# MUSIC, DEATH, AND DYING: A SYSTEMATIC REVIEW OF HOSPICE AND PALLIATIVE CARE LITERATURE

By

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#### ABSTRACT

# MUSIC, DEATH, AND DYING: A SYSTEMATIC REVIEW OF HOSPICE AND PALLIATIVE CARE LITERATURE

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The purpose of this research was to categorize, code and summarize articles and abstracts on music therapy and palliative care and hospice in order to highlight themes and trends, as well as provide direction for future research. Findings included data summaries on treatment settings, population trends, diagnoses, and treatment focuses or areas of investigation. Of 79 articles reviewed, 17 were quantitative, 12 were qualitative, 31 were clinical, 8 professional, 7 theoretical/philosophical, 2 historical, and 2 uncategorized. The common goal of the majority of the 79 articles was to look at emotional wellbeing and benefit, with the most prevalent population being adult patients. In the early 2000's there was an explosion of literature and a push toward empirical studies. Within the past 40 years we have gone from theorizing about the benefits of palliative care and hospice to producing empirical studies measuring quality of life and length of life, as well as creating songwriting tools to measure grief in children. Further breakdowns are given as well as implications for future research.

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# **DEDICATION**

I would like to dedicate this thesis to the families and their loved ones that I have had the honor and privilege to care for through hospice music therapy at end of life. You have deeply touched my life, and I am eternally grateful.

#### **ACKNOWLEDGEMENTS**

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#### **Chapter One**

# **Introduction to Hospice**

The word hospice originated from the Latin word *hospitium*, meaning guesthouse. It was originally used to describe places of shelter and rest for tired and/or sick travelers on religious pilgrimages. The modern day hospice movement as we understand in America, began in England in 1967 with Dame Cicely Saunders, an Englishwoman trained as a social worker, nurse and physician who founded St. Christopher's Hospice near London. (Berzoff & Silverman 2004, 151).

"All hospice care is palliative, but not all palliative care is hospice" (www.nhpco.org). Palliative Care seeks to address illnesses with a holistic approach utilizing an interdisciplinary team, including physician, nurse, social worker, aide, spiritual caregiver, and volunteers. This can include seeking curative methods of treatment, for example radiation and chemotherapy in the instance of cancer, and can also be the primary modality of care. Palliative care can transition to hospice should treatment not be effective in curing the diagnosed illness. Hospice, which also uses a holistic interdisciplinary approach, requires a referral from a physician that identifies a patient with a diagnosis of a terminal illness and a life expectancy of 6 months or less. Curative treatment must stop, and the main focus of care becomes comfort, symptom management, and quality of life.

Cicely Saunders' inspiration to begin an inpatient Hospice came from her work and relationship with a Polish Jewish man who escaped WWII. Throughout the time she cared for

him, they openly discussed issues and needs of dying that went beyond just the physical. He spent his final days on a busy surgical unit that did not provide the quality of life or peace that he felt was appropriate to address the spiritual and emotional needs and issues that one faces at end-of-life. From this relationship grew a whole-person philosophy. In 1948 when he died, he bequeathed 500 pounds to Saunders to create the much-needed facility that they discussed during his end-of-life care, a place where the terminally ill could receive the care they needed to make a peaceful transition to death. In 1967 Saunders opened the first freestanding hospice, St. Christopher's Hospice in a London Suburb, formally initiating the official birth of the contemporary hospice movement (Saunders, 1977).

Cicely Saunders introduced the concept of hospice care for the dying to the United States in 1963 during a lecture at Yale University. Saunders delivered her lecture to pre-professionals representing the areas of that are now included in the modern hospice team; medical students, nurses, social workers, and chaplains. She included photos of terminally ill patients and their families, presenting the apparent differences before and after the symptoms were managed. "This lecture prompted the series of events, that resulted in the development of hospice care as we know it today." (<a href="http://www.nhpco.org/i4a/pages/index.cfm?pageid=3285">http://www.nhpco.org/i4a/pages/index.cfm?pageid=3285</a>) In 1986 guidelines were developed for Medicare to reimburse hospice programs for services at a daily rate, and hospice treatment was formally added to these government benefits.

# (<a href="http://www.nhpco.org">http://www.nhpco.org</a>)

Recently, effective December 2<sup>nd</sup> 2008, guidelines for hospice and palliative care were revised and updated to address the needs of our current and rapidly changing society. Some of these revisions include; greater flexibility in care, more person/family centered, increased focus

on quality improvements and patient outcomes as well as utilizing more interdisciplinary language throughout. (<a href="http://edocket.access.gpo.gov/2008/pdf/08-1305.pdf">http://edocket.access.gpo.gov/2008/pdf/08-1305.pdf</a>).

Music Therapy and Hospice

Music therapy was introduced to hospice in the mid 1980s. Since then, research has steadily increased and supports the benefits of music therapy in physical, mental, emotional, and spiritual realms for both the patient and the family. Demmer (2004) conducted a survey with 300 randomly selected hospices to investigate the most popular forms of complimentary therapies. The survey found that the most popular forms reported were massage therapy and music therapy. This comes as no surprise, as hospice-focused presentations at national and regional music therapy conferences are on the rise, and scholarly literature in a broad variety of refereed journals is steadily increasing. Specialized credentials are now offered in the area of hospice and palliative care music therapy as well as continuing education credits for certification maintenance (www.hospicemusictherapy.org). With new programs developing in hospice and palliative care each year, it is of great interest to the profession and clinicians who work with this population to understand the growth and development of music therapy treatment with this population and the implications for future needs.

The field of hospice continues to grow and change, as does the field of music therapy. With the continued growth in the area of hospice it is the opinion of the author that Hospice guidelines and criteria that are in the near future will include provisions for complimentary therapies, including music therapy. With that being said, one must understand the current direction of the field and also address the potential needs of the future. Music therapy is now

becoming a necessity rather than a luxury in Hospice programs. From the vantage point of the author, as little as five years ago music therapy in Mid-Michigan hospice programs was considered a complimentary addition only provided by the for-profit programs. Now to stay competitive with other agencies in the Mid-Michigan area, the inclusion of some form of complimentary therapy (music therapy, massage therapy, or reiki therapy) is considered essential. Of the eight hospice programs reported in the Mid-Michigan region in 2009, five of them employ a music therapist.

#### **Chapter Two**

#### Related Research

Because of the continued growth and expansion of hospice music therapy and new clinical and therapeutic techniques developing each year, research concerning the need for music therapy, as well as to validate its effectiveness within a specific population, is in high demand. With the increase in research comes the necessity to look at past studies to have a better understanding of areas that have been studied, including treatment techniques and populations, areas that need further investigation, and populations or age groups that are neglected by the literature. Previous content analyses and meta-analyses have served to assist the profession of music therapy in doing just that. They identified trends in populations served, areas of need for future research, and the effectiveness of new techniques utilized in clinical practice. These studies also served to identify the origin, as well as a timeline and a direction for this branch of the profession.

One of the first music therapy content analysis research articles was published by Jellison in 1973. She analyzed the frequency and general mode of inquiry of research in music therapy from 1952 to 1972. In 1979 Gilbert replicated this study design by examining the content and focus of research articles published in the *Journal of Music Therapy* (JMT) from 1973 to 1978. Categories established for this analysis included general emphasis of the paper, setting for research, mode of inquiry, basis for research, and type of clientele. Gilbert reported a continued

decline in the total number of published articles, which agreed with Jellison's findings. Gilbert found increases in the areas of "hard research", shown by the high proportion of descriptive and experimental studies. In relation to those increases, Gilbert found a decrease in the proportion of philosophical and historical studies.

Six years later James (1985) examined the sources of articles published in the *Journal of Music Therapy* from 1964-1983. Data were arranged by four topic areas: year of publication, affiliation of the author, gender of the author, and credentials of the author. James found that the previous findings of Jellison and Gilbert were not verified by his study, due to her more comprehensive range and scope of the literature. While Gilbert and Jellison investigated the articles' research methods and content, James examined the articles' sources, comparing these of two decades 1964 to 1973 and 1974 to 1983. James identified that there was a stable frequency of articles published throughout the 20-year period, with a recent trend toward more female authors. Unfortunately, according to James, information identifying the authors' professional credentials was poor. James also found that, from 1974 to 1983, there was an increase of articles originating from university settings, identifying key institutions on the forefront of scholarly writing.

Codding (1987) also replicated both Jellison's and Gilbert's studies to examine JMT articles published between 1977 and 1985. These articles were categorized to describe trends in focus, research setting, and mode of inquiry. Also noted were the frequencies of the statistical and behavioral designs present in the articles. Like James, Codding (1987) found that the frequency of articles published had remained the same; the percentage of research-oriented articles continued to be greater than position papers and critical articles. Also, when investigating research settings, Codding identified a greater number of studies performed in clinical settings

verses university settings, with the mode preference being experimental over descriptive, historical and philosophical methodologies. In Codding's conclusion, along with other statistical information related to her findings, she noted that research in the public schools had increased. She is the first of the above-mentioned content reviewers to isolate and report growth within the literature on a single population.

Gfeller (1987) conducted a content analysis of the JMT from 1964 to 1984, investigating theory and practice in relation to psychological theory, physiological response to music, and theories developed within the music therapy profession, seeking to identify prominent principles and themes. Results from the analysis concluded that there was no single theory central to music therapy, but areas of emphasis could be detected; for example, the prominence of psychological theories and behavioral theories that influenced music therapy practice. From her analysis, Gfeller also asks, "whether the theoretical foundations of music therapy practice have been adequately defined."

In 1987 Decuir sought to analyze *Journal of Music Therapy* articles by disability area, also listing the mode of inquiry (type of article). One year later, Wheeler's research method followed the model used by Decuir (1987) with a few alterations, including: applying the analysis to more than just JMT, adding authors' names, adding several categories, and altering the order found in Decuir, but leaving the basic content unchanged. Wheeler (1988) sought to classify music therapy literature in three other published journals and compare findings with Decuir's analysis of JMT. She analyzed literature from selected music therapy journals and was one of the first to include multiple sources outside of JMT for music therapy research. The journals included were *Music Therapy* (Journal of the American Association for Music Therapy), *Music Therapy Perspectives*, and *Arts in Psychotherapy*. Wheeler found that, compared to JMT,

which focused mostly on research articles, the other three journals published a relatively even balance of articles focused on clinical, research, and general topics. Wheeler concluded that the focus of the other three journals was more clinically based in comparison to JMT, which was research driven.

Gregory (2002) examined all research articles from JMT from 1964 through 1999 to ascertain if the methodology included a behavioral research design such as reversal, changing criterion, or multiple baseline; case studies that did not meet the design criterion where not included in this study. Gregory examined experimental studies that used a behavioral research design, analyzing them to determine the type of design, observation method and reliability report, the client population, and the music application.

As the diasporas of music therapists trained in America took root overseas, music therapy programs developed in other countries. The need for research, reporting and validation increased the need for more refereed journals from other countries. Because of the increasing diversity of research from other countries and cross-disciplinary publications, there became a need to review and catalog findings regarding music therapy on a broader global scale.

Brooks (2003) investigated historical trends in mode of research reported in articles published in the major music therapy periodicals written in the English language but not limited to journals originating from the United States. She further categorized whether studies were quantitative, qualitative, historical, philosophical, theoretical, clinical, or professional. Brooks desired to identify historical trends within each specific journal. Brooks also compared percentages of article types within each journal as well as across all of the selected journals. Brooks analysis covered nine journals: *Journal of Music Therapy, Music Therapy: Journal of the American Music therapy Association, Music Therapy Perspectives, The Arts in Psychotherapy*,

Journal of the Association for Music & Imagery, The Australian Journal of Music Therapy, The Nordic Journal of Music Therapy, The British Journal of Music Therapy, and The New Zealand Society for Music Therapy Journal, including all years of publication. Her criteria for including a journal were as follows; a minimum of 5 years in publication, a minimum of one issue per year, and a minimum total of 40 articles on music therapy.

Her findings provided specific statistical data on the rise and fall of various research and article types. From these statistics Brooks asked the question, "To what extent do the present journals address the needs of the field in each area of inquiry?" (p. 166). The author arrived at this question based on the limited number or low percentage of historical, philosophical/theoretical, and qualitative research articles found in her study. She followed up with, "Is it possible that researchers do not see the value of and significance of these types of research as a major contribution to the literature or field?" (p. 166). Brooks' second question related to the typical developmental process for a journal. Do music therapy journals follow the same or similar developmental patterns? If so, what are those patterns? Her assessment of the development of a journal based on her research concluded that initially a young journal begins with a strong clinical focus, and, as the journal develops and editorial boards are formed, criteria and screening standards are created, and article submissions begin to diversify to include other types of inquires.

The value of Brooks' study lies in the numerous follow-up questions derived from the research statistics. Further understanding the reasons for establishing a publication and the relationship to the direction and overall impact on the field help to identify whether the relationship between the journal and the field is healthy. For example, does the journal enhance the credibility of the discipline or the justification for funding for new programs?

As outlined previously, content analyses and literature reviews have proven to be valuable in forwarding the movement, progression, and growth of music therapy as a profession. As the profession expanded and the scope of practice continued to broaden, music therapy began to impact a wider variety of populations. As acceptance for music therapy grew in the medical and therapeutic communities, with the help of strong qualitative and quantitative research, the research community in turn began accepting and publishing studies in journals not exclusive to music therapy or art therapies. With continued research and the broader spectrum of journals that accept music therapy studies, there comes a need for more focused literature reviews in regard to population. Consequently, the need has increased for population-specific analysis to assist in the identification of needs that are addressed by the broader range of journals that are now publishing music therapy research.

Brotons, Koger, and Pickett-Cooper's 1997 article, *Music and Dementia*, focused on comprehensively reviewing literature published in the areas of music, dementia, and music therapy from 1985 (the date of the earliest music and dementia publication) to1996. The purpose of this study was to categorize, code, and summarize the dementia research outcomes with the objective of outlining recommendations for clinical practice and future research.

The methodology that was utilized to identify the 69 articles analyzed in this study included the use of four online databases (MEDLINE, PsycLit, MBI database of MuSICA, and CARL UNCOVER), as well as complete searches of the *Journal of Music Therapy* and *Music Therapy Perspectives*. Of the 69 references, 42 of were empirical studies, including 30 clinical

empirical reports identified by the author as experimental, descriptive, or case study utilizing music as a therapeutic intervention as the independent variable. By identifying these articles according to the dependent variable, the author was able to outline the functional areas addressed. These areas included participation/preference for music, social and emotional skills, cognitive skills, and behavior management. The remaining 12 studies were from a neuropsychological perspective in the area of assessment or music cognition. Narrative case studies and anecdotal accounts of music in therapy or articles describing nonmusical goals accomplished through musical means were itemized as well; the authors uncovered eight (p. 207).

Brotons, Koger, and Pickett-Cooper's objective was to discuss and describe, and they included questions and implications for future research. Included in their findings and discussion was that, of the 69 studies involving music and dementia, over half (n=36) were written by other healthcare professionals. Of the professionals outside of music therapy conducting research with music, the majority were nurses. Brotons et al., highlights that while other health professionals studying and reporting the beneficial effects of music with people diagnosed with dementia might benefit the development and reputation of music therapy as a profession, it is disconcerting that people without formal training as a music therapist are implementing programs.

Implications for future research included the need for a follow-up study in the form of a meta-analysis of empiric dementia music therapy literature to isolate specific music therapy practices. Also, research comparing the effectiveness of interventions applied by non-music therapists compared to professionally trained music therapists was needed. Brotons et al also posed research questions and research suggestions including but not limited to, comparison of

the stages of dementia and the corresponding response to music, responses to live versus taped music, and investigations into type, number and frequency of treatments required to effect change, as well as longevity of the changes in behavior. This study serves as a strong example for systematically reviewing the literature regarding a specific population in the field of music therapy.

Systematic Reviews and Meta-Analyses in Hospice Care

Within the past five years, literature reviews and meta-analyses in several areas of hospice care and hospice-related studies have been published. The following studies were helpful in formulating a research method and problem questions by serving as a model for this kind of investigation into hospice music therapy. Like Brotons, Koger, and Pickett-Cooper's 1997 review of dementia literature, the following articles reviewed the literature utilizing various database search engines to identify literature applicable to the investigation, focusing the search with specific key words or phrases. These studies were also helpful in identifying databases that would filter published studies that were related to hospice, palliative care and bereavement.

In 2008, Woods, et al, investigated literature on palliative care for people with severe persistent mental illness. In this study both empirical and non-empirical studies were reviewed. The methodology used to identify articles appropriate for this study employed the use of database searches. Eight databases were used, an inclusion criterion set, and articles selected through the agreement of two researchers. Disagreements were settled through a third author to insure validity. Article search keywords consisted of palliative care or terminal care or hospice, and mental disorders or mentally ill person. Of the sixty-eight articles found, Woods, et al,

discovered that there were not many empirical studies in existence (11), and even less information identifying the needs of severe, persistent mentally ill palliative care patients.

Four main themes were uncovered when analyzing the literature; decision-making and advance care planning, access to care, provision of care, and vulnerability. By reviewing the literature for this study the author was able to identify many needs and implications for future research, including problems related to the current literature available. For example, Woods (2008) reports, "With the dearth of empirical studies there is an even larger void of information related to the palliative care needs of people with severe persistent mental illness. Potentially the literature found does not adequately represent the experience of the people, drastically limiting the generalizability of the studies' results (p. 733)."

Woods regarded future research with this specific population a research priority. As a result of the research he conducted, Woods asked for increased disclosure related to the challenges of researching marginalized, vulnerable, very ill populations where access to patients is difficult, capacity is questionable, consent is difficult to obtain, and benefit-to-burden ratio is difficult to determine. Ultimately encouraging more studies that are methodologically sound will improve outcomes of studies and better define the issues that exist for this population.

In 2008, Washington, Bickel-Swanson, and Stephens conducted a systematic review entitled Barriers to Hospice Use among African Americans. The goal of this meta-analysis was to review and explore professional literature directly pertaining to the frequency of use of hospice services by African Americans, as well as barriers and interventions designed and utilized to increase the number of African Americans served.

Like studies mentioned previously, the method for finding research relevant to this study was achieved through a systematic process using a database search. Three databases were

accessed using consistent key words (African Americans paired with hospice and minorities paired with hospice) for a thorough search. Findings were sorted and limited to studies published in peer reviewed journals in the English language excluding conceptual pieces, reviews, editorials, meta-analyses, and dissertations, as well as case studies and research with a sample size of less than or equal to three.

The total number of articles that qualified for this study was eight. Of the eight studies, five were qualitative in nature. Two studies used secondary data in a quantitative method, and the eighth study combined both quantitative and qualitative methods in the research, interviews and scales, to collect data and arrive at a conclusion.

There has yet to be an analysis of the total body of hospice music therapy literature. However, in 2005 Hilliard published a review of solely empiric data from the existing hospice music therapy literature drawing from not only refereed journals but also masters theses and doctoral dissertations. He isolated a total of eleven quantitative studies spanning from 1986 to 2004 in hospice music therapy literature, of which six reported a significant difference in outcome that supported the benefit of music therapy interventions and services. In these studies Hilliard identified the dependent variables of pain, physical comfort, fatigue and energy, anxiety and relaxation, time and duration of treatment, mood, spirituality, and quality of life, as the areas positively affected by music therapy.

Hilliard (2005) argued that similar to the findings of Woods, et al. though there are empiric articles to support hospice music therapy, there is an over abundance of qualitative research and a lack of quantitative studies, leaving a large disparity between the two approaches. Within the few empirical studies he found, he also highlighted the lack of large control groups and randomization of subjects. For future research he encouraged the use of a standard

measurement tool designed specifically for hospice care, as well as diagnosis-specific studies, since death trajectories vary by terminal diagnosis.

The previous article review served to outline the history of content analysis throughout the music therapy literature and to make the argument that more population specific analyses will be needed as the profession grows and expands. With the growing acceptance of hospice and the growing demand for music therapy within hospice, there are compelling grounds for the analysis of all the current literature to date to assess and identify implications and directions of the discipline in serving this population. The articles reviewed in this study served to guide and formulate the methodology with which this research was conducted.

#### **Chapter Three**

# Methodology.

The intent of this study was to review, analyze, and catalogue literature published in the area of music therapy and hospice/palliative care. The purpose was to categorize, code and summarize articles in order to highlight themes and trends, as well as provide direction for future research and to forecast the direction of the profession as it relates to hospice patients, a growing population served by music therapists nationally. The research problems addressed by this study were to determine (1) setting of the study (home/inpatient hospital/AFC/ECF), (2) population served under the death and dying umbrella (bereaved-child/teen/adult, patient-child/teen/adult, extended family/close Friend), (3) average age of patients studied, (4) diagnosis of the patients studied and frequency of each diagnosis found in the article, (5) method of research (Qualitative vs. Quantitative), (6) If Qualitative, what type of article: Historical, Professional, Clinical, Philosophical/Theoretical, (7) goal of research (physical, emotional, social, spiritual), (8) and variety and frequency of the dependent variables or themes found in the literature. These results are reported in aggregate as well as individually.

Qualifying Articles for Study

For articles to qualify for this study they had to meet the following criteria:

The study must be printed in a refereed journal available in the English language,
 regardless of country of origin.

 The study must include the populations of hospice and/or palliative care, including bereavement programs that address grief concerns after a love ones death (parent, sibling, extended family, close family friend).

#### Procedure

Articles were acquired and cross-referenced through the usage of four search engines; Temple University Music Therapy search engine, ProQuest-Illumina, PsycINFO, and M-CAT. The initial search engine identified the majority of the articles pertaining to music therapy research in hospice and palliative care. The same key words used in the original search were cross-referenced in four other data bases--ProQuest-Illunina, M-CAT and psycINFO--to insure that all available articles had been located. The search included articles from the earliest possible date located (1977) through December of 2010. The key words used in all four database searches were: music therapy and hospice, music therapy and palliative care, music therapy and bereavement, and music therapy and death and dying.

After identifying and qualifying the articles based on the above criteria, the articles were categorized, interpreted, and examined with the above identified research questions in mind. The previous content analyses and systematic reviews served to generate and outline these study questions. When full articles were not available abstracts were utilized. Of the 79 articles found, 55 were full text and 20 were full abstracts. Four articles were descriptive notes or qualified because of descriptive information in the title. See page 37 for the complete table of references.

#### Chapter Four.

#### Results

With the intent of reviewing, analyzing and cataloguing literature in the area of music therapy and hospice and palliative care, 79 articles that met the above criteria were indentified through the use of the aforementioned search engines. These articles were reviewed and catalogued based on the following criteria developed by Brooks and taken directly from her 2003 study published in the JMT. Her criteria were as follows:

- 1. **Quantitative Research:** Any article wherein numeric data were statistically summarized or analyzed for the purpose of making generalizations. This included experimental and descriptive research as well as studies in applied behavior analysis. Also included in this category were writings about research methods and the presentation of research protocols.
- 2. Qualitative Research: Any article involving systematic collection and analysis of non-numeric data for the purpose of deriving idiographic insights or meanings in relation to a phenomenon. This included research (individual case or small groups) labeled as naturalistic, action based, participatory, hermeneutic, heuristic, phenomenological, constructive, critical, or discursive. Also included in this category were writings about qualitative research methods and the presentation of research protocols.
- **3. Clinical Reports:** Any article describing actual clinical work with clients where there was no intent to use clinical data for research purposes. This included clinical case studies, reports of clinical programs, and presentations of treatment protocols, methods, or techniques.
- **4. Philosophical & Theoretical Research:** Any article that involved philosophical inquiry or the elaboration of theoretical constructs, but did not involve the gathering of new data. This included articles aimed at clarifying, evaluating, relating or arguing basic assumptions, beliefs, hypotheses, constructs, paradigms, principles, or discoveries guiding practice or research.
- 5. Historical Research: Any article aimed at gaining knowledge or

insights about the past by systematically studying past practices, materials, institutions and people, and so forth. This included biographies, histories of music therapy, bibliographic studies, and literature reviews.

6. **Professional Articles:** Any article that dealt with professional aspects of music therapy. This included position papers, articles dealing with music therapists, clinical training, ethics, standards, competencies, employment, credentialing and so forth.

(p.154-56)

#### All But Quantitative Studies

Of the 79 articles, 62, (79%) were classified under the heading of qualitative research, clinical report, philosophical/theoretical research, historical research or professional articles, based on Brooks (2003) criteria. These articles will be reported together and for the sake of this study will be referred to as belonging under a "qualitative umbrella" since these articles do not include any statistical data. In this grouping, 31, (51%) were clinical, 12, (18%) were qualitative research, 8, (13%) were professional, 7 (12%) were theoretical/philosophical, 2, (3%) were historic and 2, (3%) were unknown/unidentified because of lack of availability of the article or abstract (see figure 1).

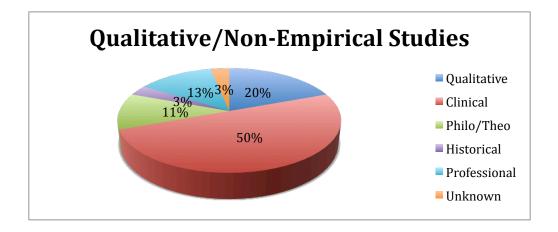
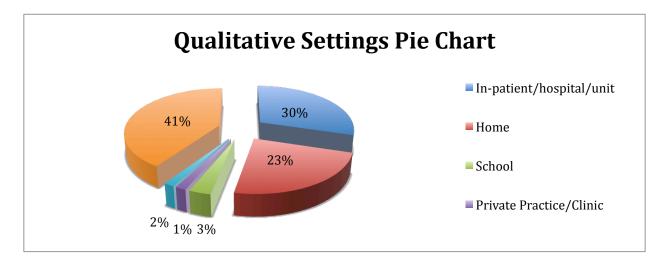


Figure 1

(For interpretation of the references to color in this and all other figures, the reader is referred to the electronic version of this thesis)

# Settings

Within the non-empirical studies the settings discussed in the articles were as follows; 19 inpatient/hospital/care unit, 15 home, 2 school, 2 private practice/clinic, 1 work/professional, 26 unknown/not applicable/unidentified because of type of article and lack of relevance to setting, or lack of availability of the article or abstract. The total number of settings exceeded 62 because some articles and studies identified more than one setting. Based on this information, inpatient/care units/hospital settings were the most discussed within the selected article cluster (see figure 2).



**Figure 2**Population

The populations served or discussed within the 62 articles were as follows; 32 adult-patient articles, 2 adult-caregiver, 2 adult-bereaved, 7 child-patient articles, 4 child-bereaved, 2 teen-bereaved, 13 unknown/not applicable/unidentified, 1 professional. One article included ages 12-18 and was included in teen bereaved and child bereaved results. Based on this information, adult patients are 52% of the population served or studied in this grouping (see figure 3).

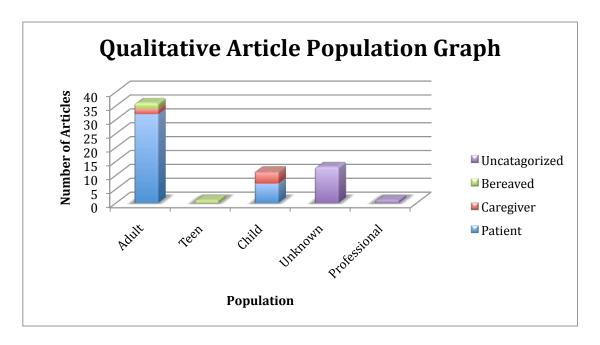


Figure 3

The ages of the participants or individuals in the case studies and articles were difficult to quantify due to the wide ranges in age discussed in various case studies. The children served ranged from 6 months to 14 years old. Children and adolescents (ages 11to 14) were variously grouped together based on how the study discussed and reported findings. This created a gray area in regard to a definitive line between children and teens. For the sake of this study teens served ranged from 15 to 18 years old. Adults served ranged from 26 to 100 years old. Some studies did not list participants' ages while others, for example, focused on five patients with a range of 50 years between the oldest and youngest. To take averages of this information would be a misrepresentation of the data given. For these reasons the author did not report an average or mean age of study participants.

#### Areas of focus within the research

The areas of focus within the articles were classified into four categories in the procedure, and a fifth category, quality of life, was added after the articles were analyzed. Additionally, some articles were categorized as informative based on the educational direction of the writing and content, the type of qualitative write-up, e.g., historical or professional, or the outcome of the research. Some studies had more than one area of focus. The ALL category was added because several studies identified all of the four initial goal areas as focuses of the article. Each item within the ALL category (spiritual, emotional, social and physical) was reflected independently in the individual categories' as well. The goals of five studies were unidentifiable based on the lack of information in the abstract or lack of available abstract.

The goals of the 62 articles were as follows: 12, (20%) physical, 22 (36%) emotional, 12 (20%) social, 11 (18%) spiritual, 2 (3%) quality of life, 7 (12%) ALL, 3 (5%) unidentified, and 25 (41%) informative. Based on this information, emotional needs were the main focus of the qualitative research and other articles under the qualitative umbrella as it relates to this study. (see figure 4.)

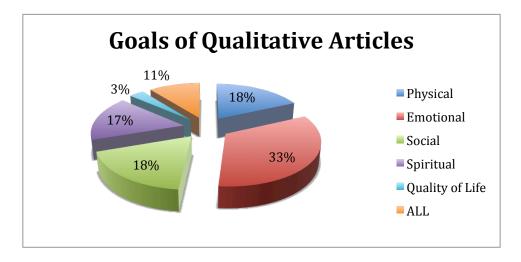


Figure 4

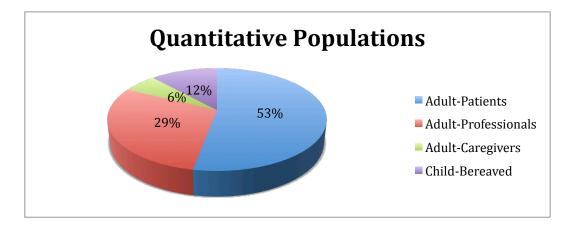
# Quantitative Research Results

Of the 79 articles reviewed, 17 (22%) were found to be quantitative based on the criteria devised by Brooks (2003). Below are the results of age, population, setting, goal and dependent variable(s) for the quantitative articles.

As with the qualitative studies, ages were difficult to quantify. In some reports ages were already averaged or offered as a mean or a range not identifying specifically what was involved in the study. For this reason age will not be offered as an average or a mean so as to not misrepresent the studies reviewed.

# Populations served

The populations served within the quantitative research were as follows; 53% adult-patients, 29% adult-professional, 12% children bereaved and 6% adult-caregiver. Adult-patient being the main focus of the 17 quantitative articles reviewed, by more than half (see figure 5).



**Figure 5**Quantitative settings

The settings served within the quantitative research were as follows; 7 care unit setting/hospital, 5 office/professional, 3 home, 3 nursing home, and 2 school. Some studies reported more than one setting, which caused the total number of settings to exceed 17 (see figure 6).

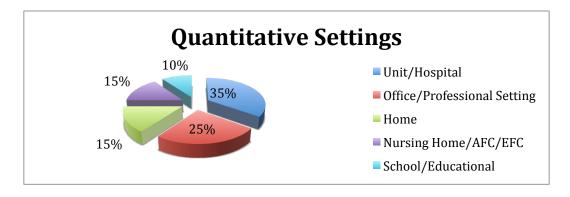
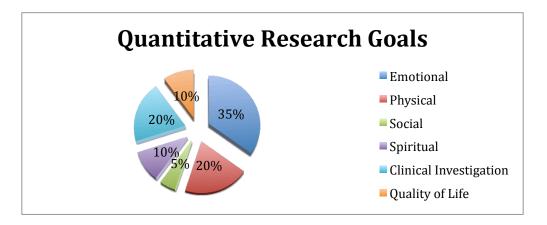


Figure 6

#### Focus within research

The research focus' identified from the quantitative research reviewed including the following; 7 emotional, 4 physical, 4 clinical investigation (dealing with patient music preference, patient time of death, administrator knowledge of music therapy, and reasoning for music therapy referral), 2 informative (dealing with professional aspects), 2 spiritual, 2 quality of life, and 1 social. Some studies investigated more than one item. For this reason the total number of goals exceed 17 (see figure 7).



Dependent variables

Figure 7

Dependent variables were only identified in 12 of the 17 quantitative studies. The reason being, one study was only available through abstract, and four studies were surveys. Of the 13 studies with dependent variables, four measured pain/physical comfort, three measured mood, three measured stress/anxiety, three measured quality of life, two measured behavior, and two studied spirituality. Some research listed more than one dependent variable based on the design; for this reason, the sum of these figures is greater than 13.

# **Chapter Five.**

#### **Discussion**

The purpose of this study was to look in-depth at the palliative care and hospice music therapy literature, catalog findings, and investigate trends, to determine where the field has come and where it is headed. With those results formulate conclusions. When viewing the 79 articles by 5 year increments, it is obvious when music therapy truly took hold in palliative care and hospice (see figure 8).

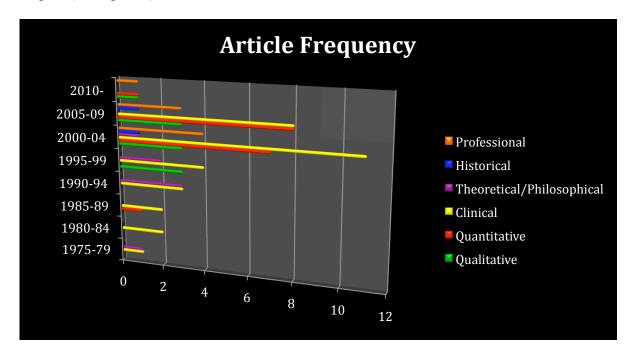


Figure 8

For the first 20 to 25 years, hospice and palliative care music therapy literature consisted of mostly clinical and theoretical articles. This made sense, as music therapy was new to the

hospice and palliative care field. Toward the later 90's qualitative researchers began exploring more in-depth the specific benefits of The Bonny Method of Guided Imagery and Music and songwriting with palliative care patients.

Then in the span of 2000 to 2004, 7 qualitative articles were written (4 from a single author) and professional papers made their way into journals, some discussing music therapy work in hospice from a personal perspective. The first historical article was written in (2003) in the *Australian Journal of Music Therapy*, reviewing literature and consolidating music therapy's future much like this study. Theoretical/philosophical articles declined and clinical articles seemed to peak, making way for a continued growth of empiric studies in the 2005 to 2009 time frame.

The evidence in this graph raises the question, are empirical studies the future method of studying hospice? Between 2000 and 2010, qualitative research has remained static, but quantitative research is on the rise, at least in contrast to the prior 25 years. When reviewing articles for this study, the author identified two contrary opinions in regards to the best method of conducting palliative care and hospice inquiries. These contradictory views are discussed in the following section.

#### Quantitative vs. Qualitative studies

Russell Hilliard, a music therapist and a well-published researcher, has been pivotal in the area of quantitative research in palliative care and hospice within the last decade. He has both contributed to and advocated for an increase in empirical data under the rationale that, "it provides greater assurance of reliability and results that can be more readily generalized than

those of qualitative research" (Hilliard 2005, p. 177). Hilliard also believes that, because the dying process is such a complex experience, more empirical research needs to be conducted to evaluate the efficacy of the support we as music therapists provide our patients. He states that, though qualitative research is valuable in illustrating the benefits to a small number of individuals, reliability is questionable and generalizing results to other terminal patients can be limited. Hilliard continues to explain that research in general needs to be conducted to ensure not only a high standard of care throughout the field but also clinical interventions that consistently meet the needs of individual patients and families. New and existing interventions need to be tested to ensure their effectiveness. Music therapists working in the field will be able to establish "best practices" in the field through creating an evidence base in hospice and palliative care music therapy (2005).

In contrast, Clare O'Callaghan and Phillipa Barry, also music therapists and researchers, argue that there are inherent methodological problems in quantitative studies in palliative care. Some of the problems include: high attrition rates and short survival times, the difficulty in assigning patients blindly into a group due to the need for informed consent (leading to potential bias due to the knowledge that they are in a treatment group, or receiving care related to a study, not wanting to disappoint), the large variability of patients and their illness manifestations, diverse backgrounds, unique treatment histories that lead to an inability to locate comparable matches for a control group, and treatment delivery variations from different therapists involved in the same study. O'Callaghan/Barry also believe that qualitative research can not only offer the same conceptual generalizations as quantitative, but provides means to insure reliability including inter-rater reliability, audit trials, member checking, and triangulation. Qualitative

research provides information that is important to the researcher but also expresses what is important to the patient involved (2009).

Further investigation is needed to better understand the benefits and limitations in both qualitative and quantitative research in the area of palliative care so as to adequately support the use of music therapy interventions, validate research findings so that they are accepted by the medical field, and properly reflect the philosophy of palliative care and hospice and the individualistic person-centered approach.

### **Individual Study Components**

Age was extremely difficult to represent in this study for two reasons. First, in the qualitative or clinical research and case study write-ups, age ranges were at times greater than 40 years. Second, taking an average of that information would misrepresent the participants involved. In the quantitative research, often a mean was already offered, to average that with other studies that reported a breakdown would also be misrepresentation.

#### Population and Setting

The population most studied within the literature was adult cancer patients, and the setting most utilized was a hospital, in-patient, or unit setting. Potential reasons for this would include the availability of patients within a hospital and the localization of them on one unit together, for example on an oncology ward. Another reason for the large focus on adults is the ease in collecting data and conducting interviews. Adults require fewer consent forms and offer more ability to self-disclose about the process they experience.

Children were the second largest group, though only accounting for 12 percent of the quantitative articles and 18 percent of the qualitative articles. When children were included in empirical research there was usually a bereavement focus (loss of significant figure) rather than the child in the role of a patient. In the qualitative research and clinical articles they maintained a patient role and less of a bereavement focus. Potential reasons for children not being studied on a larger scale could be related to societal beliefs and cultural norms, for example; parents seeking treatment versus palliative care for their child(ren). A common phrase used in relation to death and dying, "Parents never expect to bury their children, they expect their children to bury them." For this reason, in most cases all curative measures are exhausted when a child faces a life threatening illness. According to Children's Hospice International (CHI), up until a few years ago, hospices did not consider taking children. Thanks to the non-profit organization CHI, today over 3,000 hospice programs will consider accepting a child for hospice, and based on a 2002 CHI survey, approximately 450 companies have a children-specific hospice, palliative care and homecare service (www.chionline.org/).

While not a main focus of this study, some studies provided racial data to describe their participants or subjects. Little diversity was recorded with regard to races other than Caucasian. African Americans made up a small percentage, where as Hispanic-Latino Americans were not mentioned at all. From the author's experience, hospice care and patient needs vary greatly along cultural lines. For this reason more music therapy studies should focus on addressing ethnicity and cultural needs.

Goals of the hospice studies under both the quantitative and in the qualitative umbrella areas focused mostly on emotional health (grief process, self-expression/exploration, mood, etc...). However, a large portion of studies and articles focused on more than one area. Some

studies and articles reported or discussed all aspects of hospice (emotional, social, physical and spiritual), while a small percentage measured "quality of life," a category not initially included in the original problem statement of this study.

The term "quality of life" appears to be so diverse and individualistic that it would seem difficult to measure or study on a large scale, however quality of life research and quality of life measurement scales can be found throughout hospice and palliative care research literature. Two quality of life scales utilized are (1) the revised Hospice Quality of Life Index (r-HQLI), a 28 item self report instrument that includes three sub-scales and (2) the Missoula-VITAS Quality of Life Index, a 25 item patient centered index that measures 5 QOL dimensions. Quality of life represents a desired goal to assist healthcare specialists in deciding treatment options. Some challenges in studying and measuring quality of life include; missing data due to death or patient decline physically and/ or cognitively, lack of statistical power due to high attrition rates, non-randomization question generalizability, and internal validity due to interpreting results (Tang & McCorkle, 2001). According to Tang and McCorkle there is a need for selecting appropriate time frames for studying quality of life.

In music therapy literature Clare O'Callaghan (2001) utilized a grounded theory to investigate the multi-dimensional benefits of music therapy. Through this study she identified seven categories that spoke to various aspects of what could be interpreted as quality of life. Within the categories are references to affective response, social aspects, physical benefits in decreased perception of pain during music therapy, emotional release (identification and expression), and spiritual strength realized through hymns. In O'Callaghan's discussion area she states, "This research demonstrates that music therapy can help life to be better "now" for many people with cancer" (2001, p.159). Hilliard (2003) investigated not only quality of life, but also

length of life of people diagnosed with terminal cancer as it related to receiving music therapy services. He also found that the experimental group, which received music therapy, reported a higher quality of life using the Hospice Quality of Life Index-Revised. Those who received music therapy treatment continued to report scores that improved despite their condition, whereas the control group, who reported a lower quality of life initially, continued to report declining index scores as their disease process progressed without music therapy treatment.

Both studies investigated quality of life using different research methods but discovered similar results. Quality of life is a term used regularly in day-to-day discussion, team collaboration, treatment meetings and care conferences within the hospice and palliative care team. Continued research into assessing quality of life regarding music therapy and assisting in creating a better quality of life for hospice and palliative care patients and families is needed.

### Implications for the future

Music therapy in the field of palliative care and hospice has been developing and evolving since the mid 1970's. Since that time the activity has been expanding through theorizing about potential beneficial methods and program designs, implementing programs, devising and researching bereavement songwriting scales, and gathering qualitative and quantitative data that supports the multi-dimensional benefits of music therapy in end-of-life care. However, there is still room for growth. As it stands, more research is needed with other terminal diagnoses aside from cancer, for example; CHF-Congestive Heart Failure, COPD Chronic Obstructive Pulmonary Disease, Dementia/Alzheimer's, ALS/Lou Gehrig's Disease, etc. There is a dearth of studies investigating the needs and challenges of music therapists

working with different cultures and races. Though hospitals were the most reported setting in the literature, care is moving from hospital to home (Horne-Thompson, 2003). More studies are needed that investigate the challenges and benefits of home hospice and palliative care, with focus on creating and maintaining a therapeutic space and exploring the issues of difficult family dynamics within the home and how they affect quality patient care. A more far-reaching lens for music therapy could be provided by investigating broader populations, and additional places where it could be utilized. By moving beyond studying direct patient care alone, music therapy in hospice could be enhanced by studying the benefits to caregivers and field staff experiencing burnout, children in general, adult bereavement groups, and joint treatment with other disciplines.

With the intent to review, analyze, and catalogue literature published in the area of music therapy and hospice/palliative care, the purpose of this research was to categorize, code, and summarize articles in order to highlight themes and trends, as well as provide direction for future research and to forecast direction of the profession as it relates to hospice as a growing population served by music therapists nationally. In the past 40 years we have gone from theorizing about the benefits of palliative care and hospice to producing empirical studies measuring quality of life and length of life. Hospice and palliative care have embraced music therapy as a discipline that brings comfort and resolution to patients and families at end-of-life. With the prominent focus presently on emotional needs of dying patients, along with benefits in the physical, social, and spiritual areas, music therapy research of all types is necessary to increase understanding and effective clinical service for an even broader array of individuals coping with this difficult phase of life.

Appendices

APPENDIX A

Complete list of References in Chronological Order (Abstracts and full articles)

Author	Year	Publication Full	/Abstract or	nly Type of Pape	r Area of Focus
Gilbert, JP	1977	JMT, 14 (4)	Full	Clinical	MT Perspectives On Death & Dying
Bright, R	1979	AuMTAB, 2(4) N	Io Abstract (	(notes) Clinical	discussion of MT At Royal Victorian Hospital
Fagen, TS	1982	MT, 2 (1)	Full	Clinical	anxiety & fear in Terminal Pediatrics
O'Callaghan,	CC 1984	AJNZSMT, 7 (2)	Abstract	Clinical	Musical Profiles of Dying Patients
Brooks, M. O'Rourke, A	1985	AJNZSMT, 7 (2	) Abstract	Clinical 1	MT with Dying and Bereaved
Curtis, SL	1986	5 JMT, 23(1)	Full	Quantitative	Pain relief/relaxation Terminally III
Wylie, ME & Blom, RC	1986	MTP, 3	Full	Clinical (	GIM and Hospice Pts'
O'Callaghan,	CC 1990	AuJMT, 1	Abstract	Clinical	Songwriting Palliative Care
Magill- Leverault, L.	199	3 JPC, 9 (4)	Abstract	Clinical	Pain & Symptom Management
Mandel, SE	1993	JPC, 9(4)	Abstract	Clinical	MT in Hospice/ Palliative Care Team
O'Callaghan,	CC 1993	JPC, 9 (4)	Abstract	Clinical	Brain Impaired Palliative Care Pts'
Porchet- Munro, S.	1993	JPC, 9 (4)	Abstract	Professional	Perspectives in Palliative Care
Salmon, D.	1993	JPC, 9 (4)	Abstract 1	Philosophical/Theoremot	retical Music & ion in palliative care

Complete list of References in Chronological Order (Abstracts and full articles) Cont...

Author	Year	Publication	Full/Abstract on	nly Type of Pape	r Area of Focus
Webster, J.	1994	AJNZSMT,	Abstract	Clinical	Supporting Elderly Grief and Loss
Aldridge D.	1995	AP, 22 (2)	Full Philo	sophical/Theoretica	l Spirituality, Hope
Bunt, L. & Marston Wyl	1995 d, J.	MTP, 13 (1)	Full	Quantitative	Collab study of Cancer care
Jackson, M.	1995	CJMT, 3 (1)	Abstract	Clinical	Case study of Breast Cancer
O'Callaghan	CC 1996	AJNZSMT,	No Abstract		Wellbeing for Palliative Care Pts.
O'Callaghan,	CC 1996	5 JMT, 33 (2)	Full	Qualitative	Lyrical themes of Palliative Care Pts'
O'Callaghan,	CC 1997	MTP, 15 (1)	Full	Clinical	Songwriting in Palliative Care
Fuglestad, S.	1997	NJMT, 6 (1)	Abstract	Qualitative	Q.O.L. using music AIDS/HIV
Skaggs, R.	1997	MTP, 15 (1)	Full	Clinical	GIM in E.O.L. care Private practice
Hogan, B.	1998	AuJMT, 9	Full	Clinical	MT within context Of Palliative Models
Marr, J.	1998-99	JAMI, 6	Abstract	Clinical	GIM case studies a E.O.L.
Hurk, J. & Smeijster, H.	1999	JMT, 36(3)	Full	Clinical	working through grief, rediscovering identity, self esteem
Truger- Querry, B. & Haghighi, KF		HJ, 14 (1)	Abstract	Clinical	Pain & Symptom Management

Complete list of References in Chronological Order (Abstracts and full articles) Cont...

Author	Year	Publication	Full/Abstract only	Type of Pap	er Area of Focus
Daveson, B. & Kennelly, J.	2000	JPC, 16 (1)	Abstract	Clinical	MT in Palliative care for Children/Adolescents
Forrest, L. (also found in	2000 Voices 1	AuJMT, 11 (2), 2001)	Full	Clinical	Issues of ethnicity/identity
McFerran- Skewes, K.	2000	AuJMT, 11(	(3) Full	Qualitative	Psycho-dynamic grp MT w/ Bereaved teens
Aasgaard, T.	2001	JPC, 17 (3)	Full	Clinical	Pediatric Oncology
Gallagher, L. Steele A.	2001	JPC, 17 (3)	Full (	Quantitative	Computerized Database
Hartley, N.	2001	JPC, 17 (3)	Full	Professional	personal reflections on working with Terminally Ill Pts'
Hilliard, RE	2001	JMT, 38(4)	Full	Quantitative	mood/behavior in Grieving children
Hilliard, RE	2001	JPC,17(3)	Full	Clinical	Patient/family needs
Krout, RE 2	2001	AmJHPC,18 (	(6) Full	Quantitative	Pain control, physical Comfort, & relaxation
Magill, A. 2	2001	JPC, 17 (3)	Full	Clinical	Music to address Suffering in Cancer Pts'
Marmor, K.	2001	JPC, 17 (3)	Full	Clinical	Indigent & Terminally II
Nicholson, K.	2001	JPC, 17 (3)	Full	Clinical	Relaxation using Imagery and Music
O'Callaghan,	CC 2001	JPC, 17 (3)	Full	Qualitative	MT in Palliative Cancer Hospital
Rykov, M.	2001	JPC, 17 (3)	Full	Professional	Introspective Personal account

Complete list of References in Chronological Order (Abstracts and full articles) cont...

Author	Year	Publication	Full/Abstract o	nly Type of Pa	per Area of Focus
Salmon, D.	2001	JPC, 17 (3)	Full	Philosophical/The	eoretical Psycho-spiritual
Krout, RE	2002	AJNZSMT	Abstract	Clinical	Grief processing & Self expression with Bereaved children Through song
Aldridge, I	D. 2003	BJMT, 17 (1)	Abstract	Clinical	MT references relating To Cancer & Palliative
Hilliard, RI	E 2003	JMT, 40(2)	Full	Quantitative	Terminal cancer Length of life
Hilliard, RI	E 2003	JPC, 19(2)	Full	Clinical	Pediatric hospice music therapy
Horne- Thompson, (Also found		AJMT, 14 es 7(3), 2007)	Full	Clinical	Hospital-home care implications
Krout, RE	2003	AmJHPC, 200	(2) Full	Clinical	patients & family Facilitating release
Hogan, B. Cockayne,	2003 m.	AuJMT, 14	Full	Historical	Consolidating MT's Future in Palliative Care
Salmon, D.	2003	CJMT, 10 (1)	Abstract	Quantitative	Music Therapist & Coping loss/suffering
Clements- Cortes	2004	AuJHPC, 21(4	Abstract	Clinical	Terminally ill emotional expression
Hepburn, N Krout, RE	1. 2004	NZJMT, 2	No Abstract	t	Meaning, purpose Transcendence, hope Spirituality at E.O.L.
Hilliard, RI	E 2004	MTP, 22(2)	) Full	Quantitative	Hospice Admin. Analysis/Survey
Hilliard, RI	E 2004	JMT, 41(4)	Full	Quantitative	Hospice MT in the Nursing Home

Complete list of References in Chronological Order (Abstracts and full articles) cont...

Author	Year	Publication I	Full/Abstract only	y Type of Pa	per Area of Focus
Krout, RE	2004	AuJMT, 15	Full	Professiona	Syner-disciplinary treatment team
Sheridan, J. McFerran, K		AuJMT, 15	Full	Clinical	Choice/Control in MT within Ped. Hospice
Burns, D. et a	al 2005	JMT, 42 (3)	Full	Quantitative	Cancer Pts' Music Preferences
Cadrin, ML.	2005-06	JAMI, 10 (1)	No Abstract		GIM at E.O.L.
Hilliard, RE	2005	EBCAM, 2(2)	Full	Historical	Review of Empirical Literature
Krout, RE	2005	MTP, 23 (2)	Full	Clinical	MT composed songs in 1-time Bereavement Grp
Lindenfelser,	K. 2005	Voices, 5 (3)	Full	Clinical	Parent advocates in Ped. Palliative & Hospice Care
Renz, M. Mao, MS, Ce	2005 erny, T.	SCC, 13	Abstract (	Quantitative S	Spirituality, psychotherapy research in psycho- oncology
Zabin, AH	2005	MTP, 23 (1)	Full	Clinical	Stories from a MT
Cadrin, ML	2006	CJMT, 12 (1)	Abstract	Clinical	legacy work in Palliative Care
Dalton, TA & Krout, RE	2006	MTP, 24 (2)	Full	Clinical	Bereaved Adolescence MT process/protocol
Hilliard, RE	2006	AP, 33(5)	Full	Quantitative	Compassion Fatigue/team blding
Maue- Johnson, EL & Tanguay, G	2006 C.	MTP, 24 (1)	Full	Clinical	Hospice Assessment tool for MT
Roberts, M.	2006	Voices, 6 (3)	Full	Professional	Personal account of Research process

Complete list of References in Chronological Order (Abstracts and full articles) cont...

Author	Year	Publication	Full/Abstract o	only Type of Pa	nper Area of Focus
Roberts, M	2006	AuJMT, 17 (18)	) Full	Clinical	Homebased song-writing Bereaved Children & Adolescents
Groen, KM	2007	JMT, 44 (2)	Full	Clinical	Pain assessment & Management
Hilliard, RE	2007	JMT, 44(2)	Full	Clinical	Bereavement
Horne- Thompson, A Daveson, Ho		JMT, 44(2)	Full	Quantitative	MT Referral Referral trends
Lindenfelser, Grocke, McF		JMT, 45 (3)	Full	Qualitative	Bereaved Parents w/ Terminal children
Maron, MK	2008	MTP	Full	Clinical	Psychodynamics of Hospice MT
Magill, L	2009	AmJHPM, 26 (1)	Full	Qualitative	Meaning of music as Perceived by Bereaved Caregivers
Nakayama, F Kikuta, F. Ta		JMT, 46 (2)	Full	Quantitative	Effectiveness of Hospice Japan Stress/mood Psychological indicators
O'Callaghan & Barry, P	, CC 2009	Voices, 9 (3)	Full	Clinical	Practice Based Research in Cancer/Palliative Care Methods/Findings
Beck, J	2010	Voices, 10	Full	Professional	dual role as a clinician & Family member
Choi, YK	2010	JMT, 46 (2)	Full	Quantitative Q	PMR on Anxiety/fatigue O.L. in family caregivers
Dimaio, L.	2010	MTP	Full	Qualitative	Entrainment in Hospice Pain management

## APPENDIX B

# Qualitative Articles

Article	Туре	Pop./Diagnosis	Age	Setting	Goal/Themes/ Intervention			
Gilbert, JP. 77 JMT, 14 (4)	Theoretical/ Philosophical	Hospice (A-P)	n/a	n/a	Theorize benefits of Music Therapy in Hospice care			
Bright, R. 79 AuMTAB, 2	Clinical 2(4)	Hospice (A-P)	n/a	Hospital	discuss MT program Victorian Hospital			
Fagens, TS 82 MT, 2 (1)		terminally Ill ea	atency- arly ado- lescent	Hospital	discuss MT work with Terminal Peds efficacy/areas of benefit			
O'Callaghan, C 84 AJNZSMT, (No abstract)								
•	Brooks, M. O'Rourke, A. Clinical 85 AJNZSMT, 7 (2) (no abstract)							
Wylie, ME & F 86 MTP, 3	Blom, RC Qual		mid-age (I 18 Y.O. (I	, -				
O'Callaghan, C 90 AuJMT, 1 (abstract only)	CC. Clinical	palliative care (A-P)	unidenti	ified unidenti	fied MT skills used in songwriting with Palliative Pts.			
Magill- Leverault, L. 93 JPC, 9(4) (Abstract only)	Clinical	long term/ life threatening illness (A-P)	unknowi	n unknow	m MT efficacy in pain/ symptom management			
Mandel, SE. 93 JPC, 9(4) (abstract only)	Clinical	hospice/ palliative care (N/A)	unknow e	n unknowi	Hospice MT Program description			

Article	Type	Pop./Diagnosis	Age	Setting	Goal/Themes/ Intervention
O'Callaghan, 93 JPC, 9(4) (abstract only	Philosophical	Brain Impaired Palliative Pts. (A-P)	unknown	unknown	communication Through MT
Porchet- Munro, S. 93 JPC, 9(4) (abstract only)	Theoretical/ Philosophical	Palliative care (A-P)	n/a	n/a	palliative care education w/ emphasis emot exper. Non-verb expression
Salmon, D. 93 JPC, 9(4) (abstract only)	Philosophical/ Theoretical	Palliative Care (A-P)	n/a	n/a	how music and emotion play an important role in Pall Care
West, TM 94 MTP, 12(2	Clinical )	Adult Breast Ca (A-P)	74y.o.	home	psychological & Spiritual needs of Hospice Pts. Q.O.L.
Aldridge, D. 95 AP, 22 (2)	Philosophical/ Theoretical	Palliative/EOL (A-P)	n/a	n/a	spiritual needs in Palliative & EOL
Jackson, M. 95 CJMT, 3 (1) (abstract only	/	Breast Ca (A-P)	50yrs old	home	benefits of MT to Pt & family Quality of Life
•	CC. Theoretical/ Philosophical	Palliative Care (A-P)	adults	Home/in-pat	ient Theory/example Of MT in pain Management
O'Callaghan, 96 JMT, 33 (2	~	Palliative Car Patients (A-P)	re 26-80y.o	hospital/ unit setting	8 themes emerged songwriting addressed spiritual, psycho-social physical needs
Fuglestad, S. 97 NJMT, 6(1 (abstract only	)	Pall. AIDS/HIV (A-P)	unknown	unknown	challenges of Qualitative research work w/ HIV/AIDS Pts. sage of art therapies

Article	Type	Pop./Diagnosis	Age	Setting	Goal/Themes/ Intervention
Skaggs, R. 97 MTP, 15(1)	Qualitative )	Terminally ill (A-P)	Various	Private Practice	Benefits of BMGIM in global E.O.L. care -BMGIM
Hogan, B. 98 AuJMT, 9	Clinical	Pancreatic CA Carcinoma lung (A-P)	49,54 65	Hosp/Hom in-patient Cl Models	
Marr, J. 1998-99, JAM (abstract only)	*	palliative/ hospice (A-P)	unknown	Home/in- patient	BMGIM in Pall Care How to identify appropriate clients
Hurk, J & Smeijsters, H. 99 JMT, 36(3)	Qualitative	bereaved/adult (A-P)	53y.o	clinical	regaining self identity after a loss
Truger- Querry, B. & Haghighi, KR 99 HJ 14(1) (abstract only)	Clinical	hospice Pts. (A-P)	unknown	unknown	Pain & Symptom Management through art/music therapies
Daveson, B. & Kennelly, J. 00 JPC, 16(1) (abstract only)		Children/ Adolescents (C-P)	unknown	hospital	MT in Palliative care for Children/
Forrest, L. 00 AuJMT, 11 (also 01 Voice		cancer 84 (A-P)	4yrs old	hospital	Issues of ethnicity/identity
McFerran- Skewes, K. 00 AuJMT, 11	Qualitative (3)	bereaved teenagers (T-B)	13-15y.o.	high school	Psycho-dynamic grp MT w/ Bereaved teens
Aasgaard, T. 01 JPC, 17(3)	Clinical	Ped. Oncology (C-P)	14, 8, 4, 6	hospital	making love/ friendship audible through MT psycho-social/ Emotional needs

Article	Туре	Pop./Diagnos	sis Age	Setting	Goal/Themes/ Intervention
Gallagher et a 01 SCC, 9 (no abstract)	al no abstract				Palliative care/MT
Hartley, N. 01 JPC, 17(3)	Professional	palliative/ Hospice (A-P)	n/a	n/a	personal reflections on working with Terminally Ill Pts'
Hilliard, RE 01 JPC, 1(3)	Clinical	breast cancer cardiomyopath Dementia Brain tumor (A-P)	53, 100 y 87, 35	home nursing hm LTC facility	utilizing MT to cope with multi-demential hospice needs ALL
Magill, A. 01 JPC, 17(3	Clinical (A-P)	advanced CA 60	41, 54,	hospital Su	Music to address ffering in Cancer Pts' pain management psychosocial, social spiritual
Marmor, K. 01 JPC, 17(3	-	indigent/ Term. Ill (A-P)	adult	9 bed home like setting	Indigent & terminally III
Nicholson, K 01 JPC, 17(3		adult/ Cancer (A-P)	unidentified	Cancer Center	Relaxation using Imagery and Music
O'Callaghan, 01 JPC, 17(3		patients/ visitors/ Staff members (A-P) (A-C/P)	unidentified	hospital	grounded theory investigation of multi-dementional Benefits of MT Pall Care, 7 themes ALL
Rykov, M. 01 JPC, 17 (2	Professional 3)	hospice MT n/a)	n/a		work setting Personal account Introspective

Article	Type	Pop./Diagnosi	is Age	Setting	Goal/Themes/ Intervention
Salmon, D. 01 JPC, 17(3)	Philosophica Theoretical	l/ hospice Pts Adults (A-P)	1- adult	Home	Psycho-spiritual needs & facilitation through hospice MT
Krout, RE 02 AJNZSM (abstract only		Bereaved Children (B-C)	unknown	unknown	Grief processing & Self expression with Bereaved children Through song
Aldridge, D. 03 BJMT, 17 (abstract only	(1)	non-specific n/a	non-specific	non-specific	MT references relating to Cancer & Palliative
Hilliard, RE 03 JPC, 19(2)	Clinical	Pediatric Palliative care (C-P)	6 mths-14 yr	home/in- patient Hospice	Pediatric hospice music therapy
Horne- Thompson, A 03 AJMT, 14 (07 Voices 7(		n/a	n/a	n/a	Hospital-home care implications
Krout, RE 03 AmJHPC	Clinical , 20(2)	3-cancer, 1-CHI 1-Dementia (A-P)	F 77, 78, 83 85, 37	home/hospital	patients & family Facilitating release
Hogan, B. Cockayne, M Palliative Car 03 AuJMT, 14	e	n/a	n/a	n/a	Consolidating MT's Future in
Clements- Cortes 04 AuJHPC, 2 (abstract only		adult terminal (A-P)			Terminally ill emotional expression
Hepburn, M. Krout, RE 04, NZJMT, (no abstract)					Meaning, purpose Transcendence, hope Spirituality at E.O.L

Article	Type	Pop./Diagnosis	Age	Setting	Goal/Themes/ Intervention
Krout, RE 04 AuJMT,1	Professional	1			Syner-disciplinary treatment team
Sheridan, J. McFerran, K 04, AuJMT,		MD, Cystic fibrosis, Galactosemia (C-P)	6-9 y.o	in-patient hospice	Choice/Control in MT within Ped. Hospice
Cadrin, ML. 2005-06 JAN also in 09 Vo	MI, 10(1)	Cancer	47yrs old adult (A-P)	Home	GIM at E.O.L.
Hilliard, RE 05 EBCAM,	Historical 2(2)	n/a	n/a	n/a	Review of Empirical Lit.
Krout, RE 05 MTP, 23(	Clinical 2)	Bereaved Community Members (A-B)	adult	various	MT composed songs 1-time Bereavement Group
Lindenfelser, 05 Voices, 5	•	Pediatric Palliative Care (C-P)	unspecified	Hospice House	Parent advocates in Pediatric Palliative & Hospice Care
Zabin, AH 05 MTP, 23	Professional (1)	n/a	n/a	n/a	Stories from a MT
Cadrin, ML 06 CJMT, 12	Clinical 2(1)	Cancer/cancer ALS (A-P)	varied	Palliative unit	legacy work in Palliative Care
Clements- Cortes A. 06	Clinical CJMT, 12(1)	M.T's (A-Professional)		ospice Care	Occupational Hazards Among MT's
Dalton, TA & Krout, RE 2006 MTP, 2	& Qualitative 24(2)	adolescents bereaved (C-B)	12-18	public school	Bereaved Adolescence MT process/protocol

Article	Type	Pop./Diagnosis	Age	Setting	Goal/Themes/ Intervention
Maue- Johnson, EL & Tanguay, Q 2006 MTP, 2		n/a	n/a	n/a	Hospice Assessment tool for MT
Roberts, M. 06 Voices, 60	Profession (3)	al bereaved Children (C-B)	n/a	n/a	Personal account of Research process
Roberts, M 06 AuJMT, 1	Clinical 7(18)	bereaved Children/Ado (C-B)		Home-based	Homebased song- w/ bereaved Children & Adolescence
Lindenfelser, Grocke, McF 08 JMT, 45(3	erran	tive Terminally III Children (C-P)	5mths 12 Yrs.	Home- Based	MT altered perception, source of remembrance, multifaceted experience, enhanced communication, parents shared Perceptions/ Recommendations
Maron, MK 08 MTP, 26(	Clinical 1)	Cancer, Chronic Airway Obstruc- tion, COPD, Adu Failure to Thrive (A-P)	ılt	Home, In- Patient Hos Nursing Ho	<u> </u>
Magill, L 09 AmJHPM	Qualitative (, 26(1)		unknown	Home- Based	Meaning of music as Perceived by Caregivers
O'Callaghan, & Barry, P 09 Voices, 9(	•	sional n/a	n/a	n/a	Practice Based Research in Cancer/Palliative Care Methods/Findings
Beck, J 2010 Voices	Professiona	adult cancer (A-P)	unknown	home	dual role clinician & Family member

## Qualitative Articles

Article	Type	Pop./Diagnosis	Age	Setting	Goal/Themes/ Intervention
Dimaio, L. 2010 MTP	Qualitative	Parkinsons, COPD Debility Unspec. (A-P)	88, 69 93, 63	Nursing Hm, Home	Entrainment in Hospice Pain Management

## APPENDIX C

Quantitative Articles		
Author/Year	Curtis, SL. 1986 JMT, 23 (1)	Gallagher, L., Steele, A. 2001 JPC, 17 (3)
Setting	On unit	hospital
Population	Adults	Adults
Diagnosis	Terminally III	Cancer
Age	Unidentified (9 (5 men, 4 women)	Median age 67 Range 28 to 84 years (70% were female)
Independent Variables:	<ul><li>(a) no intervention,</li><li>(b) Background Sound,</li><li>(c) Music</li></ul>	music therapy session
Dependent variables:	pain relief, physical comfort Relaxation, contentment	Patient self assessed:: Mood, Pain, shortness of Breath. Music Therapist Assessed: Facial expression, movement Sleep, and verbalization
Intervention(s) used:	Music listening/recorded	live music listening 78, singing 29, song choice 20, music life review 16  Participation 12, instrument playing 7, Lyric analysis 6 verbal processing 5 (all others 2 or less) entrainment, relaxation, recorded listening, funeral planning, songwriting (n=90)
Goal:	Physical	Physical/emotional

Quantitative Articles	cont			
Author/Year	Hilliard, RE 2001 JMT, 38	(4) Hilliard, RE 2003JMT, 40 (2)		
Setting	Public Elementary School	Home Based Care		
Population	Children-bereaved	Adults-Patients		
Diagnosis	Bereaved (loss of a loved one) terminal illness 61% (cancer, AIDS, CHF) Sudden death accounted for 39%	Terminal Cancer		
Age	6 to 11 years old (Black 55%, White 44%) (25% Black, 75% Whites in equal gender distribution	40, 65+ years old 40, 64 years old and under a each grp)		
N=	n=18 (9 control) (9 experimental)	80 subjects (40 Control) (40 experimental)		
Independent Variables:	8 Session Music Therapy Bereavement Program	routine hospice service and music therapy		
Dependent variables: Behavior, mood, and grief Symptoms  Quality of life, Length of life, relationship to time of death in Days from last MT/counselor visit				
Intervention(s) used: singing, song-writing, rap- writing, rhythmic improvisation, structured drumming, lyric analysis, music listening lyric analysis, music listening  Song choice, music prompted reminiscence, singing, live music listening, lyric analysis accompaniment using iso-principle, planning funeral or memorial service, sing gifts, music- assisted supportive counseling				

Goal of research: emotional/social emotional, physical (Quality of life)

Quantitative Articles	cont	
Author/Year	Krout, RE 2001 AmJHPC, 18 (6)	Salmon, D. 2003 CJMT, 10 (1) (abstract only)
Setting	67-hospice center, 10- home 2 hospital, 1-nursing home	international survey
Population	adults-patients	adult-professionals
Diagnosis	various terminal diagnosis	music therapist
Age	38-97 years old	unidentified-abstract
N=	80 subjects, 90 sessions (33 male, 47 female)	unidentified-abstract
Independent variables	s:active and passive music therapy Experiences	exposure to death, loss and paradoxically, workload Issues, etc
Dependent variables:	Pain control, physical comfort relaxation	stressors
Intervention(s) used:	active and passive music listening Live music listening and imagery Song choice, singing, song discussion songwriting	coping not discussed in abstract
Goal	physical	investigative/informative

Quantitative Articles	cont	
Author/Year	Hilliard, RE 2004 MTP, 22 (	2) Hilliard, RE 2004 JMT 41(4)
Setting	professional	nursing home
Population	Hospice administrators Across the nation Adults	adults-patients
Diagnosis	n/a	Dementia 21, cancer 20, CHF 12, Debility unspecified 7, Cerebro-vascular Accident 8, Parkinson's 4, Chronic liver failure 2, Chronic renal failure 2,
AIDS 1,		fatitute 2, Chrome tenar fatitute 2,
		Gangrene 1, Huntington's chorea 1, Multiple sclerosis 1,
Age	n/a	40, 65+ years old 40, 64- years old (equal gender distribution)
	382 surveys returned in 95' 382 surveys returned in 01'	80 (40 control/40 experimental)
Independent variables	s: n/a	routine hospice services and music therapy
Dependent variables: n/a		length of life, time of death, comparison Of contact hours and number of visits Received by subject from Social Worker and Music Therapist
Intervention(s) used:	n/a	Singing with Guitar/piano/omnichord Instrument playing, song parody, Songwriting, rhythmic improvisation Vocal improvisation
Goal: informative increased awa Reported from From hospice Clinical Inves	admin.	Length of life, time of death comparison of contact hours received and number of visits by subject (MSW v Vs. MT) Clinical Investigation/Quality of Life

Quantitative Articles				
Author/Year	Renz, M.2005 SCC, 13 Mao, MS Cerny, T. (abstract only)	Burns, D. et al. 2005 JMT, 42 (3)		
Setting		oncology setting (unit/hospital)		
Population		Adult-patients		
Diagnosis	cancer	cancer		
Age		mean age 50 (SD 13.89)		
N=	(98-00) 80 Patients (00-03) 251 Patients	65 (60% female) (all but 1 Caucasian)		
Independent variables	S:	survey		
Dependent variables:		survey		
Intervention(s) used:		<ol> <li>Receptive, recorded, no therapist</li> <li>Interactive, live, therapist</li> </ol>		
Goal:	Spiritual	identifying interest and preference for using 2 types of music therapy interventions Clinical Investigation		

Quantitative Articles		_
Author/Year	Hilliard, RE 2006 AP, 33(5)	Horne-Thompson, A. 2007 JMT, 44(2) Daveson, B. Hogan, B.
Setting Settings	Hospice Office	9 Inpatient and Palliative Care
Population	Hospice clinicians/professionals (Social Workers, Chaplains, nurses) Adults	Allied Health, Medical, nurses, self (patient) family Adults-clinicians/Professionals
Diagnosis	burnout/compassion fatigue	not applicable to all
Age	26-60 yrs old (11 female and 6 male) (employed in hospice a min of 1 yr.)	Working age
N=	17 (2 experimental groups)	354 MT referrals
Independent variables	s:6 week music therapy group	N/A
Dependent variables:	group building and compassion fatig	gue N/A
Intervention(s) used:	Group 1. Improvisation Group 2. Breathing exercises, guide Meditation paired with live music Group drumming and chanting Music and movement, lyric analysis	
Goal:	measure team building, measure Compassion fatigue Emotional/social	Clinical Investigation

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()ııanı	titative	Articles

Author/Year Groen, KM. 2007 JMT, 44(2) Woldarczyk, N. 2007 JMT44(2)

Setting hospital in-patient hospice

Population adults-professionals adults-patients

Diagnosis hospice care professionals 5 CA (various)

MTs' and RNs' 1 renal failure

1 AIDS 1 ALS

1 Cardiomyopathy

1 CHF

20-50+Age mean age 73.5

N=72=M.T professionals 10 patients

92= Nursing Professionals (2M, 8F)

Independent Variable survey 30 minute MT session

Dependent Variable survey spiritual well Being

Interventions used: Song choice, music making, based on care plan

Improv, sing-a-longs, life review

Goal informational

> Identify pain scale Most commonly used

Intervention used for

management

measure effect of MT session on spiritual

well Being Spiritual

**Quantitative Articles** 

Author/Year Hilliard, RE 2007 JMT, 44(2)

Setting Elementary School

Population Children-bereaved

Diagnosis Bereaved

Age 5-11yrs old

N= 26 (14 males/12 females)

Independent Variable Off-Based Music Therapy

Social Work Group

Nothing

Dependent Variable Mood, Behavior, physical

Symptoms

Interventions used Orff Based Improvisation

Chanting, live music

Goal Emotional

Quantitative Articles				
Author/Year	Nakayama, H. 2009 JMT, 46(2) Kikuta, F. Takeda, H.	Choi, YK 2010 JMT, 46(2)		
Setting	Nikko Kinen Hospital Caress Mark Hospice	home, facility		
Population	adult-patient	adult-caregiver		
Diagnosis	Cancer	n/a		
Age	Mean age 73 (+/- 9.65 years)	unidentified		
N=	10 (3 males and 7 females)	32, 8 subjects per group (20 spouses of Pts', 12 adult children)		
Independent variables	s:Active and passive music therapy Group	control, music only, Progressive muscle relaxation only, music combined with Progressive muscle relaxation		
Dependent variables:	Stress, mood, fatigue, depression anxiety	anxiety, fatigue, quality of life		
Intervention(s) used:	instrumental engagement, singing Music listening, Patient song selection	music only, music with Progressive muscle relaxation, Progressive muscle Relaxation only		
Goal:	emotional	emotional		

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