. The highest mean score, 9.7 points was in response to the family’s satisfaction with the use of music therapy in the hospital setting.
Table 4 Family Satisfaction Survey Results

<table>
<thead>
<tr>
<th>Items</th>
<th>Mean Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Use of music therapy within end of life celebration is beneficial to me</td>
<td>9.4</td>
</tr>
<tr>
<td>Use of music therapy within end of life celebration is beneficial to my loved one</td>
<td>9.7</td>
</tr>
<tr>
<td>I enjoy the use of music therapy within the hospital setting</td>
<td>9.7</td>
</tr>
<tr>
<td>I believe music therapy with an end of life celebration has or will bring closure for me</td>
<td>8.9</td>
</tr>
<tr>
<td>I believe music therapy with an end of life celebration has or will bring closure for my loved one</td>
<td>8.7</td>
</tr>
<tr>
<td>The medical staff meets the need of my loved one</td>
<td>7.8</td>
</tr>
<tr>
<td>The medical staff provides support for my loved one and me</td>
<td>7.9</td>
</tr>
<tr>
<td><strong>Total satisfaction scores by subject</strong></td>
<td><strong>63</strong></td>
</tr>
</tbody>
</table>

Table 5 Family Satisfaction Percentage Score

<table>
<thead>
<tr>
<th>Ss</th>
<th>Satisfaction Percentage Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>90%</td>
</tr>
<tr>
<td>2</td>
<td>86%</td>
</tr>
<tr>
<td>3</td>
<td>91%</td>
</tr>
<tr>
<td>4</td>
<td>77%</td>
</tr>
<tr>
<td>5</td>
<td>83%</td>
</tr>
<tr>
<td>6</td>
<td>100%</td>
</tr>
<tr>
<td>7</td>
<td>91%</td>
</tr>
<tr>
<td>8</td>
<td>86%</td>
</tr>
<tr>
<td>9</td>
<td>97%</td>
</tr>
<tr>
<td>10</td>
<td>8%</td>
</tr>
<tr>
<td><strong>Mean Score</strong></td>
<td><strong>88.7%</strong></td>
</tr>
</tbody>
</table>
CHAPTER FOUR

DISCUSSION

Results from this experiment supported the use of music therapy in palliative care within the medical setting. For those experimental subjects participating in this study, anxiety scores were significantly lower than the control group. Satisfaction levels for music therapy were higher than for medical care in general. The purpose of this study determined the successful use of palliative music therapy within a hospital setting. This pilot study reported significant results that showed 97.25% satisfaction of music therapy within the medical setting. The Family Satisfaction Survey also showed 97% reported that the End-of-Life celebration was beneficial to the family’s loved one. There was no significant difference in quality of life though scores showed a trend for improvement in experimental subjects.

All of the experimental subjects received two music therapy session, those in the control group did not receive any music. In some instances, a music therapy session occurred for a few of the control group members after all necessary research data were completed. With a total number of twenty participants, seven of the experimental subjects and three control subjects independently completed and/or verbalized their answers for all the questionnaires. The other three experimental subjects and seven control subjects received assistance from their family members.

There were a variety of appreciative responses from experimental subjects in this study. The first celebration session the experimenter encountered much more patient participation than was anticipated. The subject was dancing in her wheelchair and
playing instrument along with positive comments: “You really did a song about me!” and “I love my song and I love you too”. Another subject who had expressed doubt during the initial interview session, by repeatedly saying “We’ll see how well you do”, completed changed his mind by saying “You’re a genius, how did you do it?” Another of the experimental subjects made an appointment with the music therapist so that his entire family could attend. On the day of the celebration, three generations of his family were present. This same family brought in their own recording device to record the entire celebration.

An experimental subject asked me to play at her funeral, stating “I want some good music, ok?” This same subject’s family brought in a tape recorder and asked the experimenter to record the patient’s celebration song three times, in case of malfunction or destruction during some part of the recording. One of the family members from the experimental group brought in a video-camera to document the entire session. The family expressed the sentimental value of having the celebration session documented to be viewed after their loved one passed away.

Each End-of-Life celebration was conducted differently according to each individual family member and subject’s wishes. The experimenter suggested bringing in mementos such as pictures or sentimental objects, and family members and patients were able to bring in their own family traditions and rituals that made each celebration memorable. The composition of the “end-of-life” song melody was determined during the initial session. At the initial session, the patients and family members were able to indicate music preference or name specific songs that were special to the family or patient holding some type of sentimental value. Some of the subjects picked their favorite church hymn, a song that reflected their family history, their favorite genre of music, a wedding song, and or a song with its original words. All selections important were significant to the subject.

The lyrics from the celebration song came directly out of the interview notes the experimenter took. Direct quotes were used in most of the songs. The use of direct quotes gave the experimenter the ability to reflect the subject’s personality and way of thinking, and described their emotions realistically. An important part of the interview was listening. Though the experimenter jotted notes down the entire session, being
observant of the subtle tone expressed by the patient’s voice when he/she described a specific story or how it was important was key to selection of the most meaningful issues.

The success of this pilot study supports the use of palliative music therapy in a medical setting. It improves emotional states and result in high family satisfaction ratings of music therapy. The future implementation of this pilot study would be successful with support from the medical staff that focused on Palliative Care as an integral component of the medical setting. This study required the dedication from medical personnel committed to improving quality of life, emotional state, and family satisfaction.

Those involved were committed to excellence for all of the patients and their families. Future studies may look to incorporating other disciplines in the plan of care for imminent-death patients or integrating other music therapy techniques besides songwriting/song parodies. Exploring guided imagery paired with live music, physical movement, and or lyric analysis paired with bedside counseling and comparing quality of life, emotional states, and family satisfaction would be possible area of future research.
APPENDIX A

HUMAN SUBJECTS APPROVAL
APPROVAL MEMORANDUM
from the Human Subjects Committee

Date: November 18, 2002
From: David Quadagno, Chair
To: Judy Nguyen
403 Hayden Rd., #223
Tallahassee, FL 32304
Dept: Music Therapy
Re: Use of Human subjects in Research
Project entitled: The Effect of Music Therapy on End of Life
Patients’ Quality of Life, Emotional State, and Family Satisfaction
as Measured by Self Report

The forms that you submitted to this office in regard to the use of human subjects in the
proposal referenced above have been reviewed by the Human Subjects Committee at its
meeting on November 13, 2002. Your project was approved by the Committee.

The Human Subjects Committee has not evaluated your proposal for scientific merit,
except to weigh the risk to the human participants and the aspects of the proposal
related to potential risk and benefit. This approval does not replace any departmental
or other approvals which may be required.

If the project has not been completed by November 12, 2003, you must request renewed
approval for continuation of the project.

You are advised that any change in protocol in this project must be approved by
resubmission of the project to the Committee for approval. Also, the principal investigator
must promptly report, in writing, any unexpected problems causing risks to research subjects
or others.

By copy of this memorandum, the chairman of your department and/or your major professor
is reminded that he/she is responsible for being informed concerning research projects
involving human subjects in the department, and should review protocols of such
investigations as often as needed to insure that the project is being conducted in compliance
with our institution and with DHHS regulations.

This institution has an Assurance on file with the Office for Protection from Research Risks.
The Assurance Number is IRB00000446.

APPLICATION NO. 02.571
Cc: Jayne Standley
The Music Therapy Department at the Tallahassee Memorial HealthCare, which includes Board Certified Music Therapists and Music Therapy Interns, is conducting this research. Judy Nguyen MT-BC, (850) 431-7468 is conducting this project to complete requirements for a Masters Thesis, under the supervision of Jayne Standley, PhD, MT-BC (850) 644-4565.

I freely and voluntarily and without element of force or coercion, consent to be a participant in the research project entitled “The Effects of Music Therapy on End of Life Patients’ Quality of Life, Emotional State, and Family Satisfaction as Measured by Self Report. I understand the purpose of this research is to determine if music therapy interventions during an end of life celebration improve patients’ quality of life, emotional state, and family satisfaction.

I understand my participation is completely voluntarily and I may stop participation at any time. My name will not appear on any of the results. Only group findings will be reported. No individual responses will be reported. Group results will be sent to me upon my request. All information obtained during the course of this study will remain confidential to the extent allowed by law.

I understand this consent may be withdrawn at any time without prejudice, penalty or loss of benefits to which I am otherwise entitled. I have been given the right to ask and have answered any inquiry concerning the study. Questions, if any, have been answered to my satisfaction.

I understand that I may contact the Music Therapy Department at Tallahassee Memorial HealthCare, (850) 431-7468 and the Human Subjects Committee at Florida State University, (850) 644-8827, for answers to questions about this research or my rights.

I have read and understand this consent form.

_____________________________________________________________________
Subject:       Date:
APPENDIX C

VISUAL ANALOG SCALE
Mark an X on the scale below that describes how you feel at this moment:

Calm ___________________________________________________ Anxious

Satisfied ________________________________________________ Dissatisfied

Happy ___________________________________________________ Sad

Relief ___________________________________________________ Stress

Hopeful _________________________________________________ Hopeless

Comfort ________________________________________________ Discomfort

No Pain __________________________________________________ Pain
APPENDIX C

FAMILY SATISFACTION SURVEY
Family Satisfaction Survey

Please respond to the following questions:

- The use of music therapy within an end of life celebration is beneficial to me.
  
<table>
<thead>
<tr>
<th>Strongly disagree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>0  1  2  3  4  5  6  7  8  9  10</td>
<td></td>
</tr>
</tbody>
</table>

- The use of music therapy within an end of life celebration is beneficial to my loved one.
  
<table>
<thead>
<tr>
<th>Strongly disagree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>0  1  2  3  4  5  6  7  8  9  10</td>
<td></td>
</tr>
</tbody>
</table>

- I enjoy the use of music therapy within the hospital setting.
  
<table>
<thead>
<tr>
<th>Strongly disagree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>0  1  2  3  4  5  6  7  8  9  10</td>
<td></td>
</tr>
</tbody>
</table>

- I believe music therapy with an end of life celebration has or will bring closure for me.
  
<table>
<thead>
<tr>
<th>Strongly disagree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>0  1  2  3  4  5  6  7  8  9  10</td>
<td></td>
</tr>
</tbody>
</table>

- I believe music therapy with an end of life celebration has or will bring closure for my loved one.
  
<table>
<thead>
<tr>
<th>Strongly disagree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>0  1  2  3  4  5  6  7  8  9  10</td>
<td></td>
</tr>
</tbody>
</table>

- The medical staff meets the need of my loved one.
  
<table>
<thead>
<tr>
<th>Strongly disagree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>0  1  2  3  4  5  6  7  8  9  10</td>
<td></td>
</tr>
</tbody>
</table>

- The medical staff provides support for my loved one and me.
  
<table>
<thead>
<tr>
<th>Strongly disagree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>0  1  2  3  4  5  6  7  8  9  10</td>
<td></td>
</tr>
</tbody>
</table>
APPENDIX E

HOSPICE QUALITY OF LIFE INDEX- REVISED
Hospice Quality of Life Index-Revised

The questions listed below will ask about how you are feeling at the moment and how your illness has affected you. Please circle the number on the line under each of the questions that best shows what is happening to you at the present time.

How tired do you feel?

extremely ___________________________ not at all
0 1 2 3 4 5 6 7 8 9 10

How well do you sleep?

not at all ___________________________ very well
0 1 2 3 4 5 6 7 8 9 10

How breathless do you feel?

extremely ___________________________ not at all
0 1 2 3 4 5 6 7 8 9 10

How well do you eat?

poorly ___________________________ very well
0 1 2 3 4 5 6 7 8 9 10

How constipated are you?

extremely ___________________________ not at all
0 1 2 3 4 5 6 7 8 9 10

How nauseated/sick do you feel?

extremely ___________________________ not at all
0 1 2 3 4 5 6 7 8 9 10

For Men: How masculine do you feel? For Women: How feminine do you feel?

not at all ___________________________ extremely
0 1 2 3 4 5 6 7 8 9 10
Do you have enough physical contact with those you care about? (Touching, holding hands, hugging, or other physical contact?)

<table>
<thead>
<tr>
<th>none</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>a great deal</th>
</tr>
</thead>
</table>

How sad do you feel?

<table>
<thead>
<tr>
<th>very sad</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>not at all</th>
</tr>
</thead>
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Do you believe that each day can still hold some good?

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How worried do you feel about what is happening to you?

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How worried do you feel about your family and friends?

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How angry do you feel about what is happening to you?

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How lonely do you feel?

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<th>7</th>
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<th>9</th>
<th>10</th>
<th>not at all</th>
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How satisfied do you feel with your ability to concentrate on things?

| very very dissatisfied | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | satisfied |
|-------------------------|---|---|---|---|---|---|---|---|---|---|---|---|---|
How meaningful is your life?

not at all very meaningful _____________________________________ not at all

0 1 2 3 4 5 6 7 8 9 10

How much enjoyable activity do you have?

none _____________________________________ a great deal

0 1 2 3 4 5 6 7 8 9 10

How satisfied do you feel about the amount of usual daily activities you are able to do?
(job, housework, chores, child care, etc...)

very very satisfied

very very dissatisfied 0 1 2 3 4 5 6 7 8 9 10

How satisfied are you with your level of independence?

very very satisfied

very very dissatisfied 0 1 2 3 4 5 6 7 8 9 10

How satisfied are you with the support you receive from family and friends?

very very satisfied

very very dissatisfied 0 1 2 3 4 5 6 7 8 9 10

How satisfied are you with your social life?

very very satisfied

very very dissatisfied 0 1 2 3 4 5 6 7 8 9 10

How satisfied are you with the physical care that you are receiving?

very very satisfied

very very dissatisfied 0 1 2 3 4 5 6 7 8 9 10

How satisfied are you with the emotional support you get from your health care team?

very very satisfied

very very dissatisfied 0 1 2 3 4 5 6 7 8 9 10
How satisfied are you with your relationship with God (however you define that relationship?)

<table>
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<tbody>
<tr>
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How satisfied are you with the spiritual support you get from your health care team?

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<tbody>
<tr>
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Do your surrounding help improve your sense of well-being?

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How much do you worry about your living expenses/finances?

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If you experience pain, how completely is it relieved?

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How bad is your pain when it is at its worst?

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APPENDIX F

EXPERIMENTAL GROUP SONG COMPOSITIONS
Memories
I Want Jesus to Walk with Me

Growing up in, in Quincy
With my brothers and our mom
Longing for life, filled with excitement
Oh, my life is full of love

In my life, I am blessed
Filled with family and many friends
My friend ______ and ______ share their love
I am grateful for their support

My friend _____, brought me a gift
She brought him into my life
As a puppy he was loyal
Still in my life now, he’s true to me

M______, who calls me “Sunshine”
She gave me a gift that I wear always
The cross I rub, when I feel weak
I know it provides me with some strength

“My sweet R______, at 13 now
He is soon to become a man
He’s my heart, my only son
Watching him grow is a joy to me

My whole family is my support
“I always want my mom to be protected”
I am willing to fight with confidence
“I am just going to keep on going”
G____’s Thoughts
He’s Got the Whole World in His Hands

The Lord’s made me a fighter, yes he has,
He’s given me inner strength, oh, yes he has
If God is on your side, yes he can
You can overcome and accomplish all things

Let me tell you what the doctors, they all said
I was never meant to recover, that’s what they said
“They” told me no kids, or even a career,
Oh, didn’t I sure prove them all wrong.

I was blessed so much to have my son
Blessed so much to have grandchildren
Blessed so much with a corporate career
How about all of that for an accomplishment!

God has given me the smarts, for success
I’ve learned to endure this; I’ll keep on fighting
With His help, gonna keep on living
I am determined, a gift from GOD

The Lord’s made me a fighter, yes he has,
He’s given me inner strength, oh, yes he has
If God is on your side, yes he can
You can overcome and accomplish all things
“Tell that lady that I want to talk”, that’s how D_____ and I met
We were able to talk and get more comfortable, acquainted, and friendly
  We’ve been married now, for 26 wonderful years
  Each day that we spend together is cherished

After that day of getting acquainted, we were married three years later
Our wedding was held at the local courthouse with two witnesses
  We’ve been married now, for 26 wonderful years
  Each day that we spend together is cherished

We spent our wedding night and honeymoon in Panama City
Every year since then, that’s where we celebrate every anniversary
  We’ve been married now, for 26 wonderful years
  Each day that we spend together is cherished

What a great family, lots of grandchildren, oh family’s important
A great bundle of joy the grandchildren provide, aren’t we just blessed
  We’ve been married now, for 26 wonderful years
  Each day that we spend together is cherished

D_____ and I really enjoyed gardening and being outdoors
I liked to hunt anything that moved and she caught anything that swam
  We’ve been married now, for 26 wonderful years
  Each day that we spend together is cherished
Some of T______’s Thoughts
The Way You Do The Things You Do.

I was born a country boy, slopping pigs and milking cows.
What you grow is what you eat “them was the good old days”.
I spent my life working hard and rolling in the money.
At 19, working hard, I’ll tell you my priorities
Well, the first is laying bricks and then doing drugs then the last is chasing all them girls.

When I was twenty-three vacationing in Tallahassee
Like the charmer that I am I met me a lady friend
B______ was her name eventually we got married
We had some fine times but that is all behind me
I’m a strong individual, give me all your respect, I am the one who’s in charge.

While I was working in Atlanta, at the young age of 19
At my job laying bricks the guys and I use to talk
One “ugly” guy in particular, while we mixed the mortar
The “ugly” one use to say, “You know what your problem is?
You’ve got a one track mind”, oh, how that you to piss me off!
But, boy was he right, ah, I was young!

Oh, my two Corvettes!, one was silver, the other burgundy
I was making lots of dough, working as a meat cutter
I’m a wheeler and a dealer traded in my Monte Carlo
Dropped $200 in his hands drove the ‘vette off the lot
I’m a clever business guy, doing as I wish, living my life to the fullest.
Glory, Glory Hallelujah

Growing up in Crawfordville, we attended St. P____’s Church
Glory, glory shouting hallelujah, having a good time all of us at church

Mom and Dad were churchgoing people, all nine kids always in attendance
Rarely fighting, usually getting along and working together to get things done.

The farmland was our home, using the land to feed the family
Working hard on the farm helped us make it our own way

I’ve know my J____ since he was 12, I met him at the church
He was there every Sunday he attended with his mom

There were four years of our courtship, we didn’t do much but go to church
Sitting next to him, sneaking looks, sometimes hugs when no one was looking

When I was 14 years old, J_____ and I were said to marry
On that day I remember my pink dress and the necklace given by my mom

J_____ and I moved to our own farm and worked the land just like our families
We had five kids; four were boys and our one little girl.

Some might say I’m a pretty good cook; I make my own food all from scratch
All of my bean dishes and my teacakes along with my sweet tea are the best
*Robert’s Memories
Rocky Top

I am an old-blooded rebel Mississippian, born in the county of Winston
Growing up out in the country, with my dear sister *Pam.
In 1940, I still think about living with you and *Mary.
All those great and beautiful memories still live in my heart.

“*MJ” I met him when, I was seeing another guy, “we done all the talking” and married in “fifty-five”, February “fifty-five”.

MJ and I had some great times, playing the old dog tracks.
“Here comes Rusty”, I would chant, boy we had some fun.
There was a time when MJ decided to double on the 2-7-9.
On that day he won $232, can’t believe what he did next.

MJ, what a funny fellow, he went to sit on the ground.
Yes that’s what he did he sat and counted his money, sat and counted his money.

The Railroad Company, I’ve given thirty years, in the process I met “*TR”. He sat next to me at the railroad dinner, saying I’ll call you sometime. Well he did, we were married on St. Patty’s day in 1989.
We spent the next five years traveling to some beautiful places.

We honeymooned in Hawaii traveling to Niagara Falls, Colorado Springs and the House of Gold, Oh the most beautiful places, oh those beautiful places.

*Marcus and *Jack are my pastors at *St. Joseph’s Baptist.
They and the congregation have been “beautiful” for all theses years.
For about 10 years, I was the treasurer of the church serving the Lord. With this family I share memories, ones I’ll cherish forever.

Let me tell you about “My Pew”, when you walk in the door
It sits on the second row, looking to the right, “nobody gets my seat, nobody gets my seat!!

* Names have been changed
Boogie Woogie Bugle Boy

Chorus:
A toot, a toot! A toot diddle ah-da toot. Got any Vicks Vapor Rub?
All of those delicious foods made for some great meals by the “great cook”
Love and support is held close to our hearts
Oh, those beautiful blue eyes reflect your spirit

Two sergeants in the army, running a “tight ship” at home
Meeting my E______ in the army
It’s been 57 fulfilled years.
Still showing lovey-dovey affection all of the time
The entire family provides support and strength
Keeping all of our love going strong

CHORUS

The “twins” the “baby” and the “princes”
Makes up part of our large family
This includes the 8 grand kids and 5 great grand kids with one on the way
Our lives “revolve” around food, thanks to grandma!
My favorites, I can taste the “sauce” and the rice and squash

CHORUS

An avid gardener, very good with plants
There was a time as a mother’s day present
I gave mom a beautiful orchid,
With just that one she was able to grow 50 more plants
Your ability to share all of your gifts
Amazed by your talents and your nurturing heart

CHORUS

A slick bridge player sometimes lucky
Earning some money for the “mad money” stash
Or maybe using it for a shopping spree
A very strong woman what a great role model
Keeping really great friends for all these years.
A true friend just like all “the boys”
Growin’ up in a small old town.
Waukeenah filled with childhood memories
Brothers and sisters all working hard
“That’s just how life was; I didn’t know I was poor”.

During oh, those hard times
“You didn’t know if it anything was fun,
But you always had your whole family
All of us working the land for our food

At the young age of 15 and a half
Began work at the telephone company
During that time I met the father of my children
Oh, what a sweet man, B_____ the love of my life

The courtship lasted for a few months
We went on dates as a group
Going on rides and visiting with all our friends
He was 21 and I was 18.

The wedding was held on a regular workday
We picked up mom from Waukeenah
Judge G______, mom and his wife were witnesses
I wore a printed dress and B_____ dressed in his uniform

Married for just a few years,
Giving birth to G_____ my eldest,
Then there was T_____, D_____ and D_____
Oh, my boys, I do love them so

A member of Lake Bradford since 81’
A church choir member for some time
A small church with such good preaching
Trusting the Lord, to provide me with strength
**G_____**

**Chorus:** My family’s very important
Yes you all heard me right
Oh, yes my family’s important
Yes you all heard me right
You all have always been my support
Each and every step of the way

O_____ is my daughter
Twenty years of age
She is the splitting image of me
Talks and acts like me
Oh, I love her
And I encourage her
To succeed

**Chorus**

I have three brothers
And we all get along
Then there is B_______
It’s just the two of us girls
Oh, my mother
She is my strength
And leads by great example

**Chorus**

Teacher’s aide at P_______
I’m with the kids all day
I love my work
I conquer them with love
They are expected to get badly treated,
But I surprise them
And they surprise me.

My family’s very important
Yes you all heard me right
Oh, yes my family’s important
Yes you all heard me right
You all have always been my support
Each and every step of the way
One More Day

My best friend L______ is my wife
Been married 16 years
The true love of my life
The sweetest person
Like a palm tree she sways
She is my rock, the source of all my strength

One more day, one more time
One more sunset maybe I’d be satisfied
Then again, I know what it would do
Keep me wishing still for one more day with you

I have two wonderful sons
B_____’s 11 and Z_____ is 9.
Extremely active
With sports and music
They really are my joy
Living life to the fullest and giving it their all

Chorus

Serving the Lord at O_______ Assembly
Those 4 years have brought here.
My life’s calling
Is just so rewarding
I keep living ‘cause of what I do.
Life is precious, I’m thankful for today

Chorus

Remember the trip to Pine Mountain
A small wood cabin’s where we stayed
Something unexpected
A foot of snow on the ground
Oh, those were good times
The first time for the kids to see real snow

One more day, one more time
One more sunset maybe I’d be satisfied
Then again, I know what it would do
Keep me wishing still for one more day
Keep me wishing still for one more day
Keep me wishing for one more day, with you.
APPENDIX G

RAW DATA
### Visual Analog Scale Raw Scores

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### Hospice Quality of Life-Revised Raw Score

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### Hospice Quality of Life Raw Scores

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</table>

### Family Satisfaction Survey Raw Scores

#### Family Satisfaction Survey

<table>
<thead>
<tr>
<th>Use of music therapy within end of life celebration is beneficial to me</th>
<th>9</th>
<th>10</th>
<th>7</th>
<th>10</th>
<th>9</th>
<th>10</th>
<th>10</th>
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</thead>
<tbody>
<tr>
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<td>9</td>
<td>10</td>
<td>9</td>
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<td>9</td>
<td>10</td>
<td>10</td>
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</tr>
<tr>
<td>I enjoy the use of music therapy within the hospital setting</td>
<td>9</td>
<td>10</td>
<td>10</td>
<td>10</td>
<td>9.75</td>
<td>10</td>
<td>9.5</td>
<td>10</td>
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</tr>
<tr>
<td>I believe music therapy with an end of life celebration has or will bring closure for me</td>
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<td>10</td>
<td>10</td>
<td>9</td>
<td>6.25</td>
<td>10</td>
<td>8.75</td>
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<tr>
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<td>9</td>
<td>5</td>
<td>6.5</td>
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<td>9</td>
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<tr>
<td>The medical staff meets the need of my loved one</td>
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<td>10</td>
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<tr>
<td>The medical staff provides support for my loved one and me</td>
<td>9</td>
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<td>10</td>
<td>5</td>
<td>9</td>
<td>10</td>
<td>8.25</td>
<td>5</td>
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Total individual scores

<p>| Total individual scores | 63 | 60 | 64 | 54 | 58 | 70 | 64 | 60 | 68 | 60 |</p>
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<th>Family Satisfaction Survey</th>
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<td>10</td>
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<td>I enjoy the use of music therapy within the hospital setting</td>
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REFERENCES


BIOGRAPHICAL SKETCH

Name: Judy Thuy Nguyen

Date of Birth: October 13, 1978

Place: Winter Haven, Florida

Education: The Florida State University
Tallahassee, Florida
Major: Music Therapy
Degree: Bachelor of Music in Music Therapy (2001)

The Florida State University
Tallahassee, Florida
Major: Music Therapy
Degree: Master of Music in Music Therapy (2003)


Tallahassee Memorial Behavioral Health Center
October 2001-July 2002

Tallahassee Memorial Healthcare August 2002-present