2003

The Effect of Music Therapy on the Spirituality of Persons in an In-Patient Hospice Unit as Measured by Self-Report

Natalie Wlodarczyk
THE FLORIDA STATE UNIVERSITY

SCHOOL OF MUSIC

THE EFFECT OF MUSIC THERAPY ON THE SPIRITUALITY OF PERSONS IN AN IN-PATIENT HOSPICE UNIT AS MEASURED BY SELF-REPORT

By

NATALIE WLODARCZYK

A Thesis submitted to the School of Music
In partial fulfillment of the Requirements for the degree of Master of Music

Degree Awarded:
Fall 2003
The members of the Committee approve the thesis of Natalie Wlodarczyk defended on October 6, 2003.

__________________________________________
Jayne M. Standley
Professor Directing Thesis

__________________________________________
Clifford K. Madsen
Committee Member

__________________________________________
Dianne Gregory
Committee Member

The Office of Graduate Studies has verified and approved the above named committee members
ACKNOWLEDGEMENTS

The author wishes to thank the following individuals: God, for providing me with talents and the desire to share them with others; my father, for putting that first guitar in my hands when I was just a little girl; my mother, for her endless encouragement and for being my best friend; my family and friends, for all of their love and support; Jayne Standley, for her exceptional knowledge, guidance, and for pushing me to always achieve my full potential; Clifford Madsen and Dianne Gregory, for their expertise; Jennifer Jarred, for being my “thesis accountability partner” and for always believing in me; Dena Register and Darcy Walworth, for countless lessons in music therapy, friendship, and life in general; and the music therapists, music therapy interns, and hospice house staff of Big Bend Hospice for their wonderful support and assistance.
# TABLE OF CONTENTS

List of Tables......................................................................................................................... v
Abstract ..................................................................................................................................... vi

CHAPTER 1 ................................................................................................................................ 1
   Introduction .................................................................................................................. 1
   Review of Literature................................................................................................. 2

CHAPTER 2 ............................................................................................................................... 9
   Method ........................................................................................................................... 9
   Purpose and Null Hypothesis .................................................................................... 9
   Subjects ........................................................................................................................... 9
   Setting ............................................................................................................................. 9
   Design ............................................................................................................................. 10
   Measure ........................................................................................................................... 10
   Procedure ....................................................................................................................... 10
   Summaries of Subject Visits ....................................................................................... 11

CHAPTER 3 ................................................................................................................................ 19
   Results ............................................................................................................................ 19

CHAPTER 4 ................................................................................................................................ 20
   Discussion ....................................................................................................................... 20

APPENDICES ............................................................................................................................. 21
   Appendix A: Spiritual well-being questionnaire ......................................................... 22
   Appendix B: Informed Consent .................................................................................... 25
   Appendix C: Big Bend Hospice Music Therapy Assessment Form ................................ 27
   Appendix D: Human Subjects Committee Approval .................................................. 29
   Appendix E: Raw Scores ............................................................................................... 31

REFERENCES ............................................................................................................................ 33

BIOGRAPHICAL SKETCH ....................................................................................................... 38
LIST OF TABLES

Table 1: Comparison of three psychological theories (Robertson-Gillam, 1995) ....................... 4

Table 2: Subject Demographics .................................................................................................. 9

Table 3: Mean Scores by Subject ................................................................................................ 19

Table 4: Overall Mean Scores ................................................................................................... 19

Table 5: Spiritual Content of Visits .......................................................................................... 19
ABSTRACT

The purpose of this study was to determine the effect of music therapy on the spirituality of persons in an in-patient hospice unit as measured by self-report. Subjects (N=10) were used as their own control in an ABAB design format. Session A consisted of approximately 30 minutes of music therapy, after which the patient/subject responded to a spiritual well-being questionnaire; session B consisted of approximately 30 minutes of a non-music visit, after which the patient/subject responded to a spiritual well-being questionnaire. The spiritual well-being questionnaire used in this study is an 18-item, religiously non-specific, self-report questionnaire using a Likert Scale of six degrees adapted from the Spiritual Well-Being Scale (Ellison & Paloutzian, 1982). All subjects gave written consent prior to participation in the study. Data results were graphically and statistically analyzed after four visits and four spiritual well-being questionnaires were completed for each subject. Results indicate a statistically significant increase in scores on music days.
CHAPTER 1

Introduction

When dealing with the multi-dimensional needs of hospice patients, considering the care of the “whole person,” is paramount in order to best assist and support the patient and his or her family (Hilliard, 2001). Hospice organizations provide patient care for physical, psychosocial and spiritual needs and must be flexible to keep up with an ever-changing situation.

The focus of hospice care is to palliate or manage symptoms rather than cure, and so increased quality of life is the fundamental endpoint (Axelsson & Per-Olow, 1999). Quality of life at the end of life is a multi-dimensional construct that comprises a wide range of patient needs. Interpersonal relationships, reflections of the past, acceptance and perceptions of the present, and expectations of the future are some of the influences on a patient’s perceived quality of life (Steinhauser, 2002). Quality of life may be the most helpful evaluative tool in measuring the effectiveness of palliative care (Byock, 1998).

Over the last twenty years there have been numerous quality of life measurement tools authored, tested for construct validity, and put into use to assess the effectiveness of hospice care to find out what services are beneficial to patients and their families. Through studies of this type, critical information regarding treatment alternatives is obtained in order to constantly improve patient care (Gunnars & Glimelius, 2001). The Division of Mental Health WHO classifies quality of life in six separate domains: psychological, physical, level of independence, social relationships and environment (Hilliard, 2002). Examples of facets for possible measure are pain, energy level, ability to sleep, activities of daily living, social and spiritual support, sexual activity, personal relationships, and financial stability.

Spirituality and religiousness are receiving increasing attention as potential health research variables (Underwood & Teresi, 2002) as well as the extent to which they contribute to, or undermine, a patient’s overall well being and quality of life (Fallot, 1998). Although most quality of life indexes have at least one statement, question, or subscale pertaining to spirituality, they have not been proven to accurately assess spiritual issues (Efficace & Marrone, 2002). Therefore, the trend has turned to creating spiritual or religious assessment scales to specifically assess patients’ perceptions of their spirituality in various settings dimensions.

Spirituality is gaining increasing attention in all areas of healthcare, but because of the age-old questions pairing death and spiritual issues, it is especially pertinent to hospice care. Recent studies are showing a general positive correlation between patients’ spirituality and health outcomes, as medical care is beginning to focus more on treatment of the “whole person” (Anandarajah & Hight, 2001, Edwards & Hall, 2002, Peterman & Fitchett, 2002). Although case studies examining the spiritual aspects of palliative care are quite abundant, there is a deficit in quantitative research on this topic.
Review of Literature

The chief obstacle in the study of religiousness and spirituality is the difficulty in their conceptualization and measurement (Seidtitz, 2002). There has been a significant trend from religion to spirituality over the last twenty years (Peterman & Fitchett, 2002), and there has been much debate over where the boundaries lie and what is considered spiritual. The first mistake often made when discussing spiritual issues is to interchange the terms spirituality and religion. Most researchers who have studied this topic will agree that these are two distinctly different concepts. Spirituality refers to a connection outside of the self, however defined by the individual, while religion refers to a specific denomination or tradition. Therefore it is quite possible for an individual to experience one without the other. A person can have spiritual experiences without ever having entered a church or joined a religious organization, while another individual may attend service each week, follow all the traditions of a denomination and never feel a spiritual connection. It could be said that spirituality is the experience, while religion attempts to further name that experience.

Vassallo (2001) states that spirituality is “the essence or the life principle of the person, which transcends the bio and psychosocial nature,” while religion is “a system of beliefs and practices in which a group of people seek to find the meaning in the universe, life, and a higher being.” Murray and Zentner (1989) define spirituality as “a quality that goes beyond religious affiliation, that strives for inspirations, reverence, awe, meaning and purpose, even in those who do not believe in any God.” They also state that an individual’s spirituality involves the search for answers about the infinite, which often come into focus in situations of emotional stress, physical illness, or death.

Ellison (1983) describes spirituality as a need for transcendence, which he defines as a “sense of well-being when we find purposes to commit ourselves to which involve ultimate meaning for life.” Highfield outlines the four basic spiritual needs of a person as “the need for meaning and purpose in life, the need to give love, the need to receive love, and the need for hope and creativity.”

Although there are differences in the definitions and conceptualizations of spirituality, the same themes often recur, such as the search for meaning in one’s life. Commonly, stressed persons turn to spirituality for help, seeking support to cope with unforeseen and difficult events (Fiala, 2002). When individuals are faced with terminal illnesses, spirituality may become a more integral aspect of their lives than it previously was. When patients are admitted to a hospice program, they begin a journey, which includes a roller coaster of emotions that may change on a daily basis. Many questions that were not issues before suddenly keep them awake at night, such as “What is going to happen to me when I die?” and “Will it hurt?”

An interdisciplinary hospice team, assigned to each patient, works together to support every aspect of the patient’s care, including spiritual care. An interdisciplinary team could consist of a nurse, social worker, home health aide, chaplain, and other additional therapists such as a music therapist, art therapist, or massage therapist. A chaplain, representing the pastoral care department, has traditionally been the individual to directly support the patient’s spiritual needs. However, as the focus on holistic healthcare is increasing, there has been a trend of a more team approach to spiritual support. While the chaplain or pastor is the best trained to deal with specific issues of a spiritual nature, the rest of the care team can also support the patient’s spiritual needs through a variety of interventions (Kellehear, 2000, Walter, 2002).
Agrawal and Danis (2002) have identified spiritual beliefs as one of the six domains that have been suggested for measuring a “good death.” Spiritual pain or distress is a very real concept that may preclude a peaceful death (Elsdon, 1995). Spiritual pain is different for each patient, as is each patient’s specific religious, racial or cultural background (Cohen, 1979). Robertson-Gillam (1995) defines spiritual distress as “a condition in which a person can no longer find any meaning in life and is unable to cope with or transcend the reality of the ramifications within the terminal disease.” It manifests itself differently in each patient, producing deep subjective feelings of fear, doubt, anger and confusion about their spirituality and how it will affect their death. Hospice patients need caregivers to talk to that they know will not run out of the room if the word “dying” is mentioned. Spiritual pain can also manifest in the form of unfinished business or the need for reconciliation with self, others, or a higher power (Kübler-Ross, 1969).

Maslow (1954) outlines a hierarchy of needs that each individual will move through during their lifetime: physiological, safety, to love and belong, self-esteem, self-actualization, desire to know and understand, and aesthetic needs. Maslow suggests that individuals’ basic needs must be met before they can progress to higher levels. In this hierarchy of needs, a terminally ill patient will come to terms with his own spirituality in the stage of self-actualization. Spirituality is a complex construct that may never be accurately defined, and patient with a terminal illness will experience spiritual development as an individual transitional process.

Peck (1987) describes a process of spiritual development that has four sequential stages and several degrees of attainment within each stage. Some patients never progress past the first stage, while others may move quickly between the stages. Often times, clients regress to a previous stage as their spiritual distress is heightened by their illness. The first stage of Peck’s spiritual development is the Chaotic Stage, in which the individual is self-serving, manipulative, and incapable of love toward others. The second stage is called the Formal Stage, in which the individual sees spirituality as more trouble than it is worth, and is content to remain status quo within his current way of life and thinking. The third stage, the Skeptic Stage, is where Peck places most atheists and agnostics. In the Skeptic Stage, an individual may become interested in social causes, intellectualism, and place great value on their ability to make their own judgments and decisions. The fourth and most advanced stage of Peck’s spiritual development is the Mystic Stage, in which an individual comes to believe in a common bond uniting humanity, the world, and the universe. Letting go of preconceived ideas and prejudices, those in the Mystic Stage are attracted to the mystery of spirituality and faith.

Stepnick and Perry (1992) relate spiritual distress to the five transitional stages of grief suggested by Kübler-Ross: denial, anger, bargaining, depression and acceptance. The patient can experience these stages in any order and each stage is usually revisited more than once. The eventual goal is for the patient to reach acceptance.

In the denial stage, the patient is unable to accept the terminal prognosis and may be holding out for a miracle. They may forbid talk of dying as a possibility, and helping to keep up the charade can exhaust family members. Spiritual distress can surface as denial, as the patient expresses disbelief at God for letting this happen while they feel they still have so much left to do. The next four phases are progressions toward the patient’s full acceptance of death as a personal reality (Stepnick, 1992).

Anger begins the transition toward acceptance of the impending death. This anger can be self-directed if the patient assumes personal responsibility for his illness. Failure to take better
care of himself throughout life, unhealthy habits such as smoking or not heeding a doctor’s earlier warnings in various situations may result in self-directed anger. Often God or a higher power is the target of a patient’s anger for allowing the illness to occur, and the patient may view their illness as a spiritual punishment.

Progression to the third stage, bargaining, shows that the patient has further acknowledged that death is a possibility (Kübler-Ross, 1969). Desperate attempts at reversing the chain of events may occur, such as desires for last chance medical interventions or the possibility of supernatural healing. Patients may bargain with God, promising good works on earth or the sacrifice of another aspect of life if allowed to continue living.

The fourth stage, depression, is where the patient has acknowledged the impending death and slipped into a deep sadness and personal sense of loss. Depression can have various spiritual manifestations such as the patient’s ceasing his search for meaning in life or no longer having a desire to please a higher power. The patient may feel guilty about things they have or have not done, such as church attendance, broken relationships, unfinished business, or poor health habits throughout life.

The acceptance stage is where patients fully acknowledge that their mortality is short and their life on earth is coming to a close (Stepnick, 1992). In this stage, patients have given up trying to answer impossible questions about the reasons for their illness and have let go of the painful emotions that have held them in psychological struggle and spiritual distress. The acceptance stage hopefully allows patients to once again find comfort in their spiritual beliefs or to discover a new meaning in life if spirituality was not an issue before the terminal diagnosis. They find acceptance of their situation, their illness, and enjoy a sense of peace about what is happening to them (Kübler-Ross, 1969). Sadly, many patients die before ever reaching this stage.

Worthy of noting are the many similarities between these different psychological theories and how they can lead to better understanding of patient needs. Robertson-Gillam (1995) has put together a comparison of the theories of Maslow, Peck, and Kübler-Ross in order to discern their parallels more clearly.

Table 1: Comparison of three psychological theories (Robertson-Gillam, 1995)

<table>
<thead>
<tr>
<th>MASLOW</th>
<th>PECK</th>
<th>KÜBLER-ROSS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physiological</td>
<td>Chaotic</td>
<td>Denial</td>
</tr>
<tr>
<td>Safety</td>
<td>Formal</td>
<td>Anger</td>
</tr>
<tr>
<td>To love &amp; belong</td>
<td>Skeptic</td>
<td>Bargaining</td>
</tr>
<tr>
<td>Self-esteem</td>
<td></td>
<td>Depression</td>
</tr>
<tr>
<td>Self-Actualization</td>
<td>Mystic</td>
<td>Acceptance</td>
</tr>
<tr>
<td>Desire to know &amp; understand</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Aesthetic needs</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Also important, the families of terminally ill patients will transition through these same stages of grief and spiritual distress, and may not experience them in the same order as the patient (Kübler-Ross, 1969). For example, a hospice patient may reach acceptance while the family is still in denial, or vice versa, and this can further prolong spiritual distress for the patient and the family.

Several hospice professionals have tried to categorize the spiritual aspect of dying in order to better understand and serve patient needs. Callanan and Kelly, both hospice nurses, have authored the concept of Nearing Death Awareness by simply observing and recording patterns.
and recurring patient behavior in their years of experience with hospice patients. Nearing Death Awareness is described as a time of heightened spiritual awareness when the patient may speak of being in the presence of someone no longer alive, see a resting place where they are going, know when death will occur, or express a need for some kind of reconciliation. The patient may also describe symbolic dreams or speak in symbolic language, such as talk of travel. All too often these signs are dismissed as confusion or the result of medication; however, these are important communication tactics to which families and caregivers need pay special attention in order to assist the patient in having a peaceful death (Callanan & Kelly, 1992).

Similarly, Singh (2000) identifies Nearing Death Experience, which involves a “moving beyond the separate sense of self and the increasing experience of spirit and grace.” Singh states that Nearing Death Experience is also a time of heightened spiritual awareness that can occur anywhere from a few weeks to hours before a patient’s death. Repressed emotions may emerge, relationships are repaired, altercations are forgiven, and general sense of peace comes over the patient.

When dealing with spirituality in end of life care, it is important not to make assumptions about what the patient may or may not believe. Just because a patient states that they are an adherent to a particular religious group does not necessarily mean that they subscribe to all aspects of that specific doctrine (Emblen & Pesut, 2001). In a survey of 310 congregation members from 3 different denomination churches, results suggested that religious/church attendance does not automatically imply the desired level of spiritual support and that those who feel they are receiving spiritual support are provided unique resources above and beyond those provided by social support (Fiala, 2002).

The best way to assess a patient’s spirituality is to simply ask the patient, and allow him to share his thoughts in his own time. Each individual may have a uniquely different way in which he needs spiritual support. Many healthcare professionals have reported in various surveys that supporting a patient’s spiritual needs was not part of their training, but that they learned about spiritual support from directly working with patients and allowing them to guide their intervention (DiLolo, 1994 & Schuetz, 1995). Healthcare professionals often receive the added bonus of learning about and discovering their own spirituality through supporting their patients (Hittle, 1994).

Some patients may benefit from the creation or designation of sacred space (Anderson, 2001). Our behavior tends to be different when we are in sacred spaces. We become quiet, respectful, or reflective. A patient may receive spiritual support from the creation of a prayer-like atmosphere with out being specifically religious. This sacred space could include important items to the patient, special music, art, or people. Other patients might receive spiritual support from meditation-based interventions, prayer, and other creative therapy interventions such as music and art.

Although quantitative research is scarce in the area of spirituality and health care, the increasing attention it has been receiving is promoting a trend for more studies of this type. A recent survey of a sample of physicians and their patients revealed that 91% of patients believed in the existence of God or some higher power versus 64% of physicians (Anandarajah, 2001). Of those patients polled, 40% state that their spirituality plays a role in their decisions about healthcare and that although they would benefit from their caregivers discussing spiritual implications of healthcare with them, they only did 11% of the time. These data suggest that although healthcare professionals may not view spirituality as a component of health care, it is a
factor for patients when considering their medical and treatment options and deciding on a plan of care.

In an effort to learn more about the attitudes of healthcare professionals on the topic of their patients’ spirituality, studies involving surveys of these personnel are a new development. A survey of a sample of 15 hospice nurses revealed that the spiritual dimension infiltrated all aspects of nursing care and that most hospice nurses in this poll integrated their own spirituality in how they dealt with their patients emotional and spiritual needs (Carroll, 2001). Another survey of 115 nurses suggested confusion over the nurse’s role in spiritual care, as well as a general consensus that patient’s faith in spirituality produced a positive effect on the patient and their family members (Narayanasamy & Owens, 2001). Another subscale of this survey indicated that nurses generally felt that spiritual care interventions promoted a sense of well being in the nurses as well as the patients (Narayanasamy & Owens, 2001).

The attitudes of 44 occupational therapists were surveyed on the role of spiritual care in palliative care. Only eight (18%) stated that they consistently address spirituality within patient assessments. Thirty-two (73%) stated that they thought their education had not adequately prepared then to deal with patients’ spiritual needs, and 28 (64%) reported an interest in further training in spiritual care (Rose, 1997).

Benson (1996) did a study in eliciting the relaxation response in terminally ill patients. He had the patients choose a special phrase or “mantra” to repeat while doing progressive muscle relaxation. Benson reports that 80% of patients, when given the choice between a religious or secular phrase, voluntarily chose a religious phrase, such as ”amazing grace” or “the Lord is my shepherd,” to elicit the relaxation response. One quarter of patients that participated in the study described a feeling of increased spirituality as a result of practicing the technique. Those same patients were more likely to have much better measurable medical outcomes than those who did not experience increased spirituality (Benson, 1996).

Likewise, seventy outpatients from an urban medical center with terminal illnesses were surveyed to measure correlates between spiritual well being and physical and psychosocial symptoms of death distress (death-related depression and anxiety). Higher death distress was significantly associated with lower spiritual well being (Chibnall, 2002).

Granstrom (1987) found that spiritual well-being was negatively correlated with frequency of pain, amount of pain, and degree of impairment in terminal cancer patients. Hawkins and Larson (1984) found that spiritual well being is positively correlated with self-ratings of health, and those who are higher in both spiritual well being and existential well being are closer to their ideal body weight. Spiritual well-being was also negatively correlated with blood pressure (Hawkins & Larson, 1984). Kaczorowski (1989) found that people with higher spiritual well being have less anxiety in dealing with the trauma of cancer diagnosis. Other surveys of terminally ill cancer patients report that the patients consider their spirituality important to their healthcare and to their quality of life and also show a general consensus of a desire to discuss spiritual issues and implications with their caregivers (Efficaee, 2002). Mickley (1990) found that spirituality correlated positively with hope of recovery in terminally ill patients. Cohen’s (2001) survey of patients recently admitted to a palliative care unit reported the paradoxical findings that patients felt a positive increase in their spiritual well being and outlook after admission to the palliative care unit. However, these patients also reported a significant increase in their overall quality of life after admission to the palliative care unit (Cohen, 2001).

A survey of 90 patients in an HIV/AIDS unit in an urban hospital revealed that spiritual beliefs appear to influence decisions about resuscitation status, fear of death, and feelings of guilt
or viewing the HIV status as a punishment (Kaldjian, Jekel, & Friedland, 1998). A survey of 191 women recently diagnosed with breast cancer examined the relationships between spirituality, physical well-being, functional well-being, mood, and adjustment style. Results showed significant correlations of spirituality and functional well-being. Spirituality also correlated significantly with several coping styles (Levine & Targ, 2002).

The Daily Spiritual Experience Scale (Underwood & Teresi, 2002) was given to several samples of multi-ethnic patients in medical centers in the Chicago area. Preliminary evidence showed that spirituality is related to decreased total alcohol intake, increased quality of life, and positive psychosocial status (Underwood & Teresi, 2002). Wright (2001) did a survey in hospices in England and Wales to identify key features of spiritual care. Findings support a wide range of non-religious spiritual care requirements on the part of the patients.

While there is a deficit in quantitative research in the area of healthcare and spirituality, quantitative research in the combined areas of healthcare, spirituality and creative therapy interventions, such as music therapy, is virtually non-existent (Ellison, 1983).

There is an integral relationship between music and spirituality that dates back to the beginning of history (Gilbert, 1977). Music is a natural human expression of emotion, of things for which words are not adequate, and can serve as a symbolic or spiritual language (Salmon, 1993). Music provides a way for individuals to express their spirituality, draw closer to their higher power, and derive feelings of comfort, reassurance and faith. Hospice patients frequently make associations between music and spirituality (West, 1994). Foxglove and Tyas (2000) view music “as a metaphor for wholeness symbolizing restoration, transcendence, and relationship.” A review of 52 articles from 1973 to 2000 dealing with music, spirituality, and health indicates that a number of caregivers are finding in music a way to support a patient’s spiritual needs and assist them in moving toward spiritual healing. Still, there is limited research about how musical and spiritual aspects of human experience work together to influence overall patient well-being (Lipe, 2002).

Music therapy has been gaining an increasing body of evidence supporting it as a successful intervention in the hospice setting. Moreover, music therapy has been successful with a variety of physical, psychosocial and spiritual issues for patients in palliative care (Hilliard, 2001). Music therapists are trained to reduce patients’ perception of pain, assist patients in working through the stages of grief, and provided support as they deal with issues of spiritual distress (Aldridge, 1995). Hilliard (2001) describes the music therapist as a guide on the hospice patient’s search for “hope, meaning, and a sense of purpose.”

Because music therapy is still a new field, educating other hospice professionals about what music therapy can bring to the interdisciplinary team is important (Porchet-Munro, 1993 & Mandel, 1993). Music therapy can combine with the pastoral care department to offer patients a wider range of spiritual support interventions that may include music and prayer or music as worship (Foxglove & Tyas, 2000).

Within the discipline of music therapy itself, there are a variety of techniques that may be used for spiritual support in end of life care. These are often the same music therapy techniques used in other populations or to reach other goals, but they are tailored to provide spiritual support.

Songwriting with hospice patients has proven to be a successful technique for meeting a patient’s spiritual needs (O’Callaghan, 1996). It can be used as a counseling tool, a means of comfort, and a vehicle for emotional and spiritual expression (O’Callaghan, 1997). In Callaghan’s (1996) study involving 64 songs written by 39 palliative care patients, eight lyrical
themes recurred, including prayers and gratitude to God. Songwriting can also be used as a “gift” from the patient to a loved one, provided a forum for a difficult reconciliation, or simply provide a structure or framework for a hospice patient’s ever-changing gamut of emotions. All of these songwriting activities can aid in reduction of spiritual distress.

Music therapy can also provided spiritual support in the hospice setting by providing an opportunity for worship. Hospice patients quickly become too ill to attend spiritual services or participate in church events that may have been a big part of their lives. This often results in a large void leading to spiritual distress, loneliness or depression. Music therapy provides an outlet for these patients to participate in their favorite spiritual music and increase their socialization.

A music therapy session could involve a time of music and prayer. A patient may be moved to meditate, pray silently or aloud during the music. Often times a patient has a desire to pray but may find it an uncomfortable or unfamiliar thing to do. The music can create a safe place in which patients feel comfortable to express their spirituality in whatever manner they choose. Salmon (2001) emphasizes the importance of creating a sacred space for patients “in which ventures into the realm of spiritual awareness may safely occur.”

Music can be a catalyst for emotional catharsis and spiritual exploration. The music therapist can structure life review for the patient through which spiritual distress may be alleviated if there are issues of the past that need to be dealt with. Music can help patients reminisce about spiritual events throughout their life, such as births, deaths, weddings and funerals.

When a hospice patient begins to decline and death is imminent, music therapy sessions can provide a musical structure in which family members can participate in a lasting positive interaction with the patient, say goodbye, and derive a sense of closure and peace. At this time, the patient and the family can receive spiritual support through singing of spiritual music or music that is special to the patient or the family. This time of death vigil is another setting in which creating a spiritual atmosphere or a sacred space through music can be very comforting and peaceful for all present.

Although there is a good amount of qualitative research describing successful music therapy interventions for spiritual support at the end of life, there remains a need for quantitative research in this area (Ryan, 1996). Case studies are valuable to share new techniques or ideas; however, what works with one patient may not for the next, so surveys of greater numbers of patient interventions are in demand. Research with the dying faces certain ethical considerations that are not an issue in other settings, but without further research, music therapists cannot know the most effective interventions for treatment and consequently better support their patients (Hilliard, 2001).
CHAPTER 2

METHOD

Purpose and Null Hypothesis

The purpose of this study was to determine the effect of music therapy intervention on the spirituality of patients in an in-patient hospice unit as measured by self-report. The null hypothesis for this study is there will be no significant difference between scores on the spiritual well-being questionnaire for music days versus non-music days.

Subjects

All subjects for this study (N=10) were adults, new admissions to the Hospice House who had not previously received music therapy services, and were able to appropriately respond to a questionnaire either by filling it out themselves or by having the questionnaire items read to them by the researcher and responding verbally. The researcher did not control for subject demographics such as age, gender, race, hospice diagnosis, and religious preference; however, Table 2 provides information regarding the randomized distribution of these factors.

<table>
<thead>
<tr>
<th>Sub. #</th>
<th>Age</th>
<th>Race</th>
<th>Sex</th>
<th>Hospice Diagnosis</th>
<th>Religious Preference</th>
<th># of refusals</th>
<th>Design format</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>69</td>
<td>Cau. F</td>
<td></td>
<td>lymphoma</td>
<td>Baptist</td>
<td>0</td>
<td>ABAB</td>
</tr>
<tr>
<td>2</td>
<td>54</td>
<td>Cau. M</td>
<td></td>
<td>renal failure</td>
<td>Assembly of God</td>
<td>0</td>
<td>BABA</td>
</tr>
<tr>
<td>3</td>
<td>79</td>
<td>Cau. F</td>
<td></td>
<td>stomach CA</td>
<td>Catholic</td>
<td>1</td>
<td>ABAB</td>
</tr>
<tr>
<td>4</td>
<td>47</td>
<td>Cau. F</td>
<td></td>
<td>ovarian CA</td>
<td>None specified</td>
<td>1</td>
<td>BABA</td>
</tr>
<tr>
<td>5</td>
<td>80</td>
<td>Cau. F</td>
<td></td>
<td>pancreatic CA</td>
<td>Baptist</td>
<td>0</td>
<td>ABAB</td>
</tr>
<tr>
<td>6</td>
<td>26</td>
<td>African Amer. M</td>
<td>AIDS</td>
<td>None specified</td>
<td></td>
<td>0</td>
<td>BABA</td>
</tr>
<tr>
<td>7</td>
<td>85</td>
<td>Cau. F</td>
<td></td>
<td>ALS</td>
<td>Protestant</td>
<td>0</td>
<td>ABAB</td>
</tr>
<tr>
<td>8</td>
<td>72</td>
<td>Cau. F</td>
<td></td>
<td>cardiomyopathy</td>
<td>Baptist</td>
<td>0</td>
<td>BABA</td>
</tr>
<tr>
<td>9</td>
<td>89</td>
<td>Cau. F</td>
<td></td>
<td>rectal CA</td>
<td>Presbyterian</td>
<td>0</td>
<td>ABAB</td>
</tr>
<tr>
<td>10</td>
<td>75</td>
<td>Cau. F</td>
<td></td>
<td>CHF</td>
<td>Christian</td>
<td>0</td>
<td>BABA</td>
</tr>
</tbody>
</table>

Setting

This study was conducted with patients of Big Bend Hospice, a non-profit organization that provides services to terminally ill patients and their families, across eight Florida counties (Leon, Wakulla, Franklin, Gadsden, Liberty, Jefferson, Madison, and Taylor). Subjects resided in the “Hospice House,” a 12-bed, in-patient facility on the Big Bend Hospice property. Patients can choose to stay at the Hospice House to alleviate some of the emotional stress on the family that results from having a loved one die in the home, to receive 24-hour pain management and
care, or to provide much needed respite for the family. Many in-patients at the Hospice House come directly from the hospital as new admissions to hospice care. Others have been hospice patients for some time and subsequently moved into the Hospice House. Patients in the Hospice House can be from any of the eight counties that Big Bend Hospice serves. The average patient stay in the Hospice House is two weeks.

**Design**

Subjects were used as their own control in an ABAB design format. Session A consisted of approximately 30 minutes of music therapy, after which the patient/subject responded to a spiritual well-being questionnaire; session B consisted of approximately 30 minutes of a non-music visit, after which the patient/subject responded to a spiritual well-being questionnaire. This design was counter-balanced (BABA) for half of the subjects to control for order effect. Each subject’s four visits took place within a 7-day period. Data were collected in post-test only format. The independent variable for this study was music therapy during the patient visit versus no music therapy during the patient visit. The dependent variable for this study was patient self-report of spirituality as measured by a spiritual well-being questionnaire. The researcher was the only person who interacted with subjects for the purpose of this study and collected all data.

**Measure**

Patients’ self-report of spirituality was measured by a spiritual well-being questionnaire (see Appendix A), which was adapted from the Spiritual Well-Being Scale (Ellison & Paloutzian, 1982), a widely used measurement tool with established reliability and validity of 96%. The scale was adapted to be a more universal measure void of the word “God” and religiously non-specific. The adapted scale is a 20-item self-report questionnaire using a Likert Scale of six degrees: SA = strongly agree, MA = moderately agree, A = slightly agree, D = slightly disagree, MD = moderately disagree, and SD = strongly disagree. Items are equally worded positively and negatively with the negative items reverse-scored.

**Procedure**

Upon admission, the family support counselor educated patients of the benefits of music therapy and asked if they were willing to participate in the study. If subjects agreed to participate, they were asked to sign a consent form (see Appendix B), which was approved by The Florida State University Human Subjects Committee and Big Bend Hospice. A subject could elect to be removed from the study at any time. If a potential subject refused to participate, he or she was still eligible to receive standard music therapy services and was no longer contacted regarding the study.

Music therapy visits conducted by the researcher for this study were in accordance with the cognitive behavioral music therapy model used by all Big Bend Hospice music therapists and music therapy interns. The Big Bend Hospice Music Therapy Assessment Form (see Appendix C) was filled out by the researcher once during this study for each subject, following the first music therapy visit and was then filed in the subject’s medical records. Music therapy sessions consisted of the researcher playing guitar and singing patient preferred music, facilitating patient song choice via a printed song book, and leading the patient in music-making such as singing and improvising on a variety of percussion, pitched and un-pitched instruments. Other music therapy techniques employed throughout sessions included songwriting on various levels, music as a life review stimulus, sing-a-longs with family and friends, music for prayer or worship, and
patients and family members dedicating “gift songs” to each other in memory of a loved one. Although session goals changed daily, examples included facilitating interaction with the patient and family, facilitating relaxation skills, increasing communication and socialization, elevating mood, decreasing isolation, redirecting from and reducing perceptions of pain, providing spiritual support, addressing a variety of emotional issues with the patient and family members, including children, and increasing overall quality of life.

For the purpose of this study, a non-music visit consisted of greeting the patient, inquiring about how the subject was feeling, observing patient body language and affect, and initiating and participating in conversation regarding patient-preferred topics. Examples of topics discussed included current events, weather, family, spirituality, and non-music-assisted life review. Goals for non-music visits also included those specified for music therapy visits.

The post-test was given following each music and non-music visit.

**Summaries of Subject Visits**

Subject: 1  
Diagnosis: Lymphoma  
Gender: Female  
Age: 69  
Race: Caucasian  

Summary of visit 1:  
Patient was received sitting up in bed, awake and alert. Patient exhibited a flat affect and complained of slight pain and anxiety. Music therapist played guitar and sang spiritual music as requested by patient to elevate mood, redirect patient’s attention from pain, decrease isolation, and provide spiritual support. Music therapist facilitated conversation with patient to further decrease isolation and administered therapeutic touch to provide additional comfort to patient, therefore increasing quality of life. Patient began to relax during the music as evidenced by slower breathing and less anxious verbalizations. Patient initiated discussion of her family and her health situation, but not spirituality.

Summary of visit 2:  
Patient was received sitting up in bed, awake and alert. Patient exhibited a flat affect and made anxious verbalizations upon greeting, however, patient denied pain at this time. Music therapist initiated conversation regarding family and patient’s current situation. Patient participated in conversation but did not initiate discussion of spirituality. Patient commented that she wished the Music therapist had brought her guitar. Patient remained slightly anxious and melancholy at end of visit.

Summary of visit 3:  
Patient was received sitting in wheelchair in hallway, awake and alert. Patient smiled upon greeting and expressed pleasure at the idea of a music visit. Patient denied pain but stated she was short of breath and was utilizing oxygen. Music therapist played guitar and sang spiritual music as requested by patient to maintain cheerful mood, decrease isolation, and provide spiritual support. Music therapist initiated minimal verbal responses from patient due to patient’s shortness of breath, but spoke to patient in a calm and reassuring tone and administered therapeutic touch to provide a feeling of safety and comfort for patient. Patient continued to smile throughout visit and requested specific spiritual songs that were familiar and comforting to her. Patient’s mood and affect were calm at the end of visit and patient made positive verbalizations as well as affirmative body language regarding the music and the visit in general.
Summary of visit 4:

Patient was received lying in bed, awake and alert, but exhibited a distressed affect and made anxious verbalizations upon greeting. Patient denied pain but stated that she felt like she could not breathe despite RN’s assurance that the oxygen was working properly. Music therapist spoke to patient in a calm and reassuring tone and attempted to calm and redirect patient’s focus with conversation and holding patient’s hand for support. Patient calmed only slightly as evidenced by a slight decrease in anxious verbalizations. Patient expressed disappointment because there was no music during the visit.

Subject: 2
Diagnosis: Renal failure
Gender: Male
Age: 54
Race: Caucasian

Summary of visit 1:

Patient was received sitting up in wheelchair, smiled and made cheerful verbalizations upon greeting. Patient stated he was tired but comfortable. Patient initiated conversation about his spirituality and how he believes that his life is “completely in God’s hands.” Patient engaged in life review with the music therapist with most of the focus being on how his spiritual beliefs have affected his life and how he is handling his illness. Patient commented on how much he was looking forward to the music visit.

Summary of visit 2:

Patient was received lying in bed awake and alert. Patient had two family members in the room visiting. All greeted music therapist with smiles and enthusiasm and stated that they would enjoy music as part of their interaction. Music therapist played guitar and sang spiritual music as requested by patient to maintain cheerful mood, increase socialization, and provide spiritual support. Music therapist held hands with the patient and family and participated in group prayer spoken aloud in English and in tongues by patient and family members to provide additional comfort and spiritual support to patient, therefore increasing quality of life. Patient and family members also made spontaneous prayerful exclamations during the music with eyes closed and arms raised up.

Summary of visit 3:

Patient was received lying in bed awake and alert. Patient remained silent for most of visit and seemed content to rest while the music therapist held his hand.

Summary of visit 4:

Patient was received lying in bed awake and alert. Patient complained of some nausea but denied pain. Music therapist played guitar and sang spiritual music as requested by patient to create a calm and peaceful environment, increase relaxation, redirect patient’s focus from nausea, and provide spiritual support. Music therapist held hands with the patient and administered therapeutic touch to provide additional comfort and support to patient, therefore increasing quality of life. Patient stated that he knew God was watching out for him and that he was not afraid to die. Patient did not engage in further conversation but closed his eyes during the music and raised up arms to the music as if in prayer.
Subject: 3
Diagnosis: Stomach cancer unspecified
Gender: Female
Age: 79
Race: Caucasian
Summary of visit 1:

Patient was received sitting up in bed, visiting with two friends. All three were enjoying some ice cream and were in pleasant moods upon greeting. Music therapist played guitar and sang music as requested by patient to maintain cheerful atmosphere, and provide positive interaction between patient and friends. Patient requested “upbeat oldies” and she and friends sang along and played percussion instruments to familiar tunes. Increased smiles positive verbalizations and laughter evidenced increased socialization and quality of life. Patient engaged in life review with friends but did not initiate discussion on spirituality.

Summary of visit 2:

Patient was received lying in bed, awake and alert. Music therapist participated in conversation with patient regarding patient’s travels, friends and family. Patient remained cheerful at the end of the visit.

Summary of visit 3:

Patient was received lying in bed, awake and alert, though groggy. Patient stated that she had had a lot of visitors and was feeling a little tired. Patient requested some soothing “Catholic” hymns. Music therapist played guitar and sang patient-requested music to increase relaxation, provide spiritual support and increase quality of life. Patient did not engage in conversation but closed her eyes and smile evidencing increased relaxation.

Summary of visit 4:

Patient was received sitting up in bed with a basin in her lap. Patient stated that she was feeling very nauseous but remained cheerful in her verbalizations and body language. Music therapist engaged in conversation with patient regarding the weather and her travels throughout the world. Patient remained nauseous but cheerful throughout visit and thanked music therapist for visiting her.

Subject: 4
Diagnosis: Ovarian cancer
Gender: Female
Age: 47
Race: Caucasian
Summary of visit 1:

Patient was received lying in bed, awake and alert. Patient’s young daughter was visiting with patient and was coloring pictures for her mother. Music therapist engaged in conversation with patient and daughter regarding the pictures and what the child has been learning in school to facilitate positive interaction between the group, establish rapport, increase communication and quality of life. Patient and daughter were in cheerful moods at the end of the visit.

Summary of visit 2:
Patient was received lying in bed, awake and alert. Patient exhibited a flat affect and complained of pain. RN had just given patient pain medication. Music therapist played guitar and sang soft non-religious music as requested by patient to increase relaxation, redirect patient’s attention from pain, decrease isolation, and increase quality of life. Music therapist facilitated minimal conversation with patient to further redirect patient’s attention and administered therapeutic touch to provide additional comfort to patient. Patient began to relax during the music as evidenced by slower breathing, a more relaxed affect, and less verbalizations of pain. Patient stated that the music was very relaxing and made her feel better. Patient initiated discussion of her family and her health situation, but not spirituality.

Summary of visit 3:

Patient was received lying in bed and smiled upon greeting. Patient stated that her pain was controlled at this time. Music therapist engaged in discussion with patient regarding her family and began to cry as she shared her feelings about leaving them. Music therapist provided empathetic listening, supportive counseling for anticipatory grief, and held patient’s hand as she shared her feelings.

Summary of visit 4:

Patient was received lying in bed visiting with husband and daughter. Music therapist played guitar and led daughter in singing songs for her mother while swaying colored scarves to the music. Patient and family experienced a positive interaction which elevated mood and provided a non-verbal communication as evidenced by smiles through tears and positive affirmations.

Subject: 5
Diagnosis: Pancreatic cancer
Gender: Female
Age: 80
Race: Caucasian

Summary of visit 1:

Patient was received sitting up in bed. Patient smiled upon greeting and stated she was looking forward to music. Music therapist played guitar and sang spiritual music as requested by patient to establish rapport, elevate mood, decrease isolation, and provide spiritual support. Music therapist facilitated conversation with patient to further decrease isolation and administered therapeutic touch to provided additional comfort to patient, therefore increasing quality of life. Patient discussed her family, her health situation, and her love of “the old hymns.”

Summary of visit 2:

Patient had a flat affect and stated she was feeling “down” and lonely. Patient stated she felt that she didn’t get enough visitors and that she wished her family could come more often. Music therapist provided empathetic listening and encouragement, as well as therapeutic touch. Patient’s mood seemed to elevate as evidenced by increased smiles and less negative verbalizations, however, patient stated that she wished music therapist had brought her guitar.

Summary of visit 3:

Patient smiled upon greeting and stated she was looking forward to music. Music therapist played guitar and sang spiritual music as requested by patient to elevate mood, decrease isolation, and provide spiritual support. Music therapist facilitated conversation with patient to further decrease isolation and administered therapeutic touch to provided additional comfort to patient, therefore increasing quality of life. Patient discussed her family, her health situation and
made many positive affirmations about the music and how it makes her feel “relaxed and uplifted.”

Summary of visit 4:

Patient was received in sitting up in bed watching television. Patient smiled upon greeting but immediately stated that she wished “this were a music visit.” Music therapist engaged in conversation with patient regarding her health situation and her family, and facilitated life review.

Subject: 6
Diagnosis: AIDS
Gender: Male
Age: 26
Race: African American

Summary of visit 1:

Patient was received sitting up in bed watching music videos on television, which was a good segway into a conversation about music and his likes and dislikes. Patient was friendly and talkative, and seemed to be in a cheerful mood. Patient engaged in conversation with music therapist regarding his lack of family support and the uncertainty of his future.

Summary of visit 2:

Patient was received sitting outside on the back porch. Patient smiled upon greeting and stated he would enjoy some music. Music therapist played guitar and sang non-spiritual, patient-preferred music to elevate mood, decrease isolation and increase quality of life. Music therapist facilitated conversation and counseling through lyric analysis. Patient did not initiate discussion of spirituality, but stated that he has “been away from the church for a long time.” In discussion, patient stated that spirituality was not an issue for him at this time.

Summary of visit 3:

Patient was received lying in bed watching television, awake but looking very tired. Patient stated that he was having a “bad day” and did not want to talk, however, patient stated that he was physically comfortable. Patient invited music therapist to stay awhile and watch television with him in silence. Upon music therapist’s departure, patient thanked music therapist for “checking in on him.”

Summary of visit 4:

Patient was received lying in bed with a flat affect and minimal verbalizations upon greeting. Music therapist played guitar and sang patient-preferred music to elevate mood and decrease isolation, facilitate conversation and increase quality of life. Patient began to smile during favorite songs and began to open up verbally, evidencing elevated mood and increased socialization. Patient stated that the music “really cheered him up.”

Subject: 7
Diagnosis: Amyotrophic sclerosis (Lou Gherig’s Disease)
Gender: Female
Age: 85
Race: Caucasian
Summary of visit 1:
Patient was received sitting in wheelchair in her room and greeted music therapist was a big smile and stated that she loves music of all kinds. Music therapist played guitar and sang a variety of patient-preferred music, including spiritual music, to maintain cheerful mood, increase socialization and quality of life. Patient made many positive comments regarding the music and the ability of music to “uplift and soothe.” Patient engaged in conversation with music therapist about her husband who was in the hospital recovering from heart surgery. Patient thanked music therapist for the visit, stating she felt more relaxed.

Summary of visit 2:
Patient was received sitting in wheelchair in lobby. Patient greeted music therapist with a smile and engaged in conversation regarding her husband and their travels together. Patient remained cheerful at the end of the visit.

Summary of visit 3:
Patient was received sitting in wheelchair in the lobby and greeted music therapist was a smile. Patient denied discomfort of any kind. Music therapist played guitar and sang a variety of patient-preferred music, including spiritual music, to maintain cheerful mood, increase socialization and quality of life. Patient made many positive comments regarding the music, engaged in conversation with music therapist about her husband, and asked music therapist to sing special songs that she and her husband enjoy together. Patient expressed relief at getting news that her husband was doing well, and stated that they are “blessed to still be together.” Patient thanked music therapist for the visit.

Summary of visit 4:
Patient was received sitting in wheelchair in her room. Patient stated that she was feeling quite well and was looking forward to seeing her husband soon, as he was to be discharged from the hospital. Music therapist facilitated life review with patient and patient remained positive throughout visit.

Subject: 8
Diagnosis: Cardiomyopathy
Gender: Female
Age: 72
Race: Caucasian
Summary of visit 1:
Patient was received lying in bed and stated she was feeling “alright.” Patient was very verbal throughout visit, sharing stories about family and friends. Patient’s mood seemed to elevate as a result of having company, as evidenced by increased smiles and offering a hug to music therapist at end of visit.

Summary of visit 2:
Patient was received lying in bed, awake and alert. Patient smiled upon greeting and stated she was “doing pretty well” today. Music therapist played guitar and sang patient-requested spiritual music to maintain cheerful mood, facilitate interaction with patient, provide spiritual support and increase quality of life. Patient initiated discussion of spirituality, engaged in a lyric analysis of spiritual music and stated that her spiritual beliefs are “what get her through each day.”
Summary of visit 3:
Patient was received sitting up in bed and was very talkative at greeting and throughout visit. Patient initiated conversation regarding her spiritual beliefs, her family, and her church activities. Patient commented that it was nice to have “visitors that know how to listen.”

Summary of visit 4:
Patient was received lying in bed, awake and alert. Patient smiled upon greeting and stated she “loves the music days.” Music therapist played guitar and sang patient-requested spiritual music to maintain cheerful mood, facilitate interaction with patient, provide spiritual support and increase quality of life. Patient initiated discussion of spirituality, engaged in a lyric analysis of spiritual music and shared how each hymn reminded her of a specific family member of friend.

Subject: 9
Diagnosis: Rectal cancer
Gender: Female
Age: 89
Race: Caucasian

Summary of visit 1:
Patient was received lying in bed, awake and alert. Patient had a family member present and both stated that they would enjoy music. Music therapist played guitar and sang patient-preferred spiritual music to facilitate positive interaction between patient and family member, increase socialization, elevate mood and increase quality of life through spiritual support. Patient and family member took turns requesting songs and engaged in life review with music therapist.

Summary of visit 2:
Patient was received lying in bed and smiled upon greeting. Music therapist engaged in conversation with patient regarding her career as a teacher and how much she enjoyed working with children. Patient remained positive throughout visit but commented that she wished we had had music.

Summary of visit 3:
Patient was received lying in bed, awake and alert. Patient stated she had some slight discomfort. Music therapist played guitar and sang patient-preferred spiritual music to increase relaxation, reduce patient’s perception of discomfort, provide spiritual support and increase quality of life. Patient stated she felt more relaxed as a result of the music. Patient state that the music helped to remind her that God would take care of her.

Summary of visit 4:
Patient was received laying in bed and stated she was experiencing slight pain and nausea. Music therapist spoke to patient in a calm and reassuring tone to encourage relaxation. Patient asked is music therapist could return later with her guitar.

Subject: 10
Diagnosis: Congestive heart failure
Gender: Female
Age: 75
Race: Caucasian
Summary of visit 1:
Patient was received sitting up in bed. Patient greeted music therapist enthusiastically with a large smile and positive verbalizations. Patient initiated discussion with music therapist on various topics including spirituality, stating that her trust in God gives her her positive attitude. Patient remained cheerful and positive throughout the visit.

Summary of visit 2:
Patient was received sitting up in bed and made positive and excited exclamations when she saw music therapist with instruments. Music therapist played guitar and sang a variety of music as requested by patient, including spiritual music. Patient sang along enthusiastically and made many positive verbalizations regarding the music. Patient initiated discussion of spirituality and how spiritual music makes her feel uplifted.

Summary of visit 3:
Patient was received sitting in recliner in her room. Patient immediately expressed disappointment that this was not a music visit. Patient initiated discussion about her husband and their children, her love of getting to know new people, and the importance of being a good listener.

Summary of visit 4:
Patient was received sitting up in bed and was cheerful and verbal upon greeting. Music therapist played guitar and sang patient-preferred music, including spiritual music, to maintain cheerful mood, provide spiritual support, increase socialization and quality of life. Patient sang along and again initiated discussion of the importance of her spirituality in her life and that “singing the old hymns does affirm that.”
CHAPTER 3

RESULTS

Since this study had equivalent groups and a small N, a two-tailed Walsh test was used to determine statistical significance of the mean scores on the spiritual well-being questionnaire between music and non-music visits. The null hypothesis was rejected (N=10, d=1, p=.01).

Table 3: Mean Scores by Subject

<table>
<thead>
<tr>
<th>Mean Scores</th>
<th>S1</th>
<th>S2</th>
<th>S3</th>
<th>S4</th>
<th>S5</th>
<th>S6</th>
<th>S7</th>
<th>S8</th>
<th>S9</th>
<th>S10</th>
</tr>
</thead>
<tbody>
<tr>
<td>Music</td>
<td>70</td>
<td>108</td>
<td>87.5</td>
<td>53</td>
<td>73</td>
<td>42</td>
<td>97.5</td>
<td>82</td>
<td>71.5</td>
<td>100.5</td>
</tr>
<tr>
<td>Non-music</td>
<td>66</td>
<td>108</td>
<td>86.5</td>
<td>48</td>
<td>68</td>
<td>40.5</td>
<td>94</td>
<td>71.5</td>
<td>68</td>
<td>89</td>
</tr>
<tr>
<td>d</td>
<td>4</td>
<td>0</td>
<td>1</td>
<td>5</td>
<td>5</td>
<td>1.5</td>
<td>3.5</td>
<td>10.5</td>
<td>3.5</td>
<td>11.5</td>
</tr>
</tbody>
</table>

Table 4: Overall Mean Scores

<table>
<thead>
<tr>
<th>Overall Mean Scores</th>
<th>Music</th>
<th>78.5</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Non-music</td>
<td>73.95</td>
</tr>
</tbody>
</table>

Session content was analyzed and revealed that music visits stimulated more subject-initiated discussions of spiritual issues. (See Table 5).

Table 5: Spiritual Content of Visits

<table>
<thead>
<tr>
<th></th>
<th>Music visits</th>
<th>Non-music visits</th>
</tr>
</thead>
<tbody>
<tr>
<td>Subject initiated request for</td>
<td>75%</td>
<td></td>
</tr>
<tr>
<td>spiritual music</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Subject initiated discussion</td>
<td>35%</td>
<td>15%</td>
</tr>
<tr>
<td>of spiritual issues</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Summaries of subject visits were analyzed to identify trends in patient commentary. Subjects expressed verbal disappointment regarding not having music during 80% of the non-music visits.
CHAPTER 4

DISCUSSION

The results of this investigation indicate that spirituality is truly an integral topic to be addressed with terminally ill patients and their families, and that music therapy can indeed play a strong role in that counseling area. Subjects’ spiritual well-being scale scores show a definite trend toward higher scores on the music days. It seems evident that music provided spiritual support for the patient generally but that music on a given day is not necessarily influencing their core spiritual beliefs on that day.

Spiritual music was requested by subjects on 75% of the music days, but subjects only initiated discussion of spirituality on 35% of the music days, suggesting that request or enjoyment of spiritual music does not necessarily prompt discussion, and that request of spiritual music does not indicate a specific level of spiritual belief or awareness. Often patients can take comfort in the familiarity of spiritual music without thinking about what it means or represents, either literally or figuratively. Subjects were less likely to initiate spiritual discussion on non-music days, indicating that the music stimulated thoughts about this issue.

One of the most supportive findings in this study was the notable trend of subject verbalizations regarding disappointment at not having any music on the non-music days. This reinforces music therapy as a powerful patient-preferred interaction.

A large problem encountered while doing this study was the difficulty in acquiring and retaining subjects. Originally, the researcher thought that the hospice house would be the ideal setting for the study for patient accessibility and minimization of confounding variables. However, over the course of four months, 21 subjects were enrolled in the study and only ten completed the four-day data collection period due to subjects dying or becoming non-responsive before four days of data collection could be completed.

Geographic location is another factor that may have influenced results of this study. A sample taken from north Florida may have more of a primarily Christian influence due to location than another sample taken from another part of the country. Ellison (1991) states that there is a tremendous need for research representing a broader range of religious beliefs other than Christian, especially with end-of-life patients. Ryan’s (1996) survey of music therapists working in a variety of settings reflects a strong need for more education in various religious music and traditions to broaden the population that music therapists serve. Resources for various religious music and traditions include hymnals or songbooks from nearby churches, congregations, of synagogues, reference books examining the topics of religion and spirituality, and information available on the Internet. Music therapists can use the initial assessment with a patient or client to ascertain valuable information regarding specific spiritual beliefs and traditions in order to provide more holistic services. Taking the initiative to learn more about the spiritual beliefs of patients, clients, and their families may also help to establish a stronger rapport. This thesis begins to address those issues.

Implications for future research include a duplicate of this study with hospice patients living at home and in assisted living facilities and nursing homes, as well as with their family members. Davies (2002) addressed that spirituality in pediatric palliative care has been virtually neglected and that there is a need for guidelines to assess spirituality in this population. Research is needed examining the relationships between spirituality and music therapy with pediatric patients.
APPENDIX A

SPIRITUAL WELL-BEING QUESTIONNAIRE
For the following statements, please circle the choice that best reflects how you are feeling *today*:

<table>
<thead>
<tr>
<th>Statement</th>
<th>SA</th>
<th>MA</th>
<th>A</th>
<th>D</th>
<th>MD</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Today I don’t find much satisfaction in my spiritual beliefs.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Today I don’t know who I am, where I came from, or where I am going.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Today I have experienced spirituality in my interactions with others.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Today I feel that life is a positive experience.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. My situation today is not affected by my spirituality.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Today I feel unsettled about my future.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Today I have personally benefited from my spirituality.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Today I feel very fulfilled and satisfied with my life.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Today I have not received strength and support from my spirituality.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. Today I feel a sense of well-being about what is happening to me.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
11. Today I have not enjoyed much about life.  
12. Today I feel good about my future.  
13. Today my spirituality has helped me not to feel lonely.  
14. Today I feel that life is full of conflict and unhappiness.  
15. Today my spirituality has helped me feel fulfilled.  
16. Today it feels like life doesn’t have much meaning.  
17. My spirituality has not contributed to my sense of well-being today.  
18. Today I believe there is some real purpose for my life.
APPENDIX B

INFORMED CONSENT
Informed Consent Form

I freely and voluntarily and without element of force or coercion, consent to be a participant in the study entitled, "The Effect of Music Therapy on the Spirituality of Persons in an In Patient Hospice Unit as Measured by Self-Report."

Natalie Wlodarczyk, who is a graduate student at the Florida State University and a music therapist at Big Bend Hospice, is conducting this research. I understand that the purpose of her research is to better understand the practices and effects of music therapy in hospice care. I understand that if I participate in the study I will be asked questions about my perceptions of my spirituality.

I understand that I will be asked to answer questionnaires. I understand that I will receive 4 visits from the researcher within a 7-day period, and that 2 of those visits will involve a 30-minute music therapy session. I understand that I may continue to receive music therapy services after the 7-day study period is over, if I so choose.

I understand that my participation is totally voluntary, and that I may stop participation at any time. If I decide to stop participation, I will still be entitled to all other hospice services, including music therapy, as deemed appropriate by my care plan team so long as I remain a patient of the Big Bend Hospice program. All my answers to questions and data about me will remain confidential to the extent allowed by law and will not be reported in any identifying manner in the results of this study.

I understand that there are minimal risks in participating in this study. I understand that I may talk to the researcher or any other hospice team member about my emotional discomfort at any time. I understand that I may voluntarily stop participation in the study at any time.

I understand that there are benefits to participating in this study. I understand that my own quality of life and/or spirituality may be enhanced through participation in this study. Second, I will be providing hospice clinicians with valuable information about how to better provide spiritual support for other hospice patients.

I understand that 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 or have answered any inquiry concerning this study. Questions, if any, have been answered to my satisfaction.

I understand I may contact Natalie Wlodarczyk, 1723 Mahan Center Blvd., (850) 309-1628 ext. 2182, Dr. Jayne Standley, Supervising Professor, The Florida State University School of Music, (850) 644-4565, or The Florida State University Human Subjects Committee, 644-8336, for answers to questions about this research or my rights.

I have read and understand this consent form.

Subject

Date

[Stamp: FLORIDA STATE UNIVERSITY
INSTITUTIONAL REVIEW BOARD]
APPENDIX C

BIG BEND HOSPICE MUSIC THERAPY ASSESSMENT FORM
BIG BEND HOSPICE MUSIC THERAPY ASSESSMENT

Music Therapist Signature

Patient's Age: __________________________ Date of Birth: __________________________ Spiritual/Religious Preference: __________________________

Person(s) being seen for MT (if other than patient), relationship to patient, and age (if children):

Patient was referred for MT by: □ FSC □ R.N. □ MT □ Chaplain □ Other __________________________

A. Communicative: □ Yes □ No □ How? __________________________

B. Preferred Music: __________________________

C. Previous Musical Experiences/Involvement:

D. Motivation—Music seems to be used by this client for: (choose 2 or 3)

■ relaxation
■ communication/expression
■ reminiscence
■ behavior modification

■ energy release
■ movement/exercise
■ validation
■ gaining insight

■ entertainment
■ increased esteem
■ redirect from external noise
■ reality orientation

■ escape/avoidance
■ intellectualization
■ thought organization
■ spiritual support

E. Affective response to music (observed):

F. Specific observed responses:

<table>
<thead>
<tr>
<th>Good</th>
<th>Fair</th>
<th>Poor</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Reception of MT

Awareness

Movement/Capability

Reality Orientation

Self Esteem

Social Skills

Preferred Instruments: □ Active □ Passive □ Eye contact: □ mostly □ Passive □ Responds □ Sometimes
□ Verbal □ Nonverbal □ rarely

H. Problem: (assessed)

I. Goal: (current primaries, choose 2 or 3)

■ Validate life (remission)
■ Discuss issues of death and dying
■ Maintain physical comfort
■ Facilitate decision-making
■ Facilitate relaxation skills
■ Orient to reality
■ Spiritual support

■ Identify and express emotions effectively
■ Facilitate socialization
■ Improve communication
■ Improve/maintain cognitive ability
■ Reduce perception of pain

■ Develop adequate coping skills
■ Use time constructively
■ Establish rapport
■ Modify behavior
■ Gain insight
■ Improve quality of life

J. Recommendations:

Patient Name: __________________________ (Last) __________________________ (First) MRN: __________________________

adapted/revised 1/03
APPENDIX D

HUMAN SUBJECTS COMMITTEE APPROVAL
Office of the Vice President
For Research
Tallahassee, Florida 32306-2763
(850) 644-8873 · FAX (850) 644-4392

APPROVAL MEMORANDUM
Human Subjects Committee

Date: 5/27/2003

Natalie Wlodarczyk
2677 Old Bainbridge Road, Apt. 1621
Tallahassee, FL 32303

Dept: Music

From: David Quadagno, Chair

Re: Use of Human Subjects in Research
The effect of music therapy on spirituality of persons in an in-patient hospice unit 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 Secretary, the Chair, and two members of the Human Subjects Committee. Your project is determined to be exempt per 45 CFR § 46.101(b) 2 and has been approved by an accelerated review process.

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 5/26/2004 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 assure 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.

Cc: Jayne Standley
HSC No. 2003.256
APPENDIX E

RAW SCORES
<table>
<thead>
<tr>
<th>SWB Scores/ M or Non M</th>
<th>Sub. 1</th>
<th>Sub. 2</th>
<th>Sub. 3</th>
<th>Sub. 4</th>
<th>Sub. 5</th>
<th>Sub. 6</th>
<th>Sub. 7</th>
<th>Sub. 8</th>
<th>Sub. 9</th>
<th>Sub. 10</th>
</tr>
</thead>
<tbody>
<tr>
<td>Day 1</td>
<td>68/M</td>
<td>108/N</td>
<td>87/M</td>
<td>47/N</td>
<td>70/M</td>
<td>40/N</td>
<td>95/M</td>
<td>67/N</td>
<td>70/M</td>
<td>86/N</td>
</tr>
<tr>
<td>Day 2</td>
<td>68/N</td>
<td>108/M</td>
<td>85/N</td>
<td>52/M</td>
<td>62/N</td>
<td>41/M</td>
<td>91/N</td>
<td>80/M</td>
<td>66/N</td>
<td>99/M</td>
</tr>
<tr>
<td>Day 3</td>
<td>72/M</td>
<td>108/N</td>
<td>88/M</td>
<td>49/N</td>
<td>76/M</td>
<td>41/N</td>
<td>100/M</td>
<td>76/N</td>
<td>73/M</td>
<td>92/N</td>
</tr>
<tr>
<td>Day 4</td>
<td>64/N</td>
<td>108/M</td>
<td>88/N</td>
<td>54/M</td>
<td>74/N</td>
<td>43/M</td>
<td>97/N</td>
<td>84/M</td>
<td>70/N</td>
<td>102/M</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Spiritual music requested by subject?</th>
<th>Subject 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>
</tr>
</thead>
<tbody>
<tr>
<td>Day 1</td>
<td>Y</td>
<td>N</td>
<td></td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Day 2</td>
<td></td>
<td>Y</td>
<td>N</td>
<td>N</td>
<td>Y</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Day 3</td>
<td>Y</td>
<td>Y</td>
<td></td>
<td>Y</td>
<td>Y</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Day 4</td>
<td></td>
<td>Y</td>
<td>N</td>
<td>N</td>
<td>Y</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Patient initiated discussion of spirituality on music days?</th>
<th>Subject 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>
</tr>
</thead>
<tbody>
<tr>
<td>Day 1</td>
<td>N</td>
<td>N</td>
<td></td>
<td>N</td>
<td>N</td>
<td>N</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Day 2</td>
<td></td>
<td>Y</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>Y</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Day 3</td>
<td>N</td>
<td>N</td>
<td></td>
<td>N</td>
<td>N</td>
<td>Y</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Day 4</td>
<td></td>
<td>Y</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>Y</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient initiated discussion of spirituality on non-music days?</td>
<td>Subject 1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
<td>10</td>
</tr>
<tr>
<td>---------------------------------------------------------------</td>
<td>-----------</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>----</td>
</tr>
<tr>
<td>Day 1</td>
<td></td>
<td>Y</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>Y</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Day 2</td>
<td>N</td>
<td></td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Day 3</td>
<td>N</td>
<td></td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>Y</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Day 4</td>
<td>N</td>
<td></td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
REFERENCES


BIOGRAPHICAL SKETCH

Name:
Natalie Marie Wlodarczyk

Date and Place of Birth:
April 15, 1978
Philadelphia, PA

Education:
Bachelor of Music Education
Stetson University
Deland, FL
1998-2001

Clinical Experience:
Music Therapist
Big Bend Hospice
Tallahassee, FL
5/03-present