The Effect of Music Therapy on the Perceived Quality of Life of Patients with Terminal Illness in a Hospice Setting

Caroline Marie Abbott
Western Michigan University

Follow this and additional works at: https://scholarworks.wmich.edu/masters_theses

Part of the Music Therapy Commons

Recommended Citation
https://scholarworks.wmich.edu/masters_theses/5273

This Masters Thesis-Open Access is brought to you for free and open access by the Graduate College at ScholarWorks at WMU. It has been accepted for inclusion in Masters Theses by an authorized administrator of ScholarWorks at WMU. For more information, please contact wmu-scholarworks@wmich.edu.
THE EFFECT OF MUSIC THERAPY ON THE PERCEIVED QUALITY OF LIFE OF PATIENTS WITH TERMINAL ILLNESS IN A HOSPICE SETTING

by

Caroline Marie Abbott

A Thesis
Submitted to the Faculty of The Graduate College in partial fulfillment of the requirements for the Degree of Master of Music School of Music

Western Michigan University Kalamazoo, Michigan June 1995
ACKNOWLEDGMENTS

I would like to gratefully acknowledge the following people, without whom this project could not have been completed: Carol Steger for providing child care without question or hesitation for entire days at a time so I could work on my research; Steve Abbott for computer assistance, for being a great moral support and for taking care of household tasks so I could work; to Joyce Abbott and Jennifer Kennedy for helping gather research materials and for helping with child care when needed. Without the help and support of these friends and family this research would never have been completed. I would also like to thank the members of my thesis committee, Brian Wilson, chair, Mary Scovel, and Ellen Page-Robin for their guidance and support. Thank you very much.

Caroline Marie Abbott
THE EFFECT OF MUSIC THERAPY ON THE PERCEIVED QUALITY OF LIFE OF PATIENTS WITH TERMINAL ILLNESS IN A HOSPICE SETTING

Caroline Marie Abbott, M.M.

Western Michigan University, 1995

The purpose of the study was to determine if there were any significant differences in perceived mood states between patients in hospice care who received music therapy services and patients in hospice care who did not receive music therapy services.

Twenty-eight participants were surveyed using the Profile of Mood States (short form). Fourteen participants received music therapy services for a minimum of five hours, and fourteen participants did not receive music therapy services. The participants were matched in pairs by gender, location, diagnosis, and age, and were patients in one of three hospice locations in the United States which agreed to participate in the study. Staff at each hospice location was responsible for choosing participants, securing informed consent and administering the surveys.

Results of paired t-tests revealed that there were no significant differences between the groups. Two factors approached significance, however. The participants who received music therapy had lower scores on the anger scale and higher scores on the fatigue scale than the non-music therapy participants.
TABLE OF CONTENTS

ACKNOWLEDGMENTS ................................................................. ii
LIST OF TABLES ........................................................................ vi

CHAPTER

I. INTRODUCTION

History of the Hospice Movement ........................................... 1
Historical Basis for Hospice Movement ................................. 1
History of the “Modern” Hospice ........................................... 2
Development of Hospice Philosophy ..................................... 3
Music Therapy ................................................................. 4
History and Development of Music Therapy ....................... 4
Music Therapy in Palliative/Hospice Care ......................... 6
Purpose of Study ............................................................. 7
Music Therapy and Quality of Life
in Patients With Terminal Illness ........................................... 7

II. REVIEW OF RELATED LITERATURE ............................... 10

Philosophical Issues and Hospice Care ................................. 10
Philosophy of Care in Hospice ........................................... 10
Models of Hospice Care .................................................. 11
Effectiveness of Hospice Care ........................................... 14
Issues Which Impact Quality of Life ................................. 18
Pain Control ....................................................................... 18
# Table of Contents--Continued

## CHAPTER

<table>
<thead>
<tr>
<th>Increasing Expression of Feelings</th>
<th>23</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spiritual Support</td>
<td>27</td>
</tr>
<tr>
<td>Increasing and Maintaining Quality Life Experiences</td>
<td>29</td>
</tr>
<tr>
<td>Decreasing Sense of Isolation and Regaining Personal Identity</td>
<td>30</td>
</tr>
<tr>
<td>Summary and Research Questions</td>
<td>32</td>
</tr>
</tbody>
</table>

## III. METHOD

<table>
<thead>
<tr>
<th>Design of Study</th>
<th>35</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participants</td>
<td>35</td>
</tr>
<tr>
<td>Materials</td>
<td>36</td>
</tr>
<tr>
<td>Procedure</td>
<td>38</td>
</tr>
</tbody>
</table>

## IV. RESULTS

<table>
<thead>
<tr>
<th></th>
<th>41</th>
</tr>
</thead>
</table>

## V. DISCUSSION

<table>
<thead>
<tr>
<th></th>
<th>44</th>
</tr>
</thead>
</table>

## VI. CONCLUSIONS

<table>
<thead>
<tr>
<th></th>
<th>48</th>
</tr>
</thead>
</table>

## APPENDICES

<table>
<thead>
<tr>
<th>A. Hospice Organizations Which Participated in the Study</th>
<th>50</th>
</tr>
</thead>
<tbody>
<tr>
<td>B. Protocol Clearance From the Human Subjects Institutional Review Board</td>
<td>52</td>
</tr>
<tr>
<td>C. Explanation for Not Including the Profile of Mood States Form With the Thesis Document</td>
<td>54</td>
</tr>
<tr>
<td>D. Survey Packet Given to Participants</td>
<td>56</td>
</tr>
<tr>
<td>E. Consent to Participate Form</td>
<td>62</td>
</tr>
</tbody>
</table>
LIST OF TABLES

1. Demographic Data of Participants ................................................................. 42
2. Results of t-test Analysis for Paired Samples .............................................. 42
CHAPTER I

INTRODUCTION

History of the Hospice Movement

Historical Basis for Hospice Movement

In ancient times hospices or hospitals were havens for the sick, the destitute and pilgrims traveling on journeys. The medieval hospices were generally run by religious orders. They were found throughout Europe and along the route to the Holy Land. The Knights of Hospitaller of the order of St. John of Jerusalem operated hospices in the 12th century AD throughout Europe and had land and hospices at one time in Rhodes, Cyprus, Italy, Germany and England. Hospice workers were required to be kind to patients or the workers were only given bread and water for a week and were whipped. During medieval times, life was not separated from death. Death was considered a natural part of life. Travelers, pilgrims and those who were dying were all housed together because all were on a journey and in need of comfort. During the reformation, many monasteries were closed and hospices and hospitals gradually became separate entities (Buckingham, 1983). Some hospice activity continued during this period. St. Vincent de Paul founded the Sisters of Charity in Paris in the 1600's and they operated hospitals which cared for the sick and dying. The first Protestant hospice, Kaiserwerth, was opened in Prussia over 100 years later (Backer, Hannon, & Russell, 1994).
History of the “Modern” Hospice

The first program to resemble a modern-day hospice was Our Lady's Hospice founded in Dublin in the late 1800's by the Irish Sisters of Charity. It served only patients who were dying. In 1902, five of the Sisters from Our Lady's Hospice opened St. Joseph's hospice for the poor who were dying in England. By that time, two other homes for the poor who were dying were also operating in London: (1) the Hostel of God, an Anglican home; and (2) St. Luke's, a Methodist home (Backer, Hannon, & Russell, 1994). The literature does not mention any new hospice organizations or changes in basic care within the hospices until the need was established in the 1950's for hospice type organizations to be developed more fully in England.

In 1951, the Marie Curie Memorial Foundation in England conducted a survey of patients who had cancer who were cared for in their homes. They concluded that,

> It is obvious to us that considerable hardship exists in the case of many families who are taking care of one member with cancer at home. In addition to providing skilled nursing treatment for the patient, the provision of residential homes could save much mental suffering, stress, and strain for the patients and the relatives. Beds in the hospitals might also be freed (Torrens, 1985, p. xv-introduction).

This survey established that a need existed for the type of services that hospices could provide.

At the time the Marie Curie Memorial Foundation report was published, Dr. Cicely Saunders was beginning medical school at St. Thomas's Hospital Medical School in London. Having already been trained as a nurse and a social worker, she now wanted to become qualified as a medical practitioner in order to improve the care of patients who were dying of cancer. Saunders had become friends with a man
dying of cancer in the late 1940's in a London hospital. The man bequeathed 500 English pounds to Saunders when he died to be used to build a hospice. He told Saunders, "I'll be a window in your Home." Over the next ten years, more gifts and much planning resulted in St. Christopher's Hospice. It was designed to combine the old concept of hospitality and care with the modern skills of a hospital (Buckingham, 1983). By 1967, the inpatient unit at St. Christopher's was opened, followed by the opening of a community-based service two years later (Clark, 1993). Often referred to as the founder of the modern hospice movement, Saunders was influential in starting other hospices in England and in the United States.

Hospice, Inc. in New Haven, Connecticut was the first hospice in the United States. Florence Wald, its founder, was a nurse at Yale-New Haven hospital and had considerable experience with patients who were dying. In the late 1960's she began to gather other professionals around her who had concerns about the quality of care for persons who were terminally ill. The group used St. Christopher's Hospice in England as a model, but made needed changes to accommodate the American lifestyle. Specifically, Hospice Inc.: (a) was not of or for one religious group, (b) was strictly for the terminally ill, (St. Christopher's had a wing for the elderly), and (c) used different drugs for pain relief. In 1971, the Hospice incorporated itself with a nonprofit, tax-exempt status and formally severed its ties with Yale University (DuBois, 1980).

**Development of Hospice Philosophy**

According to Ewens & Herrington (1983), in 1967, Elisabeth Kubler-Ross began to document the conversations she had with persons who were dying, their families and the nurses and doctors who were treating them. Kubler-Ross met with
much resistance when she began asking to interview patients who were dying. The patients appeared interested in talking to Kubler-Ross, and discussed the inadequacy of the present medical methods for meeting their most critical needs. In her subsequent book, *On Death and Dying*, Kubler-Ross outlined five stages of dying: (1) denial, (2) anger, (3) bargaining, (4) depression and (5) acceptance. Kubler-Ross intended these stages to be used as a teaching tool to help people understand the emotional struggles a person who is dying experiences. Although these stages continue to be challenged and misunderstood by many people, they are still regarded as the most concise and complete guide for helping those who work with persons who are dying. Even though Kubler-Ross’s research provides a general guideline for those who are working with the terminally ill, each individual experiences death differently and may not go through all the stages, or may go through them in a different order. Some individuals may spend more time in particular stages or move quickly through others. It is generally accepted, however, that a person who has reached the stage of acceptance and is at peace with him/herself will experience less emotional suffering at the time of death.

Music Therapy

**History and Development of Music Therapy**

The field of music therapy was developed as a profession at the end of World War II. Seen as primarily “activity” or “adjunctive” therapy, it was used to supplement “talk” therapy done by the psychiatrists in mental hospitals (Michel, 1976). The field of music therapy, along with similar therapeutic professions gradually became recognized as an important therapeutic psychiatric intervention for patients. Although
originally used primarily with patients in psychiatric hospitals, music therapy has expanded to a variety of populations including clients in hospice programs.

Munro defines music therapy as: "the controlled use of music, its elements and their influences on the human being to aid in the physiologic, psychologic and emotional integration of the individual during the treatment of an illness or disability" (1984, p. 104). When a music therapist works with a client of any population, the therapist uses his/her knowledge of music and its therapeutic potential as well as knowledge of the client population to bring about change in the client. Music therapy has been used with a wide variety of client populations. These include but are not limited to: (a) children with learning disabilities, (b) adults being treated for psychiatric disorders, and (c) adults suffering from dementia and other illnesses such as Alzheimer's Disease. The profession of music therapy continues to expand into other settings, including medical settings (Martin, 1989).

The fact that music is prevalent in all cultures of the world indicates its importance in our lives. Gaston stated, "There would be no music and no need for it if it were possible to communicate verbally that which is easily communicated musically" (1968, p. 23). Since musical sound has no specific meaning, it evokes emotions through common experiences learned in the social and cultural context in which one lives. Music can stand alone as communication of ideas and emotions, but it is often paired with other forms of communication, such as poetry (lyrics), or pictures (such as in television commercials or movies) to intensify the emotional content of the art form with which it is paired. In summary, "Music, while non discursive, does indeed transmit information, including emotional messages... it functions as a symbol capable of evoking feelings" (Gfeller, 1990, p. 59).
Music Therapy in Palliative/Hospice Care

Palliative/Hospice care is total care, meaning the entire person is treated, not just the physical components (Munro, 1984). The hospice philosophy of palliative care is comfort care. The use of music therapy with the terminally ill is a relatively new outreach for the profession (Martin, 1989). Over the last 15 years, several programs using music therapy with patients who are dying have been developed. Because the field of hospice care itself is quite new and is constantly evolving, it has taken time to develop workable techniques that fit into the hospice philosophy but also can be duplicated from hospice to hospice. Munro (1984) stated that: “In general, hospice care professionals know little about music therapy and music therapists are unfamiliar with terminal care” (p. vi). Her book, Music Therapy in Palliative/Hospice Care, was written to address that problem and expose other health care professionals involved in care for patients who are terminally ill to the possibilities music therapy offers in the field of palliative/hospice care. Munro explains the role of music therapy in hospice care as a catalyst or stimulus to help facilitate the patient's adjustment to life-threatening illness and impending death. “Music therapy thus aims at diminishing the impact of the crises around terminal illness and death, not resolving them” (p. 79).

The goals for music therapy with a patient who is terminally ill are different from those of other patient populations. It is necessary to identify the areas in which a person who is terminally ill needs the most support and comfort. Munro (1984) described four areas of a person's life in which adjustments must be made to cope with terminal illness and death as: (1) Physical, (2) psychologic, (3) social and (4) spiritual. “The multidimensional qualities of music allow it to touch many levels of consciousness. It can act as a catalyst in mobilizing deep feelings and can assist in both verbal and nonverbal communication” (Munro, 1984, p. 105). Brenda Calovini
and Susan Mandel of the Hospice of the Western Reserve in Cleveland, Ohio (B. S. Calovini, personal communication December, 1991) used the same basic categories to define the following goals for music therapy with patients: (a) reduction of pain perception, unrest and anxiety (Munro's physical category), (b) increasing expression of feelings (psychologic), (c) spiritual support (spiritual), (d) increasing and maintaining quality life experiences (psychologic and social), and (e) decrease sense of isolation and regain identity (social and psychologic). These goal areas identify critical factors which contribute to a person's overall quality of life.

Purpose of Study

Music Therapy and Quality of Life in Patients With Terminal Illness

There is a need for quantitative research in the field of music therapy in the hospice setting (Whittall, 1989). While objective outcome measures have been successful in other populations receiving music therapy treatment, most measures which are practical to use with the terminally ill are subjective in nature. In order to achieve more objective results, Whittall measured the heart rate, respiratory rate and extremity temperature of eight male and female subjects over a six week period. These physiological measures were chosen by the researcher as responses indicative of anxiety/relaxation in the subject. Responses were recorded ten minutes before a thirty minute music therapy intervention, every ten minutes during the intervention and ten minutes after the intervention with each subject being tested for approximately fifty minutes. The results showed a mean decrease in heart rates, a larger decrease in respiration rates and a small increase in extremity temperature. The researcher noted that the music therapy intervention involved breathing exercises to encourage
relaxation, which may have been responsible for the greater difference in respiration rates. It was also noted that bed bound patients often have poor circulation and lower extremity temperatures, which could explain the small difference in extremity temperatures. Whittall acknowledged that due to the small sample size and the fact that the subjects were only given music therapy treatment one time it is difficult to draw specific conclusions; however, this research does provide a basis for further study using physiological measures.

Forinash (1989) also acknowledged the lack of objective data supporting the use of music therapy with the terminally ill, but chose to measure her work using a phenomenological approach. Forinash felt that purely physiological data did not capture the essence of what occurs in a music therapy session, especially if the client is actively dying or is non-verbal. She wanted to find a way to capture the depth of feeling experienced in music therapy sessions with dying persons. As defined by Forinash, the phenomenological approach reports in detail what occurs during a music therapy treatment session with a client and allows the reader to draw his or her own conclusions as to the effectiveness of the treatment. The therapeutic intervention is usually reported by the client when using this approach. Forinash and a colleague played instrumental music which matched the respiration rate of the patient who was actively dying. They gradually adjusted the rate of the music to a slower tempo and adjusted the music to a more tranquil sound which led to the patient slowing her respiration rate and taking less labored breaths. The music continued to be played slowly and quietly until the patient died. Forinash reported that the intervention of music therapy appeared to have helped the patient die in a calmer, more relaxed manner. Although this measurement technique is not entirely objective, it does allow the reader to draw his or her own conclusions as to the effectiveness of the treatment
because it reports the content of the music therapy treatment session in detail as it occurred.

The challenge facing the music therapist who wants to research the effectiveness of music therapy treatment in the terminally ill population is to identify objective measures which also reflect the more subtle and subjective elements of the treatment and their effects on the clients. The purpose of this study was to determine the impact of music therapy intervention on the perceived quality of life of hospice clients who are terminally ill. This was measured by evaluating the patients' overall mood states as recorded in self-reports. Hospice clients who received music therapy services were matched in pairs with clients in the same hospice program who did not receive music therapy. The matched pairs were analyzed to determine if music therapy clients showed significant differences in mood as compared with non-music therapy clients. This study attempted to determine the impact of music therapy on the patients' quality of life. The construct of quality of life was defined according to the goal areas identified above.
CHAPTER II

REVIEW OF RELATED LITERATURE

Philosophical Issues and Hospice Care

Philosophy of Care in Hospice

Hospice philosophy affirms the living and treats the dying process as a natural part of life. Those who support the hospice philosophy acknowledge that even though dying is a natural process, many patients who are terminally ill need support physically, psychologically and spiritually in order to fully live out the remainder of their lives and to live comfortably with death (Davidson, 1985). The patient who is dying receives the message from his/her caregivers that he/she is unique and will be treated individually and in a special way. This is well stated by Dr. Cicely Saunders, “You matter because you are you. You matter to the last moment of your life, and we will do all we can not only to help you die peacefully, but also to live until you die” (Buckingham 1983, pp. 6-7). Florence Wald, founder of the first hospice in the United States, identified that (1) medical management, (2) comfort, and (3) spiritual care were the three primary objectives of hospice care (DuBois, 1980). Hospice attempts to give patients independence and control over daily events. Decisions such as scheduling, treatments, meal plans, and visitors are decided by the patient.

Hospice provides palliative, or comfort, care. This is an attempt to relieve the discomforts caused by the illness, but not to cure it. The emphasis is on quality of life when the quantity of life is limited. The hospice philosophy does not try to either
hasten or postpone death, rather the goal is to manage the patient's care as well as possible until death arrives. Hospice workers respect life and the individual person and they believe in allowing death to happen in its own time (Beresford, 1993).

Models of Hospice Care

Kubler-Ross (1981) favors the move toward hospice care for those who are terminally ill and considers hospice care superior to hospitalization for persons who are terminally ill. Kubler-Ross, as cited in Ewen and Herrington (1983), also expressed her opinion regarding the development of hospice programs:

In our eagerness to make this service of love available to all terminally ill patients, we need to go slowly, to become very selective in the choosing of the sites and especially the staff. We have to put all competition and monetary or political interests aside and work in the spirit of Mother Teresa, to serve our fellow man regardless of any other issues. We have to practice UNCONDITIONAL LOVE, as an example of living and dying. Those patients who have been cared for in this spirit will be able to talk freely about their anticipated death, they will be able to put their inner and outer houses in order and will be able to finish their unfinished business with those they will leave behind. What better way to do preventive psychiatry than to help the dying so they can teach the living! (pp. 7-8).

From this philosophy, several different models of hospice care developed in the United States. The Hospice Project Report (McCann, 1985) listed four different types of ownership models of hospices found in the United States at that time: (1) independent programs, (2) hospital based programs, (3) home health agency programs, and (4) long term care programs. Five other types of hospices also appear to be currently operating in the United States: (1) volunteer hospices, (2) coalition model hospices, (3) residential hospices, (4) hospices within health maintenance organizations, and (5) proprietary, or privately owned, profit-making enterprises
Independent programs are developed solely to provide hospice care to patients. In the United States, this model typically is home-care based. Known as "community based" hospice, the advantage of this type is that it has no priority other than caring for the dying. The disadvantage is that it does not enjoy the financial stability that comes from being a part of a larger organization (Beresford, 1993).

Hospital-based programs are administratively part of a hospital although some programs may provide some or all of the patient care in the patients' homes. Most, however, are closely integrated with the parent facility and are located on or near the oncology unit (Beresford, 1993).

Home health agency programs, as outlined by McCann (1985), provide care either by all home care staff, or by a separate hospice team within the agency. Beresford (1993) states that home health agency hospices are the closest functionally to community based hospice programs. He also states some important differences. Home health agency staff are not specialists in terminal care. Home health care reimbursement does not allow the time or intensity of care that is provided by hospice nurses, nor do they offer the full range of services, such as bereavement follow-up, provided by community based hospices.

Beresford (1993) describes long term hospice programs as similar to hospital based hospice services because they are housed in a larger facility and are only a part of the overall program of care. A section of the nursing home may be a specialized hospice unit, or services may be provided in patient's homes or both.

The volunteer hospice is run completely by volunteer staff. Beresford (1993) states that these programs are usually small and rural. McCann (1985) pointed out
that many hospice organizations began as volunteer hospices and evolved into full hospices with paid staff.

The coalition model is an umbrella group of health care agencies which contracts out the hospice services through community based programs. Beresford (1993) mentions that these hospices do not qualify for reimbursement and cannot directly control the patient care provided by the contractual agencies.

Residential hospices are hospice houses and their purpose is to provide longer term care in a home-like setting for those who cannot be cared for at home.

A small number of hospices are also based within health maintenance organizations such as Kaiser Permanente health plan in California, Group Health Cooperative of Puget Sound in Washington or other health care related agencies such as Veteran's Affairs Medical Centers.

Lastly, a few hospices in the United States are proprietary, or privately owned, profit-making enterprises. These are large scale, with a central administration which serves a large number of staff and covers several states. These hospices aggressively market their services. Some people feel this type of hospice is contrary to the idealism of the hospice philosophy, but there is no evidence the patients and families are less satisfied than those served by more traditional hospice programs (Beresford, 1993).

The hospices that participated in this study were of two different types. Two were independent hospices and one was affiliated with a health maintenance organization. The independent hospices were located in Cleveland, Ohio, a large urban area, and in Cambridge, a small rural area of Ohio. The third hospice was based in the Kaiser Permanente health maintenance organization in Los Angeles, California, which is also a large urban area (see appendix A). All three hospices provide in-home care to clients.
Collectively, hospice programs in the United States primarily serve patients with the following primary diagnoses: (a) cancer, 84%, (b) AIDS, 4%, and (c) other end-stage illnesses, 12%. Since the cost of hospice care at home, whether paid per day or per nursing visit, is likely to be prohibitive, hospices have sliding fee scales for self-payment which require only modest contributions from most families. The hospice organization is responsible for paying for all expenses for the patient from Medicare funds. Medicare hospices are so successful at managing their patients' care at home that well over 90% of the patients' days of care are spent at home, rather than in an inpatient unit (Beresford, 1993). Many hospices rely on community foundation grants as well as funding from other charitable organizations to supplement costs.

Effectiveness of Hospice Care

Since it offers a more personal, individualized program of care in which the patient is largely in control of treatment, hospice care has become widely accepted in the United States as an alternative to conventional care for the dying. Although the general assumption has been that hospice care is superior to conventional care, there is little scientific evidence regarding the effectiveness of hospice programs. In an effort to determine the effectiveness of hospice treatment Wales (1985), conducted a randomized control trial. The results of this study showed no significant differences between hospice patients and control patients in measures of pain, symptoms, activities of daily living, or affect. "Hospice patients expressed more satisfaction with the care they received, and the hospice patients' family caregivers showed somewhat more satisfaction and less anxiety than did those of controls" (Wales 1985, p. 134). There was no significant difference in inpatient hospital days, treatment procedures or costs. Wales found the randomized design of the study disrupted the normal routine of the
hospice in regard to referrals because they had to be routed through the research team instead of through the normal medical staff. Ethically, the researchers had to deal with the dilemma of denying treatment to patients who wanted hospice care but were not assigned to the hospice group, clients who wanted hospice care, but did not want to participate in the study, and those who were unable to give informed consent due to physical or mental limitations. The hospice in which the study was conducted had limited capacity and already had a waiting list and had to deny treatment on a regular basis. It was felt that the study simply changed the process by which patients were chosen for the program. Another problem was territorial jealousies between professional staff and research staff. A drop in the hospice census due to reduction of eligible candidates in the pool because of randomization was identified as another problem.

Morris, Sherwood, Wright, and Gutkin (1988) believe that quality of life has emerged as a significant, if not the most significant, factor in terminal care. They identified a series of outcome measures which they felt would be sensitive to change in a life span of only a few weeks. They are: (a) pain and symptoms, (b) functional status, both physical and mental; (c) emotional quality of life, (d) social involvement with informal supporters, and (e) satisfaction with care. They also considered the patient's quality of life as a global construct. The three issues which were considered to be critical to the evaluation of the hospice care were: (1) the length of exposure to the hospice program, (2) the measures of quality of life had to be relevant to the patient's life and sensitive to the changes brought on by hospice care, and (3) the general social environment within which hospice care was implemented had to be considered. A questionnaire was developed which considered these issues. Patients receiving hospice care at home, patients receiving hospice care in a hospital and
patients receiving conventional care were interviewed beginning within seven days of admission to the program and once every seven days after until the patient died. The principal care person, which was usually a close relative or friend answered the questions if the patient was unable to verbalize or process the information. The researchers found that pain appeared to be better managed in the institutionalized setting than in the home care setting. They found no significant differences between the three settings for overall quality of life. It was found, however, that patients in a home care setting fared significantly better in terms of social involvement than patients in a hospital setting. More social involvement was reported with persons other than the primary care person and the primary care person provided significantly more hours of care to the patient than similar patients in a hospitalized setting. No significant differences were found in regard to overall satisfaction with care. The most important finding the researchers identified was that hospice care had no negative effect on the lives of the terminally ill patients.

Wallston, Burger, Smith and Baugher (1988), question whether studies that have attempted to compare quality of life between hospices and conventional care institutions used measurement methods that are sensitive enough to capture the phenomena which hospice staff report. Although supporters of the hospice movement believe that hospice clients experience enhanced quality of life, research has not substantiated this belief. Wallston, et al. measured “quality of death” by developing a short survey in which the patients were asked what they wanted their last three days of life to be like. The authors titled the measure “quality of death” because it attempted to directly assess the stage of the patients' lives when they were actively dying. The final results of this study found that quality of death was indeed higher for clients cared for in hospices than those receiving conventional care. The measure of “quality of
death” does appear to address different issues than “quality of life”, in that it measures the differences between what the patient expected and what occurred during the active dying phase. Quality of life is more focused on maintenance of previous skills. All dying persons will naturally experience decreased quality of life if it is measured in terms of what is lost, rather than in terms of fulfillment of expectations in the dying process.

Torrens (1985) described quality of life for a person with terminal illness as having two major dimensions: (1) self perceptions and (2) discomfort. He defines self-perceptions of well-being as relating to independence in self-care, desire for food, and overall assessment of personal condition. Discomfort is described as pain and difficulty sleeping. The hospice environment promotes independence in self-care and avoids invasive procedures. Hospices also have symptom control as a major objective. These factors lead to enhanced quality of life. Torrens also states that although studies have been done which describe the negative consequences of hospitalization for persons who are terminally ill and the positive aspects of hospice care, the actual differences are uncertain. Torrens attributes this blurring of differences to the positive impact the hospice movement has had on hospitals, causing hospital care to change as a result of the hospice movement to provide some of the same benefits hospice services provide.

In summation, the research literature is somewhat inconclusive as to whether hospice care does indeed enhance quality of life. The research does appear to support the assertion that patients who chose hospice were in general satisfied with their care and content with their choice to receive hospice care. There also appeared to be no negative effects associated with hospice care as opposed to conventional care. Many hospice supporters also argued that hospice philosophy has become so widespread,
that the differences between conventional care and hospice care are not as pronounced as they once were. It is their view that the hospice movement has had a positive impact on all care for the terminally ill. It is difficult to test this assumption. Because the quality of one's life can only be determined by the individual, this study employed self-reports of mood states to determine the impact of treatment.

**Issues Which Impact Quality of Life**

There are several important issues which appear to be contributing factors to overall quality of life in terminally ill clients. These factors are discussed in relation to the goal areas previously mentioned for aiding in resolution and achieving acceptance in clients with terminal illness.

**Pain Control**

"The fear of pain is probably the first thing that comes to mind when people think of a prolonged death" (Ewens & Herrington, 1983, pp. 26-27). Ferrel, Wisdom, and Wenzl (1989) found that pain appeared to have the most impact on an individual's perception of quality of life because it impacted the physical, psychological, social, and spiritual domains of the patients they studied. When the patient was in pain, it became the focal point of his/her life. Persons who were not in pain did not mention it as being a factor in their overall quality of life.

Saunders (Torrens, 1985) felt that without pain control, little else could be done to help the patient who was dying. She experimented with new approaches to pain control such as using higher doses of pain medication than had been used in the past, and beginning to use the medication in anticipation of the pain, rather than after it
had already started. As a result of her efforts, her patients reported that they were virtually pain-free, thus allowing them to focus on other personal and emotional problems. Ewens & Herrington (1983) stated that they were able to control pain in patients who were terminally ill in 80% - 85% of cases, and that better results were achieved when medication was given on a regular basis rather than as needed.

Saunders (Buckingham, 1983) felt that the first step to treating a patient's pain or discomfort was to listen to the patient and modify treatment based on the individual’s need. She stated, “The fear of pain increases pain itself by geometric proportions” (pg. 7). This was why she advocated giving pain medication prior to the onset of pain.

Saunders (Davidson, 1985) claims that at St. Christopher's Hospice no requests have been received from patients to be mercifully killed. She believes it is due to the hospice's ability to control the dreaded conditions of dying, such as pain.

Kubler-Ross makes a similar statement regarding pain control and euthanasia requests:

> With MSC, the oral morphine medication, we are now able to take care of the patient's pain in almost 98% of cases. The request for active euthanasia has dwindled down to practically zero. If the patient's needs (physical, emotional, intellectual, and spiritual) are taken care of, no patient asks to be "put out of this life." With adequate counseling and the emphasis on the enhancement of the spiritual quadrant, the patients grow in leaps and bounds, and many of my terminal patients have emphasized to me that the last six months of their life were the most valuable months of their entire existence (Beresford, 1993, pp. xi-xii.)

LeShan (1983) suggests that a therapist can reduce a patient’s pain by helping him or her to refocus attention from the pain to outside events such as work, occupational therapy, and relating to others. Eagle and Harsh (1988) discussed the connections between music and pain. Music and pain are processed in some of the same areas of the brain. Both music and pain are sensory input. Eagle and Harsh theorized that a person in pain could be treated with music which paralleled the pain
Brown, Chen and Dworkin (1989) did a review of relevant literature of music used in pain control. The largest amount of information available was music used as audioanalgesia, mostly in dental procedures. The studies which were reviewed showed positive effects of music which allowed for less use of analgesic medication and made the patients more relaxed. The authors concluded that the reports were encouraging, but were not objectively controlled studies for determining the specific effects of music on people experiencing pain and medical problems. Brown, Chen and Dworkin also reviewed articles which dealt with the cognitive component of pain. This avenue seemed to have more potential for using music for pain control. Brown, Chen and Dworkin stated that the qualities of music which could be useful for developing effective coping strategies for pain control were the attention-distraction dimension and the affect dimension. The distraction dimension is the ability to lose
one's self so completely in the music that the sensation of pain may be diminished and
the suffering greatly reduced. The affect dimension allows the patient to express
moods and emotions through music and helps relieve the emotional pain and suffering
the patient may be experiencing. Brown, Chen and Dworkin concluded that actively
listening to music in a structured fashion may alter the perception of pain through
cognitive processes.

Using music as a distraction was an effective technique in eliminating pain and
stress in dental patients according to Anderson, Baron and Logan (1991). McCaul
and Malott (1984) reported that in regard to distraction as a technique to control pain:
“Distraction will have stronger effects on pain stimuli of low intensity” (p. 516). This
was based on review of research which used a variety of stimuli as distractions,
including music. Music by itself, obviously could not presume to control the type of
pain a terminally ill person experiences. Its ability, however, to create a more relaxing
environment and to distract the patient from focusing on the pain itself may provide
relief that medication alone cannot. It may also help the pain medication become more
effective by positively influencing the psychological, social and spiritual well-being of
the client. This in turn may allow for a reduced dosage of medication to effectively
alleviate the client's pain.

The responses of patients who were hospitalized to music therapy intervention
were studied by Goloff (1981). Goloff found that patients reporting “a lot” of physical
discomfort decreased from 19% to 11% following music therapy intervention.
Patients reporting no discomfort increased from 43% to 54%. Wolfe (1978) used
music therapy with patients in a clinic who suffered from chronic pain and found that
the patients who received music therapy exhibited increased physical activity. Godley
(1987) treated chronic pain patients with a combination of music and biofeedback.
Godley reported that patients stated that when they entered a music therapy session experiencing high levels of pain, they often left feeling much less or no pain. A decrease in pain medication use was observed in approximately 70% of patients who received music therapy and the patients often substituted listening to a tape for pain medication. Approximately 75% of the patients reported a decrease in the sensation of pain following treatment by Godley. The author qualified these findings by stating that the results were observational data collected only by the researcher.

Munro (1984) discussed the effect music therapy had on patients in the hospice program who were experiencing pain that was not being adequately controlled by medical intervention. The pain led to anxiety and depression in one patient and insomnia in another. Through musical improvisation, Munro was able to intervene with the first patient and open a discussion of feelings which increased the patient’s insight. The nurses who cared for the patient noted that he appeared relaxed and focused on outside stimuli rather than his pain following the music therapy intervention. The other patient was given music tapes and headphones by the music therapist. He later chose to listen to a tape of ocean waves which the music therapist had called to his attention. He was able to relax and fall asleep listening to the music. The patient’s pain became more controlled due to the adequate rest he achieved by using the music as a relaxation tool.

These examples illustrate the potential effect of music in reducing the perception of pain in patients who are terminally ill. In some cases, music was the most effective treatment in controlling the patient’s pain or discomfort.
Increasing Expression of Feelings

Once the physical pain has been controlled, quality of life issues begin to center on emotional pain and the need to express unresolved emotions in a way that can bring healing and lead to resolution and acceptance. Stedeford (1983) stated that it is important to establish a good rapport with patients who are dying so the patient feels free to talk and can discover the relief that comes from being understood and accepted. A number of common feelings are expressed in persons who are dying, these include: (a) dependency, (b) anger, (c) loss of self-esteem, (d) guilt, and (e) the loss of pleasure. "It is clear, however, that dying people can experience considerable pleasure and satisfaction from a variety of sources, including their own self-image and familial contacts, and often must be helped and encouraged to do this” (DuBois, 1980, p. 58).

The use of expressive arts therapy which includes music therapy and art therapy, can help patients who, “feel lonely, isolated, confused tense, or otherwise in need of the enhanced quality of life that arts activities can offer” (Beresford, 1993, p. 46). Music therapy has been used effectively to reduce state anxiety and increase relaxation in response in various types of client populations. Davis and Thaut (1989) tested the effect of preferred relaxing music on state anxiety, relaxation and physiological response of eighteen subjects ranging in age from 18 to 43. The subjects chose their own music and each subject was tested on three separate occasions. Physiological response data collected included: vascular constriction, heart rate, muscle tension and finger skin temperature. Psychological testing included the Spielberger State Anxiety Inventory and a seven-point Likert type scale for self-rated relaxation. Results indicated that state anxiety decreased and relaxation increased across all trials. The physiological response was arousal, however. Thaut (1989)
conducted an investigation of the effect of music therapy on self-rated changes in relaxation, affect and thought in psychiatric prisoner-patients. The study was conducted over a three month period with eight groups of subjects. There were 50 participants in all. Each group participated in group music therapy, instrumental group improvisation and music and relaxation. Three scales were used to measure changes. These scales were derived from a survey of 130 prisoner-patients which discussed the therapeutic benefit of participating in music therapy. The results indicated significant change in self-perceived ratings across all scales before versus after music therapy. The reduction of anxiety and increase of relaxation response appears to be most effective when preferred music is used.

The use of music with patients with cancer provides an outlet for dealing with both physical and emotional pain. "The use of songs in music therapy is effective in providing them with important means for support and tools for change. The verbal messages about people, places, feelings events, and desires encourage resolution of issues and processing of grief" (Bailey, 1984, p. 5).

Colligan (1987) wrote about a patient who was extremely tense and anxious when he entered the hospice. She began her music therapy intervention by finding songs which he had requested. Colligan discovered that the patient expended a large amount of anxious energy talking during the music. Colligan gradually focused his energy into listening, then active listening and eventually active participation in music related activities which allowed him to express his feelings. Through this process, the patient was able to move gradually closer to the stage of acceptance of terminal illness and impending death. The patient was quoted as saying, "The music took my mind off myself and put it on important matters, otherwise I would have been worrying about my illness. Besides, I love music and I can express myself." The patient also told the
Colligan, “You know, I can't tell anyone else but you how I feel. Everyone else would say I was crazy. But with you I can tell how the music and the words really make me feel with all the flowery words that I want to use. I can really tell you how I feel.”

Colligan felt the music therapy had appropriately directed the patient through the stages of dying as outlined by Kubler-Ross.

An experience in which a woman who was non-verbal and non-ambulatory wheeled herself into a room in which the music therapist was playing music was described by Brown (1992). The staff at the hospice had never seen her move anywhere on her own. Brown made a point to visit her individually after that. He played music for her. He knew she was unable to speak. He told her he knew she enjoyed music and understood everything he said. Brown described the patient's response this way, “Then, she got that indescribable look on her face I've seen on other patients since-- the look that says, 'Thank God you understand.'” (p. 13).

Through music, Brown felt he was able to bridge the gap of the patient's inability to communicate and create a common bond of musical experience.

Fagen (1982) discussed the use of music therapy with pediatric patients who were terminally ill. The music therapist focused on reducing anxiety and fear in the patients. A variety of music therapy techniques were used with the patients both in individual and group therapy. The music therapist used song writing, song selection, lyric substitution, improvisation and guided imagery to encourage the children to release their fears. Fagen reported that the music therapy intervention was significantly helpful in treating the anxiety and fear in the patients. This was not documented with any objective data, however.

The effects of music therapy and medical play therapy on the verbalization behavior of hospitalized pediatric patients were compared by Froehlich (1984). The
purpose of the study was to determine whether a music therapy session was more effective in helping the child to verbalize feelings about hospital experiences than medical play therapy. Nineteen subjects were in the play therapy group and 20 were in the music therapy group. The mean age was 7.75 years with age range of 5 through 12 years. Five music therapy activities were used for each session. Each session was conducted individually with the patient. The activities included: (1) a song for social interaction and exchange of names, (2) movement, (3) playing instruments, (4) inserting original lyrics into songs on hospitalization topics, and (5) a good-bye song/closure activity. Four questions were asked through a song about hospitalization and illness. The medical play therapy sessions began the same way as the music therapy sessions, with introductions. The therapist then read and discussed the children's story, *What Happens When You Go to the Hospital*. The patient was then encouraged to talk about feelings and personal experiences prompted by the pictures in the book. After this, the patient was allowed a period of free play, using a variety of medical tools and materials to “doctor” the therapist. The same four questions asked in the music therapy session were then asked of the patient verbally. Following this, the session was closed verbally. A significant difference was found between the two groups, with the music therapy responses being significantly more involved, meaning there was more sharing of hospital experiences and feelings, than the play therapy responses.

The ability of music to allow patients who have difficulty verbalizing emotions or have lost the ability to verbally communicate to express themselves has been documented in these case examples. The ability of music to reduce anxiety and increase relaxation response has also been documented. The use of music with the
terminally ill allows an outlet for expression that cannot be duplicated using only speech.

**Spiritual Support**

A person's view of death and acceptance of the dying process is greatly influenced by his or her spiritual belief system. It is important to recognize the importance of spiritual issues with persons who are dying and to offer support and appropriate outlets for them to express their beliefs so they may draw comfort from them. Hoy (1983) recorded this quote from the National Hospice Organization in its statement of standards in 1979:

Hospice exists in the hope and belief that, through appropriate care and the promotion of a caring community sensitive to their needs, patients and families may be free to attain a degree of mental and spiritual preparation for death that is satisfactory to them...Personal philosophic, moral, or religious belief systems are important to patients and families who are facing death...Hospice care is respectful of all patient and family belief systems (p. 180).

An encounter with a patient who was in physical and emotional pain due to a facial tumor which had caused serious disfigurement was described by Munro (1984). The music therapist had discovered that the patient loved music and used to sing in a church choir. The patient was whimpering when the music therapist entered the room and introduced herself. The music therapist began to sing a well-known hymn. As soon as the music began, the patient stopped whimpering and reached for the music therapist's hand. The therapist kept singing different hymns and the patient continued to squeeze the therapist's hand each time a new song began. The patient attempted to mouth some of the words to the hymns. The music therapist described the effect of the music this way: "The hymns had transformed the hospital room into a sacred place filled suddenly with an inexplicable divine presence." After awhile the music therapist
stopped singing and the therapist and patient sat in silence. When the music therapist got up to leave, the patient squeezed the therapist's hand and quietly said, "Thank you." The patient died the next day.

Colligan (1987) discussed a patient who was diagnosed with terminal cancer. The patient had taught piano lessons for years and also was a Catholic and had found comfort in the Lord throughout her lifetime. The music therapist discovered the type of music which the patient appeared to like the most. The music therapist then incorporated this music into relaxation exercises. The relaxation routine was to listen to the music, then read scripture and pray while the music continued. The patient was greatly comforted by Biblical passages, especially the 23rd Psalm. The patient often commented after a session, "You have no idea how much better I feel." As the patient drew nearer to death, she wanted less from the music therapist, but still wanted the support and the presence the therapist offered. The patient asked the music therapist to remain with her awhile after the formal sessions were completed and just hold her hand, or play the piano softly. The music therapist reported that the patient reached her ultimate understanding. The patient had asked, "Does God love me?" and had found the answer through her sessions with the music therapist. Colligan stated: "Music therapy had helped her in her journey" (p. 118).

For many individuals, music is a vital part of the expression of their religious beliefs. Because of this, music has the power to comfort the individual in a unique way. Some patients and/or families request religious music to be played even as the patient is actively dying. In many instances, the music therapist may be asked to participate in the memorial service after the patient has died.
A dying person may feel he or she has become useless and is a burden to others. Often the individual begins to see himself or herself as the disease rather than as the person he or she is. When the patient is given appropriate outlets for creative expression, he or she may begin to feel there are still areas in which he or she can contribute to life and can still experience satisfaction from living.

In discussing the role occupational therapy has in maintaining the quality of life for patients with terminal illness, Tigges (1983) states that, “Life without self-direction, independence, self-esteem, purpose and the ability to interact constructively with or to influence other people seems to have no value or meaning” (p. 161). It is Tigges' assertion that through the intervention of occupational therapy, the patient can find purpose, self-esteem and the ability to interact constructively with other people. Music therapy addresses many of these same goals, but uses music to open the door to creative self-expression.

Munro (1984) treated a patient who became interested in buying a piano. The patient had not played previously, but wanted to learn. The drive for the piano and the desire to express himself on it once he obtained it gave him purpose in life. When the patient became too ill to play the piano, his wife taught herself to play and played it for him. The patient stated: “The great thing with music is that you can enjoy it even when strength fails you.” (p. 5). The music therapist had taught the patient to improvise to express his feelings as well as playing traditional music. The therapist had also left several recordings with the patient for him to listen to when she could not be there. Following the death of the patient, his wife wrote to the music therapist and explained how important the music had been in enriching the last days of his life. The
patient's wife found comfort in listening to the music she and her husband had listened to together before he died.

The quality of a person’s life appears to be best determined by the individual who is experiencing terminal illness. A person who has enjoyed music throughout his or her lifetime may find it to be a satisfying experience to participate in music, even playing instruments that he or she may never have had the time to pursue during the more active phases of life. For some individuals it is an opportunity to experience something they always wanted to do before they die. This can bring joy and satisfaction to a person who is facing their final days on earth.

Decreasing Sense of Isolation and Regaining Personal Identity

A person suffering from terminal illness may become so engulfed by the disease that he or she sees him/herself as the disease and no longer as a person. A sense of isolation may also develop due to the person being house-bound or bed-bound with minimal contact with others except for the primary caregiver.

As human beings, it is our tendency to isolate and ignore what frightens us and we have been afraid of death, states Buckingham (1983). Persons who were dying in the recent past and even sometimes today were sent to hospitals simply because they were dying, even if the hospital could do nothing for them. The hospice environment allows the patient to be cared for at home where he/she is not isolated from the rest of the community and death becomes a more naturally accepted event. Wallston, Burger, Smith and Baugher (1988) compared the quality of death of patients who were dying in conventional care institutions such as hospitals and patients who were cared for by hospice organizations. In the process of developing the tool they used to measure quality of death, the researchers asked the patients to describe what they most desired
for the last 3 days of their lives. The top two responses were: (1) to have people the
patient wanted present with him/her, and (2) to physically be able to do what he/she
wanted to do.

Lewis (1982) researched how experienced personal control, or the ability to
control the circumstances around oneself, affected the quality of life for late stage
patients with cancer. He used a self esteem scale, a locus of control scale an anxiety
scale and a purpose in life scale to determine the patient's perception of quality of life.
Lewis found that experienced personal control over one's life was the most significant
predictor of quality of life. Personal control over life was significantly correlated with
anxiety, self-esteem and purpose in life.

The effects of live music versus tape recorded music on hospitalized patients
with cancer were compared by Bailey (1983). She recorded pre and post music mood
states using the Profile of Mood States (POMS) questionnaire and found that the live
music subjects reported significantly less Tension-Anxiety and more Vigor than did the
subjects who received taped music intervention. The live music subjects also reported
significantly more changes in physical discomfort, changes in mood, changes in mood
for the better, and recommended music sessions for others. Bailey concluded that the
human contact in the music therapy intervention made a significant difference in the
mood states of the clients.

Lochner and Stevenson (1988) described an encounter with a 40 year old
woman who was dying of ovarian cancer. The patient had accepted the fact that she
was dying and could discuss it freely, but she felt a sense of isolation from her
children. The music therapist talked to the children and found that they were afraid of
losing control and crying in front of their mother. The music therapist tried to get the
family to talk about these issues, but the family could not seem to get started. The
music therapist wrote a song which he felt expressed the patient's feelings. The music therapist played the song for the patient and asked if he could share it with the rest of the family. The patient agreed, and the music therapist got the family together and played the song which he had entitled, “Stay By My Side”. The family members began to cry and the song opened the door for them to discuss their feelings with the patient.

The ability of music to draw family members together, facilitate the expression of their feelings to one another, and even to increase their personal insight helps bridge the isolation that can occur even when family members are around. The positive expression of feelings and personal insights also helps the patient and the family members to become a cohesive unit in which they can strengthen one another and avoid isolation of the patient or any other family members.

Summary and Research Questions

According to the professional literature, reducing pain perception, increasing expression of feelings, spiritual support, increasing and maintaining quality of life, decreasing isolation, and regaining identity may positively influence both the mood state and the quality of life of the patient. It was the purpose of this study to determine if music therapy interventions designed to address the aforementioned goals could significantly increase the quality of life of hospice patients. Specifically, the study attempted to answer the following questions:

1. Do hospice patients that receive music therapy have lower levels of depression than similar patients who have not received music therapy?

2. Do hospice patients that receive music therapy have lower levels of anger than similar patients who have not received music therapy?
3. Do hospice patients that receive music therapy have lower levels of fatigue than similar patients who have not received music therapy?

4. Do hospice patients that receive music therapy have lower levels of confusion than similar patients who have not received music therapy?

5. Do hospice patients that receive music therapy have higher levels of vigor than similar patients who have not received music therapy?

6. Do hospice patients that receive music therapy have lower levels of tension than similar patients who have not received music therapy?

7. Do hospice patients that receive music therapy have a lower Total Mood Disturbance score on the Profile of Mood States (POMS) than similar patients who have not received music therapy?

The following null hypotheses were tested using the Profile of Mood States (POMS) as a measuring tool:

1. There will be no significant difference between the scores of patients receiving music therapy and patients who have not received music therapy on the depression/dejection scale of the POMS questionnaire.

2. There will be no significant difference between the scores of patients receiving music therapy and patients who have not received music therapy on the anger/hostility scale of the POMS questionnaire.

3. There will be no significant difference between the scores of patients receiving music therapy and patients who have not received music therapy on the fatigue/inertia scale of the POMS questionnaire.

4. There will be no significant difference between the scores of patients receiving music therapy and patients who have not received music therapy on the confusion/bewilderment scale of the POMS questionnaire.
5. There will be no significant difference between the scores of patients receiving music therapy and patients who have not received music therapy on the vigor/activity scale of the POMS questionnaire.

6. There will be no significant difference between the scores of patients receiving music therapy and patients who have not received music therapy on the tension/anxiety scale of the POMS questionnaire.

7. There will be no significant difference between the scores of patients receiving music therapy and patients who have not received music therapy on the Total Mood Disturbance score.
CHAPTER III

METHOD

Design of Study

Participants

Study participants were clients who received hospice care for terminal illness. These patients were chosen from three hospice organizations in the United States which provided music therapy services to their clients. All three hospices provided treatment to their patients in the patients' homes. Two of the hospices were community-based, non-profit hospice organizations, the third hospice was based in a Health Maintenance Organization, but provided services in the patients' homes (see Appendix A). Fourteen participants comprised each group. The subjects were matched in pairs by the music therapists at the participating hospices. One member of each pair was a patient who received music therapy and the other member was a patient who did not receive music therapy. Music therapists at each site were responsible for selection of music therapy clients. Clients who were in the non-music therapy group were chosen by the music therapists in conjunction with other hospice staff. Participants were chosen for the music therapy group who had received music therapy services for at least five hours and were able to complete a consent form personally. Non-music therapy clients were chosen as matches to those in the music therapy group based on age, gender, location, and diagnosis. The non-music therapy clients were required to be able to complete a consent form personally, as well.
Materials

The tool that was used to measure the perceived quality of life of the study participants was the Profile of Mood States, (POMS) short form, published by Edits. This tool was chosen because of its brevity and the non-threatening question format. In a pilot study conducted by this researcher the “Quality of Life Instrument” (QOLI), developed by Ferrell, B.R., Wisdom, C., & Wenzl, C. (1989), was administered along with the POMS. The return rate for the QOLI was less than 50%, the POMS had a return rate of approximately 85%. Patients who participated in the study appeared to be threatened by the direct language in the QOLI, which asked specific questions about terminal illness. Patients and nurses reported the POMS was less threatening, easier to understand, and easier to administer. Although the information collected by the POMS is less specific than the information in the QOLI, the decision was made to use a survey which could yield the highest return rate possible.

According to McNair, Lorr, and Droppleman (1992) “mood scales have proved to be particularly useful descriptive measures for assessing psychiatric outpatients and very sensitive indicators of their responses to various therapeutic approaches” (p.1). The POMS measures moods in six categories: (1) Tension-Anxiety, (2) Depression-Dejection, (3) Anger-Hostility, (4) Vigor-Activity, (5) Fatigue-Inertia, and (6) Confusion-Bewilderment. This test has established reliability and validity. Internal consistency is reported by McNair, et al. as follows, “All these indices of the extent to which the individual items within the six mood scales measure the same factor are near .90 or above” (p. 7). The indices referred to are data from studies done by the developers of the POMS scale to test its reliability. Test-retest reliabilities ranged from .65 for Vigor to .74 for Depression. McNair, et al. explain the lower stability scores as an indication of changing mood states. The test is
not intended to measure personality factors which are consistent, but to test moods, which are variable, so they would likely change from one testing time to the next. Although this tool was developed for use with psychiatric patients, the publishers cited four specific studies in which the POMS was used to measure mood disturbances in cancer patients. The distributors suggest that the test can be completed in 3-5 minutes. This is desirable when testing a population which is easily fatigued.

In determining effectiveness of treatment with live music versus taped music with cancer patients, Bailey (1983) measured her patients' mood states using the Profile of Mood States (POMS). Fifty subjects ranging in age from 17 to 69 and who were diagnosed with cancer participated in the study. The subjects each listened to 25 minutes of either live or tape recorded music. The POMS questionnaire was administered before and after the music listening sessions. The live music subjects reported significantly less (p < .05) Tension-Anxiety and more Vigor than did the taped music subjects. The live music subjects also reported significantly more changes in physical discomfort (p < .05), changes in mood (p < .01), and changes in mood for the better (p < .001); and would recommend music sessions for others (p < .01). Bailey concluded that the POMS yielded useful results with hospitalized cancer patients.

Because approximately 84% of hospice patients are diagnosed with cancer (Beresford 1993), the POMS was chosen as an appropriate tool to measure mood states in hospice patients. Based on information gathered in a pilot study by this researcher, the POMS short form appeared to be relatively easy to understand and administer and asked questions which were non-threatening in nature, which assured greater participation from subjects.
Procedure

A list of all music therapists working in hospice settings who were members of the National Association for Music Therapy and the American Association for Music Therapy were compiled from their membership directories. Music therapists affiliated with twelve hospices in the United States and Canada were initially contacted by the researcher from the list. Other music therapists who were working in hospice settings were also recommended to the researcher by persons who were initially contacted. Seven hospices were eventually identified in which the music therapist was willing to participate in the study and the clients were well enough to participate. One of these was eliminated because (a) it was hospital-based and all the others were community-based and (b) the music therapist would have to do all surveying personally without assistance from other staff members. Of the remaining six hospices, only three consented to participate in the study. Each participating hospice completed a Consent to Participate form (see Appendix E) which required the signatures of both the music therapist and the executive director of the hospice indicating that they understood the purpose and requirements of the study.

The music therapist at each site was asked to use personal judgment in tandem with the above stated guidelines when choosing appropriate participants. Each participating music therapist received packets of survey materials. The packet for each subject included a directions for administration of survey materials sheet, two patient consent forms, a statement to be read to the clients prior to administration of surveys which includes some brief demographic information which had to be filled out by the client, and a copy of the survey form (see Appendix E). The music therapist was instructed to ask another staff person at the hospice to administer the surveys to the clients. In order to diminish the possibility of the patients answering the questions
in a falsely positive manner to please the music therapist, a primary nurse, social worker, or other staff person with whom the client was comfortable administered the survey according to the guidelines included in the survey packet. The staff members who administered the surveys were asked to do so before the interventions they were scheduled to complete that day were done to insure that the treatment provided would not bias the information the client recorded on the surveys. The staff person read a prepared statement to the patient which explained the study and that it was the patient's choice to participate, not an obligation. The patient was asked to read and sign the consent form before completing the surveys. The patient had to be able to sign the consent form personally to participate. Included in the survey packet was a brief demographic information sheet which the patient was asked to complete along with the Profile of Mood States form. The staff members could assist the patients by reading the forms to them, and by recording answers, but the patients were required to provide all answers without asking the opinion of the surveyor. The staff person who administered the survey returned the entire packet of information, including the consent forms to the music therapist at the hospice, who organized the participants into matched pairs and then sent the completed forms to the researcher for analysis.

The music therapists who participated in the study used a variety of music therapy techniques tailored the treatment to fit the need of their individual patients. The types of interventions typically used by the music therapists who participated in the study included: (a) active listening to music (this involved having the client discuss the song, its meanings and any relationship it may have had to his or her own situation); (b) relaxation to music (this included guided imagery, progressive relaxation, and listening to preferred music without therapist intervention); (c) life review activities (this involved using songs to help the client recall memories and
discuss feelings and events which impacted his/her life); (d) song composition (this was done with varying levels of assistance from the music therapist); (e) recording compositions and improvisations, (f) playing instruments in either a structured manner or an improvisational manner, and (g) creating and gathering music for memorial services.
CHAPTER IV

RESULTS

Demographic data indicated that of the fourteen participants in the music therapy group, 9 were female and 5 were male. Since the groups were matched for gender, the non-music therapy group also had 9 female members and 5 male members. The diagnoses in the music therapy group were as follows: Cancer - 50%, AIDS - 14.3%, Heart Disease - 7.1%, Chronic Obstructive Pulmonary Disease (COPD) - 14.3%, Lymphoma - 7.1% and Amyotrophic Lateral Sclerosis (ALS) - 7.1%. The non-music therapy group was comprised of the following diagnoses: Cancer - 57.1%, AIDS - 14.3%, Heart Disease - 7.1%, COPD - 14.3%, and Lymphoma - 7.1%. All pairs were matched by diagnosis, except one pair which included one female patient with cancer who did not receive music therapy and one female patient with ALS who did receive music therapy. The participants ages were in the following ranges: 30 - 49 years - 5 participants, 50 - 59 years - 2 participants, 60 - 69 years - 6 participants, 70 - 79 years - 11 participants and 80 - 89 years - 4 participants (see Table 1).

Paired t-tests were run on the matched pairs of subjects for each of the six factors measured by the Profile of Mood States and on the total mood disturbance scores of each pair. The factors were: (1) Tension/Anxiety, (2) Depression/Dejection, (3) Anger/Hostility, (4) Vigor, (5) Fatigue, and (6) Confusion. There were no significant differences found between any of the pairs on any of the factors. Two of the factors did approach significance and could be viewed as trends. The music therapy participants exhibited less anger, \( p = .095 \) than did non-music therapy participants.
The music therapy participants also displayed more fatigue than non-music participants, (p = .057) (see Table 2).

Table 1
Demographic Data From Participants

<table>
<thead>
<tr>
<th></th>
<th>Music</th>
<th>Non - music</th>
<th>Male</th>
<th>Female</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer</td>
<td>50%</td>
<td>57.1%</td>
<td>4</td>
<td>11</td>
</tr>
<tr>
<td>AIDS</td>
<td>14.3%</td>
<td>14.3%</td>
<td>4</td>
<td>0</td>
</tr>
<tr>
<td>Heart Disease</td>
<td>7.1%</td>
<td>7.1%</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>COPD</td>
<td>14.3%</td>
<td>14.3%</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Lymphoma</td>
<td>7.1%</td>
<td>7.1%</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>ALS</td>
<td>7.1%</td>
<td>0%</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>30 - 49 years</td>
<td>3</td>
<td>2</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td>50 - 59 years</td>
<td>0</td>
<td>2</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>60 - 69 years</td>
<td>3</td>
<td>3</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>70 - 79 years</td>
<td>5</td>
<td>6</td>
<td>3</td>
<td>8</td>
</tr>
<tr>
<td>80 - 89 years</td>
<td>3</td>
<td>1</td>
<td>2</td>
<td>2</td>
</tr>
</tbody>
</table>

Table 2
Results of t-test Analysis for Paired Samples

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean</th>
<th>SD</th>
<th>t value</th>
<th>2 -tailed sig</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tension</td>
<td>Music</td>
<td>6.0</td>
<td>3.961</td>
<td>.52</td>
</tr>
<tr>
<td></td>
<td>Non-music</td>
<td>5.4286</td>
<td>4.926</td>
<td></td>
</tr>
<tr>
<td>Variable</td>
<td>Mean</td>
<td>SD</td>
<td>t value</td>
<td>2-tailed sig.</td>
</tr>
<tr>
<td>----------</td>
<td>------</td>
<td>-----</td>
<td>---------</td>
<td>----------------</td>
</tr>
<tr>
<td>Vigor</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Music</td>
<td>-5.4286</td>
<td>5.049</td>
<td>1.08</td>
<td>.300</td>
</tr>
<tr>
<td>Non-music</td>
<td>-7.4286</td>
<td>4.702</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fatigue</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Music</td>
<td>10.3571</td>
<td>5.786</td>
<td>2.09</td>
<td>.057</td>
</tr>
<tr>
<td>Non-music</td>
<td>6.0</td>
<td>6.276</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Confusion</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Music</td>
<td>3.5714</td>
<td>3.180</td>
<td>1.29</td>
<td>.220</td>
</tr>
<tr>
<td>Non-music</td>
<td>2.1429</td>
<td>2.568</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Music</td>
<td>23.0714</td>
<td>16.864</td>
<td>1.35</td>
<td>201</td>
</tr>
<tr>
<td>Non-music</td>
<td>16.0714</td>
<td>24.487</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* p < .05

Based on the results of the statistical analysis, all null hypotheses were accepted.
CHAPTER V

DISCUSSION

Although none of the paired t-tests reached significant levels, the trend toward lower anger among music therapy participants was a positive outcome which might benefit from further study. As Brown (1992) had reported about a hostile, angry patient who responded to the intervention of music in a positive manner, the music therapists who participated in this study reported that the intervention of music therapy had allowed angry patients to work through their angry feelings and come to a point of resolution. One of the patients who participated in the study was dying of AIDS. The patient was dealing with many angry feelings and made recordings of rhythmic patterns on a four track recorder with the music therapist. The patient named each composition for the feelings he was experiencing while recording the tracks. The music therapist noted that all of the composition titles dealt with some aspect of anger, and that after the patient’s death the family members were able to review the recordings and deal effectively with their own feelings of anger and grief.

Another music therapist who participated in the study related how a patient who was dying of breast cancer used specific songs to tell the music therapist during treatment sessions exactly how she felt. The patient chose songs in which the lyrics discussed the feelings she was experiencing at that moment. The music therapist stated that this patient was dealing directly with many anger issues. Another participating music therapist had a hostile patient who became distracted from his anger during music therapy sessions and focused on other issues during that time, even though he returned to his angry, hostile behavior after the music therapy intervention was completed.
Bailey (1984) discussed how music therapy encourages resolution of issues and processing of grief. Anger is certainly a major issue with some patients who are terminally ill, and the intervention of music therapy seems to be effective in some cases in bringing about resolution of anger issues for these clients.

The trend toward increased levels of fatigue among music therapy clients may be due to several factors. The music therapists who participated in the study explained that clients who received music therapy were most likely receiving other services which the non-music therapy clients were also receiving. This required the music therapy clients to put out the energy for an extra intervention not required of the non-music therapy clients. Another possible factor cited by participating music therapists was the simulative nature of music. Davis and Thaut (1989) found that music therapy intervention decreased state anxiety and increased relaxation response, but resulted in physiological arousal based on data collected on vascular restriction, heart rate, muscle tension and finger skin temperature although this arousal may not cause fatigue in a member of the normal population, a person who is terminally ill may respond more dramatically since he or she is so compromised physically.

The lack of significant findings for the other factors may be partly due to the referral process by which music therapy clients are placed in the hospice organizations. Participating music therapists reported that clients referred for music therapy services have an obvious need to deal with emotional issues and who are exhibiting needs which are not being met by other hospice interventions. It might be assumed, therefore that clients who were not referred for music therapy had less difficulty dealing with specific emotional issues or were able to meet their physical and emotional needs through other services provided by the hospice. One of the participating music therapists described this process as the music therapy intervention
bringing the music therapy clients up to the level the non-music therapy clients had already achieved. It was the suggestion of the participating music therapist to compare clients on the waiting list for music therapy who had not yet received services to those who had received music therapy intervention to determine if differences existed on the measured factors.

The small sample size made it difficult to find significant differences between groups. The participating hospices were able to collect data from only 28 participants, 14 participants who received music therapy and 14 participants who did not receive music therapy, even though data collection took place over a nine month period in three different hospices. Several factors limited the ability of staff members at the hospices to collect data from participants. The participating music therapists reported that the patients' limited energy kept them from completing the survey forms. Some patients became overwhelmed when they saw the number of pages included in the survey and declined to participate before the surveyor could explain the purpose of each page. In some cases the patient's condition deteriorated between the initial contact and the time the surveyor arrived, so that he or she was unable to complete the survey. In other cases, the patients died before the next visit from a staff member who was administering the survey, or before they had completed the five hours of music therapy intervention required to participate in the study for the music therapy participants. Due to the nature of the illness, patients diagnosed with ALS were all referred for music therapy treatment because other forms of treatment were inappropriate. This created a situation in which there were no non-music therapy clients with the same diagnosis to match to the music therapy clients. One of the participating hospices was so small that the music therapist saw all of the hospice
patients during lower census times, so it was difficult to find matching non-music therapy patients to interview.
CHAPTER VI

CONCLUSIONS

The small sample size was a confounding factor in the study. If this study were to be replicated, it would be helpful if more hospice organizations would participate in data collection. Because it is difficult to collect data from patients who are in the terminal phase of an illness, it might be helpful to interview primary caregivers or family members to determine the mood states of the client. This of course, would be a third party view of the client that might not accurately reflect the patient's feelings. If the purpose of the researcher is to determine effectiveness of music therapy treatment in hospice, the opinion of the caregiver may be as useful to the researcher as the opinion of the patient who does not live to see the long term effects of the treatment on the entire family system.

Other methods of data collection which do not require as much participation from the patient, should be considered in future research. Whittall (1989) used the physiological measures of heart rate, respiratory rate and extremity temperature to test responses of clients who were terminally ill before and after receiving a music therapy intervention. This required less physical effort on the part of the patients and was relatively non-intrusive. If this method was used by more than one researcher in a variety of locations, careful attention would be required to assure data collection was consistent across all collection locations.

The phenomenological approach, as used by Forinash (1989) is not as objective, but reports in detail the entire content of a music therapy treatment session and allows the reader to determine the effectiveness of treatment. This approach does
capture the phenomenon that occurs when a patient with terminal illness is touched by music in a music therapy session. It is difficult to describe the effect the music has on the patient, or the intensity of emotions that are often exchanged between the music therapist and the patient. Objective data cannot report this information, and therefore only gives a partial view of what is accomplished between the music therapist and the patient. The measures required to collect objective data may interfere with treatment and create a different result than may have occurred without the data collection, or the data collection may not be an appropriate measurement of the types of changes seen in patients who have received music therapy intervention.

It is important that both quantitative and qualitative research methods be considered as valid measures of the effect of music therapy treatment. Both forms of research are equally important and must continue to be reported to portray an accurate and balanced picture of the effect music therapy has on the terminally ill. Although there are many obstacles to completing any type of research with patients who are terminally ill, it is critical that more research of both types be done to support the use of music therapy with the terminally ill and to increase the effectiveness of those who are already practicing music therapy in hospice organizations.
Appendix A

Hospice Organizations Which Participated in the Study
Names and addresses of participating hospice organizations:

Hospice of Guernsey, Inc.
P.O. Box 1537
Cambridge, OH 43725
(614) 432-7440

Kaiser Permanente Hospice
Los Angeles, CA
(310) 807-6620

Hospice of the Western Reserve
10645 Euclid Avenue
Cleveland, OH 44106
(216) 231-8650
Appendix B

Protocol Clearance From the Human Subjects
Institutional Review Board
Date: May, 9 1994

To: Caroline Abbott

From: Kevin Hollenbeck, Chair

Re: HSIRB Project Number 94-04-03

This letter will serve as confirmation that your research project entitled "The effect of music therapy intervention on the perceived quality of life of terminally ill patients in a Hospice setting" has been approved under the full category of review by the Human Subjects Institutional Review Board. The conditions and duration of this approval are specified in the Policies of Western Michigan University. You may now begin to implement the research as described in the application.

You must seek reapproval for any changes in this design. You must also seek reapproval if the project extends beyond the termination date.

The Board wishes you success in the pursuit of your research goals.

Approval Termination: May 9, 1995

xc: Wilson, School of Music
Appendix C

Explanation for Not Including the Profile of Mood States Form With the Thesis Document
Caroline M. Abbott, RMT-BC
5271 W. C Ave.
Kalamazoo, MI 49009

February 6, 1995

Dear Ms. Abbott,

I am writing in regard to the inclusion of the POMS short form in your Master's thesis. Due to the restricted nature of psychological tests it is the general policy that these not be bound with theses and dissertations. EdITS adheres to this policy which I am sure will be understood by your committee.

Please feel free to contact me if you have any questions, or if I can be of any other service.

Sincerely,

Sharla Burwick
Permissions Department
Appendix D

Survey Packet Given to Participants
Directions for Administration of Survey Materials

1. The person who administers the survey form to the client should not be the music therapist assigned to that client.
2. Please schedule the administration of the survey so that it may be completed before you begin treatment procedures for that day with that client. This is to insure that the treatment provided will not bias the information the client records on the survey. Schedule this so it does not interfere with important treatment procedures.
3. Read the client the statement printed on the form stapled to the survey. Be sure the client knows it is his/her choice to participate, and that he/she should not feel obligated to do so if he/she doesn't want to.
4. Have the client fill out the information at the bottom of the statement form. You may assist him/her if necessary.
5. Have the client read and sign two consent forms before administering the surveys. If he or she is unable to read it, please read it to him or her. The client must be able to sign the consent form to participate. Leave one copy of the consent form with the patient.
6. Have the client complete the survey form. If he or she needs assistance to complete it, you may help, however, do not tell him or her what answers to put down, encourage the individual to express his or her own opinion as honestly as possible. Explain that the results of this survey will not personally impact any members of the staff at the hospice.
7. Return the entire survey packet to the music therapist or other designated person at your hospice. Please make sure the consent form is kept separate and that no identifying information, such as the client's name is on any of the data collection forms. This is to insure the client's confidentiality. Please staple the survey forms and the statement form which has the brief demographic information together.
8. The music therapist should include a list of the types of activities she does with clients at the hospice. Please do not give specific details of therapy with participants in the study, just a general list of frequently used interventions.
Statement to be read to participants prior to administration of surveys

You are being invited to participate in a research study which is a Master's thesis. The purpose of the study is to determine the impact certain therapeutic interventions available at this hospice have on your overall quality of life. You will be asked to complete a survey and a few questions about yourself which will help the researcher but will not identify you individually. When the researcher has completed her thesis, the entire study will be made available to your hospice. Individual results from surveys will not be available. You may choose to participate or not to participate without any penalty or obligation. You will not be required to do anything beyond completing the survey and the questions about yourself which are at the bottom of this form. You will be asked to sign a consent form which states that you agree to participate and understand what you have agreed to do. You will be given a copy of the consent form to keep. You may ask the staff person who is giving you the survey forms to help you read or write the answers. Please do not ask the staff person to answer the questions for you. It is important for you to express your own opinions as honestly as possible. Thank you for your consideration.

Please answer the following questions after you have completed the informed consent form:

What is the name of the Hospice that is caring for you?

________________________________________

What is your diagnosis?

________________________________________

Please check any of the following services you receive or have received at some time as a part of your hospice care. Put an approximate number of how many times you have received each service next to its listing:

☐ Social work
☐ Chaplain
☐ Occupational therapy
☐ Music therapy
☐ Speech and language therapy
☐ Physical therapy
☐ Volunteer services
☐ Other (please specify)
Please check the age range which you are in:

- [ ] 18 - 29 years
- [ ] 30 - 49 years
- [ ] 50 - 59 years
- [ ] 60 - 69 years
- [ ] 70 - 79 years
- [ ] 80 - 89 years
- [ ] 90 + years
Western Michigan University
School of Music
Principal Investigator: Brian Wilson, M.M., RMT-BC
Research Associate: Caroline M. Abbott, RMT-BC

I have been invited to participate in a study entitled "The Effect of Therapeutic Intervention on the Perceived Quality of Life of Terminally Ill Patients in a Hospice Setting". I understand that the purpose of this study is to see if different therapeutic interventions within the Hospice program positively affect my attitudes toward life. I understand that this is Caroline M. Abbott's thesis project.

My consent to participate indicates that I will fill out a questionnaire which will be given to me by a staff person from the Hospice organization in which I am a patient/client. The questionnaire is called the Profile of Mood States (short form). When I have completed the questionnaire, I will return it to the staff person who gave it to me. If I need physical assistance to complete the questionnaire, the staff person who gave it to me will provide that assistance.

As in all research, there may be unforeseen risks to the participant. If an accidental injury occurs, appropriate emergency measures will be taken; however, no compensation or treatment will be made available to the subject except as otherwise stated in this consent form. If the questions on the form upset me in any way, I know the Hospice staff are available to listen to my concerns and counsel me if necessary.

I understand that this research may be beneficial because it may help this Hospice and others like it across the country to continue to improve the services they provide to clients like myself. General results of the study will be made available to all participants, however specific information such as individual scores will not be available.

I understand that all information collected from me is confidential. My name will only be on this form, which will be kept separate from the survey forms to protect my confidentiality. The researcher, Caroline M. Abbott, will know what services I am receiving, which Hospice I am in, my general age range and my diagnosis. The information collected will be coded to protect my confidentiality. My name will not appear on the survey forms. This consent form and the survey forms will be kept in a locked box which only the researcher will be able to open.
I understand that I may refuse to participate or quit at any time during the study without any prejudice or penalty. If I have any questions or concerns about this study, I may contact either Brian Wilson at (616) 387-4724 or Caroline M. Abbott at (616) 381-6361. I may also contact the Chair of the Human Subjects Institutional Review Board or the Vice President for Research at Western Michigan University in Kalamazoo, Michigan with any concerns I may have. My signature below indicates that I understand the purpose and requirements of the study and that I agree to participate.

__________________________  __________________________
Signature                          Date
Appendix E

Consent to Participate Form
Participating hospice address

April 4, 1994

Dear,

Thank you for your willingness to participate in the study I am completing for my Master's thesis. I would like to outline in more detail what the study will entail and what I am asking you to do. The purpose of the study is to determine if the intervention of music therapy enhances the quality of life of hospice patients as compared to similar patients who have not received music therapy. Criterion for inclusion in the study would be: the music therapy clients must have received at least 5 music therapy sessions, and all clients participating must be able to complete a consent form. I would like you, as the music therapist at the hospice, to determine which music therapy clients meet the criteria for inclusion. After you have chosen the music therapy clients who will participate, I need you to find an equal number of clients who are not receiving music therapy to participate. You may need to rely on other staff members at your hospice to help you with this. It would be best if the clients in the two groups were matched as equally as possible in regard to length of participation in the hospice program, length of time since diagnosis and type of illness. They will be asked to sign a consent form. I will include some questions regarding demographic information, but no identifying information will be requested of the clients, so their confidentiality is assured.

I will send survey forms to you when it is time for the study to begin. I am enclosing samples of survey forms I may be using. Each survey package will include consent forms, demographic questions and the survey forms. I need neutral staff members, preferably primary nurses or social workers to administer the survey forms to the clients. This is to prevent biased answers from the clients to please the music therapist. The staff person who is administering the forms should do so before beginning the treatment they came to perform that day. This will prevent bias from the treatment being performed. The staff person may read the questions and record the client's answers if the client is unable to complete it personally. When the survey forms are completed, they need to be returned to the music therapist at the hospice. I will provide an envelope for the forms to be returned to me when they are compiled and completed. When all of the completed surveys have been returned to me and I have analyzed the data and completed the study, I will share the results with everyone who participated.

I understand that your participation requires a commitment of time and resources on your part. I appreciate your willingness to do this. I am asking for your
cooperation in order to collect enough data from enough clients to have a valid study. I need to interview clients in several different hospices in order to accomplish this. I know you understand the need to justify the inclusion of music therapy services in hospice settings, and to increase the research base in this area. I would like to again express my appreciation for your willingness to help.

If you are willing to participate and feel you understand what I am asking you to do, please indicate your consent by signing the form attached to this letter. I also need the executive director of your hospice to read and sign the form. If you have any questions regarding this, please call me at the number listed at the top of the page. When you have completed the consent form, please return it to me as promptly as possible. If you have the facilities to FAX, please FAX it to me at 616-694-4614, attn.: Steve Abbott. You may write and sign your own letter of consent if that is more convenient for you.

Thank you again for your cooperation and consideration.

Sincerely,

Caroline M. Abbott, RMT-BC
AGREEMENT TO PARTICIPATE IN RESEARCH STUDY

I understand the research study which is being proposed by Caroline M. Abbott, RMT-BC. I understand that this research study is a thesis project which is a requirement for the completion of her Master's degree. I am willing to participate in the study as outlined by Caroline M. Abbott, RMT-BC. I understand what is to be required of me and other staff members at this hospice. If I decide at any time to discontinue participation I may do so without obligation to the researcher. I understand that all findings and results from this study will be made available to me upon completion of the research study.

Music Therapist participating in study (including professional title)

Executive Director of Hospice (including professional title)

Name of Hospice organization

Street address of Hospice

City State Zip

Hospice telephone number
BIBLIOGRAPHY


