

Supporting Family Caregivers in End-of-Life Care: A Systematic Literature Review of
Music Therapy Resources 1990 to 2012

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ABSTRACT

Supporting Family Caregivers in End-of-Life Care: A Systematic Review of Music Therapy Resources 1990 to 2012

Yee Chun Sincere Tung

This research involved a systematic literature review of music therapy research studies on the use of music therapy for end-of-life family caregivers published from 1990 to 2012 in peer-reviewed music therapy and non-music therapy journals, master theses, doctoral dissertations, and edited book chapters. A total of 14 music therapy studies were identified, and analyzed using a template with 22 categories that were derived and modified from Aigen's 2008 templates. Several categories were particularly noteworthy: author, publishing venue, types of presentational form and context, topic and focus of the study; research method and procedures, evaluation standards and procedures, and the description of findings. Important findings included: more than half of the identified journal articles are found in non-music therapy journals, the most frequently-used methods are designed within a qualitative approach; and naturalistic inquiry is the most commonly-used methodology. In assessing these publications, it was found that more attention is needed on such particular areas as selection criteria, choice of evaluation standards and procedures, and the influence of dual relationships. Because of the great needs of end-of-life family caregivers, further research is still needed.

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Chapter 1: Introduction

Researcher's Inspirations

The primary inspiration for this research was derived from the researcher's practicum and internship experiences as a student music therapist working with patients and family caregivers at a palliative care setting. Research questions emerged concerning the use of music therapy to support hospice and palliative care family givers based on the researcher's interactions with patients and their families. When a loved one is diagnosed with a life-threatening illness, their family caregivers must also adjust and adapt to dramatic changes in their lives. Family caregivers may experience some of the many symptoms such as anxiety, depression, fear, sadness, anger, and sleep and concentration difficulties (Waldrop, 2007). As they anticipate the patient's impending death, they may find it difficult to express feelings, thoughts, and last wishes. Questions surrounding the impact of these issues facing caregivers served as a primary impetus for the research which follows.

The second inspiration for this research evolved out of the researcher's professional clinical experience of working at a palliative care unit with dying patients and their family caregivers. In working closely with these people, the researcher became aware of the general lack of available support for the quality of life of family caregivers. The researcher also witnessed the positive impact of music therapy on palliative care family caregivers. Thus, the researcher began to develop a vision for offering support to end-of-life care family caregivers and became motivated to explore and accumulate interventions and resources that applied to end-of-life care family caregivers.

The third and final inspiration for this study originated from the researcher's personal experience while visiting healthcare facilities (including palliative care inpatients and outpatients unit) in Hong Kong. These visits provided opportunities for the researcher to share music therapy experiences with other healthcare professionals at hospitals, community clinics and daycare centres in Hong Kong. During the researcher's interactions with healthcare organizations outpatients and inpatients staff, patients and their family caregivers, he learned that patients can often be the sole subject of care receiving strong support from staff and family caregivers, while the family members themselves are often of secondary concern. One staff described the caregiving role as burdensome for family members such as spouses, children, parents, and relatives because most patients and families form tight-knit groups and often do not accept help from others. In one instance, the researcher asked a family caregiver how she managed multiple workloads and familial responsibilities with the additional caregiving role. The family caregiver indicated that adequate self-care strategies, social support from her relatives, friends, and co-workers; and her religious beliefs all assisted her in managing these multiple roles. A shared concern of both staff and family caregivers was that this burden of caregiving upon the family caregivers was hidden and less likely to be recognized when compared to the needs of the patient. This was because family caregivers typically paid much less attention on their own well-being when caring for their loved ones at the end of the life stage.

Through the researcher's experience in Hong Kong, he came to notice three particular features of the Hong Kong healthcare system. First, the entire healthcare system primarily emphasizes the well-being and quality of life of the patients, while

giving much less attention to the well-being and quality of life of family caregivers or other primary caregivers. Second, not all family caregivers have access to or knowledge of resources that could alleviate their personal stress and benefit their body-mind-spiritual well-being. Third, only a small number of healthcare professionals are familiar with music therapy, understand its underlying concepts, or acknowledge the many benefits it may offer to patients and families.

The potential of music therapy for end-of-life family caregivers became clearer. The researcher became inspired to expand the scope of practice beyond the impact of music therapy on patients, to examine its impact on family caregivers and to make readily available for others, a summary of the information and evidence that exists on the benefits of music therapy for family caregivers. As a result, three overarching initial questions emerged:

1. Were there any music therapy resources specifically for end-of-life family caregivers? If so, how many?
2. Where are the relevant music therapy resources located?

Chapter Overview

Having looked at the researcher's inspiration for this research, Chapter 2 will provide a context for the study by presenting a brief overview of the literature on music therapy in end-of-life care and the primary research question that emerged. Chapter 3 will describe the research methods, and the procedures of data inclusion and analysis. Chapter 4 will document detailed findings of the study as they relate to the research question. The final chapter will present a discussion of the study, including the conclusions and potential areas for future music therapy research.

Chapter 2: A Brief Literature Review

End-of-Life Patients

When facing death, patients with terminal medical conditions and their families may come into contact with end-of-life services (Dileo & Dneaster, 2005; Newton, Bell, Lambert, & Feering, 2002). As a result of their illness, patients often have a difficult time coping with perceived present and future losses, and they may find themselves suffering from pain, loss of control, anxiety, and consequential losses of hope (Magill, 2006). According to Puchalski (2002), the emotional and spiritual distress for end-of-life patients can be profound, as patients may question the meaning, purpose and value of their lives. Within end-of-life conditions, patients may frequently seek new ways to express and understand the many feelings that arise (Health & Lings, 2012). However, once a patient and their caregiver's complex needs and feelings are acknowledged, they may express and share feelings in a meaningful manner, despite decline in the patient's health (Krout, 2001; Lucchese & Krout, 2000; Munro, 1984, Starr, 1999). Music therapy has been shown as a viable way to help process those feelings (Clements-Cortes, 2004; Hilliard, 2001; Magill, 2001, 2006).

Music Therapy for End-of-Life Patients

In end-of-life care, music therapy serves as a professionally-informed and creative use of music within a therapeutic relationship which includes physical, psychosocial, or spiritual care for people who have incurable illnesses (Aldridge, 2003; O'Callaghan, 2010). Increasingly, music therapy is being acknowledged as a beneficial adjunct service and is being incorporated into healthcare settings worldwide, particularly in end-of-life care (Aasgaard, 1999; Aldridge, 1995, 1999, 2003; Gallagher, 2011; Gallagher & Steele,

2001; Gallagher, Huston, Nelson, Walsh & Steele, 2001; Gallagher, Lagman, Walsh, Davis, & LeGrand, 2006; Haghghi & Pansch, 2001; Hilliard, 2001; Hirsch & Meckes, 2001; Krout, 2000; Magill, 2001; Marrelli, 1999; Mramor, 2001; Porchet-Munro, 1993; Rykov & Salmon, 1998, 2001; Trager-Querry & Haghghi, 1999; Zuberbueler, 2001).

A growing body of clinical publications suggests that music therapy is effective in addressing physical issues (Daveson & Kennelly, 2000; Groen, 2007; Hogan, 2002; Magill, 2001; O'Callaghan, 1996a; Trager-Querry & Haghghi, 1999), as well as emotional needs (Aldridge, 1999; Clements-Cortes, 2004; Hilliard, 2005b; Hogan, 1998; Ibberson, 1996; Krout, 2003; West, 1994), and spiritual needs (Foxglove & Tyas, 2000; Magill, 2005; Robertson-Gillam, 1995; Salmon, 2001; Wlodarczyk, 2007) of end of life care patients. Also, several studies have found that music therapy can be beneficial for those experiencing end-of-life by providing pain relief, promoting relaxation and feelings of comfort, and diminishing feelings of fatigue (Dileo & Bradt, 1999; Magill-Levreault, 1993; Magill, 2001, 2006; Magill & Luzzato, 2002; O'Callaghan, 2001; Salmon 2001). Music therapy can also assist patients in expressing their inner emotions (Health & Lings, 2012), and help foster communication between the patients and their loved ones (O'Callaghan, 1996b). Furthermore, Gallagher, Lagman, Walsh, Davis, and LeGrand (2006) found that patients who received music therapy experienced a decrease in anxiety and sadness, improved mood, facial expressions, and enhanced body movement.

While focusing on the needs of the patient, end-of-life philosophy is also concerned with the needs of the patient's family. The impact of taking care of a dying loved one on family caregivers is an area of focus and concern, as it can impact family

caregivers across multiple levels of need, including physical, psychological, emotional, and spiritual needs (Glajchen, 2004; Zabora & Loscalzo, 2002).

Being Family Caregivers for End-of-Life Care Patients

End-of-life illness is a distressing and painful event for both the patient and the patient's family caregivers. Family caregivers' multifaceted needs encompass emotional highs and lows as new events, stressors, and developmental changes influence the caregiving process (Haley, LaMonde, Han, Narramore, & Schonwetter, 2001). As caregivers endure the stress of caring for the dying loved one they rarely recognize the importance of remaining physically and mentally healthy, which often leads to caregiver fatigue and poor health (Andrews, 2001; Blanchard, Albrecht, & Ruckdeschel, 1997; Bramwell, Mackenzie, Laschinger, & Cameron, 1995; Decker & Young, 1991; Gysels & Higginson, 2009; Kristhanson & Ashcroff, 1994; Haley, LaMonde, Han, Narramore, & Schonwetter, 2001; Walsh & Schmidt, 2003; Yates, 1999). The burden of being end-of-life caregivers from the perspective of family caregivers has been well documented (Grbich, Parker, & Maddocks, 2001; Hull, 1990). Feelings of fear, anxiety, depress, helplessness, uncertainty, anger, and guilt are some of the common emotions experienced by end-of-life family caregivers (Hileman & Lackey, 1990; Hilliard, 2001; Kinsella, Cooper, Picton, & Murtagh, 1998; O'Callaghan, Hudson, & Zalcborg, 2011). However, research has indicated that through opportunities to engage in the arts and to develop creative expression, patients and their family caregivers can be enabled to mourn, grieve, celebrate life, be empowered to cope with their difficult situation, and find closure (Gallagher, Houston, Abdullah & Walsh, 1998; Gallagher, Houston, Nelson; Walsh & Steele, 2001). As such, music therapy is a field of practice within the creative arts

therapies professions that can be invaluable in providing support to end-of-life family caregivers (Hilliard, 2001).

Music Therapy and End-of-Life Family Caregivers

Music is a type of arts medium that has a therapeutic effect, as well as the capacity to bond patients and family members together (Rees, 2005). Music therapy has been successfully used in addressing physical, emotional and spiritual distresses experienced by end-of-life family caregivers (Magill, 2009b). According to the literature, family caregivers who experienced music therapy were empowered and comforted by its therapeutic and positive effects on their body, soul, well-being as they lived through some of the most hectic and stressful moments of their lives (Magill, 2011; Porchet-Munro, 1993; Rees, 2005). They also experienced improved quality of life through enhanced communication with their loved ones (Hilliard, 2003; Magill, 2009c).

Specific music therapy strategies employed in sessions by music therapists to support family caregivers included song writing (O'Kelly, 2008), song sharing (Dileo & Parker, 2005; Krout, 2003), patient and caregiver group activities (Stewart et al, 2005), and creation of legacy work with their loved ones (O'Callaghan & Jordan, 2011). These strategies helped caregivers to ease their own moments of stress, by reducing emotional distress, providing opportunities for anticipatory grieving, mitigating distressful physical and psychological symptoms, reducing levels of anxiety and fatigue, easing agitation, fostering and maintaining meaningful interactions between the patients and the family caregivers, and renewing a sense of purpose in a meaningful manner despite the decline in the patient's health (Choi, 2010; Horne-Thompson, 2003; Jackson, 1993; Krout, 2001, 2003; Lucchese & Krout, 2000; Magill, 2001; Magill & Berenson, 2008; O'Callaghan,

1999). While a variety of music therapy techniques have been used to offer solace, comfort, support and spiritual healing to end-of-life caregivers while they are caring for their loved one (Aldridge, 2003; Magill, 2006), music therapy has also been shown to have a positive effect on family caregivers during the grieving period after their loved one has died.

Music Therapy and End-of-Life Family Caregivers Dealing with Grief

The death of the patient is often expected by family caregivers in end-of-life care. Often when a loved one passes away, the family caregiver reacts with a mixture of relief and grief and this may be a time of momentous transitions and major challenges (Dalton & Krout, 2005; Allen, Haley, Small, Schonwetter, & McMillan, 2013). According to Magill (2009a), music therapy has long-lasting ramifications, and could potentially provide a medium through which grief and bereavement for the family caregivers can be processed healthily. Studies on using music therapy interventions to facilitate healthy grieving after the death of a loved one have also been documented. Research found that most participants were able to release their feelings and emotions, and enhance their quality of life, as well as develop personal growth through writing their own songs and lyrics, and through improvisation, singing, and music sharing during music therapy sessions (Dalton & Krout, 2005; Krout, 2005; Lindenfelser, Grocke, & McFerran, 2008; Magill, 2007, 2009a, 2009b, 2009c; O'Callaghan, McDermott, Hudson, & Zalberg, 2013).

In summary, a brief review of the literature indicates a growing body of information focused on music therapy interventions for the end of life population and their family caregivers. While some existing studies examine the needs of family

caregivers of end-of-life care patients, there has not yet been a systematic literature review on this topic. With a growing demand for music therapy with caregiving families within end-of-life care, there are compelling grounds to conduct a systematic literature review in order to analyze, compile and integrate information that will help to identify direction for the discipline of music therapy and serve to help end-of-life patients' family caregivers.

Statement of Purpose and Primary Research Question

The purpose of the present research study is to meet the identified need for a systematic review of the literature in the area of music therapy to support family caregivers in end-of-life care. Such a systematic literature review would: simplify and summarize the searching process for future researchers; provide in-depth analysis of the existing related music therapy database; and make information more readily available and accessible for family caregivers and end of life healthcare professionals.

In pursuit of this purpose, the following primary research question was established:

1. What music therapy literature exists that examines the role of music therapy with family caregivers of patients living in hospice/palliative care?

Assumptions and Personal Biases

Having trained and worked as a student music therapist at end-of-life care practicum and internship placements, the researcher has an assumption that end-of-life care family caregivers are part of a vulnerable population which requires multiple levels of support. The researcher also believes that most families appreciated the presence of music throughout the various circumstances and difficult moments they experienced

while caring for dying loved ones. Since music therapy is recognized for its contributions to end-of-life patients and their families (Hilliard, 2001; Lindenfelser Hense, & McFerran, 2012), the researcher has an assumption that family caregivers would appreciate and agree that music therapy is an effective treatment for providing stress relief and improving their wellness and quality of life.

Delimitations

This study was limited to peer-reviewed journal articles and edited books examining the use of music therapy for family caregivers of patients living in end-of-life care. It was also limited to only resources written in English and published from January 1990 to December 2012. In terms of online resources, only websites that were written in English and created by national or provincial music therapy associations and end-of-life associations were included. No media resources were included.

Operational Definitions

For the purposes of this study, *end-of-life family caregivers* is defined as an unpaid related individual or group of individuals, such as spouses, adult children, parents, or grandchildren, who provide care and physical, social, and emotional support to their loved one who is experiencing a terminal illness and requiring end-of-life care (Smith, 2001; World Health Organization [WHO], 2004). End-of-life family caregivers can be found in end-of-life care, hospice care, palliative care, and cancer care. Caregivers are often prefixed with “family” or “spousal” to distinguish from paid caregiving staff such as personal care assistants, nurses, or professional caregivers (Mitnick, Leffler, & Hood, 2010, Snyder, 2005).

Professional caregivers are defined as paid, employed persons who help disabled or chronically ill people with their daily living, whether it is within the home, outside the home, or both (WHO, 2010).

End-of-life care is a holistic medical model on providing both physical, mental, and emotional comfort, as well as social and spiritual support to patients who are close to dying as a means of allowing them to die with dignity and free of pain while surrounded by their loved ones (National Cancer Institute [NCI], 2012). It also supports the patients' families from diagnosis to the end of life and bereavement (WHO, 2013). The term *end-of-life care* encompasses hospice, and palliative care, as well as any terminal care frequently equated to end-of-life care.

Hospice care, which is frequently equated with end-of-life care, assists patients in the last days, weeks of life. When patients are at an advanced stage of illness, and curative and disease-focused treatments have ceased, end-of-life care is needed (Haley, LaMonde, Han, Narramore, & Schonwetter, 2001; Meyers & Linders, 2003). Hospice service can be provided at hospitals, hospice centers, nursing homes, or in the patient's home and is available to patients regardless of age, religion, race or illness. While in hospice care all curative or disease focused medical treatments and procedures are stopped.

Palliative care is a specific medical discipline with an approach to care for people who are living with a terminal illness. The focus of care is on achieving comfort, ensuring respect for the person nearing death, and maximizing quality of life for the patient, family and loved ones (Health Canada, 2009). Unlike hospice care where

curative measures must cease, no specific therapy is necessarily excluded in palliative care (Canadian Hospice Palliative Care Association [CHPCA], 1997).

Cancer care is a treatment program intended to cure or considerably prolong the life of patients who are diagnosed with cancer as a means of ensuring the best possible quality of life possible to the patients. Once the diagnosis and the extent to which the tumor has spread is in advanced stages and not curative, a decision must be made regarding the most effective treatment for the cancer patients. For them, the only realistic option is palliative care. Effective approaches such as pain relief are available to improve the quality of life for cancer patients in advanced stages (WHO, 2013).

Grief is defined as an individual experience that is a subjective reaction or response to loss (Corr, 2000). For the purposes of this research, the term grief is the response to a loss of a loved one, such as a spouse, parent, or child. It also represents the state of having lost a significant relationship through death (Waldrop, 2007). *Bereaved* is a term often used to describe the objective condition of a person having experienced a major loss such as the death of a parent, spouse, or loved one (Corr, Nabe, & Corr, 2000; Rando, 1993).

Having reviewed the literature and identified the research purpose and question, along with assumptions and delimitations, the chapter which follows will examine the research methodology.

Chapter 3: Method

Systematic literature reviews in music therapy have been published in the United States as early back as 1973, when Jellison published the results of her review and analysis of music therapy literature in *Council for Research in Music Education*. Subsequently, many journal articles have been published that have utilized systematic content analyses and literature reviews (Aigen, 2008a, 2008b; Borton, Koger, & Pickett-Cooper, 1997; Brooks, 2003; Gillbertson, 2009; Gregory, 2002; Hilliard, 2005a). These studies served as an excellent foundation of the structure of systemic literature review for the researcher. They also helped the researcher in the identification of databases that would filter published studies that were related to caregiving in hospice, palliative care and bereaved family caregivers.

Search Strategy

In order to locate applicable English-language literature and references through electronic databases, a complex search strategy containing a variety of search procedures was carefully designed and conducted. The purpose of this data search style was to locate articles in journals outside of music therapy field (Aigen, 2008a). The first step of the strategy involved searching selected electronic databases known to index journals in which material related to music therapy has been published. The second step of the strategy involved searching through print resources by hand, otherwise known as hand searching.

Electronic Databases Search Strategy

A total of 12 electronic databases were searched (see Table 1). Specific keywords and search terms were used to search the electronic databases. Similar to Brotons, Koger,

and Pickett-Cooper's (1997) literature review, the researcher reviewed the literature using different database search engines to identify literature applicable to the analysis collection by focusing the search to specific key words or phrases. When searching databases the researcher put the terms "'music therapy' AND 'family caregivers'" or "'music therapy' AND 'caregivers'" in the top search box, and then combined it with the terms "hospice care", "palliative care", "end-of-life", and "terminal illness" in the secondary search box. The same key words and terms used in the original search were cross-referenced with other databases, including medical subject databases, to ensure all electronic articles had been located.

Table 1

Electronic Databases Searched

Drexel University Library Online Resource
ERIC
Health and Psychosocial Instruments
ProQuest dissertations and theses
PsycARTICLES
PsycINFO
PubMed (Free Journals)
PubMed(MEDLINE)
RILM Abstract of Music Literature
Social Sciences Abstract
SocINDEX
Temple University Music Therapy Database

Search Strategy for Edited Books

In addition to the electronic databases search, hand-searching of reference lists with previously identified publications were also carried out. Edited books from several music therapy publishers including Barcelona, Jessica Kingsley, Oxford University Press, and Routledge were reviewed. The researcher searched for books that had titles or

contained chapter titles that indicated that the content was relevant to purpose of this thesis on the role of music therapy with family caregivers of those in end-of-life care.

Search Strategy for Peer-reviewed Journals

All the content of major music therapy journals and non-music therapy journals were examined through full-text electronic versions of articles, by hand, or in some cases, through electronic indexes. Inter-Library Loan (COLOMBO) was used to obtain print copies of volumes/issues that contained relevant material but remained in-accessible through the Concordia University library electronic database indexes.

Multiple volumes from two journals were obtained from an electronic database produced by the American Music Therapy Association (AMTA) consisting journals that were not widely distributed in electronic form. The first journal, *Music Therapy*, was from the American Association for Music Therapy which stopped publication in 1996. Volumes 9 to 14, representing *Music Therapy* journal publications 1990 to 1996 were examined. The second journal examined was the AMTA's *Music Therapy Perspectives*, from which volumes 8 to 26 representing journal publications from 1990 to 2008 were examined for material relevant to this thesis. The remaining volumes of *Music therapy Perspectives* published in volumes 27 to 30 from 2009 to 2012 were searched through electronic indexes.

The *Journal of Music Therapy* was searched through electronic index for volumes 27-44 published from 1990-2007 and hand searched for volumes 45-49 published from 2008-2012. In addition, the researcher hand searched all volumes published from 1990 to 2012 of the *British Journal of Music Therapy*, formally called the *Journal of British Music Therapy*, as well as the *Canadian Journal of Music Therapy* that were stored at

the libraries of Concordia University, in Montreal Canada. All volumes published from 1990-2012 of the *Australian Journal of Music Therapy*, *New Zealand Journal of Music Therapy*, *Nordic Journal of Music Therapy*, *Music and Medicine*, *The Arts in Psychotherapy*, and *Voices* were also searched through each journal's electronic index. Lastly, *Music Therapy Today* was search through electronic index for publication at World Federation of Music Therapy [WFMT].

Online Sources Search Strategy

The Internet has become a new modality for health resources for communities and groups (Im, 2011). As a result the researcher reviewed online research sources to examine what family caregiver resources were being offered on their websites. This included searches of national and provincial music therapy associations and websites across Canada that are established, updated and supervised by music therapy associations. This included the Canadian Association for Music Therapy, American Music Therapy Association, Australian Music Therapy Association, Music Therapy New Zealand, and British Association for Music Therapy.

Since the primary focus was specifically on music therapy resources and not general resources or support groups for hospice and palliative care family caregivers, the researcher excluded most of the national, provincial, or regional palliative care association websites with the exception of two well-known and publicly recognized associations: the Canadian Hospice Palliative Care Association (<http://www.chpca.net/>) and National Hospice and Palliative Care Organization (<http://www.nhpco.org/>).

Selection Criteria

Whether a publication is an example of music therapy with families or family caregivers is open to different interpretation; however, the researcher developed and undertook a strategic plan that involved selecting specific criteria through which articles were filtered. Publications were included in the analysis if they contained all the following elements:

1. The publications were peer-reviewed journal articles, book chapters, master's theses, doctoral dissertations, or online resources that examined quantitative and/or qualitative data on the use of music therapy with family caregivers of patients living in end-of-life care, or bereaved family caregivers of patients previously lived in hospice or palliative care.
2. The family caregivers had participated in music therapy with or without their loved ones, or after their loved ones had died.
3. Only publications written and published in English were included.
4. All included publications were written and published by music therapists from 1990 to 2012.
5. Websites were created or updated by music therapists sometime between 1990 and 2012.
6. Publications had to include a description and discussion of the use of music therapy techniques in a way that music therapists would identify and document as a legitimate application of the term music therapy.

In addition to the above-mentioned selection criteria set out by the researcher, the issue of whether to include literature on the use of music therapy support groups with

family caregivers of patients with advanced cancer or family caregivers of people dying from terminal illness arose. As the literature in question encompassed the topics of the use of music therapy for family caregivers of patients with advanced cancer care, with parents of children in paediatric hospice and palliative care, and bereaved family caregivers of patients who died following time in end-of-life care units, the researcher felt that these sources could be valuable resources and should not be ignored. In fact, literature reported in-depth information on the impact music therapy played on family caregivers while they cared for their loved ones in end-of-life care. Also, on the paediatric hospice or palliative care units, parents are always the family caregivers, so including them would enrich the findings and enlighten the public to the role of music therapy in the family-centered context.

In addition to establishing the selection criteria, whether or not to include literature that did not include terms such as family caregivers, family or families, or caregivers in the title was another issue that arose. As a result the researcher read all these publications in order to decide if they met all 6 inclusion requirements.

Inclusion Criteria and Issues of Quality

To address issues of quality, all of the included scholarly articles and book chapters related to music therapy came from peer-review journals, music therapy publishers, and websites of national music therapy associations throughout the globe. In general, all included publications were externally reviewed. Some unpublished Master's theses and Doctoral dissertations were included because they met all the criteria for this research study. All the literature that was reviewed could provide a greater understanding

on families of individuals in end-of-life care, and the caregiving environment as it relates to the use of music therapy with family caregivers.

Exclusion Criteria

Studies in the first group of literature excluded were clinically oriented but whose claim as music therapy studies came into question. These included studies that were not carried out by a music therapist. Studies were found that used music interventions to support caregivers, with the interventions conducted by clinicians or researchers who were not music therapists (e.g., professionals in other healthcare fields such as physicians, nurses, social workers, chaplains, psychologists, and psychiatrists). Including them into research data might enhance insight of how other healthcare professions used music as an intervention to assist, support, and comfort their clients' physical, emotional, psychological, and mental well-being; however, their inclusion would deviate from the original purpose and the selection criteria of this research. Other studies excluded in this group involved clinical work that was primarily based on psychotherapy principles and incorporated little to no application of theories and practices of music therapy.

The second group excluded was comprised of abbreviated case reports and vignettes on larger, more complete studies. Vignettes or case reports were often attached in a journal article and published and referenced as research studies. However, not every study had sufficient information or comprehensive examples of the use of music therapy with family caregivers specifically, which could be described, evaluated, and discussed within the context of this thesis. For this reason, the researcher excluded case reports and vignettes if:

1. the publication context was clearly focusing on coding, reviewing, analyzing patient responses and feelings;
2. the publication indicated family members were present at the session, but did not report their participation during the music therapist's visit;
3. the publication only reported families' feedback regarding the impact of music therapy on their dying loved ones but not the family caregivers;
4. the publication only mentioned a song request made by a family caregiver, comments in between music or after music but no further information regarding family caregivers was made by the researchers.

The third group of literature excluded was comprised of literature that was clearly researching a different therapy modality but utilized musical elements during their therapy session. For example, studies where art therapy intervention took place while listening to background music, the use of background music with therapeutic touch, and music listening in verbal therapy were not included.

Furthermore, documentary films, compact discs (CDs), and video clips were excluded from the data collection unless they were created and posted on the websites of music therapy associations or from national hospice and palliative care websites. Personal blogs and personal websites were also excluded because while these resources may be available online, not all of them are supervised and managed in keeping with professional standards. The researcher will further elaborate on issues pertaining to the inclusion/exclusion criteria in the discussion chapter.

Developing Systematic Review Guide and Templates

When conducting literature review research, the analysis component plays a critical role in delivering results. The researcher searched for similar previous systematic literature reviews and utilized them as research guides. Gilbertson and Aldridge (2003a; 2003b), and Aigen (2008a; 2008b) suggested strategies, guides, and templates which subsequently led the researcher to design a modified template based on a combination of Gilbertson and Aldridge's (2003a; 2003b), as well as Aigen's (2008a; 2008b) research methods. Those guidelines included: easier ways to perform electronic database and hand search, personal peer consultation for data analysis and evaluations, as well as how to use a template to assist in the analysis process. The literature was therefore reviewed through the researcher's modified template.

Data Analysis Procedure: Implementing the Template for Analysis

After the journal articles, books chapters, and online resources were retrieved, each resource was analyzed through a template consisting of 22 categories (see Table 2) to determine if they met the predetermined criteria for inclusion in this research. The analysis template was utilized as both a data gathering tool and an outcome of this systematic research. It was adjusted as the researcher went along, and all journal articles, books, and websites were analyzed twice.

During the first run-through, several issues arose and the researcher needed to repeatedly adjust the template to accommodate elements that emerged from the selected readings. The second time through, the researcher used the newly adjusted template to analyze the previously gathered information, as well as the areas that the former template that had not been equipped to examine in the first analysis of the literature.

Table 2

Analysis Template

Author, Publishing Venue, and Report Characteristics

Author (single, multiple)
Author gender
Year of publication
Publishing venue
Types of presentational form
Types of context provided

Topic and Focus of the Study

Broad topical area
Any dual roles in the research, is the relations addressed?
Concept through which the purpose of the research is articulated
Client group studied
Music therapy techniques described

Research method and Procedures

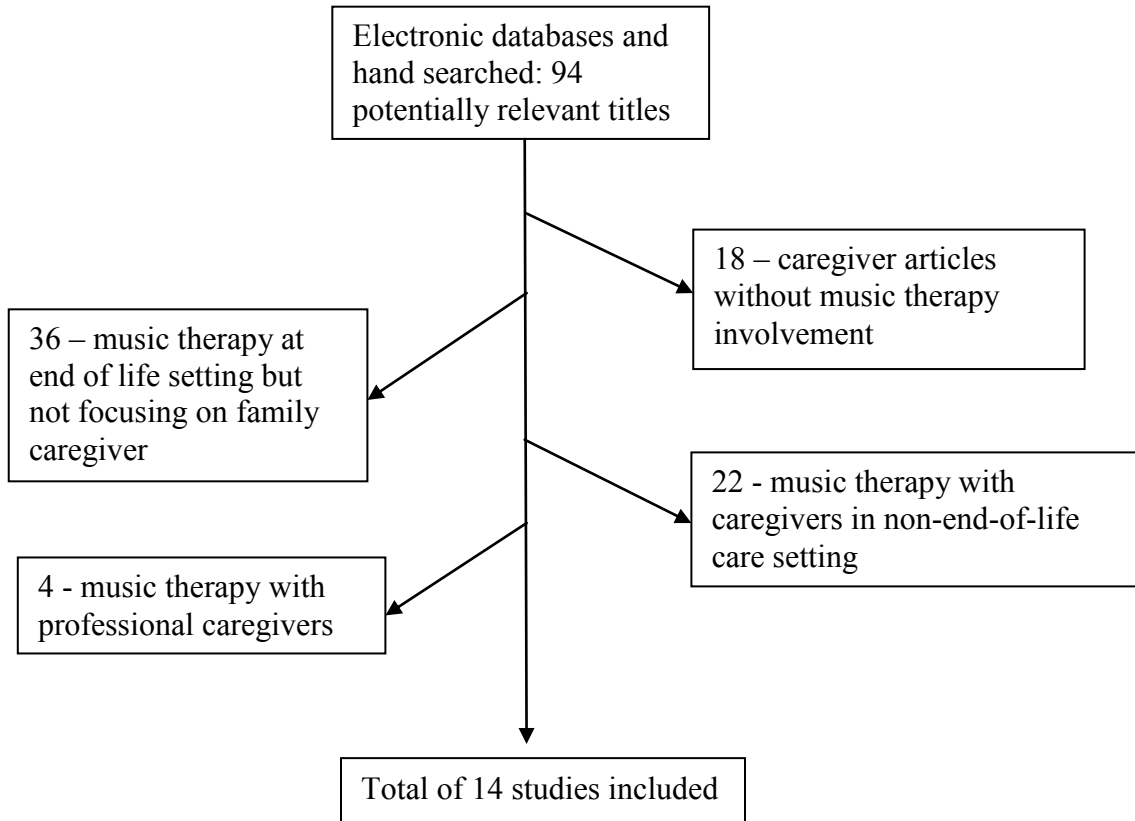
Qualitative, quantitative, or combined methods
Was a specific research method identified?
Data gathering described
Data analysis described
Computer analysis used
Data sources
Data gathering method
Types of evaluation standards mentioned (if any)
Types of evaluation procedures employed (if any)

Research Findings

Findings type
Findings form

The initial literature search generated 94 publications. The first analysis pared this list down to 76 publications. During the second analysis an additional 62 publications were dropped from the study because they fell under the exclusion criteria, leaving 14 studies in total eligible for this systematic review.

Figure 1. Result of eligible data



Data Analysis Procedure: Tables Creation and Representation

All 14 publications were categorized and interpreted with the identified research questions in mind. The researcher then entered these categories into a table. The table organizes all the information about each selected resource in the following columns: (a) author; (b) year of publication; (c) type of publication; (d) name of source (journal name or book title); (e) type of report; (f) setting. Upon completing the columns of the table, the researcher was able to get a sense of the total numbers of the scholarly articles, book chapters, and resources that were completed since 1990 to 2012, and the content of each publication and resource. The researcher also created a table to visually demonstrate how many resources have been published per year, starting from 1990 to 2012. In addition, the

researcher constructed a table to illustrate the total amount each journal published individually. This table was intended to assist readers in understanding which peer-journals had published more on the use of music therapy with end-of-life family caregivers. All of these tables will be presented in Chapter 4.

Chapter 4: Results

Authors and Publishing Venues

A total of 14 items, including nine journal articles, two book chapters, two master's theses, and one doctoral dissertation were examined; no acceptable online resources were found. Of the 14 resources, 11 (79%) had one author, 2 (14%) had three authors, and 1 (7%) had nine authors. There were a total of 4 male authors and 20 female authors. However, this does not mean there were 24 authors. For example, if a female author wrote four studies this would be counted four times and demonstrate as four author designations.

As shown in Table 3, there has been a dramatic increase music therapy publication on end-of-life family caregivers in the last 12 years. All 14 resources were published from the year 2003 onward. Since 2005, at least one resource a year has been published. Out of the 14 resources, nine resources (64%) were published from 2005 to 2009.

Table 3

Year and Number of Published Literature Resources

Individual year totals					5-year totals
1990 (0)	1991 (0)	1992 (0)	1993 (0)	1994 (0)	0
1995 (0)	1996 (0)	1997 (0)	1998 (0)	1999 (0)	0
2000 (0)	2001 (0)	2002 (0)	2003 (1)	2004 (0)	1
2005 (1)	2006 (0)	2007 (2)	2008 (3)	2009 (3)	9
2010 (1)	2011 (1)	2012 (2)			4

Tables 4 and 5 show the peer-reviewed journals within which nine articles appeared. Two studies were appeared in edited books (Flower, 2008; Stewart, et al,

2005), two were master theses (Anderson, 2012; Choi, 2007), and one was a doctoral dissertation (Magill, 2007). Table 4 illustrates how the journal articles were distributed. Non-music therapy journals published more articles on the use of music therapy with end-of-life family caregivers than music therapy journals. Five different medical journals published six articles (67%) compared to three articles (33%) published in two different music therapy journals.

Table 4

Publishing Venue for Journal Articles

<i>American Journal of Hospice and Palliative Medicine</i>	2
<i>American Journal of Hospice and Palliative Care</i>	1
<i>International Journal of Palliative Nursing</i>	1
<i>Journal of Music Therapy</i>	2
<i>Journal of Palliative Care</i>	1
<i>Music and Medicine</i>	1
<i>Palliative and Supportive Care</i>	1

Table 5

Publication Details

Author	Year of Publication	Type of Publication	Name of Source (Journal, Book or Thesis Title)
Krout, R. E.	2003	Journal article	<i>American Journal of Hospice and Palliative Care</i>
Stewart, K., et al.	2005	Book chapter	<i>Music Therapy at the End of Life</i>
Choi, Y, K	2007	Master thesis	<i>The Effect of Music and Progressive Muscle Relaxation On Anxiety, Fatigue, and Quality of life in Family Caregivers of Hospice Patients</i>
Magill, L.	2007	Dissertation	<i>The Spiritual Meaning Of Music Therapy After the Death of A Loved One: A Qualitative Study of Surviving Caregivers</i>
Flower, C.	2008	Book chapter	<i>Music Therapy with</i>

			<i>Children and Their Families</i>
O'Kelly, J.	2008	Journal article	<i>International Journal Of Palliative Nursing</i>
Lindenfelser, K. J., Grocke, D., & McFerran, K.	2008	Journal article	<i>Journal of Music Therapy</i>
Magill, L.	2009a	Journal article	<i>Journal of Palliative Care</i>
Magill, L.	2009b	Journal article	<i>American Journal of Hospice and Palliative Medicine</i>
Magill, L.	2009c	Journal article	<i>Palliative and Supportive Care</i>
Choi, Y, K.	2010	Journal article	<i>Journal of Music Therapy</i>
Magill, L.	2011	Journal article	<i>Music and Medicine</i>
Lindenfelser, K. J., Hense, C., & McFerran, K.	2012	Journal article	<i>American Journal of Hospice and Palliative Medicine</i>
Anderson, J. C.	2012	Master thesis	The Effect of Original Songwriting in Music Therapy Sessions on the Hospice Experience and Bereavement Process of Patients and Their Families

Characteristics of Resources

The authors used different structures and writing styles when presenting their research. Three formats were identified: *traditional academic*, *individualized academic*, and *narrative/content*. A traditional academic format presents the information in the following order: Introduction, Literature Review, Method, Results, Discussion and Conclusion (sometimes the discussion and conclusion are combined into one section). The individualized academic format may have incorporated most of the traditional form; however, the research is presented under content or topic headings that are unique to the studies themselves rather than the generic labels used in the traditional format (Aigen, 2008b). Narrative/content formatted studies employed novel and progressive formats to illustrate the content of the study (Aigen, 2008b).

When analyzing content, studies classified as traditional academic studies were generally written with a style and content consistent with quantitative studies. In order to maintain a scholarly distance throughout the study, the writing voice was also composed in a neutral or third-person. Furthermore, this writing style typically does not include any background information about the researcher(s) (Aigen, 2008b). In addition, there are two other categories regarding to the writing content: *progressive academic* and *personalized/novel narrative*. The progressive academic writing style provided some background information about the researcher and created some new forms to report findings rather than using the more traditional ways of report findings. The personalized/novel narrative generally contained more in-depth information about both the researchers' and participants' background, and also presents the information with a novel writing structure (Aigen, 2008b).

A traditional academic form was used in ten (71%) of the studies, two (14%) studies used the individualized academic form, and two (14%) studies used narrative/content driven form. In terms of content, 12 studies (86%) were designated as traditional academic, content written with progressive academic was found in one study (7%) and one study (7%) was designated as personalized/novel narrative. As for background information, in 14 studies, only one (7%) study discussed the researcher's background, and 12 (86%) studies presented the participants' background information.

Topic and Focus

Bruscia's (2005) classification of research topics as *professional*, *disciplinary*, or *foundational* was employed to classify the resources in this systematic literature review. Foundational research topics were not chosen in the research examined, and was deemed

an exclusionary criterion because the foundational category includes anything related to therapy, health care, or music which is too broad for research inclusion. The researcher found no study could be classified under professional research topics such as education, training, or history. Therefore all studies analyzed were those written in disciplinary research topics.

Aigen's (2008a) guidelines to divide discipline research topics into the three sub-categories of *Treatment-Focus on Client*, *Treatment-Focus on Intervention, Process or Model (IPM)*, and *Treatment-Other* were adopted for the purpose of this study. There were seven studies that were classified under Treatment-Focus on Client, seven studies were IPM-focused, and none were classified as Treatment-Other. In the client-focused category, all seven studies were focused on the clients' views from the music therapy process or of the experiences. Studies in the IPM-focused category described a particular music therapy intervention and how music therapists used the intervention. Treatment-other was focused on the music therapist's experience and reflection during the music therapy process.

The incidence of dual roles is not uncommon in music therapy research. For instance, when research on therapeutic processes or sessions takes place, it is often the case that researchers studied their own clients, thus serving as therapist-researchers. Also, students may participate in research projects in which the researcher also served as their educator. Colleagues may also participate as clients in some research studies. Of the 14 studies, nine studies (64%) involved some type of dual relationship, yet only three studies addressed this dual role as therapist-researcher. Interestingly, all three studies that

mentioned dual roles were written by the same author (Magill, 2007; Magill, 2009c; Magill, 2011).

When reporting research, research purpose or aims are usually identified or described. In this systematic literature review, research questions were found in three studies, a research purpose was found in two studies, a research aim was described in six studies each, and three studies included a research objective.

While the clinical area of all of the 14 studies was in end-of-life setting (see Table 6), nine involved participants from hospice settings, three involved participants from palliative care, and only two mentioned end-of-life care. In addition, three studies focused on family caregivers of children in end-of-life care, three focused on hospice family caregivers, one study on palliative family caregivers, one focused mostly on family caregivers with some sections on professional caregivers and six focused on bereaved family caregivers that had participated and experienced music therapy with their loved ones.

Table 6

Overview of the Type of Report and Research Setting

Author	Year of Publication	Type of Report	Research Participants and Setting
Krout, R. E.	2003	Practice report, case examples	Hospice patients and their families
Stewart, K., et, al.	2005	Book chapter with interventions	End-of-life caregivers (family and professional)
Choi, Y, K.	2007	Theoretical paper (Quantitative)	Thirty-two family caregivers from hospice
Magill, L.	2007	Theoretical paper (Naturalistic-inquiry)	Seven bereaved mothers from Palliative Care
Flower, C.	2008	Book chapter	Music Therapy with three end-of-life patients and their family caregivers
O’Kelly, J.	2008	Practice report with	Family caregivers at a

		interventions, and case vignette	hospice
Lindenfelser, K. J., Grocke, D., & McFerran, K.	2008	Theoretical paper (Phenomenology)	Seven bereaved mothers from a palliative care
Magill, L.	2009a	Theoretical paper (Naturalistic-inquiry)	Seven bereaved family caregivers from home hospice service
Magill, L.	2009b	Theoretical paper (Naturalistic-inquiry)	Seven bereaved family caregivers from home hospice service
Magill, L.	2009c	Theoretical paper (Naturalistic-inquiry)	Seven bereaved family caregivers from home hospice service
Choi, Y, K.	2010	Theoretical paper (Quantitative)	Thirty-two family caregivers from hospice
Magill, L.	2011	Theoretical paper (Content analysis)	Seven Bereaved family caregivers from home hospice
Lindenfelser, K. J., Hense, C., & McFerran, K.	2012	Theoretical paper (mixed method: pre/post test and phenomenology)	Fourteen Family Caregivers at Pediatric Palliative Care
Anderson, J. C.	2012	Multiple case study	Eight Hospice Family Caregivers

Music Therapy Techniques

Many music therapy techniques related to the use of music therapy on end-of-life family caregivers were documented by the researchers. These interventions included: improvisation (vocal, lyric, instrumental), song writing, music listening, music and movement, guided music relaxation/imagery, mindful music listening, vocal exercises, chanting/toning, singing, musical reflection, music and progressive muscle relaxation, music imagery, music making, music composition, and audio/vocal recording for legacy projects. Not every resource demonstrated the use of music therapy techniques directly with the end-of-life family caregivers; however, each family caregiver that was being studied and reported on had experienced music therapy with or without their loved one.

Research Methods and Procedures

As seen in Table 6, 11 (79%) studies used qualitative methods exclusively, two (14%) used quantitative methods (Choi, 2007; 2010), and one (7%) used mixed methods (Lindenfelser, Hense, & McFerran, 2012). While ten (71%) of the studies made reference to a specific qualitative or quantitative method, the remaining four (29%) made no such reference. Of these 14 studies, five studies used naturalistic inquiry, followed by two interventional-based methods, two examples of case studies, one with pre/post-test and one phenomenological, while content analysis and phenomenology were each mentioned once.

The results related to the description of data gathering and analysis can be seen in Table 7. Of the studies, 71 percent described their processes for gathering and analyzing data. Only two (14%) studies used computer programs to assist with the data analysis.

Table 7

Description of Data Gathering and Analysis

Area of concern	Yes	No
Process described for data gathering	10 (71%)	4 (29%)
Process described for data analysis	10 (71%)	4 (29%)
Computer analysis used	2 (14%)	12 (86%)

Table 8 illustrates the rich variety of data sources within each study. Nine studies (64%) used two or more data sources while the remaining five studies used a single data source. For the purpose of the present study, the category of clients referred to patients in end-of-life care. As for data gathering methods some studies were found to use more than one method to gather data. Interviewing was used in four studies, written and audio

documentation was used in 11 studies, and questionnaires were used in three. In the area of evaluation standards and procedures it was found that over half (57%) of the studies did not reference any evaluation standard and half of the studies (50%) did not mention any procedures employed to address the need for evaluation. In the five studies that addressed this topic, the following standards were employed: elimination of subjective bias (1); reliability (1); trustworthiness (2); and triangulation (1). In the procedures related to evaluation: peer debriefing was used in four studies (Anderson, 2012; Magill, 2007, 2009c; Lindenfelser, Grocke, & McFerran, 2008), member/participant checking was used in two studies (Magill, 2007;2009), and recursive analysis was employed in three studies (Magill, 2009a; 2009b; 2011). Within the studies that employed evaluation procedures, single evaluation procedures were used in four studies (Anderson, 2012; Magill, 2009a, 2009b, 2011), and multiple evaluation procedures were used in three studies (Lindenfelser, Grocke, & McFerran, 2008; Magill, 2007, 2009c).

Table 8

Frequency of Data Sources

Source	Frequency
Family caregivers	9
Music therapy sessions	6
Clients	3
Written document	7
Pre-existing (5)	
Generated during study (2)	
Recording document (audio)	3
Generated audio (3)	
Literature	2

Research Findings

Adopted from Aigen's (2008a, 2008b) guidelines, the researcher classified all the studies into one of four categories, which ranged from less interpretive to most interpretive. The categories were: (a) descriptive, (b) descriptive with interpretation, (c) interpretive and (d) interpretive with reintegration. Descriptive studies present the findings by describing what happens in a music therapy session; Descriptive with Interpretation studies contain interpretations of the meaning or significance of the descriptive accounts; Interpretive studies present interpretive statements of the events from therapy sessions; and Interpretive with Reintegration studies include interpretations of the meaning of the therapy session reintegrated into larger context, such as researcher's life or client's life (Aigen, 2008a). There were four studies with findings that were classified as primarily descriptive (Anderson, 2012; O'Kelly, 2008; Choi, 2007, 2010); three studies that were classified as descriptive with interpretation (Flower, 2008; Krout, 2003; Lindenfelser, Hense & McFerran, 2012), seven studies that were classified as interpretive (Lindenfelser, Grocke, & McFerran, 2008; Magill, 2007, 2009a, 2009b, 2009c, 2011; Stewart, et al, 2005), and no study was classified as interpretive with reintegration.

For the purposes of this systematic literature review the orientation of the different purposes of each resource's findings was analyzed. The two categories of *insight*, and *information* were adapted from Aigen (2008b). Insight aims to enhance the sense of meaning for the research participant, client, researcher, or reader. Information aims primarily to organize evidence for professional or discipline fields. The studies were divided, with eight studies (57%) focusing on providing insight, and the reminding six

studies (43%) focus on supplying information. Table 9 indicates that the category of *themes* was the most common form in which findings were presented, followed by *narrative* findings.

Table 9

Forms of Research Findings

Form	Numbers
Themes	8
Narrative	4
Correlation	2
Method	1
Essences	1

The results of this systematic literature review have included an examination of each study's publication venue, presentation type, topic focus, and findings. In addition, through a combination of text and tables, it has provided visual comprehensive yet accessible description for the readers. Although the number of studies analyzed was small, the analysis process was not simple. The chapter which follows will look at the ramifications, limitations, conclusions, and future indications of this systematic literature review.

Chapter 5: Discussion

Having looked at the findings in the previous chapter, this last chapter will present an overview of the results, discuss the challenges and limitations, and identify future research considerations.

Overview of Publishing Venues

From 1990 to 2004, only one music therapy publication was found on the use of music therapy for end-of-life family caregivers. In 2003, Krout published a study about the use of music therapy with dying patients and their families. The number of publications increased dramatically from 2005 to 2012. A total of 13 studies were published from 2005 to 2012, which is encouraging for end-of-life family caregivers as well as to the music therapy profession as it may indicate a growing acknowledgement of the needs of end-of-life family caregivers.

As mentioned in Chapter 4, five academic medical journals published a total of six articles, and two music therapy journals published a total of three articles between them on the subject of the use of music therapy for end-of-life family caregivers. With 67% compared to 33%, this is two times higher than peer-reviewed music therapy journals. The reason for the lack of articles found in music therapy journals was unknown; however, the findings indicated two things. First, music therapy articles on end-of-life family caregivers can be found in medically-based journals, for example: the *Journal of Palliative Care*, the *American Journal of Hospice and Palliative Care*, and the *International Journal of Palliative Care* among others.

Second, in medically-based journals, editors usually publish articles on the medical treatments, symptoms management techniques, intervention effects, medicine

side-effect, etc. The inclusion of complementary healthcare research such as music therapy research by the editors of medically-based journals can serve to promote the profession of music therapy to other allied healthcare professionals. Although the majority of publications were presented in journal article format, Table 5 indicated that music therapy students, music therapists, and researchers are also distributing their publications through other publishing venues. This included: peer-reviewed journal articles, edited book chapters, a doctoral dissertation, and master's theses.

Characteristics of Resources

In this research study, three academic writing formats were identified: the traditional academic format, the individualized academic format, and the narrative/content driven format. Ten of the studies were written in the traditional academic format, two were written in the individualized academic format, and two were written in the narrative/content driven format. This result indicated that the traditional academic format of reporting research findings, which includes an introduction, literature review, methodology, results and discussion, is used five times more than the other two research reporting formats seen within this study.

Regarding on content, 12 studies were designated as traditionally academic, one study's content was written with progressive academic and one study's content was written in personalized/novel narrative, which means traditional academic content was used the most. In combining the numbers for the two non-traditional designations in form (28%) and content (14%), it appeared writing in the style of traditional academic was used by most researchers in terms of presenting content; however, some researchers preferred using styles other than the traditional academic form. This may indicate that

researchers are choosing to write in a way that best conveys the results of the study for the intended readers. Out of the 14 studies, 12 studies used traditional academic content, nine studies were peer-reviewed journal articles, two were master theses, and one was a doctoral dissertation. The two studies that were not designated as traditional academic content were book chapters (Flower, 2008; Stewart, et al, 2005).

Flower (2008) used first person voice to describe her work with three end-of-life families. The chapter was written with a first personal perspective, as it contained more information about the context of research participants to a greater extent. Stewart et al. (2005) utilized progressive academic content for readers by broadly examining the role of music therapy in caring for different types of end-of-life caregivers (e.g., family caregivers and professional caregivers). Although it was not written in first person perspective like Flower's (2005) study, Stewart et al.'s (2005) publication contained some contextual information about each of the nine authors in the chapter. Stewart et al. (2005) also presented their research in six parts and ended with a summary section. Their publication represents a non-traditional content form, as it utilized an unorthodox way to present their results compared to traditional research reporting.

As for the remaining 12 studies, all of them structured their content in the third person or a neutral writing voice, and maintained distance throughout their reporting. Of the 12 studies, 11 did not provide any contextual information about researchers, with the exception of Magill (2007).

In terms of background information, only Magill's (2007) doctoral dissertation provided complete background information on both herself as a researcher and all the research participants. Interestingly, the two master's theses did not provide researcher

background information (see Table 5). Although very few of the sources examined within the context of this research included researcher background information, this may not be surprising as journal articles and book chapters offer limited space, which means their focus may be more on reporting findings. On the other hand, 12 studies (86%) contained research participants' background information. This illustrated that providing context relating to research participants is important as assists readers in understanding the population the researcher(s) is studying.

Diversity of Research and Computer Data Analysis

The data collected for this research demonstrated a diversity of qualitative and quantitative research methods. Qualitative research methods included content analysis, interventional research, naturalistic-inquiry, multiple case studies, and phenomenology. Quantitative research included the use of ANOVA and pre- and post-test analysis. The use of seven different research methods in 14 studies shows music therapists are utilizing a diversity of qualitative and quantitative research approaches when designing research projects for end-of-life family caregivers. This is encouraging because through diverse research approaches music therapists can provide more conceptual and foundational groundwork on the use of music therapy with end-of-life family caregivers, while also broadening societal perspectives by demonstrating music therapy's benefits to the public in multiple dimensions.

There was a broad coverage of research settings and participants within the 14 studies examined. Settings such as adult and paediatric hospice, palliative care and terminal care were described. Within the 14 studies, participants included parents, adult children, and spouses. Also, different types of caregivers have been researched including:

bereaved caregivers (Anderson, 2012; Lindenfelser, Grocke, & McFerran, 2008; Magill, 2007; 2009a; 2009b; 2009c; 2011); parents of children with terminal illness (Flower, 2009; Lindenfelser, Hense, & McFerran, 2012); family caregivers of impending dying patients (Krout, 2003), music therapy for hospice caregivers (Choi, 2007; Choi, 2010; O’Kelly, 2008) and family caregivers in different situations (Stewart, et al, 2005). The fact that multiple areas of end-of-life care were addressed provides groundwork for future researcher to build on.

The information in Table 7 indicates that 10 out of 14 studies included a description data gathering and analysis methods. Only two studies (Choi, 2007; 2010) employed computerized data analysis, both of which were quantitative studies. That means the remaining studies, including mixed methods (Lindenfelser, Hense, & McFerran, 2012), used more traditional forms of data analysis such as coding interview notes by hand rather than inputting interviews into a computer and utilizing computer software to help process the data. Of course, whether or not to use computer programs to assist data analysis is influenced by the objective of the research studies and the researchers.

Dual Roles

As presented earlier, researchers sometimes studied their work with their own clients, or students participated as clients in their professors’ research; therefore, the presence of dual roles was not rare within the studies examined. Nine of the 14 studies involved some form of a dual role, yet only three studies, consisting of a doctoral dissertation and two peer-reviewed journal articles, addressed the issue of dual roles in their reporting. Interestingly, no reference was found to the issue of dual roles in the

master thesis (Anderson, 2012) that used a qualitative research method; yet identifying dual roles (if any) is part of most academic ethics requirements for theses and dissertations. Although not all research has the issue of dual roles, paying attention to the possibility of dual roles can provide important information in evaluating the research findings, particularly in qualitative studies.

Evaluation Standards and Procedures

In addition, the findings in the area of evaluation standards also mark an important outcome in the study. As mentioned in Chapter Four, 64% of the studies examined did not refer to any evaluation standards, and 50% of the studies examined did not describe any evaluation procedures. As only five studies documented evaluation methods in their studies, the issue of documentation and awareness of evaluation is an area of concern. As Aigen (2008a) argued “the complexity and lack of consensus in this area is not a legitimate reason for the issue of evaluation to be ignored by so many authors” (p. 257). Furthermore, having evaluation standards when conducting research can provide stronger evidence to support results, especially for qualitative studies where methods can vary widely.

Challenges

Three major challenges arose in the completion of this research: inclusion and exclusion criteria, in-text citations, and accessibility of music therapy resources. First, when obtaining the data, many studies utilized terms such as “family members”, “families”, or “carers” in their titles and abstract rather than the term “family caregivers”. At first, the initial electronic and hand searches yielded many resources, but after reading through each study it became clear that a number of studies were actually examining the

effect of music therapy on end-of-life patients and paid little or no attention on the effect of music therapy on end-of-life family caregivers. Although, some studies described family caregivers briefly in the results, case examples, or summary sections, a read-through of the introduction, literature review, and methodology sections revealed that the studies were not focusing on the family caregivers.

Second, the inaccuracy of in-text citations was a major issue. Often, authors put in-text citations after summarizing findings or directly quoting other authors, saving readers' time by accessing resources through in-text citations. It was found that some in-text citations were used incorrectly. For example, a few studies referenced the fact that music therapy helped family caregivers, but the original studies described them as families and not as caregivers.

Third, some studies were not accessible through inter-library loan services or through other online devices such as Google books. With the exception of journal articles, even those sources which the researcher was able to obtain through inter-library loan services had restricted loan periods, which prevented the researcher from re-analyzes them, unless he repetitively re-submitted requests to extend the loaning period. Thus the limited access presented was a limitation when gathering potential data.

Limitations

The following are some limitations of this research study. First, this study only explored music therapy publications written in English. Second, all the music therapy publications that were examined in this research study were published from 1990 to 2012. A wider time-range delimitation for this study may have allowed for more opportunities to discover additional studies on music therapy with end-of-life family caregivers.

Fourth, this study only provides information that was gathered from journal articles, edited book chapters, doctoral dissertations, and master theses. However, the findings of this research still offer valuable information for health professionals such as physicians, social workers, nurses, psychologists, and others who work with end-of-life family caregivers.

Future Research Considerations and Recommendations

This systematic review of music therapy literature can serve as an introductory database on family caregivers of end-of-life patients for researchers and clinicians to review. However, more research is needed on how music therapy can target end-of-life family caregivers as well as professional caregivers (e.g. nurses). Both qualitative and quantitative studies can provide valuable information for clinicians to develop interventions for end-of-life family caregivers. Potential for music therapy intervention with other types of family or professional caregivers could be explored using a method similar to that of the current study, such as a systematic literature review on family caregivers of persons with dementia. Building up a database for allied clinicians to obtain sources from can shed light on the growth and development of music therapy in healthcare settings, as well as provide information on areas that we need to be aware of when working in a challenging environment, which can be used to help prevent burnout for end-of-life caregivers. Music therapists should continue to research the effect of music therapy on end-of-life family caregivers, and generate more sources for music therapists to take into their practice. In closing, as music therapists, we are on the front line serving various populations and in order let our clients feel the power of music, it is the current author's opinion that there are three elements needed by all music therapists:

fact (academic training, practice and research); feeling (working experience, personal reflections, etc); and faith (belief in what you are doing).

Conclusion

To the best of the researcher's knowledge, this is the first study to systematically review music therapy literature with end-of-life family caregivers. Overall, this review provides music therapy data and publication figures up to 2012 on the use of music therapy for end-of-life family caregivers. In considering the information provided in the studies, it is currently clear that a small amount of music therapy resources for end-of-life family caregivers have been published, but more attention could be paid to researching and providing music therapy to end-of-life family caregivers. On a positive note it is evident that end-of-life family caregivers are receiving music therapy services as music therapists have documented the outcomes in their studies. In addition, the 14 studies illustrated that music therapists and researchers are aware of the concerns of end-of-life family caregivers, and with an increase in qualitative and quantitative publications on the subject in the past 10 years, it seems that increased attention is leading to the gradual development of music therapy practices to meet the needs of end-of-life family caregivers.

The findings, however, demonstrate a need for clarification regarding the term family caregivers in future research. This area of improvement is much needed as researchers are not properly indicating whether their studies are focused on family caregivers or patients. It is also recommended that more attention should be paid by researchers on proper differentiation between visiting family members and family caregivers in the future research. Reporting relating to dual roles and evaluation of researching also need improvement, particularly in journal articles. While this research

reviewed all 14 studies on music therapy with end-of-life caregivers published from 1990-2012, it is recommended that more quantitative and qualitative music therapy studies on the area of end-of-life family caregivers be done in the future.

“In the final stages of life, when biological imperatives fail to be reconciled with existential needs, when suffering has to be resolved as well as pain relieved, then it is music that takes us beyond words” (Aldridge, 1999, p.26).

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