Sponsoring Committee:  Professor Barbara Hesser, Chairperson
Professor Kenneth Aigen, D.A.
Jimmie Holland, MD

THE SPIRITUAL MEANING OF MUSIC THERAPY
AFTER THE DEATH OF A LOVED ONE:
A QUALITATIVE STUDY OF
SURVIVING CAREGIVERS

Lucanne Magill
Program in Music Therapy
Department of Music and Performing Arts Professions

Submitted in partial fulfillment
of the requirements for the degree of
Doctor of Arts in
The Steinhardt School of Education
New York University
2007
I hereby guarantee that no part of the dissertation which I have submitted for publication has been heretofore published and/or copyrighted in the United States of America, except in the case of passages quoted from other published sources; that I am the sole author and proprietor of said dissertation; that the dissertation contains no matter which, if published, will be libelous or otherwise injurious, or infringe in any way the copyright of any other property; and that I will defend, indemnify and hold harmless New York University against all suits and proceedings which may be brought and against all claims which may be made against New York University by reason of the publication of said dissertation.

Signed: Lucille Anne McEl
8/31/2006
ACKNOWLEDGEMENTS

I am deeply grateful to the patients and caregivers who have been and are my inspiration and teachers throughout all of my work as music therapist and through the duration this study. This study was conceived and built upon their words of wisdom and the remarkable courage and love that they maintain in their lives.

I express deep gratitude for my committee. Barbara Hesser has been a mentor and guide throughout my long-term studies at New York University. Her deep sense of insight and her deep compassion for others have been a source of inspiration to me over the years and were important beacons for me throughout this study. Thank you, Barbara, for your guidance, your ongoing and faithful support and your keen sense of perception. Ken Aigen has offered much wisdom and guidance throughout my doctoral studies. Thank you, Ken, for your words and suggestions, and for accompanying and mentoring me throughout the long course of this study. Dr. Jimmie Holland has been a source of knowledge and support throughout most of my music therapy career. I thank her for her continual support, her sense of compassion for cancer patients and families and her presence in my life as mentor and colleague.
I thank my peers with whom I worked closely throughout the course of this study. I thank Cheryl Dileo for her ongoing words of insight and her deep sense of compassion for others. Her knowledge and skill as clinician and researcher are true inspirations to me. Cheryl, thank you for your ongoing presence and perceptive support to me in my life and throughout the journey of these studies. I thank Nessa Coyle who has been a source of inspiration to me throughout all of my years as music therapist. Nessa, thank you for your ongoing words of wisdom, your insightful questions and your ongoing support throughout this study as well as throughout all of my work with cancer patients and families. I also thank David Aldridge for his wisdom, support and his prolific writings on spirituality, healing and music therapy. David, your words were an inspiration to me throughout this study.

I wish to thank the larger group of music therapy peers with whom I have journeyed this path over the years: Peter Jampel, Tina Brescia, Diane Austin, Rebecca Lovesy, Alan Turry, David Ramsey, Carolyn Arnason and Mijiin Kim. I appreciate your words of support and walking with you throughout these studies.

I wish to thank the New York University staff for the guidance they offer students. I thank Dr. Lawrence Ferrara for his support through these studies. I thank Susan Feiner for her presence and guidance in the Music Therapy Program. I also wish to thank Nancy Hall in the Graduate Studies
Office for her ongoing support. Thank you, Nancy, for your suggestions and ongoing help to me and to all graduate students.

I wish to thank the staff of Cabrini Hospice. I thank Mary Cooke for her steadfast leadership of the Hospice Program and her support of this study. I also thank Jill Koproski and Elle Steinhardt for their support of music therapy and the excellent care they offer patients and families. I also thank the home care nurses and Laurie Leonard, the Social Worker who has provided me with referrals and who offers her sensitivity and perception in doing so.

I wish to thank my friends who have maintained a steadfast presence with me over the years. I thank Cheryl Dileo, Clare O’Callaghan, Wendy Miner, Susan Berenson, David and Gudrun Aldridge, Deena Engel, Bridget Hogan, Susan Feiner, Yvonne Rosetti, and many others who have offered me support, encouragement and empathy. I also thank Barrie Cassileth for her ongoing support and encouragement for completing this study.

I extend my heartfelt gratitude for my family. I am forever grateful for my mother, Jane Magill, who has always been a beacon of light to me throughout my life and has been the person who taught me to love and care deeply for the well-being of others. Her love for people and for life have been an inspiration behind all of my music therapy work. Thank you for teaching me spirituality, for nurturing my love for people and for your ongoing presence in my life as friend and mentor. I am deeply grateful to my two wonderful daughters, Angelica and Celeste. Their sensitivity, perceptiveness and love
have grounded me and have been a primary source of strength throughout my years with them. Thank you, Angelica and Celeste, for accompanying me on this journey of life and for your ongoing presence and love. I also thank my sisters, Barbara, Pamela and Debby and my brother-in-law Steve Wood for their ongoing prayers, support and friendship that are continual sources of strength and guidance for me.

My final thank you is to God. This journey is based in His love, faith and wisdom that leads and inspires me every day.
TABLE OF CONTENTS

ACKNOWLEDGEMENTS iii

LIST OF FIGURE x

CHAPTER

I THE RESEARCH OBJECTIVE 1

Purpose of the Study 1
Origin and Need for the Study 4
Research Questions 10
Definitions 11

II MUSIC THERAPY AND SPIRITUALITY 14

Definitions of Spirituality 14
Spirituality in End-of-Life Care 19
Caregivers and End-of-Life Care 27
Music Therapy and Spirituality 33
Music Therapy in Cancer and Palliative Care 39

III MUSIC THERAPY IN END-OF-LIFE CARE:
CLINICAL PROCEDURES AND PROCESSES 45

Introduction 45
Hospice Home Care Setting 45
Theory of Clinical Practice 47
Session Procedures 48
Assessment 48
Goals 50
Techniques 52

continued
Stages of the Music Therapy Sessions 57
  Contact Stage 57
  Development Stage 58
  Closing Stage 58
  The Role of Caregivers 59
  Summary 60

IV  THE RESEARCH METHOD 62
  Spirituality in Context: A Qualitative Approach 62
  Participant Selection 65
  The Participants 67
  Data Collection and Analysis 67
  Trustworthiness 72
  Stance of the Researcher 74

V  THE CAREGIVERS' REFLECTIONS:
RESPONSES TO EXPERIENCES IN
MUSIC THERAPY 77
  Introduction 77
  Profiles of the Participants 78
  The Themes Presented in this Chapter 82
  Joy 82
    Autonomous Joy 83
    Empathetic Joy 87
  Empowerment 90
  Summary 97

VI  THE CAREGIVERS' REFLECTIONS:
CONNECTEDNESS, REMEMBRANCE
AND HOPE 99
  Introduction 99
  Connectedness 101
    Connectedness with Self 102
    Connectedness with Others 116
    Connectedness with the Beyond 122
  Remembrance 129
  Hope 136
  Summary 141
VII | THE CAREGIVERS’ REFLECTIONS ON
THE ROLES OF MUSIC AND THE MUSIC
THERAPIST | 142

| Introduction | 142
| The Role of Music | 142
| Music is a Conduit | 143
| Music Gets Inside Us | 146
| The Format of Music Makes a Difference | 149
| Music is Love | 151
| The Role of the Music Therapist | 154
| Summary | 161

VIII | TRANSCENDENCE INTO MEANING: THE
LIVED EXPERIENCES OF THE CAREGIVERS | 163

| Introduction | 163
| Transcendence | 165
| Meaning | 166
| Transcendence into Meaning in the Context of
the Caregivers’ Experiences | 168
| Transcendence into Meaning: A Proposed
Model of Spiritual Reorganization | 175
| Summary | 178

IX | REFLECTIONS ON THE STUDY | 179

| The Interview Process | 179
| Reflections on the Overall Scope of this Study | 181
| Implications of this Study for Music Therapy | 182
| Limitations and Future Considerations | 183
| Summary | 185

REFERENCES | 187

APPENDICES | 202

| A | OVERVIEW OF THEME STATEMENTS | 202
| B | CONSENT FORM | 203
LIST OF FIGURE

1. Model of Spiritual Reorganization 176
CHAPTER I

THE RESEARCH OBJECTIVE

**Purpose of the Study**

The purpose of this study was to learn how music therapy sessions, held prior to the death of a loved one, impact spirituality in surviving caregivers of advanced cancer patients. This study consisted of interviews with those surviving caregivers who witnessed music therapy sessions in their homes prior to the death of the loved one, in order to gain an understanding of the meaning of these experiences after the death of the loved one. While music therapy clinicians have reviewed and contributed anecdotal testimonies and theoretical discourses, little research has been formally designed to document and explore the impact that the music therapy sessions held during the end stage of cancer have on those surviving caregivers who witnessed these sessions.

Cancer is commonly called a family illness because it can devastate the entire family and create an upheaval in life and living. The impact of illness on the family and caregivers has become an area of focus and concern (Zabora & Loscalzo, 2002). Despite advances in research and treatments, a diagnosis of advanced cancer often results in a range of physical and psychosocial problems.
for all those involved in the care of the patient. Commonly, there is turmoil in
the lives of the caregivers, e.g., a shift in roles, major changes in daily and
long-term plans, loss of finances, and perhaps most significantly, the psycho-
emotional stress of potential absence of the loved one. Families often have to
face watching the advancing of illness and the care shifting from cure to
comfort care. These shifts in focus of care often result in existential crises and
increased feelings of loss. Thus, as witnesses to advancing disease in the
patients for whom they attend, caregivers commonly experience a range of
physical and psycho emotional symptoms. Their reactions vary according to
disease issues, life stressors, caregiver burden, caregiver coping mechanisms,
social and family changes, and spiritual concerns (Muir, McDonagh &
Gooding, 2002).

In caring for patients with advanced cancer, caregivers maintain key
roles that are multifaceted and complex. Their involvement has been found to
be essential in the care and treatment of the patient, influencing treatment
conformity and regulation of care. Their roles often encompass a range of
responsibilities, such as monitoring symptoms, maintaining records,
administering medications, arranging for provision of care for the physical and
psycho emotional needs, and the making of potentially challenging decisions
(Glajchen, 2004). In addition, the setting of care has shifted in recent years
from hospital to home, especially in end-of-life care, due to shortened hospital
stays and the trend for care to be at home (Hileman, Lackey & Hassanein,
1992). Often caregivers have little or no time to prepare for and adjust to the changes and demands in their lives, nor do they sometimes have enough reflective time to prepare for the eventual loss of the dying patient.

Coping with the death of a loved one is considered to be one of the greatest times of stress in a person’s life (Worden, 2002). The process of bereavement is influenced by various factors, such as degree of psychological preparation, coping mechanisms, familial and financial burdens and pre/post death psychosocial support. Other factors affect the process of grief, such as the nature of the attachment, the mode of death, personality characteristics and social factors (Worden, 2002). Supportive interventions, before and after death, have been found to potentially assuage feelings of guilt and enhance ability to cope with the loss ((Kissane, Bloch, McKenzie, Mc Dowell & Nitzan, 1998).

Music therapy is an intervention that is used to address the multifaceted needs of cancer patients and caregivers. In the care and treatment of advanced cancer patients, the music therapist holds sessions often in the presence of the caregiver(s). It is common for the caregiver(s) to witness the sessions. Since caregivers experience a wide range of emotions in relation to the advancing illness and their needs are multifaceted, the witnessing of music therapy sessions can offer them a range of benefits, such as providing for anticipatory grieving, reduction in distressful symptoms, improvement in communication between patients and their carers and opportunities to regain sense of meaning and purpose.
Origin and Need for the Study

There are two dimensions of origin and need for this study. The first is a review of the need for this study from a professional standpoint. The second dimension of origin relates to the interest in this topic in my personal life and career. In the following, I will first describe the need for this study in the broader fields of oncology, palliative care and music therapy. I will then address the origin as it pertains to my professional path.

In recent years there has been an increase in interest in the role of spirituality in health. Modern medicine has granted the general public the means to live longer in the midst of simultaneously increasing personal and occupational levels of stress. When contending with stress and losses in life, individuals are commonly faced with circumstances that naturally call into question the meaning, purpose and value of life. While this search for personal significance has been and is a life-long quest for the general public, it is recognized that this search is of even greater importance for those contending with the threat of loss of life (Puchalski, 2002).

Illness and dying can cause people to suffer deeply. Patients and caregivers can experience significant physical health and social difficulties, and are often faced with associated losses of faith, hope, identity and community belonging. Spiritual and existential issues are a major focus and concern in patients and caregivers facing the challenges of end-of-life (Breitbart, 2001). Since emotional suffering at the end-of-life can be profound,
medical institutions have set quality end-of-life care as a high national priority (Puchalski, 2002).

In Palliative Medicine, the area of medicine that treats patients receiving end-of-life and comfort care and their caregivers, it has become apparent that adequate palliative care must expand beyond the scope of treating pain and other symptoms and must include focus on the psychosocial, spiritual and existential issues of the patient and of all those involved in the patient’s care (Cherny, Coyle & Foley, 1996). While pain and physical symptoms are sources of distress and must be managed appropriately, it has become increasingly evident that psychological and spiritual concerns are also areas of great anguish that need to be addressed and included in protocols of care in order to sufficiently diminish suffering and enhance quality of life in patients and those who care for them (Breitbart, 2001). Teams working with the dying and their families have thus become multidisciplinary in order to attend to the multifaceted issues and needs.

In recent years, there have been other developments in the care of the dying. For example, there is a major trend for care at the end-of-life to take place in homes or hospices. In particular, care tends to be provided in the home when longer periods of care are required (Schachter & Holland, 1996), and when care shifts from curative to palliative. Significant others tend to assume the role of caregivers and are needed to provide care to the patient. The transition from a medical setting to the home has been found to often cause
anxiety in the caregivers, as they have the day-to-day responsibilities for delivering primary physical and psychosocial care for the loved one at home. There often is stress as they contend with the emotional and physical aspects and attempt to maintain stability in the midst of transition and loss (Schachter & Coyle, 1998). Generally, caregivers have minimal knowledge and skill for caring for dying persons in the home. The needs of those providing care to these patients are multifaceted and hospice and palliative care health care professionals assume important roles in providing support. Organizations, such as The National Hospice and Palliative Care Organization (NHPCO), a nonprofit organization representing hospice and palliative care programs in the U.S., are dedicated to improving end-of-life care for those who are dying and their loved ones (www.nhpco.org). Health care professionals recognize that there is, therefore, a great need to offer services that can ease the suffering of caregivers and offer support in ways that can nurture and enhance the quality of time at home. Services offered prior to death tend to enhance caregiver coping mechanisms and improve grief outcome (Kissane, Bloch, McKenzie et. al., 1998)

Music therapy, a healthcare treatment modality that uses music to address physical, emotional, cognitive and social needs of individuals of all ages (AMTA, www.musictherapy.org), is being utilized in hospices and hospitals due to the potential of music therapy to treat multi symptoms. Music therapy is known by clinicians to enhance well-being and foster renewed
understanding of personal life meaning (Magill, 2005). As a result of these significant developments in paradigm thinking in the world of modern medicine, as depicted in the trend for holistic treatment of disease, there is a call for increased understanding of the overall and yet very specific qualitative dimensions of the practice of music therapy in the care of all of those dealing with the loss of life (Aldridge, 1995). While the role of music therapy in treating patients receiving palliative care is well recognized (Aldridge, 1999; Lee, 1995a; Magill-Levrault, 1993; Martin, 1991; Munro, 1984; Salmon, 1993), the highly regarded impact of this therapy on the spiritual realm in caregivers is less understood.

The value of music therapy in helping foster creativity, reduce symptoms and helping improve quality of life in patients is well recognized (Hanser, 1985; O’Callaghan, 2001; Standley, 1996). While it is understood that music therapy plays an important role in those contending with end-of-life, there is little research that has specifically explored the spiritual influences of music therapy sessions on caregivers in the period after the death of a loved one. This study, therefore, aimed to afford music therapists and other palliative medicine professionals' opportunities to better understand how music therapy sessions that are held during the patient’s final stages of life impact the caregiver’s time in bereavement. This study also aimed to help professionals understand the specific aspects of spirituality that are deemed significant, as observed by caregivers.
The second dimension of the origin and need for this study relates to the origin of this study in my personal life. My personal interest in this study stemmed from my many years of work with cancer patients, their families and caregivers. Over the past thirty-three years, I have worked as a music therapist with a very large number of patients, using music to meet the wide range of physical, psycho-emotional, social and spiritual needs presented during varying stages of cancer. I have published documents pertaining to my theory, practice and research results regarding various dimensions of this work (Bailey, 1983a; Bailey, 1983b; Bailey, 1984; Bailey, 1986; Coyle, Loscalzo & Magill, 1990; Coyle, Handzo, Loscalzo & Magill, 1997; Dileo & Magill, 2005; Magill, 2001; Magill, 2005; Magill, 2006; Magill-Levreault 1993; Magill & Luzzato, 2002; Slivka & Magill, 1986;). During these years, a major focus has been to provide care to the patient. Often there are caregivers who are present and who witness the music therapy work. Also a focus has been to offer and provide sessions over time to patients in the presence of caregivers, to build therapeutic relationships and allow for further exploration of issues and expression of thoughts and feelings.

In my work in cancer care, I have observed the mobilizing effects of music therapy, that is, the enhanced communication between patient and caregivers, the enhanced sense of control, and the improved sense of self-identity and feelings of self worth. I have actively pursued feedback due to my deep interest in learning if, how and why music therapy has been meaningful
to the patients and the caregivers. At times I have also been in communication with caregivers post-death, as at times they have sent me cards or letters, and have noted their responses that have indicated feelings of relief, gratitude and spiritual renewal as a result of witnessing the music therapy sessions with the loved one.

There is a pre-existing belief in this study that music enhances awareness of life meaning, facilitates transcendence in those contending with loss and is a catalyst in promoting a sense of spirituality. In my work I have repeatedly witnessed the effects that music has on patients and caregivers. I observe music therapy inspiring thoughts of faith, hope, the meaning of one’s life, and connection and/or reconnection with others and with that which is greater than the self.

My long-term interest in this topic led me to want to undertake this study, to more deeply understand the spiritual meanings of the long-term effects of the music therapy sessions on the caregivers who witnessed the music therapy. I often ask myself what it is about music that brings others to the deeply felt places of inspiration and revelation. I question the influence of these sessions on their thoughts of faith, hope, and acceptance during bereavement. My in-depth experiences in observing the spiritual significance of music therapy in cancer care led me to determine the need to partake in this study as a way to gain deeper insight, clarity and understanding.
Therefore, the personal origin of this study was born from my long-term involvement as a music therapist with cancer and palliative care patients and their caregivers. Over my years of practice, I have gained depth of insight about the music therapy process with this population. I have been immersed in this work, have my own clinical determinations, and also have much knowledge about the needs and issues common to this group. I am very close to this work and this population. While I came to this study with these somewhat advantageous attributes, I realized that I also had the disadvantage of potentially having a harder time looking at this work from other perspectives. Because this study is strongly influenced by the precepts of naturalistic inquiry, I took my perspectives openly into account as I sought the views of the participants in interviews.

In addition, this study is of personal interest due to the fact that spirituality plays an important role in my personal life. While spirituality has always been important to me throughout my life, its significance continues to deepen, especially as a result of working for many years with those facing the end-of-life. Throughout the research I sought to take into account the personal origin for this study.

Research Questions

My primary research focus was to glean insight into the spiritual meaning of the music therapy sessions that caregivers witnessed prior to the
death of their loved ones, and how this might be playing a role after death. From a qualitative perspective, the research examined the words and reflections, as obtained in open-ended interviews, of surviving caregivers after the death of the person for whom they cared. The sub-questions originally stated in the proposal remained the same and were:

1. To identify particular aspects of spirituality, as defined on pages 11-13, which are meaningful to caregivers in the period after death of the loved one.

2. To explore the impact that witnessing music therapy, prior to death of the loved one, has on the caregivers’ feelings of spirituality during bereavement, and to explore this impact on each caregiver’s ability to cope with the death of the loved one.

3. To explore the impact that music prior to death has on the caregivers’ experiences of grief during bereavement

While remaining open to looking for other emerging trends, these questions guided me initially through the interviews and data analysis and have served as an outline for me.

Definitions

Advanced Cancer. The diagnosis of advanced cancer will have been determined by the primary physician. Advanced cancer is a stage of illness when patients receive end stage and/or palliative care. Patients with advanced
cancer may actively receive treatments for the cancer that has metastacized from the primary point of origin and may receive interventions to help prolong life and enhance comfort. In many cases, there are a limited number of treatment options left available to help the patient.

Caregivers. Caregivers in this study are those significant others who were actively involved in the life of the patient during the advanced stage of illness. Caregivers can be family members, close friends, partners or professional or hired staff. Caregivers in this study are those who were intimately involved in the care and who were present during some or all of the out-patient home care music therapy sessions.

Spirituality. Spirituality is a broad term that encompasses a wide range of meanings. I am defining spirituality in a pragmatic way to include (1) anything that patients or caregivers describe overtly as “spiritual;” and (2) any expression that pertains to aspects of experience relating to areas such as:

a. faith: a belief in, devotion to or trust in God, a Higher Power or somebody or something;

b. hope: to have a sense of trust or to have a wish or desire to get or do something; to have a wish for something to be true, or for something to happen; or to have a sense of trust that something seems likely to bring relief;

c. meaning and purpose: the reason for which something or someone exists; the reason for one’s life;
d. *transcendence*: the quality or state of going beyond one’s current state of being; the state of experiencing existence above and apart from the material world;

e. *connectedness*: the quality or state of feeling in union with oneself, others and the universe; a process that can occur during the end of one’s life in which there is a search for attainment of the completion of relationship with self, others and the universe;

f. *awareness of nature*: an interest and awareness of life on earth and the world of the universe beyond the earth; awareness of time and timelessness;

g. *peace*: a state of mental calm and serenity, with no anxiety or worry.
CHAPTER II
MUSIC THERAPY AND SPIRITUALITY

This chapter focuses on the topic of music therapy and spirituality as it has been reviewed throughout literature. This chapter serves to substantiate the professional context of this study and to highlight work done to date. Literature will be covered in these specific areas: Definitions of Spirituality, Spirituality in End-of-Life Care, Caregivers and End-of-life Care, Music Therapy and Spirituality, and Music Therapy in Cancer and Palliative Medicine.

Definitions of Spirituality

The term “spirituality” is broad and covers an immense scope of ideas and speculations. In preparation for this study, a comprehensive review of possible meanings for the term was undertaken. The literature displayed meanings that ranged from religion to philosophical and to transpersonal theories. In this section, some of the predominant themes of definitions of the term ‘spirituality’ will be described.

Presented by Muldoon and King (1995), a definition of spirituality is found to cover a spectrum of human values that are inclusive rather than exclusive. This definition refers to the universal quest for the meaning of life.
This universal quest includes "questions and concerns that belong to the human condition: the inquiry into nature, identity and specificity of the human being, the consideration of the meaning and the end of human action (morality); the quest for truth in knowledge; relations with others (social organizations, sexual identity), and the eventual relation to a transcendent" (p. 333). For these authors, "spirituality is... the experiential integration of one's life in terms of one's ultimate values and meanings" (p. 330).

Spirituality has been considered to be that dimension of a person that exists beyond the physical realm and portrays the deeper realities of existence. According to Hiatt (1986), spirit refers to that "noncorporeal and nonmental dimension of the person that is the source of unity and meaning, and spirituality refers to the concepts, attitudes, and behaviors that derive from one's experience of that dimension. Spirit can be addressed only indirectly and inferentially, while spirituality can be understood in psychologic terms" (p. 742). Likewise, Doyle (1992) explained that spiritual is "in essence, searching for existential meaning" (p.303). In other words, persons can and often do have a dimension to life that is separate from religion and refers to the search for meaning and the significance of one's life and the reasons for living.

This human spiritual dimension is also described by Emblen (1992). This author describes the spiritual dimension as being that which "refers to a quality beyond religious affiliation that is used to inspire or harmonize answers
to questions regarding infinite subjects, e.g., meaning and purpose of life and one’s relation to the universe” (p. 43).

The term, ‘spirituality,’ also considers a focus on transcendence. For example, Kuhn (1988) explains that spiritual elements are those capacities that enable a human being to rise above or transcend any experience at hand. They are characterized by the capacity to seek meaning and purpose, to have faith, to love, to forgive, to pray, to meditate, to worship, and to seek beyond present circumstances. (p. 91)

This definition of spirituality covers a wide range of elements and is one that addresses the human capacities for spiritual growth in everyday life. Likewise, Reed (1987) explains that the indicators of spirituality include “prayer, sense of meaning in life, reading and contemplation, sense of closeness to a higher being, interactions with others and other experiences which reflect spiritual interaction or awareness” (p. 336).

Transcendence is seen as an important quality in spiritualism. Several authors have defined ‘spiritual’ as “pertaining to the innate capacity to, and tendency to seek to, transcend one’s current locus of centricity, which involves increased love and knowledge” (Chandler, Holden & Kolander, 1992, p. 169). Transcendence is a process that is seen as one’s moving beyond the limitations of body and personality, to have an interest in others, the world and the life beyond the physical (Aldridge, 2000). Transcendence can enhance insight and lead to greater feelings of love. Definitions of the term ‘spirituality’ consider transcendence an important element in this realm of existence.
While the spiritual dimension is often considered to be separate from religious practices and theorems, religion is widely viewed as an aspect of spirituality, and several definitions include in them the relationships that one has with the Divine, a Higher Power, a transcendent being, as defined by the individual. Borman and Dixon (1998) state that spirituality “pertains to one’s relationship with others, with oneself and with one’s higher power, which is defined by the individual and need not be associated with a formal religion” (p. 287). Also, Lukoff, Provenzano, Lu & Turner (1999) found that spirituality refers “to the degree of involvement or state of awareness or devotion to a higher being or life philosophy, not always related to conventional beliefs” (p. 65). Lukoff, et.al. (1999) add:

Religiosity is associated with religious organizations and religious personnel...Religion involves subscribing to a set of beliefs and doctrines that are institutionalized...People...can be religious without being spiritual by perfunctorily performing the necessary rituals. However, in many cases, spiritual experiences do accompany spiritual practices. (p. 65)

Another definition of spirituality, put forth by the American Council on Science and Health, was located on the World Wide Web. This definition of spirituality also considers the religious affiliations with the concept, and defines spirituality as: “an inclination or desire for a relationship with the transcendent or God; as sensitivity or attachment to religious values; and/or concern about souls, afterlives or other forms of supernatural entities” (Raso, 1997-2000).
Lerner (1994) offers an elaborative explanation of the coexistence of
the spiritual realm and religion. He states:

It is useful to think of spirit, spirituality, and religion as different points
on a continuum. Spirit is the source dimension behind every personal or
collective experience of spirituality. It is also the source dimension
behind every religion. Spirituality can be considered closer to the
source dimension than everyday religion that has moved far from the
experience of spirit and serves moral and social purposes. Spirit is
said...to be the realm that unites us. (p. 115)

This explanation refers to the supposed underlying influences of spirituality,
even in the areas of religious practices and theories.

Spirituality has thus been viewed as encompassing a range of
ideologies and meanings. There has been an expansion of interest in
spirituality that began in the 1920s, and many of the descriptions explained that
matter and spirit were seen as different manifestations of life (Aldridge, 2000).

According to Sims (1994), there are numerous meanings to the term,
'spirituality,' including what a person lives for, and an indefinable power
beyond description. Sims outlined five aspects of meaning for spirituality:
"looking for meaning in life...the interrelatedness of all...wholeness of the
person, in which spirit is not separate from body and mind...what is seen as
good, beautiful and enjoyable...[and]...the connection between god and man"
(p.444). Likewise, a definition by Boyd (1995) includes the inner and outer
presence of spirit. This author states that "the spirit refers to what is inside a
person; what we would call thoughts, feelings, energy, spirituality, the
subjective viewpoint, mind, personality, psychology, or breath. But the spirit
could also be outside a living person, and the implication would be that the internal spirit probably originated outside and invaded, so the person was ‘inspired’ (p.155).

The term, ‘spirituality,’ has meanings that cover a wide scope of existential beliefs and philosophies. In essence, spirituality is viewed as the core of human life and refers to the ineffable place within hearts, minds and souls that seeks inspiration and answers to questions regarding infinite subjects, such as meaning and purpose of life and one’s relation to the universe. These broad, overarching meanings of the term, ‘spirituality,’ reflect the vast non-physical realm that humans associate with the concept of spirituality.

**Spirituality in End-of-Life Care**

A review of literature on the topic of spirituality includes a narrower examination of the term as it pertains to end-of-life care. Health care professionals view spirituality as a dimension that needs to be included in the holistic treatment of patients and caregivers. In the following paragraphs, several definitions and research findings are presented that help explain the significance of spirituality in this area of medicine.

McSherry and Draper (1997) have written on the topic of spirituality in medicine, specifically in attempts to heighten the presence of this topic in nursing curricula. They explain that “spirituality is a quality that goes beyond
religious affiliation, that strives for inspirations, reverence, awe and purpose...tries to be in harmony with the universe, strives for answers about the infinite, and comes into focus when the person faces emotional stress, physical illness or death” (p.413). This premise is pertinent to palliative care since the existential meaning of life gains importance during the process of dying. McSherry and Draper emphasize the unifying aspect of spirituality that attempts to bring a person in harmony with the universe and the infinite (Aldridge, 2000).

Highfield (1992) has also contributed to nursing literature on the significance of spirituality in the care of oncology patients. This author explains that:

the spiritual dimension of persons can be uniquely defined as the human capacity to transcend self, which is phenomenologically reflected in three basic spiritual needs: (a) the need for self-acceptance, a trusting relationship with self based on a sense of meaning and purpose in life; (b) the need for relationship with others and/or a supreme other (e.g. God) characterized by nonconditional love, trust and forgiveness; and (c) the need for hope, which is the need to imagine and participate in the enhancement of a positive future. All persons experience these spiritual needs, whether or not they are part of a formal religious organization. (p.3)

These spiritual needs, as outlined by Highfield, are those perceived by nurses and patients to be critical in end-of-life care. Ross (1994) also explains spirituality from a nursing perspective. This author states that spirituality is:

“(a) the need to find meaning, purpose, fulfillment in life, suffering and death; (b) the need for hope/will to live; and (c) the need for belief and faith in self, others and God” (p. 439).
Several other authors have discussed the construct of ‘spirituality’ as it pertains to oncology and palliative medicine. Puchalski and Romer (2000) describe spirituality as that which allows a person to experience transcendence and meaning in life. Also, Karasu (1999) explains that spirituality involves concepts of faith and/or meaning. Faith is seen as a belief in a transcendent power, that is either internal or external, and one’s relationship with and connectedness with this transcendent power, or spirit, is an essential component of the spiritual experience and is related to the concept of meaning (Breitbart, 2001).

The concept of “meaning” has been embodied in literature and brought into the medical arena in recent years. Viktor Frankl (1959/1992) wrote profound treatises on his experiences in concentration camps and the insightful knowledge he gained as a result. He wrote extensively on the notion of meaning. He explained that meaning, or having a sense that one’s life has meaning, “involves the conviction that one is fulfilling a unique role and purpose in life that is a gift, a life that comes with a responsibility to live up to one’s full potential as a human being and, in so doing, being able to achieve a sense of peace, contentment, or even transcendence through connectedness with something greater than oneself” (Breitbart, 2001, p. 3). Frankl viewed suffering as a catalyst, both to having a need for meaning and for finding it (Breitbart, 2001). The cancer literature is full of stories of life changes and reevaluations intended to improve one’s life. The diagnosis of a terminal
illness may, in and of itself, result in growth and acquisition of meaning in those contending with the illness, or an opportunity for change, potentially enhancing the ability to cope. Terminally ill patients and caregivers often have a heightened sense of meaning and purpose due to the realization that time left is very limited. Thus, the value of the time remaining becomes even more intensely important and they make positive appraisal of events (Breitbart, 2001, Park & Folkman, 1997). The significance of the spiritual element of meaning and purpose has been well documented in recent literature and is currently being studied in an ongoing meaning-centered group psychotherapy protocol at Memorial Sloan-Kettering Cancer Center (Breitbart, 2003).

A recently developed spiritual well-being measurement scale reflects the significance of the concepts of faith and meaning in the construct of spirituality. This measurement tool, called the FACIT Spiritual Well-Being Scale, is currently widely used in hospitals and hospices. This scale has a total score and two subscales, one corresponding to Faith and the other to Meaning/Peace. The “faith” component is often associated with religious beliefs, whereas the “meaning” component appears to be a more universal concept that can exist separately or in conjunction with religious beliefs (Peterman, Fitchett, Brady, Hernandez & Cella, 2000).

Faith and religious beliefs are considered to be aspects of spirituality. Researchers theorize that religious beliefs may play a part in helping patients and caregivers construct a meaning for their suffering inherent in illness,
potentially assuaging feelings of remorse and abandonment (Mickley, Pargament, Brant & Hipp, 1998). Ganzvoort (1998) writes that religion is important for coping with crises. This author explains that maintaining an identity is an important factor for coping and facilitates a personal sense of worth, meaning and belonging. Likewise, prayer can promote a sense of camaraderie with others and a dedication to a commonly acknowledged purpose.

VandeCreek, Rogers & Lester (1999) inquired about alternative practices for breast cancer patients. They found that prayer was seen as being a major interest for 84.5% of the breast cancer outpatients, and spiritual healing, for 48.3% of the outpatients. Recent studies have found that religion and spirituality generally play a positive role in helping people cope with cancer and life threatening illnesses (Baider, Russak, Perry, Kash, Gronet, Fox, Holland & Kaplan-Denour, 1999). How spirituality and faith-oriented modalities contribute to health and coping is unclear. It has been observed, however, that those seeking God’s help or having faith in God and/or visions of God, have coping resources that are sometimes associated with improved health care outcomes (Koenig, Pargament & Nielsen, 1998). Also, it has been observed that patients show less psychological distress if they turn to God, a spiritual belief, or a spiritual community for comfort, reconciliation, and support (Koenig, et. al., 1998). Thus, faith and religious beliefs are also
considered to be important components to the concept of spirituality in end-of-life care.

Hope is considered to be a beneficial factor enhancing the quality of life. Hope has been identified as “a multi-faceted phenomenon that is a valuable human response, even in the face of a severe reduction in life expectation” (Aldridge, 1995, p. 106). Nurse-researcher Herth (1990) explains hope as an inner power directed toward enrichment of the human being. In this study, this author found seven hope-fostering categories: interpersonal connectedness, attainable aims, spiritual aims, spiritual base, personable attributes, light-heartedness, uplifting memories and affirmation of worth. There were also three hope-hindering categories: abandonment and isolation, uncontrollable pain and discomfort, devaluation of personhood (Herth, 1990).

Religious beliefs have been reported to offer a sense of hope (Puchalski, 2002). For patients facing death, there is a need to transcend death, which may be manifested through living on through one’s relationships or one’s accomplishments and actions (VandeCreek & Nye, 1994). According to Aldridge (1995), the true meaning of hope is “that of an inclination toward something that we do not know. There is a longing for the unknown. We are all waiting for a change …and this expectation is hope…It is an attainment that may be described as beyond happiness and death” (p. 106).

In recent years, measures to address physical, psychological and spiritual domains of end-of-life care have been identified as priorities by
medical organizations and by cancer patients. In an Institute of Medicine report, entitled "Approaching Death: Improving Care at the End of Life," domains of quality end-of-life care were identified. These domains included: overall quality of life; physical and psychosocial well being and functioning; spiritual well-being; patient perception of care; and family well-being and functioning (Field & Cassell, 1997). In a Gallup poll, "Spiritual Beliefs and the Dying Process," 40% of the public in the U.S.A. said that, if they were dying, it would be "very important" to have a doctor who is spiritually sensitive to them. The greatest concerns for 50-60% of those questioned in this survey were: not being forgiven by God; not reconciling with others, and dying while removed or cut off from God or a higher power (Breitbart, 2001). In another survey of 248 ethnically diverse cancer patients, researchers asked what patients' most important needs were. Results revealed that 51% said that they needed help overcoming fears, 41% needed help to find hope, 40% needed help to find meaning in life, 43% needed help to find peace of mind, and 39% needed help to find spiritual resources. (Moadal, Morgan, Fatone, Grennan, Carter, Laruffa, Skummy & Dutcher, 1999).

Other studies have documented similar findings that stress the significance of spiritual care at the end-of-life. Singer, Martin, Kelner & Marm (1999) conducted an extensive qualitative study of cancer patients to learn about the domains of end-of-life care that they considered most important. These domains included: (1) receiving adequate pain and symptom control; (2)
avoiding inappropriate prolongation of dying; (3) achieving a sense of spiritual peace; (4) relieving burden; and (5) strengthening relationships with loved ones. In a similar qualitative study on the spiritual needs of dying patients, Hermann (2001) interviewed nineteen hospice patients. The author found that participants explained that spirituality was a part of their total existence. These six themes of spiritual needs were identified: need for religion, need for companionship, need for involvement and control, need to finish business, need to experience nature, and need for positive outlook. The author determined that addressing patients’ spiritual needs is necessary in order to enhance quality of life.

In another hermeneutic study, Chao, Chen and Yen (2002) studied the essence of spirituality with terminally ill patients. These authors found four constitutive patterns, including (1) communion with self (e.g., self-identity, wholeness and inner peace); (2) communion with others (e.g., love and reconciliation); (3) communion with nature (e.g., inspiration and creativity); and (4) communion with Higher Being (e.g., faithfulness, hope and gratitude). These surveys and studies point to the expressed essentiality of the inclusion of spiritual elements in quality end-of-life care.

Pulchalski and Romer (2000) have suggested the importance of incorporating a ‘spiritual history’ into the standard practice of taking medical histories, especially with those patients with advanced and terminal diseases and their caregivers. These authors believe that such a history provides
clinicians with information that would help them address the important spiritual needs that are crucial in supportive care. Some of the items addressed in this history explore: faith and beliefs (e.g., what are the faith and beliefs); importance and influence (e.g., what is important in one's life); community (e.g., is there a spiritual community?); and address (e.g., how to address these issues and needs) (Brietbart, 2001). Such elements are beginning to be included in medical histories due to the growing recognition of the importance of the role of spirituality in the care of patients at the end-of-life.

The literature regarding the significance of spirituality at the end-of-life is vast. Research studies, as well as theoretical discourses, overwhelmingly address the need for the inclusion of spiritual elements in patient care, especially in care of those facing end-of-life, due to the urgency and value of time. The articles referred to in the above review are important samplings of the current literature available in this field of study.

**Caregivers and End-of-Life Care**

As the care for patients with advanced cancer has been tending to shift away from medical hospital settings and into homes, the caregiver's role has become an area of focus and concern. In recent years there have been empirical studies and theoretical discourses in the literature pertaining to the potential benefits and challenges of care giving during end-of-life stages of cancer.
Literature describes the multifaceted roles assumed by caregivers in cancer care. Glajchen (2004) depicts some of the roles to include: the management of physical symptoms including the administration of pain medications; functioning as home health aides and companions; providing emotional support to patient and other family members, as well as providing support during times of transitions; providing for the care of daily needs, such as meals, transportation, personal care; and acting as legal, financial and medical assistants. This author explains that these multifaceted roles can impact the caregiver’s quality of life and that caregivers can therefore benefit from interventions aiming to support their roles and their needs. As per this author, the multifaceted expectations may erode the health and well-being of the caregiver. Glajchen states, “Without proper support, caregivers face an extreme burden, both psychologically and physically” (Glajchen, 2004, p. 147). Family members caring for a dying patient at home often need to manage technological equipment, such as feeding tubes, catheters, and oxygen tanks, in caring for the patient, and it has been noted that these difficult roles and tasks can place added emotional burden on caregivers (Ferrell & Hastie, 2002).

Literature describes the needs of caregivers. In a study of 492 home caregivers, Hileman, Lackey & Hassanein (1992) identified six categories of needs: psychological, informational, care of patient, personal, spiritual and household. In another report, caregivers identified needing help with
adjustment to illness, psychosocial support, transportation, financial assistance, home care and medical information (Shelby, Taylor, Kerner, Coleman & Blum, 2002). Similar results were found in a study assessing the needs reported by patients and caregivers, such as their needs for assistance with transportation, homemaking services, nursing and personal care and support (Emanuel, Fairclough, Slutsky & Emanuel, 2000).

Caregivers have been identified as being vulnerable to physical and mental health problems, reporting depression and physical symptoms related to excess strain (Googe & Varrichio, 1981; Hinds, 1985). Also, caregivers note fatigue and exhaustion due to the physical and psychological demands to be a significant source of hardship (Jensen & Given, 1991). Often caregivers are in the elderly age range, therefore having potentially limited physical and mental health resources and associated coping skills (Hileman, Lackey & Hassanein, 1992). Other authors refer to the effects of the caregiving of hospice patients, reporting that caregiver health, negative social interactions and lack of perceived subjective benefits from caregiving may result in depression and impaired caregiver well-being (Haley, LaMonde, Han, Burton & Schonwetter, 2001).

The financial burden on caregivers also is a source of stress (Given, Given, Strommel, Collins, Kings & Franklin, 1992). In 1997, The United Hospital Fund relayed their findings that were reported by caregivers providing home care to patients with long-term conditions. In a sampling of 2000
patients, they found that at least one member had to quit work in order to care for the patient at home in 20% of the families. Likewise, approximately 31% reported losing all savings, while others reported loss of jobs and having to make other financial sacrifices (United Hospital Fund, 1997). Ferrell and Ferrell (1991) explain that the costs and of the equipment and care can add additional stress and burden on caregivers.

Literature refers to the areas of stress that are identified by caregivers of advanced cancer patients. Caregivers note distress when the patient’s symptoms are uncontrolled. In 1993, researchers studied the impact of giving care at home on 207 caregivers. The caregivers noted ongoing distress when symptoms, such as nausea, dyspnea, mental status changes and pain were not controlled (Jones, Hansford & Fiske, 1993). Other stressors noted by caregivers include fear of abandonment, issues related to sexuality and changes in body and self-image (McMillan, 1996).

There is literature describing the spiritual needs of caregivers. In 2003, Taylor (2003a) surveyed patients and their caregivers to gather information about their spiritual needs. Participants in this study reported their spiritual needs as being the need for prayer, need for qualities of kindness and authenticity, and need for help with mobilizing religious and spiritual resources. In another study, patients and caregivers noted needing a sense of meaning and purpose, love, and sometimes needing transcendence (Murray, Kendall, Boyd, Worth & Benton, 2004). Similar spiritual needs were identified
in a qualitative study of twenty-eight patients and their caregivers. These participants reported the need for an Ultimate Other, need for hope, need to give and receive love, need for meaning, need to review beliefs, and the needs relating to religion and preparing for death (Taylor, 2003b). In another qualitative study of cancer and cardiac patients and caregivers, topics were identified as causing spiritual distress, such as difficult changes in relationships and roles, feeling isolated and unsupported, and increased dependence on others. Spiritual needs were characterized by feelings of hopelessness, isolation and altered image of self (Murray, Kendal, Boyd, Worth & Benton, 2004). Also, in another study, spiritual factors were found to be important for caregivers. In this study, Chang, Noonan and Tennstedt (1998) found that spiritual coping strategies influenced caregiver distress and that those caregivers who used religion or spiritual beliefs in coping had more positive relationships with the patients and noted less depression.

Caregiving has been found to result in positive incentives and feelings of satisfaction during a patient’s illness as well as during the bereavement period. One study revealed that caregivers of palliative care patients reported finding enrichment in their experiences, in that they were able to spend quality time with the patients, gained a greater sense of meaning, were able to be in closer communication, and were able to give and receive with one another (Stajduhar, 2003). Holland (2002, 2001, 1998) has written extensively about the needs of cancer patients and their caregivers and the importance of having
quality of life as well as positive feelings regarding their caregiving experiences. Considered the “Mother of psycho-oncology” (Holland, 2004), she has been a leader in educating health care professionals in the needs of cancer patients and families, encouraging professionals to assist in the management of grief and loss. Other studies document the positive effects of caregiver participation. Surviving caregivers who had participated in hospice were found to have less guilt, less despair, less dependency and less disbelief (Steele, 1990). In another study, caregivers had positive bereavement outcome as a result of realizing that they overcame difficult challenges and partook in a valuable life experience. These caregivers reported both positive outcomes (feelings of accomplishment and improved familial relationships) and negative outcomes (images and feelings of failure), however, they reported that their positive outcomes predominated their experiences (Koop & Strang, 2003). Another study looked at the predictors of severity of grief and found that bereavement was influenced by factors, such as the number of adverse life events, the carer’s coping strategies, prior experiences with separation and bereavement, the relationship with the patient and also the severity of the patient’s illness and illness symptoms (Kelly, Edwards, Synott, Neil, Baillie & Battistutta, 1999). In a literature review, authors found that the regularity and frequency of the presence of professional caregivers contributes to family caregivers’ satisfaction with care, and that this factor, among others, was a predictor of bereavement outcome (Koop & Strang, 1997). Spiritual beliefs
have been found to impact bereavement outcome. In another study, caregivers with strong spiritual beliefs resolved their grief progressively over fourteen months post death, and those with no spiritual beliefs had not resolved their grief by the end of the same period. Thus, people who professed strong spiritual beliefs seemed to resolve grief more rapidly and completely (Walsh, King, Jones, Tookman & Blizard, 2002).

The literature in this topic covers a wide range of caregiver issues. Overall, there is a trend reflecting the broad scope of challenges and needs faced by caregivers, all of which are influenced by situational variables.

Literature refers to the overwhelming need for professional psycho emotional assessment and support, as well as the need for provision of services.

Music Therapy and Spirituality

Music therapy is a discipline that offers music, as an experience of time that is ordered, and offers the elements of human compassion through the presence of a music therapist. Music therapy is a professional intervention that has become recognized as beneficial in addressing the spiritual needs of patients and is a method that has been found to improve physical, psycho-emotional and existential well being. The following literature portrays some of the current work done in this growing area of interest and practice.

Several authors have discussed the potential for spirituality in music therapy work. These considerations are likely due to the transcendental nature
of music as well as the spiritual responses that are common in music therapy
sessions (Magill, 2005). The expressive qualities of music therapy allow for
the creative process to emerge. Artistic and creative experiences resonate in
deeper realms of human feeling and knowing. Bailey (1997) has theorized that
music therapy provides order through which a person is better able to gain a
sense of meaning about life, e.g., through creativity, connecting with others
and being reminded that they are remembered, through enhancing one’s sense
of courage, and through restoring feelings of hope and faith.

Music therapy has been found to offer experiences that lead to altered
states of consciousness. For example, Ruud (1998) has theorized about the
spiritual value of peak experiences in music therapy. In his writings, he refers
to the tendency of music to bring people to altered states of consciousness, for
example by providing a sense of union with a context, such as nature and the
infinite, that is ‘larger than life’” (p.65). Ruud also explains that many themes
in music therapy connote the human search for meaning and that music therapy
ultimately needs to offer clients opportunities for experiences that promote
transcendence (Ruud, 1998).

In the medically ill and/or functioning group of clients, music therapists
have been called upon to work in hospitals, clinics and in psychotherapeutic
private practices. Some primary spiritual interests for this group of people have
been noted to include (1) a search for meaning, purpose, and fulfillment in life,
(2) a search for transcendence and an existential understanding of oneself and
the world, (3) a need for hope, (3) a need for faith in oneself, with others, with a Higher Power, (5) a need to experience the presence of a Higher purpose or calling in one’s life, and a desire to carry out the intention for one’s life, and (6) a wish to participate in rituals and spiritual practices of meaning (Aldridge, 1993, 1996; Chappelle, 2000; Kuhn, 1988; Magill, 2005; Marom, 2002).

Recently, there has been a growing interest in the general public about the use of music therapy as a method for psycho-spiritual healing. For example, in referring to her work as a music psychotherapist, Scheiby (1995) has written about the death/rebirth experiences released by means of improvisation. She has noted that “simple musical improvisations can provide and release… a deep and important event” (p. 212).

Death and rebirth issues are central issues in spirituality literature. Magill (2005) refers to the benefits of music therapy sessions with those contending with issues pertaining to the suffering at end-of-life. Nakkach (2005) has written about the use of music therapy as contemplative music in healing. She explains that vocal toning sound formulas become the vocal pathways to invoke and manifest the union with the Divine within. Dileo and Zanders (2005) have expounded on the practice of music therapy with inpatients awaiting a heart transplant. According to them, spiritual needs are among the prominent needs of these patients and include: “to find meaning in their experiences, to prepare for life, to prepare for death, to trust in something beyond themselves, to find hope and to be at peace” (p.67). Analytic Music
Therapy has been found to benefit some medically ill adults through the uncovering of deeper issues surrounding psychosomatic symptoms (Scheiby, 1999).

Pain and suffering can trigger existential crises. Existential questions commonly surface, such as: "Why am I suffering?" "What is the reason for my life?" "What will become of me and my loved ones?" Work is being done to develop the use of music with pain, such as in addressing suffering (Magill, 2001) and in the application of techniques such as entrainment (Dileo & Bradt, 1999; Rider, 1997), and the use of non rhythmic, slow tempos and low frequencies to enhance relaxation and to diminish pain (Tomaino, 1999). It has been documented that, with the guidance of a music therapist, music can facilitate change in pain mechanisms and psycho-neurological processes, sensory (counter-stimulation), affective (enhanced self expression and change in mood) and cognitive (distraction, enhanced sense of control and use of prior skills), thereby influencing a person’s total pain experience (Magill-Levreault, 1993). Loewy (1999) has noted the necessity of assessing the emotional and physical parameters of pediatric pain in order to determine appropriate pain interventions and to facilitate self-expression and the processing of issues in the life of children, their family members, caregivers and staff.

There is also literature describing the impact of music therapy on spirituality in the geriatric population. Aging symbolizes progressing from states of active living to states of decreased activity, deterioration and dying.
Older adults often pursue religion and spirituality as ways of dealing with deteriorating physical stature. This group has been found to have needs, such as: to understand life, to achieve peace and serenity in the midst of pain and decline in status, to maintain relationship with God, to resolve sorrows from past and to love and be loved. (Clair, 1996; Sorajjakool, 1998). The process of aging is often complicated by problems associated with dementia and Alzheimer’s disease. Music therapists work with geriatric patients in a large number of settings and encounter spiritual issues and needs. Clair (1996) has written about her work with the geriatric population. She notes that music stirs thoughts about spirituality. She finds the use of relaxation techniques helpful in bringing tranquility and inducing meditative states. She has also described her use of songs and vocal techniques to facilitate working through grief and inspiring forgiveness of self, others and God. Kirkland and McIlveen (1999), a chaplain and a music therapist, found that they were able to address spiritual needs through a collaborative program in which they used songs pertaining to spiritual themes. Scott (1998) has also reported his experiences with adults diagnosed with dementia and his findings that music helped residents express their sense of spirituality.

With regard to psychiatric diagnoses, issues of spirituality and religious belief are complex and present challenges, in that therapists need to distinguish between normal spirituality from abnormal or pathological thinking. It is commonly understood that delusions may sometimes be religious in nature,
and beliefs may appear unconventional. In clinical work, it is paramount for the boundaries between the rational and irrational to be made clear. For many of these clients, e.g., for those with addictions, it is common to note feelings of spiritual void, loneliness, inner emptiness and isolation (Nakken, 1996). Other music therapists who work with addicted clients have found that spirituality comes into focus through working to enhance relationships with self, others and a Higher Power through song techniques (Walker, 1995). Music therapist Borczon (1997) has written about his work with abuse survivors to help them address identity and existential issues through a variety of music therapy techniques.

Music therapists have elaborated extensively on the essence of the music-therapeutic relationship that resides in the human contact and the supportive, caring presence of the therapist (Aldridge & Aldridge, 1999; Amir, 1992; Bailey, 1983a; Hesser, 1995). In writing about the theoretical context, authors have discussed the relationship between the music therapist and the client. Kenny (1989) developed a concept of a “Field of Play.” She theorizes that this ‘Field of Play’ is the safe and sacred relationship that emerges between the music therapist and the client and is contained within the “Musical Space.” She also refers to the four elements that characterize the “Musical Space:” ritual, state of consciousness, power and creative process (Kenny, 1989). Along these lines, Salmon (2001) has theorized about the psycho-spiritual processes of music therapy sessions. She describes the sacred space,
consisting of the patient, therapist and music, that affords patients opportunities to journey to depths and to return, enabling them to experience connections with a spiritual realm. Magill (2005) has elaborated on the potential significance of the presence of the music therapist in music therapy sessions: “the compassion, love, empathy and the energy that the therapist brings to others along with the intangible grace of music, creates the temple within which others may safely experience their feelings, hopes, wishes, dreams, images, memories, and prayers” (p. 7).

Marom (2002) conducted a qualitative study of the music therapist’s experience of spiritual moments in music therapy. She found that therapists had spiritual experiences of their own in sessions and played key roles in the spiritual moments. From the discussions with therapists, she also found that there is a degree of spiritual preparedness that is required of therapists.

The literature on the impact of music therapy on spirituality covers a range of populations and issues. As noted, most of the literature to date has been anecdotal and theoretically based. The literature review points to the growing interest in this area of practice as well as the need for more research.

Music Therapy in Cancer and Palliative Care

The literature on music therapy in palliative care and the care of those contending with advanced illnesses is widely discussed. Literature in this area of music therapy is commonly concerned with the spiritual issues and needs
due to the life threatening circumstances of the patients and families involved. Over the past decade in particular, there has been an influx of the use of music therapy in palliative care and oncology settings. Music therapists have been writing extensively on clinical experiences in working with the seriously ill, the dying and their caregivers.

Music therapy in palliative care and supportive oncology settings has been found to provide many benefits to patients, families and caregivers. Early and more recent literature describes the effectiveness of music to break the cyclical nature of pain exacerbations (Bailey, 1986; Magill-Levreault, 1993; Munro and Mount, 1978), to alter mood (Bailey, 1983a; Curtis 1986), to reduce anxiety and promote relaxation (Bailey, 1986; Lane 1992; Mandel, 1991; Whittal, 1989; Cassileth, Vickers & Magill, 2003) and improve communication (Martin, 1991; Munro, 1984; O'Callaghan 1993; Salmon 1993; Slivka & Magill, 1986). Authors have also described the expressive nature of music as it assists patients and family members to cope with cancer and the process of dying (Aldridge, D., 1999; Dileo, 1999; Loewy, 1997; Schroeder Sheker, 1993). Lee (2005) states that, in palliative care, music therapy can assist the patient in finding a “musical opening—one that will allow the client a means of expression that is beyond illness and loss” (p. 149). Music therapists and other health care professionals have begun to research the impact that music has on the various components of the human experience in life-threatening and terminal illnesses, i.e., physiological (improved cardiac,
respiratory and adrenal functioning as well as decreased symptoms of nausea, insomnia or fatigue), psycho-emotional (alteration in mood and enhanced coping styles) and social (enhanced communication) (Forinash, 1990; Hanser, 1985; O'Callaghan, 2001; Standley, 1992). Other clinicians have documented the use of melodic and improvisational music with breast cancer (Aldridge G., 1999) and HIV/AIDS (Bruscia, 1992; Hartley, 1999; Lee, 1995b; Rykov & Hewitt, 1994).

Music therapists have expounded on the psychological and spiritual needs in cancer and palliative care patients in their work. Munro and Mount (1978) wrote about common psycho-spiritual problems in the terminally ill. They explained that suffering, anxiety, withdrawal, intractable pain and communication difficulties could be classified as spiritual issues and that these issues are addressed in music therapy. Turry and Turry (1999) explained that the process of improvising songs can help patients experience spontaneous, creative expression as a way to gain feelings of well-being while facing physical deterioration. Also, O'Callaghan (1996) analyzed songs written by cancer patients in a qualitative study. The holistic themes that emerged from patients and staff reports referred to the positive effects of music therapy, helping patients cope with their illness and connect with people and the world beyond themselves. Other music therapists have written about their use of songs with cancer and hospice patients as techniques to enhance sense of life meaning and to help diminish suffering (Bailey, 1984; Lane, 1994; Magill,
2001; Salmon, 1993). In the use of songs, for example, patients are offered song lists from which they may select songs that say what they wish to hear or express. This self-expressive process often diminishes emotional tension. Also, songs elicit memories, and through the use of songs, the music therapists may assist the patient and family in the process of life review, a process that occurs naturally as patients reminisce around music. Gilbert (1977) proposed that when working with the terminally ill, "Music and lyrics can constitute a source of comfort and reassurance...[and]...the benefits of music therapy also include the ability of music to help individuals draw closer to God and derive a feeling of assurance through religious faith" (p170). Dileo (1999) has described various song techniques that address spiritual needs, such as: listening to songs and examining lyrics; song-writing to help inspire hope and feelings of self-value; song reminiscence to facilitate forgiveness.

The transcendental nature of music plays an important role in spirituality. Aldridge (1995) maintains that music enables terminally ill patients to transcend, "to extend beyond the immediate context to achieve new perspectives...where they are encouraged to maintain a sense of well-being in the face of imminent biological and social loss" (p.107). Likewise, Lee (2005), states that: "the eloquence of music to provide a non-verbal path of meaning in the face of loss is a transcendental phenomenon of the greatest proportions" (p. 149). In addition, music provides form to what may appear chaotic and can offer an important aspect in spirituality, namely hope (Aldridge, 1995). Bruscia
(1992) has also written on his use of Guided Imagery and Music with AIDS patients, noting that images of deceased loved ones came to visit the imaging person and gave him a meaningful message. Bruscia has suggested that these experiences in GIM can enhance growth in finding new meaning in suffering, thereby enhancing the therapeutic process (Bruscia, 1991).

Music therapy has been found to address issues and needs of persons caring for end-of-life patients. Clair (1996) found that sessions of music therapy were effective in increasing mutual engagement in caregiving and care-receiving couples with late stage dementia. Through review of case examples, Krout (2003) reports that music therapy facilitates communication between patient and family members when a patient is dying, and is a way to ease communication and sharing between dying patients and their caregivers. Hilliard (2001) also describes the benefits of music therapy to meet the multidimensional needs of hospice patients and their caregivers, assisting them through anxiety, loss and grief. Slivka and Magill (1986) found that a collaborative approach combining social work and music therapy facilitated the family members’ processing of issues pertaining to loss and grief. While this work occurred with children of adult cancer patients, they found that the benefits carried over to the older family members caring for the patients. Bailey (1984) found that song material facilitates communication between patients and caregivers aiding in the diminishing of suffering during illness and following death. In a more recent study, Hilliard (2001) explored the use of
music therapy with grieving children. He found that participation in music therapy-based bereavement groups served to reduce grief symptoms in the children. While Hilliard's study focused on children, there is a tendency, as noted above, for there to be a carry over effect when children receive psychological support during times of grief and loss, impacting the well-being of the older caregivers in the family as well.

It has become increasingly evident that music therapy can play a powerful role in the care of the dying and their caregivers. Music therapists regard the significance and the importance of their roles in establishing and maintaining a compassionate, attentive and creative milieu within which patients and their caregivers can experience a sense of dignity and existential meaning (Magill, 2005).
CHAPTER III

MUSIC THERAPY IN END-OF-LIFE CARE: CLINICAL PROCEDURES AND PROCESSES

Introduction

Music therapy in the care of those facing the end of life is a specialized area of practice. Patients and their caregivers have multiple physical, psycho-emotional and spiritual needs and issues. Therefore, the skills necessary for this work are multifaceted, and techniques are designed to meet each unique life situation. This chapter intends to describe the music therapy clinical work as a frame of reference for the content of this study. In the following, I will review: the hospice home care setting; the theory informing this clinical music therapy practice; the session procedures, including assessment, goals and techniques; the general stages of music therapy sessions; and the role of the caregivers.

Hospice Home Care Setting

Patients receiving hospice home care services are nearing the end of life and are in need of supportive care. Often they are limited in physical mobility and have a range of cognitive and neurological functioning abilities. Patients and caregivers each contend with a wide range of emotions as they
attempt to cope with the losses they are facing. They receive regular visits by specialized hospice professionals and have part- or full-time personal assistance. Often the patients have twenty-four hour health care attendants, and many have close family members who are present during some or most of their days. Patients are ethnically diverse and represent a wide range of socio economic backgrounds.

In this study, the music therapist is part of a multidisciplinary team that also consists of a home care coordinator, a physician, several social workers, several nurses, and a chaplain. The music therapist is referred to work with patients who are having difficulty coping and have a range of issues and needs. Reasons for referral include isolation; poor communication skills or abilities; challenging mood disturbances, such as depression or anxiety; and/or difficult-to-manage pain. She receives referrals from team members and then schedules appointments after making initial contact by telephone. The music therapist generally makes weekly home visits, the frequency of which is determined by a music therapy assessment and patient/caregiver requests.

As the music therapist in this study, I visit approximately ten patients per week, all living in various locations throughout a large urban community. There are caregivers present in sessions, such as family members or health care attendants. The sessions vary in length, however generally last approximately forty-five minutes. I work in ongoing, close collaboration with the hospice
team members and provide services to the patient during the duration of the illness.

**Theory of Clinical Practice**

In end-of-life care, music therapy aims to address the multi-faceted needs presented by patients and their caregivers. The core focus of the clinical work is to offer support, improve comfort and to enhance overall quality of life. The music therapist uses the multi-dimensional medium of music to treat the patient holistically, attention being given to the various aspects of the suffering experience. Components of the total suffering experience may include pain, feelings of helplessness, anxiety and/or depression, and feelings of loss and grief. Thus, the physical, psychosocial and spiritual needs are kept at the helm of the work and are approached in such a way as to reduce symptoms of suffering and to enhance the patient’s sense of control, feelings of well-being and overall sense of personal life meaning. The fundamental principle of music therapy in this setting involves the therapist’s having a caring, compassionate and sensitive attitude towards those receiving the service. The therapist endeavors to bring a listening presence with respect for the individual needs presented by each person. The diversity of techniques that are available in music therapy explains its value in this setting, as music therapy, sensitively applied, potentially crosses all boundaries and can reach beyond words, thereby meeting patients’ comprehensive needs.
Session Procedures

There are several aspects to the overall process of music therapy. Astute, ongoing assessment is vital in this work, and techniques are designed to meet the moment-by-moment needs of the patients. In this section, I will describe the session procedures that I follow in my work, including assessment, goals and the techniques used with patients.

Assessment

Regular and thorough assessments are fundamental to this work. Through keen observation, attentive listening and sensitive questioning, the therapist gathers information concerning the patient’s immediate physical needs, mood state and degree of emotional fragility. It is necessary to gain a perspective of the patient’s total suffering, e.g., the affective, cognitive and sensory processes that underlie the patient’s experience. Therefore, it is crucial to gain a thorough understanding of the in-the-moment needs as well as an understanding of the patient’s history and life status, including meaningful life experiences and personal values. It is also important to attain knowledge about prior musical skills, since, by incorporating these skills, the music therapist can help foster a patient’s sense of identity and can help enhance the integration of music therapy into the therapeutic processes.

As I approach a patient, I carefully observe him or her in order to gain an initial understanding of the patient’s overall status. I watch for physical
symptoms, such as rate of respiration and any possible areas of discomfort; and also observe functioning status, such as capacity to voluntarily mobilize self and the ability to respond to prompting. I observe facial expressions and the patient’s ability to interact, including the making of eye contact. I also carefully attend to verbal statements, as initial comments tend to reveal the patient’s wishes, needs and often the most prominent patient or caregiver concerns. Verbalizations, or lack thereof, also inform me about the patient’s level of orientation to person, place and time. There are numerous cues that are all important to attend to, such as the light in room, presence of the support of others, and most importantly, the verbal statements of all who are present in the session. All cues assist me in understanding the patient’s degree of emotional fragility. Are emotions near the surface? Does the patient have the physical and emotional abilities to handle expression of feelings at this time? These questions help guide me in setting the tone and pace of the music initially, as helping the patient feel a sense of comfort and sense of control is essential.

Once this initial assessment is made, I continue to monitor the patient’s verbal and nonverbal feedback in sessions. I carefully observe physical status and facial expressions and listen attentively for cues that indicate any changes in status. Since contentment and well-being are primary aims, I watch for favorable responses, such as increased relaxation, improvement in mood, and enhancement of communication and interrelatedness; or adverse responses,
such as increased agitation, restlessness, increased apathy or withdrawal. During sessions, I also become more acquainted with the patient’s and caregiver’s life experiences as a way to build on strengths and facilitate personal exploration. Thus, on a moment-by-moment basis, assessments are made to assure for comfort and overall well-being.

**Goals**

Music therapy goals are determined based on the assessments made in sessions. There are short-term goals that address the immediate needs and also long-term goals that aim to enhance meaningful transformations in intrapersonal and interpersonal processes. The long-term goals are viewed as paths of direction that can help lead to fulfillment in psycho-emotional, social and spiritual domains. These goals are determined as the broader needs become apparent and may include, for example, resolution of deeper feelings of remorse or guilt. Short-term goals are addressed initially in sessions, since the most prominent needs, as determined through assessment, are attended to first. The long-term goals are often addressed over time and are integral aspects of the processes that evolve. In end-of-life care, time is of the essence and the amount of time patients and families have left together, while unpredictable, is sometimes very short. Short-term goals are always addressed within each session and as time permits, long-term goals are considered as a way to help bring deeper fulfillment and sense of peace to all present. Often,
due to the urgency of time, patients and families will address deeper issues immediately, especially with the supportive presence of the music therapist. Therefore, short and long-term needs and issues may be addressed in one session. The therapist needs to be able to transverse through and across the journeys of the patients’ and caregivers’ lives, sometimes within the span of one hour. The therapist, then, stays flexible and fluent in approach, moving with the needs and interests that emerge. In the following, I will highlight examples of each of these types of goals.

**Short-term goals.** Short-term goals address immediate, short-term needs and may include:

To decrease adverse physiological symptoms: diminish pain, agitation, nausea, fatigue, cardiac irregularities, apnea, and dyspnea

To increase relaxation and sense of comfort

To provide sensory stimulation

To enhance cognitive orientation

To enhance communication and promote social integration

To enhance physical and neurological functioning abilities

To provide techniques designed to enhance coping with stress, e.g. to use during times of exacerbation of symptoms, during times of fear and anxiety, during medical procedures, during periods of insomnia, and during other stress-inducing situations.
Long-term goals. Long-term goals are those designed to enhance life meaning, while addressing the unique long-term life situations of the patients and caregivers. These may include:

To express, identify and resolve feelings, wishes and needs
To identify and resolve sources of anxiety, fear, anger, frustration and guilt
To enhance self-identity and feelings of self worth
To reminisce as a way to review one’s life and reconnect with self and others
To attain sense of meaning in life, understanding one’s purpose in life and one’s unique contribution to the world
To achieve resolution in relationships
To enhance self awareness
To attain a greater sense of inner peace that reflects an inner resolution and acceptance

Techniques

There are several techniques that are used in sessions. Selection of techniques is based on assessment and patient/caregiver preferences. In sessions, I strive to create a space into which the patients and their caregivers can enter, a space that invites expression, reflection and identification of thoughts, feelings, attitudes and needs. Music is selected by the patient, the
caregiver and/or me as the music therapist, and is designed to reflect the overall moods and needs. Generally live music is used because I can easily adapt the music to changing needs in sessions. Live music also invites interaction and communication. There are a variety of instruments that are used in sessions, such as guitar, keyboard, drums and small hand instruments. I primarily use a nylon stringed guitar due to its acoustic qualities and my ability to play a wide variety of styles of music, such as folk, classical and multicultural. I also carry with me small, easy-to-hold hand instruments for patients and caregivers to play in sessions. The patients and caregivers often select specific techniques, for example, as in requesting to hear certain songs. I also select techniques, as I consider the presenting needs and determine the approaches that will meet short and long-term goals. In the following, I will describe common techniques that I use in sessions on home visits.

Use of pre-composed songs. Songs are commonly used in sessions. Songs are unique forms of musical presentations in that they are combinations of words and music. Songs are less threatening vehicles through which patients and caregivers can express their often difficult-to-express thoughts, feelings and needs. Individuals in sessions often select songs that convey the messages that are foremost in their minds, such as deep wishes, longings, prayers, hopes and dreams. Sometimes people are not aware of their symbolic associations with songs, but find relief in musically expressing their feelings and thoughts. Songs are linked to memories, places and people, tending to enhance
reminiscence as well as interrelatedness between patients and caregivers. I also find songs to be helpful with emotionally fragile patients since the structure of lyrics in songs, such as in the images or ideas that are suggested, can guide frightened thoughts.

**Lyric improvisation.** The lyrics within songs are often spontaneously adapted to meet individual patient situations. New songs are composed from familiar melodies and are created by the words and life stories presented in sessions. Lyric improvisation is often used as a way to personalize sessions and to assist the patient in articulating needs and wishes. It is also a technique that enhances a sense of personal value since the lyrics are often selected to represent strengths and personal attributes. Meaningful memories are also included as lyrics for these compositions. Patients often gain a sense of affirmation as they hear their past accomplishments included in the songs. An example of this technique is the use of the song "Take Me Home, Country Roads," substituting new lyrics to describe the patient's sense of "home."

Another style of lyric improvisation involves the use of chants. Simple, repetitive melodies, with words that are selected by the patient, help induce a sense of calm and can also increase attentiveness. This vocal technique includes the use of tempo. I will often match the tempo to the patient’s breathing, for example, and then adjust the tempo to help enhance relaxation. This gentle music is accompanied by the presence of the human voice that is repeating calming and affirming words. Chanting is usually comforting,
soothing and lulling for those present. Chants are multicultural and address a variety of symptoms and needs.

**Imagery in music.** There are times when I invite the patient to attend to the imagery that I sing. This technique is helpful when patients have episodic pain or disturbing physical symptoms, such as nausea or dyspnea; and is also helpful with people who may have difficulty articulating or who are unable to speak. In this technique, I invite the patient or caregiver to select an image that brings a sense of peace and feelings of pleasure. I either use a chant form or improvise a simple melody while playing the guitar and sing the words that are reflecting the images of choice. I encourage the patient to follow the images. Thus, the patient is actively involved internally, a process which enhances sense of control and feelings of empowerment. This technique is versatile and the words, melodies and rhythms are adapted to meet the specific moods and needs.

**Music listening.** Patients often request to listen to the live music in sessions. Listening to music provides opportunities to refocus attention and reflect. Listening to familiar music naturally stimulates association with memories and significant times in the past. Patients often request to hear specific song or instrumental selections as ways to go back in time and rebuild connections with transformative events in life. Such events may include, for example, moments in relationships with significant others or travels to special places. In end-of-life care, patients have a tendency to focus attention on the
past in order to review and come to terms with their lives and resolve unfinished issues. This process can also help patients introspect, gather a sense of meaning and view the purpose of their lives, as they reflect on accomplishments and achievements. During such reminiscence, the supportive presence of the music therapist can enhance exploration and facilitate communication within the space of creativity, trust and encouragement.

Listening to music is also beneficial when patients need calming sounds to help soothe symptoms of distress. In these situations, I invite patients to follow and focus attention on the aesthetic sounds of the music. Sometimes unfamiliar or improvised music is helpful since this music does not necessarily contain the associative qualities that familiar music does. I use unfamiliar music when there is pain or emotional fragility due to this potential for engagement without the strong presence of memories. As patients listen to music, I adapt the rhythm and mode to suit the patients' overall physical and emotional needs. For example, in distressed patients, I set the rhythm to initially meet the rate of breath and then alter the rhythm in order to help induce greater sense of relaxation. Likewise, for patients who may need uplifting, I set the rhythm at a gently moderate pace and use a major mode. The attention and focus that is experienced during music listening often result in a diminution of anxiety and restlessness, leading to an improved state of relaxation.
Stages of the Music Therapy Sessions

Each music therapy session is unique. Needs and issues change moment-to-moment and day-to-day in the home care hospice setting. Thus, the therapist seeks to meet the patients and caregivers with openness, aiming to learn the needs and desires that are prominent in each individual visit. Sessions tend to flow through a series of three stages within which the therapist strives to use continual assessment and flexibility of approach. In the following, I will describe these stages that may be understood as a process and not as a highly defined set of procedures. There is an ebb and flow between and among the stages, and there is overlap and fluidity from one stage to the next.

Contact Stage

In this initial stage, the music therapist, patient and caregivers come together and organize themselves in communication. The music therapist gathers initial assessment information in the beginning moments and gains perspective into overall status, including the primary needs and the feelings that may be present. During this initial stage, the therapist sets the tone in such a way as to address primary needs and help the patient experience comfort and a sense of control. For example, if the patient is restless or agitated, the music therapist generally provides calming soothing sounds to ease the distress, perhaps using lyrics to help guide the patient into relaxation. During this stage, the music therapist may see an initial theme or topic emerging from statements
or interactions. This theme is sometimes carried into lyrics as a method of offering support to those present.

Development Stage

In this stage, there is generally more elaboration that occurs. There may be reminiscence that often evolves into enhanced exploration and communication. Often, patients identify feelings associated with the past or they may realize unresolved issues. The therapist may introduce creative techniques, as described above, to help those in sessions express thoughts and gain insight. Since music has a powerful effect on mood, patients sometimes become engaged, energized and interactive. These significant responses often lead into improved self-awareness and sense of relatedness. During this stage, then, the music therapist offers support and listens to the themes that are emerging, finding ways to ground the themes in the music, for example in song lyrics.

Closing Stage

In this stage, the focus is centered on closing the session. Generally, after thirty to forty-five minutes, the session comes to a natural conclusion, as evidenced by indications of relaxation, beneficial changes in mood and other symptoms that were distressing the patient. At this stage, there also seems to be a resolution of feelings that may have surfaced in sessions. The therapist
generally finds a closing song into which themes that had emerged in sessions may be articulated in the lyrics. Or, there may be a special song, the lyrics of which that depict the essence of the time spent together. The Closing stage, then, is the time and place where patients and their caregivers are left with a sense of control, feelings of inner peace and images or thoughts that are affirming and gratifying.

The Role of Caregivers

Caregivers are almost always present in hospice home care sessions. They play an important role in the life of the patient, as they are usually the primary significant other(s) that attend to the daily needs. Whether they are family members or home health attendants, the caregivers are those people with whom the patient may entrust their physical and psycho-emotional needs, as well as their possessions and affairs of estate. It goes without saying that stress can be significant for all involved in these often loss-filled situations.

The caregivers who are present in music therapy generally assist the patients in singing, selecting songs or in participating in the music. While the primary focus is on attending to the needs presented by the patients, the music therapist also offers support to the caregivers and aims to help them achieve such goals as relaxation, improved sense of control, and enhanced expression of feelings and needs. The caregivers are the ones that are left to carry on with the affairs and need the support of the health care providers during the patient’s
end stage of illness. Thus, they are encouraged to be present in sessions so as to also benefit from the soothing, calming and pleasurable attributes of music. The caregivers are offered opportunities to speak their thoughts to their loved one through lyrics as a way to help them prepare for the death and as a way to also help them find resolution of their own feelings of guilt or remorse. The caregivers also benefit from witnessing the improved communication in patients that so commonly occurs. They are an integral part of the ongoing musical and lyrical dialogue that emerges in sessions and thus play a significant role throughout each and all sessions.

Summary

Music therapy in the hospice home care setting maintains the fundamental principle of aiming to promote enhancement of well-being and quality of life in patients and caregivers. Since the needs and issues are diverse, as are the personal backgrounds and life experiences, the music therapist uses astute assessment skills and strives to incorporate individualized techniques to address short and long-term goals. The music therapy sessions are generally replete with moments of meaningful explorations and interpersonal interactions. Reminiscence and identification of personal attributes and important life experiences naturally occur within the context of music, such as in the hearing and selecting of songs. Caregivers play an important role in the
lives of patients and their presence in sessions provides the patients, as well as themselves, with healing moments of intimacy.
CHAPTER IV
THE RESEARCH METHOD

Spirituality in Context: A Qualitative Approach

Because the purpose of this study was to discover and describe, from surviving caregivers' points of view, the spiritual meaning of the music therapy witnessed before the death of a loved one, I needed to take a research approach that aimed to discover the essences of experience through open-ended inquiry. This study aimed to illuminate meaningfulness and understand how and in what ways witnessing music therapy prior to the death of a loved one impacted the caregiver's bereavement period. Therefore, I selected a method and data analysis based on the qualitative ideas of naturalistic inquiry.

Naturalistic inquiry allows for inquiry to evolve within naturally occurring contexts. In his review of the origins of naturalistic inquiry, Aigen (2005), states,

Naturalistic inquiry was put forth as a means for gaining insight into social situations by revealing patterns of interaction ... [and that] ... a number of researcher practices were valued at the outset: participating in the social setting being studied; making efforts to gain the perspectives of those being studied; investigating all aspects of the affective inner life of humans; and maintaining a broad definition of data that includes pictures, images and verbal descriptions. (p. 353)
Thus, in naturalistic inquiry the researcher seeks to gain knowledge regarding the inner perspectives of those being studied. Aigen (2005) also states that the "natural setting is the source of the study because the context it provides is necessary to establish the meaning and significance of its findings (p. 357). This study was heavily influenced by naturalistic methods, such as the use of researcher-as-instrument, the use of tacit knowledge, the incorporation of purposive sampling and the use of inductive data analysis (Lincoln & Guba 1985). In addition, this study incorporated and occurred within the natural setting, which in this case was the context of the caregivers' experiences. This was particularly appropriate since this study intended to explore the caregivers' perspectives during their bereavement period. The mode of inquiry was through interviews with the surviving caregivers and also through my notes as researcher, in the form of journal entries and observation notes.

Another contextual factor considered in naturalistic inquiry is the context of interpersonal relationships. In this study, as researcher, I had a pre-existing relationship with the caregivers who were the participants in this study. The caregivers were present during the sessions, and they were witnesses to my working with the patients for whom they cared and heard the live music I created for the patient. These preexistent relationships afforded me, as researcher, the opportunity to understand the context of their experiences. While, as researcher, I was not in a service-providing role to the caregivers during bereavement, nor is it the role of the music therapist to
provide bereavement services, I was aware that my role as researcher at times needed to involve the offering of support, as there were emotional expressions pertaining to the loss of the loved one. I considered these aspects of the interview process as I collected and analyzed data. As I conducted the interviews, I realized that the time they spent with me may have afforded the caregivers time to reflect on their experiences and process feelings of grief. It is possible that the interviews may have benefited them since they had this reflective time, and the interviews ultimately may have improved the outcome of bereavement.

One of the features of qualitative research is that the researcher is researcher-as-instrument. According to Guba and Lincoln (1981), the researcher has human qualities, such as the ability to respond to subtleties (e.g., tone of voice); has the ability to assess the intricacies of words and expressions and assess these in relation to the context of those being interviewed; and has the ability to respond immediately to the data and change the direction of inquiry if needed. As Aigen (2005) explains, “only human beings are complex and multi-leveled enough to grasp the multitude of factors that influence people in social settings” (p.355). In naturalistic inquiry, then, the human as research data-gathering instrument can adapt to the variety of realities that may be encountered and can grasp and evaluate the meanings of interactions (Lincoln & Guba 1985). Therefore, this naturalistic method of inquiry allowed me to use myself-as-instrument, to guide the direction of the interviews in
ways that assured flexibility, open-endedness and also allowed for the comfort and well-being of the participants. I used ongoing journal writings as ways for me to identify my personal reactions and thoughts.

Along these lines, naturalistic inquiry also includes tacit knowledge as legitimate knowledge to be included in the collection of data and in analysis. Tacit knowledge, “intuitive, felt” (Lincoln & Guba, 1985, p. 40) knowledge is natural in interviews because “much of the interaction between investigator and respondent…occurs at this level” (p. 40). This study took tacit knowledge into account. As discussed, interviews were open-ended and emerged naturally, with attention being made to my sense of tacit knowledge that was used as a way for me to gain perspective of the meanings of the participants’ words and verbal/non verbal expressions. In this study, the elements of words and nonverbal expressions were key aspects that were listened to and observed in this research.

**Participant Selection**

Participants in this study were those caregivers who had witnessed music therapy prior to the death of the loved one. Since this study aimed to understand the spiritual meaning of music therapy, I needed to select those caregivers with whom there had been some reference to the underlying themes of spirituality in the sessions of their family member. These themes were:
1. mention and/or focus on a Higher Power, God, a Higher Being, as defined by the participants;
2. mention and/or focus on faith, e.g. in self, others, Higher Being;
3. reflection on the meaning and purpose of life and living, self-value and personal significance;
4. mention and/or focus on feelings or thoughts of hope;
5. mention and/or focus on transcendence, the being ‘lifted out of’ or ‘transported’ to another realm or place; and
6. mention and/or focus on nature, beauty, infinity.

Naturalistic inquiry allows for purposive sampling to allow the researcher to select participants that will “increase the scope or range of data exposed...as well as the likelihood that the full array of multiple realities will be uncovered” (Lincoln & Guba 1985, p.40). This form of sampling helped me in my recruitment phase. According to Lincoln and Guba (1985), sampling has two main objectives, such as finding enough variations in participants in order to gain thorough understanding and also to find participants who will add more knowledge and insight into data being explored. I recruited participants from the hospice database of approximately fifty caregivers who had witnessed music therapy sessions prior to the death of their loved one, thirty of whom there had been some expressed reference to spirituality as described above. Purposive sampling in this way afforded me the opportunity to study the
research questions and therefore gain deeper understanding and knowledge of the topic of interest.

The Participants

This study included interviews with seven caregivers of seven different patients, six women and one man, who are referred to, throughout the body of this paper, with these pseudonyms: Dahlia, Flora, Abe, Ruth, Mary, Miranda and Toni. In selecting the participants, I was interested in talking to caregivers from a variety of caregiver relationships. Thus, gender was not a criterion for selection. Rather, with the intention in mind of researching participants having some relationship and personal background variations, I selected participants with these caregiver relationships: two spouses, one long-time friend, one adult daughter, one niece, one long-time personal care assistant and one sister-in-law. From the pool of caregivers who had some reference to spirituality in session, these seven were selected, then, due to their backgrounds, availability and interest in participating. They each completed the Participant Consent Form, approved by the New York University’s Committee on Activities Involving Human Subjects (see Appendix A).

Data Collection and Analysis

As the researcher, I recruited participants, selected questions, transcribed the interviews, organized and analyzed all the data. As Lincoln and
Guba (1985) explain, the research method of naturalistic inquiry requires the researcher to be the instrument of data gathering and analysis. The research was analyzed through my eyes and my values. It is natural for this type of research to be 'value bound' and my values are evident in the topic choice and the presentation of the data.

Data collection and analysis occurred simultaneously. During and following the interview with the first participant, I attended to caregiver comments that seemed noticeably pertinent. While I had a set of questions in mind as I proceeded through interviews, I allowed the flow of the interviews to emerge naturally, primarily because I knew these caregivers were in bereavement and I wanted to allow them the lead in talking about their experiences. I began each interview with a simple general question: "As you reflect on your times in music therapy, what are your impressions about the ways those times influenced you then and now?" Often before I asked the first question, the caregivers began to reminisce openly, sometimes grieving initially and then moving into expressions of happiness as they recalled special moments of communication. There were usually smiles and laughter. My tacit knowledge was used in the interviews since I observed the verbal and nonverbal communications and used their cues in deciding if and when to ask a question. I also found questions emerging based on each participant's unique experience and story. In the interviews, I allowed for the participants to freely relate what they deemed to be meaningful to them with regard to having
witnessed music therapy with the loved ones. I chose this free and open-ended approach in interviews since I was interested in hearing their unique explanations and perceptions and also interested in learning about the potential impact that witnessing music therapy sessions had on the caregiver’s attitudes and ability to cope with the loss.

Each caregiver was interviewed one time. After each interview I transcribed the audio recording. As I listened to the recording, I was also able to grow close to the data and develop a more detailed and intimate perspective of the interviews. After each interview and during the analysis, I kept a journal in which I recorded my observations and impressions of the interviews. I also took notes on emerging trends that I saw developing. These journal entries were notes about my reflections on the process of interviewing and contained my observations, insights and perspectives. They also contained my observations of facial and emotional expressions, eye contact, movements and changes in positions that occurred during interviews. The journal entries also contained my thoughts pertaining to any moments of insight or reflection that I may have had as well as my responses to verbal and nonverbal language occurring during interviews. These notes acted as a way for me to identify and acknowledge my viewpoints and perspectives.

Throughout the entire data collection and analysis phase, I repeated this simple statement to myself “what is important to them, and not to me.” I made a sincere, deliberate and stringently conscious effort to see and hear all trends
from their perspectives. I felt a need to have and maintain this focus since I am very close to this topic and have years of experience in assessing and synthesizing patients' experiences, and years of experience in teaching this topic to others as author, researcher, educator and intern supervisor.

The areas of predetermined interest that I had in mind before each interview were these: reflections on the music therapy experiences, reflections on spirituality, as defined on pp. 11-13, and reflections on the role of music. These were topics that were sub questions, however, I allowed the course and topics in the interview to emerge naturally.

Once I began to see trends that were occurring in the notes I was keeping in my journal, I found that I had reached saturation in data. After the seventh interview was transcribed, I sat with all the transcripts and reviewed them recursively a number of times. I made notes in the margins where statements seemed significant and looked for patterns that reflected areas of focus within each interview, and then across interviews. These notes followed the data analysis proposed by Bogden and Biklen (1992). This method suggests sorting the data so that topic specific information can be sorted out of the data. I highlighted and then coded statements in the transcripts and looked for similarities across interviews. I reviewed the transcripts frequently, reading them each through numerous times. As I did this, I found three larger bins of data that were emerging.
In the analysis, I followed a format of theme development that was described by Ely, Anzul, Friedman, Garner and Steinmetz (1991). She defines theme as: “a statement of meaning that (1) runs through all or most of the pertinent data, or (2) one in the minority that carries heavy or emotional or factual impact” (p. 150). As I reviewed the transcripts and pondered the words of the caregivers, I asked myself several questions, for example, “What are the specific salient features of their reflections?” “Which topics are they naturally addressing in interviews?” “What is the essence of their reflections and what meaning do these reflections have in the scope of their lives?” I wanted to see what themes were present and these questions helped me look beyond psycho emotional responses and delve into the caregivers’ specific areas of interest in regard to their experiences in music therapy. These questions guided me in listening carefully to the content and context of their words as a way to see if and how spiritual themes might be in the data.

Once I found the three larger bins of data, I sorted through the coded data and found themes that had emerged. From this process I was able to decipher theme categories that occurred across interviews. As I continued comparing and analyzing the data, I created what Ely, Vinz, Downing and Anzul (1997) call cross-case theme statements that I present in the written analysis of the data in this document. These theme statements are presented in the first person. I also constructed poetry as a way to express caregiver views. Ely et al. (1997) suggest that “forms shape the subject matter to enrich
meanings and understandings” (p. 59). The poetry is written in the first person and is taken from transcript excerpts. Finally, as a result of recursive review and analysis, a larger thematic trend emerged across interviews that seemed to serve as a fundamental aspect underlying the overall processes in which the caregivers were partaking. I also participated in member checking, holding phone discussions with the caregivers as a way to hear their perceptions of the analysis.

Trustworthiness

In naturalistic inquiry studies, procedures for trustworthiness are necessary. As explained by Aigen (2005) who summarizes the premises set forth by Guba and Lincoln (1989), there are five authenticity criteria for trustworthiness, such as “fairness and ontological, educative, catalytic and tactical authenticity” (p. 360). Overall, these criteria serve to ensure that “researchers actively seek to illuminate the constructions and values of research participants, enhance these constructions within the minds of participants, and stimulate and empower participants to action based on their enhanced constructions” (Aigen, 2005, p. 360). The procedures to ensure trustworthiness, among others, may include: journal writings and “peers of the researcher, research participants, and academic research advisors” (Aigen, 2005, p. 357).
Throughout this study, I sought to establish trustworthiness. One area that I pursued in order to establish trustworthiness was the process of peer debriefing. I had two colleagues with whom I debriefed throughout the study. Both are professionals in end-of-life care, i.e. a music therapist and an oncology nurse. Both of these professionals have been familiar with my work as music therapist through the years in this field. I met and conferred with them several times. As they looked over the data and reviewed the emerging themes, they also provided me with valuable insight and probed me with questions that helped me further develop an analysis. For example, one peer asked me questions concerning the context of the themes that were emerging. From these questions, I was able to see the groupings of various themes, for example, the overall reflections on music therapy sessions versus the specific spiritual themes relating to their thoughts regarding the impact that these experiences in music therapy had on them. Thus, this probing assisted me in further sorting the themes that were emerging. Also, I was questioned concerning the impact of my role as music therapist and how the caregivers may have perceived this role. For example, in reviewing the interview transcripts, one peer indicated noticing other references to the significance of the presence of the music therapist that I had not previously considered. Some of the discussions on this matter helped me to further analyze the data to more thoroughly ascertain the participants’ statements that indicated their reflections on the roles of music and music therapist. Another question was poised to me
regarding the differences between the types of feelings that the caregivers referred to in their overall reflections on the sessions. These questions also helped me in further sorting the data.

In addition to the above, I participated in member checking as a way to ensure trustworthiness. As Ely, et.al. (1991) explain, member checking is a procedure whereby the researcher checks “our interpretations periodically with the very people we are studying” (p. 165). I participated in member checking by providing six of the seven caregiver participants with the themes and categories as a way to check my findings and to help establish credibility. These conversations were held over the phone due to scheduling difficulties. The caregivers found, overall, that the themes represented their sentiments. They agreed with the findings and confirmed that these themes captured the essence of their feelings and experiences.

Stance of the Researcher

In the personal source and origin of this study explained in Chapter I, I described the context of this study as it pertains to my values and predetermined beliefs that have evolved and developed through my years of practice as music therapist. I entered this study with assumptions, such as the fact that music therapy in end-of-life care facilitates spiritual explorations and invites patients and caregivers to experience a deepened sense of spirituality. I have witnessed music therapy enhancing communication, transcendence and
life review, which are some of the overall aspects that further enhance a sense of spirituality in patients and caregivers. I entered this study with these experiences and beliefs, and entered the study with this stance. I also entered this research with curiosity, wanting to hear, from the caregivers’ perspectives, their impressions regarding the spiritual meaning of times spent in music therapy.

My interests in spirituality, while they have grown as a result of my years of time watching and accompanying people who are facing the end their lives, have been a part of me throughout my life. I have explored and relied on my faith over the years and continue to find that it is of central importance to me, sustaining me through times of trial and difficulties, as well as times of personal gains and losses. I entered this study understanding the closeness of this topic for me. As a clinician I have grown accustomed to focusing on the needs, beliefs and values of the patients and families with whom I have worked closely and have learned to rely on my faith for me personally, as a source of support for me internally. Therefore, I found myself able to set my values aside, as thoroughly as possible, throughout this study.

Another area of value for me is my own personal experiences in music. I have long believed in the power of music to help humans transcend out of circumstances and into memories or places of beauty and peace. I experience this tendency in music personally almost every time I listen to music. While this trait of music is a common trait that has been well established in literature,
I was aware of my personal beliefs in this area as I partook in this study.

Finally, music has been a personal source of strength and support for me throughout my life. I have been with many people as they have made the transition from life to death and have witnessed the power of music to provide solace, respite and comfort to family members as well as to myself. Music, for me, has always been a source of spiritual strength as I find myself reconnecting with that place within me that I call home.

I believe in spirituality and, while finding ways to maintain clinical and professional boundaries, have found spirituality to play a key role in music therapy practice with end-of-life patients and caregivers. These basic beliefs in spirituality and music and my experiences as a long-time clinician in this field underscore my stance as the researcher in this study. My beliefs and experiences to date influenced my research topic selection, and my interest in this topic drove me through data analysis. While I was careful and mindful of my thoughts and feelings throughout the data collection and analysis phases of this study, these values and beliefs are important aspects in this study.
CHAPTER V

THE CAREGIVERS' REFLECTIONS: RESPONSES TO EXPERIENCES IN MUSIC THERAPY

Introduction

"The music therapy brought serenity, joy and strength to all of us."

These words, stated by one of the caregivers, exemplified the thoughts and feelings portrayed by all of the caregivers in various ways throughout this study. It seemed that their experiences stirred these sentiments and characterized their overall responses to their times spent in the music therapy.

This chapter focuses on the themes that emerged from the caregivers’ reflections on their responses to the experiences in music therapy with their loved ones. These themes are what I found to be sustaining themes, themes that pervaded the interviews throughout a range of topics and seemed to nurture the caregivers through the illness and beyond. These were themes that captured the essence of their contemplations and were the aspects of the sessions that seemed to drive them forward, assisting them in transcending into finding meaning throughout the course of their loved ones' illnesses. The two themes that emerged, then, describe the essence of their overall responses to their experiences: Joy (autonomous joy and empathic joy) and Empowerment.
This study sought to examine, from the caregivers’ perspectives, the spiritual meanings of music therapy. Review of data revealed, however, these psycho emotional attributes. The aspects of the caregivers’ experiences that are illuminated and described in this chapter are not subsumable under the category of “spiritual experiences,” however are salient themes and significant findings that must be included in the data analysis. While I intend to include a broad analysis of all of this study’s data in Chapter VIII, I would like to bring mention here to the fact that there were findings in this study that went beyond my original search for spiritual meaning, such as the results covered in this chapter regarding the caregivers’ reflections on their overall responses to their experiences in music therapy.

As a preface to the presentation of the data in this chapter, I will first introduce the participants who participated in this study. Each of the caregivers has a unique background and set of life experiences that characterize who he or she is and the role that was maintained throughout the patient’s illness.

Profiles of the Participants

In order to convey the characteristics and life situations of the caregivers, I introduce them here through the form of constructs. As stated by Aigen (2005), “The primary rationale for the use of these devices is that they demonstrate that the researcher has lived through the experiences being reported, and they give the reader the same sense of living through something.”
(p. 359). The constructs that are presented in the following paragraphs thus aim to establish a view into the lives of the caregivers in this study.

**Dahlia.** I am a middle-aged woman with 2 adult children. I moved here from South America when my children were little and began to work for Mrs. S as a nanny for her young children. It was hard for me to be away from my daughters, though I needed to earn money. I had my children come to the United States so they could be with me. Sometimes I regret this since they had a hard time and did not finish school. But they are married now and have children. It was hard for them and for me. After Mr. S. died and Mrs. S was sick, I knew she needed me. She was alone because her children had moved out too. I didn’t want to leave her. I knew she needed me. I decided then to stay with her until she died. It is something that you know is going to happen, but when it happens it is hard. It has been thirty years now since I have known her and been her personal assistant. I am a part of her family, like a mother to her children. We all love each other. My life has been hard, and I have a lot of faith. I pray to God each day.

**Flora.** I am older now, in my late 70’s. My husband was older than me and died not long ago. We both had been married before, so this was our second marriage. Mark and I were married for 35 years. I am European, from Italy, though I speak other languages too. I have traveled a lot, and my work is centered in humanitarian work, running my foundation for women and children in poor communities in South America. Mark was the president of a foundation
too, and we traveled together a great deal. I have always wanted to sing, though never followed it as a profession. I am very busy with all my work and traveling. I am close to Mark’s adult children and love music. I miss him.

Abe. I am in my 60’s and was a close friend with Patty for several years before she died. I am a native New Yorker and am a retired businessman. I grew up not having much confidence in myself, and then several years ago, I went on a Buddhist retreat and realized that I actually am very smart and capable, since I discovered that I have much inner knowledge. I have a deep appreciation for the lessons that we all have to learn in this life and am very grateful for the years of time I had as Patty’s friend. She was 98 when she died from the breast cancer that she had for a long time, and I learned a lot from her.

Ruth. I am in my late 80’s. Joe and I were going to celebrate our 60th wedding anniversary soon. He died recently. I am very active and independent. In fact, I can’t sit still very long, always need to be doing something, and I love to help my grandchildren raise their children. They are all my life. Joe and I met in high school and got married when I was 16 and he was 19. We have lived in a few places when he was stationed down south. And then he passed the Bar and we have been living in this large city here most of the time since then. Joe and I used to dance and listen to music all the time. I miss him and am trying to keep really busy.

Mary. I am in my late 40’s and am a single professional in this large city. I have one brother, though I am the one who spent most of the time with
my mother since he lives farther away. When she became sick, I felt ‘out of the woods.’ I am a social worker though knew nothing about caring for an adult since my work is with children. Not only that, it was my mother with whom I was always very close. My father died quite a long time ago. When we were growing up, we always sang folk songs together as a family. I feel good that I could help my mother die with grace and gracefulness.

**Miranda.** I am in my 50’s and am a busy health care professional, a nurse in a large hospital. My husband and I live in this city and have been together for a long time. His aunt became sick right after her husband died not long ago and then she gave up her will to live. We decided then and there to move her into our apartment so that she wouldn’t be alone. She was Scottish, as is my husband, and we had many interesting conversations together over the years. I care about the well being of others, and having this time with her before she died helped us all.

**Toni.** I am in my 40’s. I live in another country though come to this city often since I am a professor. My brother, who died a few years ago, was the partner of Randy. When Randy became very sick last year, I began to come more frequently so that I could help care for him in my brother’s place. Since Randy’s career was in music and theater, I was so happy to see him with music during the last few months of his life. I know this is how my brother would have wanted this time to be. I am a single mom with a son who is in college.
My son was close to Randy too. It will be different now since they are both gone. In a way, Randy was my link to my brother.

The Themes Presented in this Chapter

The fundamental themes of finding joy and strength in and through the music therapy sessions described the essence of the caregivers’ responses to their experiences in music therapy. As I heard these words stated in various ways throughout the interviews, I considered their implications. Feelings of joy and empowerment are often the antithesis of pain and suffering. How significant an intervention music therapy is to help people find inner strength and acquire ways to care for their loved ones, as well as to find happiness in the midst of impending death. In facing the loss of a loved one, the relief that they all seemed to find in these sessions was, as Mary stated, “a gift.”

Joy

In reviewing the caregivers’ reflections on their experiences witnessing music therapy, the theme of joy prevailed throughout the interviews: “These times were times of great joy and pleasure for me.” While all the caregivers did not use the word joy, the term does portray the fundamental nature of the mood that was conveyed by them in sessions, the general great happiness they felt as a result of the positive effects of music therapy. The term joy, then, depicts the qualitative character and nature of their verbal expressions. In the
following poem, the voices of the caregivers reflect the joy that was experienced:

Music brings serenity and joy to everyone
These were in fact the best memories we have of this period
The rest of the day was very down for him and for us
We were all very, very happy with this
As we could see her sing and smile
She was happy and I felt happy seeing her so happy
She was peaceful and this helped me feel peace and pleasure
Seeing her so content and with smiles, singing
The sessions helped us all feel happy
Now we have these happy times to remember

The caregivers all expressed these sentiments at different points in the interviews. As I reviewed transcripts, I observed two sub-themes regarding the derivation of joy: autonomous joy: the music affected the caregiver’s feelings of happiness directly: “I loved the music and felt uplifted by the sessions”; and empathic joy: the caregivers’ joy was a result of witnessing the patient’s happiness: “my joy was seeing him feel happy.” These sub-themes were prevalent and seemed to be outstanding features of the music therapy sessions as the caregivers reflected on their experiences. In the following, I review transcript references to these sub-themes.

Autonomous Joy

Here, the music affected the caregiver directly. Several caregivers referred to their personal love for music and their feelings regarding its effects on them as individuals during the music therapy sessions. In the following
transcript, Flora shared her thoughts about her responses to the music. She stated:

I have not told this to anyone. I have been a sociologist, I have been a teacher, I have been a photographer, but what I really would have liked to do in my life was to sing...So the music always affects me, especially when the voice is involved. So for me too, by itself, the pleasure of singing...so music affects me very much and I understand it can affect people in a positive way. It is liberating and also what comes out is irrational. These feelings are something you cannot describe with words. You let yourself roll. And the sounds...are also pleasing and soothing... So it brings serenity and joy to everybody.

Ruth also relayed her thoughts about the joy she felt in the music as she witnessed the music therapy sessions. She stated:

I didn’t want to go away when you came. I left him alone with the other therapist....When someone comes in and plays a guitar it makes a big difference...It is all worthwhile. We were all young sometime... Your music made a connection with him and with me and helped bring happiness to us... I remember sitting on the floor listening to Perry Como with our big radios. The music brought love back into our days. I felt that love and happiness when I heard the music here.

For both Flora and Ruth, the music brought them a sense of joy and happiness. They both identified their own relationships with music and found the music affecting them internally during the sessions. Other caregivers had similar thoughts. Mary talked about her reflections:

As a health care professional I spent a lot of the last couple of years being very angry and frustrated and testifying before the caregiver committee of city council that I couldn’t get the services I needed. And I’m a professional social worker. I have a background in public health and government. I understand all that stuff and I felt I wasn’t in my own woods because this wasn’t where I knew I could get help. Well, lots of support groups that people wanted me to come to. I said I don’t need a support group...It was terribly frustrating. So in the end when we got hospice it was wonderful because I got what I needed and more.
Like you. Something that was special and wonderful and that made the last days really special for me.

For Mary, the times in music also brought her satisfaction and pleasure as a caregiver. She also referred to the music this way:

I think it was fun, nostalgic... It was a break from the dullness of the days; and when my dad was ill, every day was like every other day, even for us. The last couple of days we couldn't go out with my mom the way she was. It was boring. The times in music were such a brightness for me.... It was fun, because I like singing. It was a physical activity that we could engage in. We could sing the songs that we like. So, I enjoyed it a lot myself too.... for me it was fun.

Mary referred to the memories surrounding her father's illness as each day being "like every other day." She contrasted this with her times with her mother and the "fun" and "brightness" she experienced in music therapy.

Miranda also found that the music in the sessions affected her directly. She relayed this sentiment:

I was trying, when you were present, not to invade her privacy, but I couldn't help but come into the room because it was a pleasant thing going on. It gave me a sense of peace and pleasure... It is a tiny apartment and I couldn't help hearing the music. It made me feel calmer and happier too.

Toni referred to an observation that she had about the effects of music on her and the others who were present when she was in the sessions:

[in thinking about a small group of us singing to Randy two days before he died] What I realize too is that it [the music and singing] took the best out of us in a way which was very important for each of us and for Randy. We were all so focused together in such a nice way on singing those songs for him. ... I guess the music brought me to this place [a relaxed place] as I was relaxed too. All of us were there in that place. The music did it, yes, and it was a combination of the whole thing.
For Toni, the music brought “the best” out of the people present. She was able to also go to a place of relaxation and contentment within herself and this helped her as well as the others, according to her observations. For her, this sense of contentment that she found in hearing the music helped her feel pleasure in being “focused together in such a nice way.”

Dahlia referred to the effects of music on her directly:

it touched us, all of us, all of us, all of us. I was feeling happy too. I like the music…I think it is the best...to cure any state you feel...if you feel depressed...I think that no matter how the psychologists talk to you...with the music you don’t even have to say anything... the way that the music touches one...is so beautiful... She continues... And the music brought so much joy, not just to her [the patient] but to me, to all of us.

Music had a direct effect on each of these caregivers as they each witnessed the music therapy sessions. They each spoke about wanting to be near the music, and finding the sounds to bring pleasure and happiness. The caregivers also referred to the pleasure of singing and hearing songs that they knew. While the joy they felt in hearing the songs they knew may have also been a connection for them to people, places and times in their lives, the point of interest here is the fact that they were each affected internally by the presence of the music. These caregivers experienced autonomous joy, joy that exemplified their own responses of happiness and contentment resulting from the music therapy sessions.
Empathic Joy

The caregivers' joy was a result of witnessing the patient's joy. Empathic joy may be thought of as that joy a person derives from seeing someone else happy. In experiencing empathic joy, the individual tends to base his or her emotional responses of happiness on how another person may be feeling, e.g., in this case, the patient. Empathic joy was a common trend across the interviews and was heard in comments that reflected this thought: "the music therapy brought her happiness and therefore I felt happy." In this study, the caregivers almost unanimously talked about this aspect of the times for them as they witnessed the music therapy. They each, in their own unique voices, described the joy and happiness they felt in seeing their loved ones happy, relaxed and smiling. This was a striking theme and signified a sense of deep concern for the patients' well-being as well as their own sense of relief at not seeing the patient in pain, discomfort, agitation, and sadness.

Flora expressed her empathic joy in this way:

In that moment, it [the music] was taking me back to the moment when he was in good shape, when he was healthy; but I was centered on him. My pleasure was seeing him reacting and enjoying and being more alive...I never thought so much of what I was thinking. I hear music and I always love music very much. In that moment, I was centered on what he was feeling and grateful that he could be himself for a short time. ... Music always does for me because I love music very much. It helped me because of the effect on him, not so much as the effect on me. Of course, I love to hear music, but this was a special occasion in which music had a different meaning...in this case I was with him...He [Mark] was going back to being himself, like when he was singing ... which was typical when he was happy, and so I was happy too because I saw something of him that I thought had disappeared completely.
Flora referred to this aspect of feeling joy in the sessions, that is, that she found happiness and pleasure in seeing Mark feeling happy and participating meaningfully with her and the family. Flora felt great happiness in observing these responses in Mark and clearly articulated that her feelings were based in seeing her husband happy again. Dahlia had similar thoughts:

Because it [the music] touched us much and I particularly felt happy seeing Mrs. S. happy .... I was so happy seeing Mrs. S. so happy.

Miranda also experienced empathic joy. There were a few times in her interview during which she conveyed this feeling:

[in recalling the events of times immediately following music therapy sessions with Miranda and her aunt]...She [Jacqueline] was with me, we were joking, she was talking about Johnny [her nephew] and talking about her husband. He had worked for the State Department of Jersey. Every time there was an election, he worked for the election board. So, she enjoyed talking and that brought me a sense of calm and peace as well. I think you changed her mood. You changed her way of looking at things for the moment...I think it brought a sense of calmness to her, and then to me, because she was not in pain and not refusing everything that you want to take care of them. .... That last day you came was a sad day for me. When you think about the fact that I was anticipating her death, it did help me through those moments.... It did help me feel better in that moment in time and after, since I knew she was more peaceful.

For Miranda, the music therapy brought benefits to her aunt, such as a sense of peace and calm as well as diminished pain. This sense of peace that she observed in her aunt seemed to help Miranda feel comfort and contentment, that is, "It did help me feel better...since I knew she was more peaceful." She referred to the peace that she felt as a result of seeing her aunt more relaxed
and calm. Mary also talked about the joy she felt seeing her mother respond to the music:

On the last time you came, you sang “My Funny Valentine” which was my mother’s favorite song, and she really responded, smiling. The way she responded was quite noticeable. So I thought that was pretty special and it was just something so enjoyable. It was such a gift; it was something special. Something that she liked very much, music and to sing...

Mary found enjoyment in seeing her mother with a smile on her face, seeing her pleasure in hearing the song she loved, “My Funny Valentine.” Her mother was limited in responsiveness on my last visit before she died. This glimmer of joy that she saw in her mother meant a great deal to her and helped her also feel a sense of joy.

Toni recalled her experience in music therapy shortly before her brother-in-law Randy died. She shared this thought:

He loved music, as you know. It was part of his life. It was so helpful to see his peace and calm. The music brought him there. It seemed to lift him and carry him, didn’t it? And that helped me and my mood.

Toni found that her mood was “helped” as a result of seeing the music bring comfort to Randy. Toni’s affect in the interview also conveyed joy. In my post-interview journal entry, I state these thoughts regarding my observations:

Toni sat across from me in the interview today. She initially seemed tired as we started the interview. I noticed, however, a remarkable shift in energy as she talked about her memories observing the positive effects of music on Randy. She became very animated, smiling, laughing at times and also seemed relieved as she shared her thoughts about seeing Randy relax in sessions. As she talked today, her face and gestures displayed happiness.
Abe had similar reactions. He felt intense joy as he saw the face of his dear friend Patty singing her favorite Irish songs. During the interview he stated, “She [Patty] was so, so happy, and I was so, so happy seeing her happy.”

Each of these caregivers experienced this empathic joy, this sense of happiness, satisfaction and pleasure they felt as a result of seeing a declining loved one feeling happy, relaxed, calm and peaceful during and after the music therapy sessions. These memories stood out for these caregivers as significant moments for them. They all experienced some form of emotion, ranging from tears to laughter, as they recalled seeing these responses in sessions. They also identified how seeing their patients’ responses affected them as caregivers. The impact of music therapy on the patient and then on them, as caregivers, brought a sense of memorable joy to each of them. These feelings seemed to assist them in preparing for the eventual death of their loved ones in that they knew the patients had moments of joy and peace before dying. Empathetic joy, then, seemed to help sustain them through the death and during bereavement.

Empowerment

“I feel happy that I was able to help and give something to my loved one.” A second sustaining theme that prevailed as the caregivers reflected on their memories of music therapy is the theme of empowerment. The caregivers
conveyed the relief that they felt in being able, in some way, to relieve the

distress their loved one was experiencing. A collection of their voices follows:

I was able to give pleasure of music
Through you, I could.
I was able to give back to her
The way she gave to me for so long.
It was hard to see him in pain,
Moving around.
Our singing
It brought him peace.
I could smile again.

Suffering is difficult for caregivers to witness. Flora articulated the
sense of suffering she felt very poignantly: “The pain is to see the person
decline and lose the best. The real pain is to see the person losing his
personality, losing the best aspect of his personality. It is very painful.” The
sense of loss and the lack of knowing if, how and in what ways to offer
assistance, can exacerbate caregivers. Feelings of helplessness are common in
those caring for loved ones facing end-of-life. Literature is replete with articles
and studies that refer to the common tendency to feel helpless in the site of
witnessing a loved one’s demise.

Suffering refers to a perceived threat to the integrity of the self (Cassell,
1991). There are often feelings of helplessness in the face of that threat and
exhaustion of psychosocial and personal resources for coping (Chapman &
Gavin, 1993). Palliative care specialists work towards addressing suffering by
treating symptoms of pain as well as promoting psychosocial well-being.
Patients and caregivers alike experience symptoms of suffering due to loss of
control, the perceived threat to existence and the ensuing feelings of helplessness and hopelessness.

Empowerment as a way to reduce sense of helplessness is one of the primary psychosocial goals in Palliative Medicine (Mok, Chan, Chan & Yeung, 2002; Wilkes, White & O’Riordan, 2000). Music therapy has been recognized as being an intervention that can help enhance sense of control and reduce sense of helplessness. In this study, the theme of empowerment emerged throughout the interviews in various ways and was one of the sustaining themes that seemed to signify the inner gratification they felt as a result of their roles in providing for the benefits of music therapy.

Miranda spoke about her satisfaction of being able to provide, through the service of music therapy, meaningful care to her aunt before she died. She stated:

She [Jacqueline] was lingering in a state of no hope, no connection to this world. She wanted to move on. So when you [Lucanne] came it was towards the end. At first she didn’t want any company. She was very private...we had hired nursing assistants and attendants and she wanted to fire them all. But I convinced her..."how about listening to some music?" because she did like music. So I noticed that particular day, even though she was resisting prior to your coming, after you left, she was at more peace, she felt calmer. There was this sense of joy....with the music therapy she definitely felt peaceful. That was a good sign for me because we could just let her go peacefully...and I think she was resolved then that everything was okay.

For Miranda, knowing that she had “convinced” her aunt to have the music therapy brought her much satisfaction. She spoke of the positive effects of music therapy and referred to the significance of the changes she witnessed.
Two times in our interview, Miranda referred to the fact that her aunt thanked her for the music therapy. Miranda continued…

I realize that on that particular day [referring to my last visit with patient], she had less pain medication. She didn’t need it as much as she would have, and I think she slept more which was good. That was a significant thing for me. And she actually thanked me for getting the music therapist. She was not a thank you person… and… I was nervous because I thought she was going to die that day. And I think it [the music] gave her more energy, more strength to live a few more days. Because she died that week. And for me it brought me a sense of peace that I did bring her something. She really did thank me for arranging the music therapy. She appreciated it. In fact it gave her more strength. She ate some of the soup. I couldn’t get her to eat and drink, and after that she ate and drank. She herself felt calmer and more peaceful, and wasn’t focused on dying, but was focusing on being in the moment.

Miranda referred to this pleasure that she experienced as a result of knowing that she had played a significant role in providing a source of peace and pleasure for her aunt, i.e., “I did bring her something.” As she stated, the fact that she was able to care for her aunt, assuring that she ate, slept and was in comfort, was important. Miranda is a nurse, thus this ability to provide comfort and peace meant a great deal to her, as she had, prior to me coming, felt helpless in attempting to assuage her aunt’s sense of hopelessness.

Dahlia also reported similar sentiments:

It was very little things. There were very little things for Mrs. S. to not even be able to eat a good steak, not even cooking something that she likes; very little pleasures that she was having. But to see her smiling and transported, to when she was listening to music and when she was singing…. We had very little to offer her, pleasures that she can have… There was not too many things that we could offer her. And one of the best, the best, the best things she had was the music around her.
Dahlia relayed her thoughts regarding her gratitude for being able to provide Mrs. S. the pleasure of music. This feeling of gratitude in being able to bring relief to distress is common with caregivers, as there is often very little that they feel they can do to help their loved ones as they approach death.

Mary also conveyed thoughts regarding this theme:

This was the music that we sang... these songs were the songs that we could sing, ages eight and eighteen, and this was the same music we sat down with and did together [in music therapy] were the songs that we sang. So it was really nice and beautiful... and maybe we can think too that she gave me this music and I gave her the pleasure of music through you... I gave it back to her.

Mary reflected on the cyclical nature of giving and receiving in life. She referred to her memories of communal time spent in music with her family.

She was pleased to be able to give the “pleasure of music” back to her mother. She also was pleased at her own hard work and perseverance in advocating for services for her mother prior to hospice, and stated near the end of our interview:

I am very grateful because... it [the music therapy and hospice care] was special, the kind of things she would really value... she was comfortable, she had pleasure until the end.

Toni also experienced this sense of empowerment as she reflected on her experiences with Randy in the music therapy:

The creativity, the singing of harmonies. I was able to do something for him and bring him some beauty. He loved music, as you know, it was a part of his life.
While Flora did not relate these sentiments directly in our interview, she did refer to the meaning of the sessions and her being able to sing to Mark, "He had a richer life because of the music... [and]... these were the happiest moments...[and]... these were our happiest memories of all." I recalled my impressions of Flora that I held deeply in my mind, that is, the memories of seeing her standing next to Mark in our lengthy sessions. I saw and heard a dignified strength in her in our sessions as she sang, song after song. The following is an excerpt from my post-interview journal entry:

Flora always joined in singing immediately and then would initiate songs too. She actively contributed in the sessions, sometimes taking the lead. The look of joy and strength that I remember so clearly on her face as she sang song after song, guiding Mark to join us - the same strength I witnessed tonight as she sat across from me in her Mexican skirt and flowered blouse. This wise woman brings much joy around the world to others, and speaks so graciously about her gratitude for the music therapy sessions and the joy she knew it brought to Mark. I am honored to be a part of Mark and Flora's life's journey.

Perhaps for Flora words could not or did not need to convey this feeling of empowerment, as it is already such a significant part of her life. Her life's work is to help women become empowered to care for themselves. From my point of view, as a witness to the music therapy sessions as well, I did observe Flora finding relief in being able to bring the joy of music to her dying husband. In some 'beyond words' kind of way, she did feel to be a contributor to the joy that was brought to Mark through the music.

Abe, as well, did not directly articulate this in his interview. He had been a hospice volunteer when he originally met Patty. He was a Buddhist and
believed in service work and, as per him in other conversations, derived a great
deal of personal meaning in serving others and in helping others find inner
peace. On many occasions as we left Patty’s bedside, he would say to me “She
is better now. I am glad I could come today and bring her the music that I sang
with you. She always likes for me to read her the ‘Good Book’.” The
following is an excerpt from my post-interview log:

Today, as I sat across from Abe in the open Starbuck’s outdoor patio in
the East Village, as the chatting early Friday evening crowds strolled
by, I was struck by the softness in his brown eyes and the tears that
were rolling down his cheeks as he recalled Patty’s last days as she was
dying in the inpatient hospice unit. He recalled those moments so
vividly...the moments when she heard him sing her favorite song,
“Danny Boy,” and she turned her head to look at him. Those moments
seemed to be very special to him, as he had tears and smiles as he
talked about those moments. He said that he knew that his being there
was felt by Patty... “she heard me, she heard me alright.” I was taken
by his inner strength as I sat in front of him. His life has been a
challenge, one that he has faced with a sense of openness and
compassion for others as well as for himself.

As with Flora, I witnessed in Abe an underlying satisfaction that he felt as a
result of participating in the provision of music for his friend, Patty. He
articulated knowing that he helped her find a greater sense of peace in his
reading the Bible and singing “Danny Boy” to her as she was dying. It seemed
clear to me, as an observer of him, that he also experienced empowerment in
knowing he had ways of assisting her through her illness and dying.

Each of these caregivers found comfort and fulfillment in knowing that
they had contributed in bringing care and pleasure to their loved ones before
they died. These experiences seemed to be helping them cope during the end-
of-life and during the bereavement. The feelings of empowerment that they attained in, and as a result of, music therapy helped reduce their own sense of helplessness and helped them feel prepared, as Miranda stated, to let them “go in peace.”

Summary

The caregivers’ reflections on their times in music therapy indicated the happiness, comfort and relief they experienced as they heard the music and as they observed the positive effects of the sessions on their loved ones. These psycho emotional responses recurred throughout the data. At times, the caregivers found the music directly influencing their own emotions in ways that led them to feel pleasure and contentment, characterizing autonomous joy. Other times, their feelings of joy were based specifically on the patients’ feelings, as described in the data concerning empathetic joy. There was this general trend throughout the data towards the enhancement of their emotions, as they described their feelings of happiness and joy. There was also the trend towards the acquisition of feelings of empowerment, as the caregivers described the relief they found in being able to actively help their loved ones find happiness, peace and relaxation. Joy and empowerment were sustaining themes, as these were qualities that assisted the caregivers in feeling strengthened and uplifted as they progressed through the illness and into bereavement. These themes extend beyond the parameters of “spirituality” in
that they describe broader psycho emotional responses and convey the importance of music therapy sessions in helping caregivers experience comfort during times of loss.
CHAPTER VI
THE CAREGIVERS' REFLECTIONS: CONNECTEDNESS, REMEMBRANCE AND HOPE

Introduction

Spirituality is a broad concept and has been defined by many authors. A thorough review of these definitions exists in Chapter II. It is helpful at this point to think again about the meaning of spirituality as we endeavor to explore the interview transcriptions. According to Pulchalski (2002), "spirituality is concerned with a transcendent or existential way to live one's life at a deeper level" (p.799). In addition, Highfield (1992) states:

the spiritual dimension of persons can be uniquely defined as the human capacity to transcend self, which is phenomenologically reflected in three basic spiritual needs: (a) the need for self-acceptance; a trusting relationship with self based on a sense of meaning and purpose in life; (b) the need for relationship with others and/or a supreme other (e.g., God) characterized by non-conditional love, trust and forgiveness; and (c) the need for hope, which is the need to imagine and participate in the enhancement of a positive future. All persons experience these spiritual needs, whether or not they are part of a formal religious organization. (p. 3)

In another study, Chao et al. (2002) found the essence of spirituality to be centered in the importance of relationships. They found four constitutive patterns, including (1) communion with self (e.g., self-identity, wholeness and inner peace); (2) communion with others (e.g., love and reconciliation); (3)
communion with nature (e.g., inspiration and creativity); and (4) communion with Higher Being (e.g., faithfulness, hope and gratitude). Spirituality then is a quality that goes beyond religion and is the human striving for inspiration, purpose, harmony and existential meaning. It also pertains to relationship or one’s sense of connectedness with self, others and the infinite.

In my review of the interview transcriptions and my journal entries, I found emergent themes conveying aspects of spirituality. This chapter focuses on these spiritual themes as conveyed through the caregivers’ reflections on their experiences in music therapy. As I reviewed the data and coded, sorted and found patterns and trends in the themes that were surfacing, I sorted them according to the processes of reflection that were unanimously occurring, i.e. the specific reflections on the present, the past and the future. From there I was able to group the themes and found these larger thematic bins:

Reflection on the Present: Connectedness
Reflection on the Past: Remembrance
Reflection on the future: Hope

A larger spiritual theme, that is, transcendence, seemed to be an overarching theme present throughout the interviews and within each of these processes of reflection. Transcendence was occurring throughout the interviews, assisting the caregivers in experiencing a greater sense of connectedness, life purpose and sense of hope. A deeper exploration on this topic occurs in Chapter VIII. In the following I will review the transcript citations as they elucidate the spiritual themes that emerged.
The particular processes of reflection, that is, naturally emerging areas of concentration, that they commonly focused on during the interviews were: a reflection on the present, including the meanings of their 'in the moment' experiences as they observed the patient in music therapy; a reflection on their lives in the past, with and/or without the patient; and a reflection on the future. These processes of reflection seemed to guide them into understanding the gestalt of their lives and were processes that had been inspired by the music therapy sessions. In the following, I review transcription excerpts that portray each of these three themes: connectedness, remembrance and hope.

Connectedness

"In these moments, I found connection with my loved one and the greater scheme of things." Caregivers referred to the theme of connectedness throughout the interviews. As described in Chapter II, connectedness in palliative care is understood as a process that reflects a concern with one's sense of relationship with life. It is considered a process that involves spirituality in that it pertains to the search for a holistic view of one's role in life in relation to self, others and the infinite. People coping with the ending of life tend to seek to gain a completion of the circle of their lives, from past to present and towards the future.

The caregivers repeatedly focused on connectedness in their interviews. The caregivers’ comments indicated an interest in being in touch with
themselves, with who they are as individuals in the larger schema of their lives, as well as an interest in the patients’ connections with self in sessions. They also focused on their own sense of connectedness with the patients, as they referred to the deeper communion they were able to experience with them in sessions. In addition, the caregivers referred to a sense of connectedness with a supreme dimension, or the beyond, the dimension that exists in relation to the infinite, as seen for example, in references to God, angels and previously deceased loved ones. These three sub-themes emerged, then, as: connectedness with self (self of patient and self of caregiver); connectedness with others; and connectedness with the beyond.

**Connectedness with Self**

Caregivers reflected on the connectedness with self in two ways: patient-self and caregiver-self. Self of patient refers to their thoughts pertaining to observing the patients coming “back to life” and having a “renewal of self”. Self of caregiver refers to their thoughts regarding their own sense of being in communion with who they, as caregivers, are as individual persons in life. In the following, I shall describe each of these areas of Connectedness with Self as depicted by the caregivers.

1. **Self of patient.** The caregivers seemed moved and intrigued by the power of music in sessions to help restore the patient’s connection to his or herself. Often this meant seeing glimpses of the patients’ attributes and
strengths once again. In this study, the caregivers referred to two aspects of this theme: the patients are brought “back to life” and have a “renewal of self.”

2. Back to life. The voices of the caregivers, spoken through faces and eyes filled with passion, described the meaning of their experiences in music therapy. In their reflections, they referred to the significance of seeing their loved one coming “back to life.” This was a striking theme that appeared numerous times as I reviewed the transcripts. As I looked across interviews, I heard the words that conveyed this message and have in the following united some of the comments together in the format of a poem:

    My loved one is going to another place
    Where is this person I once knew so well?
    As I sit here during the day
    His eyes are closed...no words.
    She is somewhere else, slipping, far away
    The music enters and I sit and watch
    He opens his eyes and closes his mouth
    There is laughter, once again
    In his eyes and in his voice
    We sing and dance
    He comes back to life
    He is not half dead anymore
    Now I can remember him as a living person.

Several caregivers referred to this feature of the music therapy sessions. Flora described her experiences as she watched Mark respond to the music. For her, this aspect of the music that helped “bring her husband back to life” played a key role in helping her be in touch with him again and in touch with the essence of who Mark was to her and others throughout his whole life. She explained:
Well, I would say, in the beginning it was a great surprise and pleasure when the first time you came and he was kind of comatose; he was with his eyes closed and he was not speaking, and you started playing and his lips start moving and then he starts singing, with a very soft voice, but he became alive again, and before he was not communicating with anyone, and more and more than in the other days, his voice was much stronger and he was obviously enjoying it tremendously, which as an incredible surprise because he was very passive and kind of like in a coma, detached with no response. So this was the first great impression, seeing someone who comes back to life.

For Flora, seeing Mark “come back to life” was significant. As is common with caregivers of end-of-life patients, seeing a loved one decline and lose the ‘livingness’ that was an essential part of who he was can be very difficult. In the interview, Flora sometimes wept as she recalled this ‘awakening’ that Mark experienced in the sessions. She referred often to her feelings of “surprise” and “pleasure” in witnessing these responses. Flora also explained:

He was remembering more of his life, because his life...he liked to sing “Goody, Goody” and others. I never heard them before and knowing that they were coming after fifty years of just being inside him and noticing he was also left more alive after singing and was not falling into his coma; he was awakened. The effect was lasting also. The daughters and I were all very happy about this.

Flora, then, found meaning in seeing qualities of Mark arise again in sessions. This “awakening” was inspiring Flora to review Mark’s life and regain an understanding of his life as a whole as she saw him in touch with times from “fifty years” ago.

Ruth also referred to the significance of this aspect of the music therapy sessions. For her, seeing her husband ‘come alive’ after being quiet and listless
for hours on end was a surprise and brought meaning to her. She referred to this aspect several times in the interview. She explains:

Because of the music, I don’t think of him as a dead man. Ordinarily, if you didn’t come that hour, he would sit like this (she closes eyes and opens mouth). He was nothing like that when you came. You never saw that. He was very alert when you came. His eyes would open up. The music was registering in him, the music. When you came with the music, his eyes opened and he moved his body. When you came in with the music it alerted him to be alive.

As with Flora, seeing her husband “not as a dead man” was important to her. She was able to “see” his alertness and aliveness again and was able to watch him enjoy himself again. She also explains:

It [the times in music therapy] put him on a different track. When you came, he opened his eyes, which were usually like this. He stopped opening his mouth. He closed his mouth. We found him humming. And the songs were so old that he knew the words and would sing. It was important. And as soon as you went, I put the music on and we danced.

Ruth had expressions of happiness on her face during the interview as she recalled these times. In the post interview journal entry, I wrote:

As I sat across from Ruth, I found myself wanting to get up and dance. As she talked about her husband dancing with her after the music therapy sessions, she swung around the living room briefly and also tapped her feet as she sat on her big white couch in her living room that overlooked a major performing arts center. She talked excitedly, seeming very eager to share with others, with me, this remarkable shift in Joe that she had witnessed, the shift that helped her dance again with him. The soft smile lines across her face moved vibrantly as she laughed, recalling her moments with him during his last months.

Ruth also explained:

He was half dead. But spiritually....that’s what it is. You bring out the spirit in him with the music. There is not a man or woman alive that doesn’t have the music in them. She remembers the music from when
she was seventeen. She may not remember what she ate yesterday, but she can remember the music. Everyone can relate to the music.

Again, she refers to this aspect that meant a great deal to her, that is, that with the help of the music, she was able to see him not half dead or dead, but *alive* again. For many caregivers, feelings of loss are exacerbated by the diminished sense of presence in their loved ones. These moments in music therapy helped Ruth be in touch with Joe in ways that seemed to be helping her gain a life-long view of their long relationship.

Ruth Bright (1988) has written about the caregivers’ experiences as they are with a loved one who has become withdrawn due to the illness. She states: “for many families it is only through music that they see a restoration of the person they once knew...It is the change from an active involved person to an apathetic one, that families find most distressing, so that to provide an environment in which the personality...is restored, even if only for a few minutes, is a source of joy to the family” (pp. 53-54).

Music therapy has a unique way of ‘rekindling’ the spark of life within the patient, as witnessed by Flora and Ruth. As described by them, these moments can bring pleasure and joy, as well as a deepened sense of meaning in that they are given opportunities to review life in the context of their long-term relationships.

Mary explained her view of this aspect in the music therapy, that is, this tendency to bring a person *back to life*. She described her experience the day before her mother died during my last session with them:
When my nieces were there on the second day and my mother was fairly withdrawn at that point, we were giving her morphine when my younger niece came, she hadn’t really had the chance to have an exchange with my mother. And while I had a hesititation about kind of bringing my mother back, I wanted to let her go; when you came and played, she came back to us enough. It didn’t seem disruptive to her leaving. It was a very gentle kind of coming back. I feel she was only back on this level of music, was aware that the younger granddaughter was present, but she didn’t have to completely wake up and come back to full living.

Mary also experienced the music bringing the patient gently back from a place of being “fairly withdrawn” to a place of being present with her granddaughters and daughter. For her, this was an aspect of music therapy that brought her a sense of satisfaction in that she was able to continue to let her mother “go” while also provide for the moments of presence with her teenage niece who had arrived that morning. In the interview, Mary referred to these moments as being an important aspect of her time in music therapy, providing for meaningful connections with her mother who was in the process of transitioning from life to death.

For these participants, this “back to life” quality of our time together in music therapy stood out as being one of the most memorable times during their loved ones’ end-of-life journey. They were able to have their loved ones present, living until the end. These moments brought them each a great deal of meaning in that they could access the ‘living’ essence of their loved ones and could gain a holistic perspective of their lives. This aspect of our time together also seemed to help them each prepare for the death and brought them memories of faces, eyes and voices filled with smiles, laughter and songs.
3. Renewal of self. Across the interviews, the caregivers commented on their observations of seeing their loved one display personal traits in music therapy sessions that had been otherwise absent during the illness. This theme of seeing the patient’s reconnection with self as a renewal of self recurred throughout interviews. According to several caregivers, the patients found a sense of connectedness with themselves again in music therapy. This connectedness helped restore a sense of wholeness within the patient as observed by the caregivers. The implications of this trend in sessions is significant, as the caregivers were given opportunities to re-view the patients’ attributes and gain a deeper understanding of the overall purpose of the patients’ lives. In the following, I share a collection of their voices:

The pain is seeing him lose who he was
In the music, he had the sparkle and laughter in his eyes
Once more.
She wanted to move, sing and smile.
We could see her person
Once again,
This is how she really is.

The caregivers noted these significant moments as they reflected on times in music therapy. Miranda offered her thoughts regarding her Aunt Jacqueline’s renewal of self. She states:

She did like to have conversations and like to chat. And then she became so quiet and withdrawn, and then having the music therapy, she did chat more…so with the music, she would chat more and that was nice. This brought me a sense of peace.
Miranda, then, noted that the music seemed to reach Jacqueline and aided her in accessing her personality and activities that she likes, such as ‘chatting.’ She continues:

She worked all her life. She was an immigrant. She was Scottish; she came through Canada to the United States. Plus she was single, she went out a lot. She liked going to parties. She liked to go out a lot. She traveled a lot. She and her husband traveled all over Europe, all over Florida. They were always entertaining themselves. So I think the music brought back what she enjoyed. She wasn’t a TV person and she wasn’t a reader. The music brought some joy and peace to her at the end of her life.

Miranda also stated, in referring to the minutes and hours following music therapy sessions, “She was with me, we were joking; she was talking about Johnny, talking about her husband.” In these moments, Miranda saw Jacqueline come back to an aspect of herself, that is, her interest in talking to people. Jacqueline, according to Miranda, had been a socially active woman. Her emotional withdrawal was difficult for Miranda and her husband as they felt at a loss as to how to reach and help their aunt. Miranda believed this quality of the time in music therapy helped restore Jacqueline’s sense of connectedness with herself in a way that could help her have some joy and peace at the end of her life. This was meaningful to Miranda in that she was again able to ‘be with’ her aunt in familiar ways and gain a view of Jacqueline’s life in totality.

Mary also shared these thoughts in reflecting on music therapy and its effect on her mother.
I think the first time was fun and nostalgic, and from a therapeutic perspective in my world, it gave my mother an opportunity to be confident. Because none of us could remember all of the lyrics, but this was something she knew, and she could do it. She couldn’t walk but she could sing, and she could enjoy and appreciate... it allowed her to be confident. . . . [the music was helping her and me] be normal. It gave us the chance to be the way we are.

Mary recalled this aspect of the music therapy experiences, that is, that they had a normalizing effect on them as a family and also that the sessions helped renew a quality of her mother’s sense of confidence. For Mary, this was significant. She wanted her mother to have an honorable death with grace and dignity. She stated:

It [the music therapy] made the transition easier, smoother, from life to death... a way that she wanted to do it. I could say with dignity... she went gracefully. My mother wanted this and I wanted it for her.

Mary found this aspect of music therapy to be important. As she saw her mother having moments of confidence and “dignity” again, Mary was comforted in knowing that her mother had accessed some of her inner attributes and had a “graceful” death. These aspects of connectedness with self go beyond constructs of ‘self identity,’ as the dying patients and their caregivers experience connectedness to the patients’ overall essence of who they are as people and the purposes of their lives.

Flora referred to her surprise and admiration in seeing her husband exhibit some of his personality again. She stated:

the other surprise was the fact that before he seemed to be very feeble and weak, so he couldn’t do something, he couldn’t read the newspaper for more than ten minutes, but singing, he could go on for one hour, without getting tired, remembering all the words, and obviously
enjoying it, . . . because he was going back to being himself, like, when he was singing “What a friend we have in Jesus”, which was typical when he was happy, and so, so I was happy too, because I saw something of him that I thought had disappeared completely. . . . The pain is to see a person decline and lose the best. The music, he, Mark, is still at his best. It was the only time in which I could think of him as he was before.

Seeing Mark regain his sense of self in the music was deeply satisfying and meaningful for Flora. Her words and facial expressions indicated a sense of deep pleasure in having those moments seeing him again as he ‘came back to himself’ in the music. Flora was able to be see and hear Mark again, a process that assisted her in reflecting on his attributes and qualities as a person.

Ruth had similar thoughts. She stated:

His mouth was closed and he was humming and he had laughter in his eyes. You know he did...he had laughter in his eyes. He was always smiling, always smiling. He was a wonderful man. . . . When you came it was such a relief for him. It was an access out of his own mind. It was so good, I can’t tell you.

Ruth again referred to the renewal of Joe’s sense of self here:

[Regarding music therapy]... He was very alert when you came. His eyes would open up. The music was registering in him, the music...there is something still alert in them. But when you came with the music and his eyes opened and he moved his body. . . . You walk in and you are like a psychiatrist. Joe’s eyes, I see him sit there in that chair over there. You could see, even if he didn’t talk, you could see his eyes were alert, his eyes were open, not like this (closes eyes).

For Ruth, then, there was a frequent referral to Joe’s coming back to aspects of himself, connecting with his personal qualities again. This renewal of self that she observed in Joe played an important role in helping her appraise the value of their lives together, as she heard him sing and watched him interact again.
Dahlia referred to the renewal of Mrs. S in this way:

But to see her smiling and, transported, to when she was listening to music and when she was singing. Did you see that face, when she was singing?

Dahlia also stated an interesting view of this aspect of music therapy. She referred to the tendency of music to “transport” and “bring to another world.” She states, “It [the music] really does a lot, it really does a lot to a person. We listened to Mrs. S. She was really, like in another world. She was like...she forgot everything, how she felt.” For Dahlia, this being in ‘another world’ meant forgetting problems and experiencing attributes of oneself again. Later in the interview, for example, she again explained this attribute of music in relation to herself, “You don’t remember about anything. It really wipes all the problems from your head and you are just enjoying the moment.” For Dahlia, then, music therapy helped Mrs. S. ‘forget her problems’ and come back to herself. This meant a great deal to Dahlia as she was able to see Mrs. S. transcending her own circumstances and being in ‘the moment’ with her loved ones.

Each of these caregivers witnessed the music reaching their loved ones and bringing them back to a place of connectedness. The patient-self connection gave the caregivers opportunities to see, touch and commune with their loved ones in ways they had not yet experienced at this stage of illness, leaving them with memories of humanness in the midst of deterioration and decline.
4. Self of caregiver: The caregiver’s connectedness with self. The caregivers made references to their own personal connections with themselves within the content of the interviews. These ‘Self of Caregiver’ connections were important to the caregivers, as they were able to perceive their own inner strengths and attributes and gain an enhanced sense of meaning as they reflected on the larger themes and roles in their own lives. Flora referred to her work in her foundation. She states:

I have seen the effect of the music in my work on the foundation. I was in a village that I went to and the effect was on the children that I saw. Flora shifted the focus of the interview away from her times with Mark to her individual times in South America helping indigenous women and children there. While she did not make direct reference to herself, she made a symbolic reference to herself in describing experiences she had on her own. This shift of focus in the interview seemed to signify a ‘coming back’ to self again, reconnecting to her sense of self and her life experiences that bring her great fulfillment.

Flora also referred to her own responses to music. She goes on to say:

So the music always affects me, especially when the voice is involved. So, by itself, the pleasure of singing. It was very rare that I would sing to someone, and I knew all those folk songs, before even Mark, and it as not something I was singing usually, but, so music affects me very much.

Here, Flora refers to a self-connection in music that extends beyond her times with Mark. She also refers to her appreciation for vocal music and singing. As per Flora, singing had been a life-long aspiration of hers. Flora was able to
attain connection to self through this self-driven love for music. She adds these thoughts, “I hear more music now. There are times when I wake up in the night with a song in my head. If I want to relax I put on music.” Throughout Flora’s interview, then, there was reference to her own sense of connection with aspects of herself, a connection that provided her with moments of life review and affirmation.

Toni also shared thoughts regarding her own connection with self. She states:

[in thinking about music and spirituality] [I am] close to my feelings, close to my emotions as in being in a totally a relaxed situation; the music brought me to this place, as I was relaxed too. . . . What I realize too is that it [the times in the music] almost took the best out of us in a way which was very important for each of us.

Toni describes the aspect of feeling “close to her emotions.” She found that the music “brought the best” out of her and helped her feel relaxed within herself. This aspect of connection with self is sometimes difficult for caregivers to identify, as they are often very immersed in the patient’s state of being. Thus, as we heard in Flora and Toni’s comments, the music was affecting the caregivers in ways that enhanced their own sense of self-awareness, providing for moments of gratification and rejuvenation.

Abe recalled his experiences in Patty’s Memorial Service in which he found spiritual refreshment for himself. He stated:

It was so beautiful, so beautiful. That whole service by the Priest. He is talking and I am going “Yes...yes...yes...yes”. I was like the old Jew how they dove...like this (Abe bows). That is how I meditate... “yes...yes...yes...” . . . And he [the Priest] went up, gave the Holy
Communion. At first he invited all the family members. Then he said even if you’re not Catholic but you believe... (Abe cries), so I went up... to Holy Communion. Oh it was so beautiful, so wonderful.

These reflections were important to Abe as he had not had Holy Communion ever before in his life. These thoughts signified a sense of connection with self beyond his experiences with Patty. He referred to his own practices of meditation as well as the special meaning of being able to partake in Holy Communion. These were moments of self-connection in Abe.

Miranda also referred to herself in the interview. Her comments were centered on what it was like for her to see her aunt respond favorably to the music. She states:

She herself felt calmer and more peaceful and wasn’t focusing on dying, but was focusing on being in the moment. She was with me, we were joking, she was talking about Johnny, talking about her husband. So, she enjoyed talking and that brought me a sense of calm and peace as well.

Miranda felt a sense of connection with herself as she realized and articulated her own personal experiences as caregiver witnessing her aunt in music therapy, and the positive effects that the sessions were having on them both.

Ruth, on the other hand, related fragments of thoughts and stories that centered on her own personal experiences in her life with people and music.

Through these reflections, she identified connection with self. She states:

We all feel the connection... I love the music.... And so that’s what it is. The music is wonderful... There is laughter with the music, we need the laughter... I remember when I was young, sitting on the floor in the living room listening to Perry Como with our big radios. The music brought love back... I felt that love... when I heard the music with you here.
The caregivers in this study focused on their own sense of connection with themselves. As we heard in their comments, they did this by focusing on aspects of themselves as individuals apart from their relationship with the patient. This shift towards connection with self may be seen as a healthy coping mechanism; that during times of loss, one can muster enough inner strength to be able to 'carry-on' with themselves as individuals. The music therapy seems to have contributed to this through opportunities to reminisce and identify times of meaning, as they each recalled memories centering around music in their lives; for example as Ruth did in remembering sitting on the floor as a child listening to Perry Como records and Flora did in referring to her love for folk songs. This process plays an important role in facilitating acquisition of sense of meaning and purpose in the lives of caregivers as well as in patients.

**Connectedness with Others**

Patients facing end-of-life and their loved ones yearn for sense of connectedness with one another and others. There is a common tendency among family members, facing the death of a loved one, to desire to be in contact and communication with each other. At times the illness prevails, and relatedness is difficult. Music therapy literature refers to the benefits of music therapy to help retrieve and revive communication between patients and loved ones (Gardner, 1999; Hanser, 1985). Restoration of meaningful
communication prior to death can assuage feelings of guilt and remorse and can allow for opportunities for relationship completion and preparation for death, processes that play an important role in the attainment of resolution and sense of life fulfillment.

Connectedness with others was a significant theme in this study. The participants made references to this theme throughout and across interviews, most commonly in referring to their sense of connection with the patient in and around music. This theme also emerged around the topic of communication.

When you came and sang,
He opened his eyes
And we danced
In the music
We were together again
And doing something together,
Again.

Ruth made several references to experiencing sense of connectedness with others. In the following transcript, she talks about her feelings of connection with Joe and with her three-year old granddaughter. She also refers to making a connection with me in sessions. She states:

[Reflecting on the sessions] Yes...because I saw him...through his eyes, that he was contented. He was enjoying it. You know when you enjoy something. The baby knows what crying is and when you cry this means you are sad. So, one day [here Ruth begins to talk about her granddaughter] I bought her a beautiful pink umbrella and I said to her, "Let's open our umbrellas and we'll pretend that we are out in the rain and we'll sing "we're singing in the rain" (Ruth sings some) and she was doing it so cute and I started to cry. And she said, "Gramma, aren't we having fun. Why are you crying?" And I said, "Yes...there are tears and sometimes there are happy tears" and went on to tell her what happy tears are and she would see me crying over her and she would ask "are those happy tears?" and I said "I love you so much" to her and
she was happy and singing (Ruth sings “Singing in the Rain”). So you see... this is what happens when you make a connection. When someone like you comes in. You are a therapist. You come in and you have to be the first connection. He has to be happy to see you. He made connections. And so did I...You made it easy.

Ruth made clear, direct references to her interest in connection. She found this aspect of music therapy to be very important. Through the music, she felt a connection with Joe, her granddaughter and with her family members, explaining that “everyone can relate to the music...we all feel the connection.”

She also referred to her moments of dancing with Joe immediately after I departed, since during the sessions she preferred for us to sit together so he could sing. She recalls:

When you came, he opened his eyes which were usually like this... He closed his mouth. We found him humming. And the songs were so old that he knew the words and he would sing. It was important. And as soon as you went, I put on the music and we danced.

Toni also referred to a sense of connectedness with Randy. She relates this experience:

And also it is nice for the people around the patient...to do together and be together...that is what I feel very strongly too...you played music that we both liked. I felt more connected to him. It was a bond between us, for him and for me, the people who are so close. So it worked on both sides. It helped him and me too. I felt this bond.

Mary also found that she felt a connection with her mother as a result of the music therapy. She states this:

Although there were songs on the first day that were in the book...for me it was fun and it is something that has me very connected to my mother about, considering that I was raised on the...Army marching songs.
Mary and her family had spent a great deal of time singing together when she was a child. She felt connected to her mother in the singing and also in bringing familiar songs to her mother. Mary also referred to feeling a sense of connection with her mother during bereavement. She relates this here:

When my father died, she [mother] used to think that she saw him on the street. Today, I was walking on the street, I saw this woman who had hair the exact way my mother’s hair was. I immediately thought of and felt my mom and said: “It is because Lucanne is coming here today.”

The sense of connection Mary maintained with her mother throughout her life plays an important role in Mary’s life. The sense of connectedness she experienced in music therapy helped Mary look back over their lives together and added meaning to their moments as she was dying.

Flora experienced a sense of connection with Mark during times in music therapy and reflected on this in our interview. She stated:

But singing, he could go on for one hour, without getting tired, remembering all the words, and obviously enjoying it, and also, a really positive thing that finally we were able to share something with him, that we could sing with him, do something along with him. Before we were doing something but he was very passive and he was not responding. For the first time in a way we were doing together something with him.

Flora described her connection with Mark in the music. In this case, she was able to do something with him. She goes on to say:

This was a special occasion in which music had a different meaning, which was not, you know, when you hear music, you are alone, you are by your self, you are alone, you are in a concert, there are a thousand people around, but you alone with the music. In this case, I was with him, which is...much more important.
Flora depicted her experiences in music, clearly portraying the uniqueness of this situation, that is, the importance of being with Mark in the music, being in connection with him. For her, the context of this experience was important, i.e. that in music, and only in music, they could be together in emotions, memories and in interactions. She adds:

This was the only way of communication and activity doing something together. In the music, we were doing something together, which was a better level also involving feelings and all these memories that he had.

Abe also referred to sense of connectedness with Patty. He relates events surrounding her death in the In-Patient hospice unit:

And they admitted her. I went to sit by her and she turned her head to look at me as I sang “Danny Boy” . . . And she was so happy. And when she was in the hospital, I came in and I was holding her hand and she turned her head and opened her eyes and we had our beautiful, beautiful time together with the “Danny Boy, oh Danny Boy.”

Abe experienced connectedness with Patty as he sat next to her singing her favorite song, the song that Patty sang during every music therapy session. He also referred to the nature of the music. He stated that Patty’s music helped him to feel the connection with her. He states this in reference to his thoughts about his witnessing music therapy:

For me it was to make the connection with her. It was her music. For me, it was to help me make that connection with her in her music.

Dahlia referred to her sense of connection with Mrs. S. as she attempted to sing her favorite song as she was dying:

Her breathing and it wasn’t that great and it was changing and I was a little tired but I got near her bed and I started to sing “Wind beneath my wings” and I couldn’t follow. I couldn’t . . . I started and I couldn’t . . . I
couldn’t do it, but I tried. And since then I sit down and I start praying, and praying, and praying, praying until she went.

For Dahlia, the music was a strong mode of connection with Mrs. S, as this was Mrs. S.’s favorite song and the song that we all sang during every music therapy session together. She found it difficult to sing that day due to the intensity of the connection.

Each of the caregivers experienced a sense of connectedness with their loved ones. This connection was experienced in the music, as with Flora, Maddy, Toni, Abe and Dahlia. The sense of connection was experienced around the music, as with Ruth and Miranda when they communicated with their loved ones after the sessions had ended by dancing or talking together. This sense of connection with others played an important role for these participants. They all reflected on the moments inspired by music when they had the ‘connection,’ the ‘bond’ and were ‘with’ the patient again in meaningful communication. A few caregivers referred to the significance of being able to ‘do something with’ the patient again. The connectedness that the caregivers experienced with the patients seemed to play a role in helping them find completion as they reviewed the meaning and significance of their relationships. As shared by the participants, the memories surrounding these moments of connection with their loved ones seemed to be some of the most memorable highlights of the times they recalled spending in music therapy and was a salient feature in the data.


Connectedness with the Beyond

When faced with end-of-life, it is common for people to turn to a relationship with that which exists beyond the human being. Aldridge (2000) states: “this reality is said to be beyond the senses, the physical world being only one perceptive reality that is available to us” (p.36). When facing the end-of-life, this construct, i.e., the sense of awareness of a dimension that relates to infinity and the beyond, can be a source of support and can sometimes provide answers to difficult-to-answer questions. People often refer to having a sense of faith, or using prayer, meditation and time with nature to regain an understanding about the dilemma of their suffering, their feelings of sorrow, fear and distress.

In this study, the participants indicated having a sense of connection with the beyond. They referred to this in several ways and using various terms. Throughout the references, however, there is an indication of focusing on an existence beyond this world. The poem of their voices and the transcript samples highlight their sense of connections to this concept.

When I hear the music,  
I hear the angels  
With us  
And feel  
like I am talking to God.  
I know she is seeing her loved ones as we sing  
Even though they are somewhere beyond us  
I know she is happy and in peace  
In that place.
For Dahlia, this theme was prevalent. She referred to a connection with the beyond in multiple ways. Here she makes reference to angels:

It was beautiful for Mrs. S and for us too, all of us, all of us, and the family too. Everybody was really touched by that. The fact that, that you were coming, like I feel like an angel. To bring us that, that time where we really enjoy the music. The meaning of the whole thing. The meaning of what the music was doing to all of us... And she agreed with me that you look like an angel. Mrs. S, your angel Lucanne is coming... Mrs. S your angel is coming to play the music. To relieve the pains physically and mentally. She is coming to play the music for us. It really meant a lot to us.

Throughout the interview, Dahlia referred to her experiences in music therapy as being with an ‘angel’, portraying an interest in a connection with this dimension. She also referred to the comfort she receives from her sense of connection to this belief in her reference to ‘relief from pain’. As she recalled the events surrounding the death of Mrs. S, Dahlia talked about her focus on God:

I said Mrs. S, I cannot tell you what to do; but you know something, you pray to God right now. Talk to God. He is listening, looking at you and He is with you. Talk to God and ask Him for anything you want... anything. He’ll hear you and He’ll be with you. And you know what? Pray and ask God ask Him for forgiveness of your sins and ask Him for whatever you like. And she looked like this (Dahlia looks up); and I say “Mrs. S, are you talking to God?”, and she says “Yes”. After that, she just sat and was breathing, breathing, talking to God.

Dahlia also refers to her own personal sense of faith and how music affects her:

When I go to church on Sundays. I love to sing the songs... I really love them. I love them. And when I am singing I feel like I am talking to God. I love them. It takes you to a place that I can’t explain. That... it is so different. You don’t remember about anything. It really
wipes all the problems from your head and you are just enjoying the moment.

Dahlia spoke about her connection to God through singing as “talking to God” and was affected by the music. Here she refers to her faith:

I am sure that He is with me. My faith. That something will happen. The help I have been getting from God here and there. My faith hasn’t gone down despite all the problems I have had.

Dahlia also referred to God in reference to her present feelings and thoughts regarding Mrs. S.:

But I was so happy she didn’t suffer that much. It was fast. Thank God, thank God. And now. If you ask me? I am sure she is next to God. No doubt, no doubt.

For Dahlia, then, this sense of connection with the beyond manifested itself through faith and belief in God. She also indicated feeling a connection to the beyond in and through music as well. Dahlia found support in her sense of faith.

Mary referred to this sense of connection with the beyond through a focus on that which is beyond the physical. Here she makes reference to this:

In the last four nights, my mom was reaching a lot in the night, and really struggling and reaching, really clear that she was trying to go somewhere…and it really seemed to me that my mother could see things. She would say, “Do you see a face?” and “I said no, who is it? Is it daddy?” and she said, “No.” I said: “Well who is it?” She said: “I can’t tell, it’s in profile.” And she’s perfectly lucid, but you know. So in the night the day she died, I turned the photographs of my father, her parents, and grandmother toward her, and I told her that “Daddy and granny and bump-bump…are waiting for you.” And then very clearly, though her speech was sluggish, very clearly she said: “Where are they?” She’s reaching and she’s looking and I said: “I don’t know, they are probably someplace nice” And she said “But where are they?” My neighbor, who is a little bit older than my mother and is friends with
her thought this was inspired. I said: “Maybe they are looking for you.” At that moment I fell instantly asleep.

Mary referred to her mother’s ‘reaching for something’ and communicating with something beyond. During the interview, Mary’s reference to the beyond had to do with a sense of connection with those no longer alive. I include here an excerpt from my post-interview journal entry:

Mary talked about her memories of our last session when we met his evening. She referred to the song “I am a Poor Wayfaring Stranger” and it brought to mind the words she used that day in our session. She filled in all the names of those family members who are deceased as she sang to her mother about ‘going home’ to see her loved ones. That day she lovingly encouraged her mother to feel free to go there, to go towards her loved ones and go home to where her father is too. Mary poignantly spoke this evening about how she wanted to help her mother die ‘with grace.’ I was in admiration of her sense of strength.

For Mary, then, this sense of connection to the beyond was in and through thoughts of people. She also makes reference to ‘seeing’ her mother after she died. She states, “Today, I was walking on the street, I saw this woman who had hair the exact way my mother’s hair was. I immediately thought of and felt my mom.” Mary maintained a sense of connection with her mother beyond the physical, a connectedness that seemed strengthened by her experiences during her mother’s “graceful” death.

Abe referred to his sense of connection to the beyond a few times in our interview. Here he recalled a visit with Patty:

A few months before, at Christmas time, I was there with her and I’m reading Mother Cabrini’s text and she said Baby Jesus came to her last night, and I said: “no kidding”. And she said “Yes...he was there sitting on my belly... and we were playing, just enjoying each other, little Baby Jesus,” She said: “I’m making signs at him, making baby sounds
and signs.” And she said: “He is here right now.” And I said “That’s wonderful, Patty. I have been waiting to hear that and now we know everything is okay,” She was playing with Baby Jesus sitting on her stomach, dancing up and down, and she was so happy...she was so happy. And she said: “He is here now”. She was so happy... She was ready, she was ready. And we talked about how she is going to carry on Mother Cabrini’s work in her next life. She is going to be a nun, wanting to be a nun. And I said: “Me too. You and I will be nuns in our next life. We’ll carry on all the good work.”

Connection with the beyond plays a significant role in Abe’s life. I return again to Abe’s reference to partaking in Holy Communion during Patty’s funeral service. He found great meaning in being able to have Communion, stating, “Then he [the priest] said, “even if you’re not Catholic but you believe”...(Abe cries), so I went up... to Holy Communion. Oh...it was so beautiful, so wonderful.”

In our interview, Abe also referred to the link between music and the beyond. He sees music as a “track” to bring people to another place. He states:

It is immediately connecting to that track and she knew that that would take her to a beautiful place. The music helps lead to that place. And for Patty, the music led her to Baby Jesus.

Miranda also referred to a sense of connection with the beyond. For her, this connection had to do with her faith as well as what she observed in her aunt as she approached death. Here she refers to her aunt and states:

Because at the time, that last Saturday, she was agitated, upset, ornery. I remember you came very early that last Saturday, and you stayed a long time, and by the time you left she was 360 degrees different. She was calmer, peaceful, and again had opened up, was chatty and talking, trying to talk about things. She was reaching for something beyond...She had a spirituality, but it was something that was foreign to me. It was something I didn’t understand. I am a religious person, and so is my husband. But she didn’t believe that stuff. Even though
she was brought up religious. ...she had this bell that she would ring if she needed me, and every now and then, and to this day, I think I hear bells (Miranda laughs). She would say that she felt her husband’s presence towards the end of her life... We would joke and when something happened that was either funny, or we would drop something, she would say: “that’s Uncle Dick. Uncle Dick is here.” And there was one point when I was sleeping and I heard her name being called. And I woke up very suddenly and I could have sworn that it was him calling her. She didn’t die that day, but not long after. So the spirituality, she did have it, but she was looking forward to being with her husband, moving beyond the earthly possessions. She was looking to be with her husband, very much so.

Miranda referred to this sense of connection with the beyond as she identified her aunt’s seeking to “move beyond her earthly possessions” and “be with her husband.” She also makes reference to her personal sense of faith, as she stated, “I am a religious person, and so is my husband.”

Ruth frequently referred to her belief in God in her interview and reflected having a sense of connectedness with the beyond through this belief.

She states:

As God shall be my witness. In the hospice the day he was dying, a song came on the radio “Because you’re mine” (Ruth sings it). I couldn’t believe it came on the radio. I came out of the room and I said to myself, “God is playing my song.” You see that song made a connection with me. “Because God made thee mine, I cherish thee” (Ruth sings it)...I couldn’t believe it. God has been good to me.

Ruth found her sense of connection with the beyond in her belief in God. She also articulated finding a connection to God through the song, firmly believing God brought her the song as her husband was dying. She was very moved by this event and referred to this song’s making a connection with her at the time before her husband died.
Each of these caregivers referred to experiencing a sense of connection with the beyond. This connection was described in various ways, such as 'God', 'faith', 'angels,' in thinking about 'moving on to another place,' and feeling the presence of deceased loved ones. References were made to music and its potential to act as a medium through which and by which a connection to this realm could be made. Having a sense of connection with the beyond seemed to inspire faith and offer the caregivers in this study support. This connectedness with the beyond also seemed to serve to bring them closer to their loved ones.

In summary, connectedness was a recurrent theme in this study. In reviewing the data, the most salient aspect of this theme was the caregivers' desire to have a sense of connection with others, particularly the patients. There were references to the caregivers' appreciation for the motivating and reaching attributes of music, helping build bridges and facilitate communication. They also indicated gratitude for the ways the sessions helped the patients come 'back to life' and 'renew self' through regaining aspects of their dwindling personalities. The caregivers also seemed to feel supported by the presence of the music therapist and the connection that they felt with their perceptions of the 'beyond.'
Remembrance

"My life has been a long and full journey. I am grateful for my loved one." Another process of reflection occurring in the data was the caregivers' recurrent focusing on the past. This spiritual theme of remembrance was also a salient theme, reappearing frequently throughout and across the interviews. The caregivers were drawn, on their own initiative, to review and reflect on their lives, to thinking and talking about times both with the patient as well as times apart from the patient. This reminiscence seemed to be a means of helping the caregivers find meaning in their overall lives and also to help them process their grief over the death of their loved ones. As can be seen in the interview transcript excerpts that follow, the reflections in the interviews were sometimes centered on memories that the music elicited in sessions. Other reflections seemed to be a means of 'coming back to oneself' since the death of the loved one. The tendency to reflect on the past was common throughout the interviews and was a prominent feature in this study.

I remember when I was little
Listening to music as a family
We sang and danced
He sang as we stood next to the Temple
I learned so much from her;
He sang to his children
Every day.

Dahlia looked back over her life in the interview. Here she recalls her early days with Mrs. S. and states:

[In referring to Mrs. S.’s children]...The children, Brenda was 8 and Mike was 11. They left early. They left early...16, 15...And...I stay
with them, Mr. S and Mrs. S. I went to college because Ms. S was feeling, wasn’t the way she was at the end. And Mr. S was with her and I had my weekends off. Mr. S was with her and I must say he was like an angel to her. He was really an angel with her. She was really spoiled from Mr. S. Anything that she wanted, he was right there for her... So after that [Mr. S’s dying] it got in my mind. Mrs. S doesn’t have anybody, yes the children, but the children they have their lives. And...she only had me around. And I was trying to be there for her...but I’m sure she preferred to be with the children, but that doesn’t stop me from being with her. To spoil her too. Whatever she wanted...most of the time it was very nice, like a family. I really felt that it, she was part of my family, she was part of me, or I was part of her. It was thirty years, half of my life.

Recalling these memories of her early days with Mrs. S. seemed to help Dahlia gain a holistic perspective of the purpose of her time with Mrs. S. and her family. She was, in essence, exploring a sense of meaning in this process of reflection. Dahlia also reflected on the events surrounding the death of Mrs. S:

Mrs. S told Brenda: “Brenda I want to die”. Very definite. “I want to die”. Brenda say: “That’s what you want mom?”...You do whatever you want to do. It’s ok. It’s your body. It’s you, whatever you want.” I happen to be right there, sitting at the edge of the bed. She told Brenda: “I can’t”...like that. Brenda say: “Why”. “Because Dahlia doesn’t let me.” And I got near her and I say “Mrs. S...I have been all this time with you, thirty years of my life just to help you in whatever you want. Up to now, I know what you wanted. But now, you say you want something else. I’m with you. I’ve been here all this time just to help you. Ok. I love you and whatever is your decision, I’m with you. I’ve been with you all the times so whatever you want”...She look at me and she smile and I got closer and she gave me a kiss...I say “Mrs. S. I love you and I’m with you and whatever you want, just do anything you want...I’m with you”... She never say “I want to die” until that day. So I respect that. But I am so glad I had the chance to tell her.

As Dahlia reflected on these events, it seemed as if she was reconciling aspects of this event, that is, the fact that Mrs. S. believed that Dahlia wouldn’t “let her
die." She referred to her feelings of gratitude that she had the "chance to tell her." She also recalled the tender moments around the death:

It was really beautiful, as a matter of fact when, that day when it was the last day, maybe the last two hours of her life, I was sitting there looking at her because Brenda was sitting on one side of the bed and Tess on the other side, holding her hands...she looked at me...

Recalling these events seemed to be a way to process some of her feelings and thoughts regarding the death of Mrs. S. Dahlia also reflected on her life outside of Mrs. S. She states:

They didn't finish school. They got married and have children. But despite that I have been praying and asking for help. I am sure that He is with me. My faith, that something will happen...I didn't want to leave Mrs. S. I decided to stay with her until she was gone. Every year it was worse and worse and worse. But it is something that you know is going to happen but you are never ready, never.

Again Dahlia seemed to reminisce as a way to resolve some feelings of regret that she had concerning bringing her children to this country. The reviewing of events in her life with and separate from Mrs. S. seemed to afford Dahlia a sense of life meaning as she seemed to review the bigger picture of the reasons for her decisions. During the interview, she covered many events and topics as she reviewed different times in her life. She referred to the role of her faith in coping with the difficulties.

Mary also reflected on the past in her interview. She recalled her past as a child:

It [the music] is something that has me very connected to my mother... Most people had very negative messages about sexuality, everybody except me. My brother and I talked about this. We came from a very loving home. We had good lessons. We had a lot of freedom. We were
respected. I had a good childhood, a good childhood. I had good parents, consistent parents.

These recollections seemed to convey the sense of gratitude for the “good childhood” and “good parents” that she had. She also reflected on time with her parents.

I mean it was her life, and I knew this was what she wanted. I would have liked a little more time. And she had said that at one point. But I think she actually just decided it was time. My father died when I was approaching thirty. I didn’t feel like I was cheated out of what he had to teach me. I got cheated out of time, but he really gave me what he had to give me. With my mother, I got both. I got time, and what she had to teach me. I mean, there are things I’d like to ask her, and I have moments when I want to call her up and tell her something, I want her take on something.

Mary also recalls an attribute of her mother’s that she appreciates:

One day the angels came to me and said at noon... “You have until one o’clock” and I would go to the nearest French pastry shop and have coffee and whatever pastry that I wanted, and I’d like to be able to think about how well I did yesterday. She liked that. But for me, it’s the active thing because I am not always living everyday, whereas my mother did. No question about it. Every day she had a great day. She enjoyed whatever she did. Where because me working two jobs and writing in a magazine and caring for her. I’m running from one of them to the other and I’m not doing it at a pace that I would like to. So, there’s what she showed me. And I feel that I can’t completely get there until I finish what I am doing, like a paper to write...

Remembrance for Mary seemed to bring her in touch with aspects of her own life, particularly as she was influenced by the experiences with her mother and father. This review seemed to be a natural way for her to be in touch with a sense of purpose, with the meaning of who she is as a person today.
Flora reflected on her past in the interview. Flora looked at her life experiences separate from times with Mark as well as times with him. She recalls her work in her foundation:

I was in a village that I went to and the effect was on the children that I saw. (Flora continues after long pause and tears) It was a tragic story, in a village called Actual. Most people were in the church praying, women and children, the men were probably at work, and some patrol came into the church with machine guns and killed forty-three people. This was a few years ago in Mexico. The survivors of Actual ran away and were taken in by the village which I visited, and the children were who had survived...some children had been killed. And there was a child who went to the funeral [of his parents] with sixteen of his relatives and he was totally shaken...probably eight years old. The music for them was really an incredible moment of joy. There was no reason to be joyful. The place was absolutely squalor. There a few huts and the setting where the school existed was plain, there was a teacher...no toys, no play...nothing. The grown up children were working in the field, picking coffee with their parents. When this girl with her guitar showed up, there was absolutely joy...they were dancing, singing; she taught them some simple songs. And then we went away and there was a song of goodbye. I had given them some candy; and there was a song about picking up what they had left behind. They were picking up and singing. These children...they had nothing to be happy about. They had no future, and that moment of music was the only moment of happiness they had during that week.

Flora seems to gain a great deal of meaning from her work helping indigenous women and children in South America. Her recollections in the interview seemed to help her piece together her experiences with music as well as provide herself support as she thought about her humanitarian endeavors and contributions.

She also recalled moments with Mark in their travels together:

But when he was happy he would sing “What a friend we have in Jesus”. And I remember we were once at the sea in Greece, sitting on front of the Temple of Adur. It was very nice, and he started singing
this song, the first time I heard it. And also Joan [Flora’s step daughter] heard it. Again, we were on vacation and there was the beautiful landscape, and he started singing.

She also referred to the impact of the music as a medium that ‘takes her back.’ She states, “In that moment, it was taking me back to the moment when he was in good shape, when he was healthy.” Flora’s reflections on the past centered in her life’s work and in her memories of her times traveling with Mark. In our interview she also recalled significant moments of connection in the music therapy when music was “taking her back.” The process of reflecting on the past was an area of focus in Flora that played a role in helping her review the meaning of the events in her life to date, both with Mark and in her work apart from Mark.

Abe also reviewed some of his life in the interview. He recalled times with Patty, e.g., “She would say to me, “It’s time to read the Good Book,” and I would take out the Book and read to her.” Abe also recalled his life as a child, “My parents thought I was not smart and I grew up thinking this. When I became a Buddhist I realized I had much inner knowledge.” Abe seemed interested in reviewing his times with Patty in our interview and also sought opportunities to talk about the meaning of his Buddhist path with me.

Miranda recalled times with her aunt and reflected on her aunt’s history and the events surrounding her illness in her interview. Here she related fragments about her Aunt Jacqueline’s life:

She worked all her life. She was an immigrant. She was Scottish, she came through Canada to the United States. Plus she was single, she
went out a lot. She liked going to parties. She liked to go out a lot... She and her husband traveled all over Europe, all over. She worked all her life... They were always entertaining themselves she was one of these fashion models. She worked in the Empire State Building for the Canadian Consult. So she was always dressed to the nines in her business suit. Even though she was in her seventies, she was still working into her seventies. I think she only stopped working in 2001 when she fell during the world trade center and injured her hip and couldn’t get up and down the stairs very well. When she was getting home to Jersey, she got knocked over by people trying to escape... She couldn’t get back to work. She had hurt her hip but didn’t want to get it fixed. She decided to get it fixed when her husband died because she was worried about insurance and wanted to get it fixed before she didn’t have insurance. And then six months later found out that she had liver disease. She wasn’t feeling well and didn’t know why. Her husband died December 28th. On December 31st she had her hip fracture repaired and then moved in right away.

Miranda seemed to use this process of reminiscence as a way to process the death of her aunt. This process of reflection seemed to comfort her, as she was eager to share all these recollections that flowed freely from her.

Ruth also reflected on the past in the interview. Many of her memories were centered in the topic of music and times with music. She recalled times before Joe’s illness, “When Helene was born after the war, we had our record player in Canarsie. Music was our life.” Ruth also reminisced about her brother and his love for music and dancing:

And my brother dances. When we were on a cruise, they invited him to speak at the University of Florida. He gave a talk there-how to keep dancing through life. Don’t stop dancing. Keep the music going. Keep the music going. He has a good heart... My brother was on a destroyer in 1942. He never stopped the music, in fact he asked me to send him a record of ‘Stardust’. I found it and sent it to him. With battles going on, he sent me a message. “I don’t stop the record”, he said.

She also talked about living in Florida:
We were down there for ten years. He didn’t have the energy anymore to play bridge. But the music and the dancing went on. When I think of it now. For that, Joe had the energy. When you have energy, you don’t need the mind.

Each of these caregivers entered into the process of reflecting on their pasts. This process of remembrance seemed to bring them in touch with aspects of their lives that were meaningful to them in which they found associations between the past and present life events. This self-led weaving between the past and the present seemed to be a way for them to gather a larger view of the experiences they had been through in music therapy as well as throughout their whole lives. Some reflections centered in the topic of music. Other reflections were focused on early life experiences. Likewise, other reflections were of their times with the patient. Remembrance was a major theme through the course of each and all interviews.

Hope

“I am looking forward to doing some of the things I want to do now.”

Hope is a common theme in patients and caregivers facing end of life. Hope has been defined as “an inner power directed toward enrichment of ‘being’” (Herth, 1990). It is also seen as an inclination toward something that we do not know (Aldridge, 1995). Aldridge explains: “There is a longing for the unknown. We are waiting for a change, even if it is a material change of circumstances, and this expectation is hope. Such hope cannot be touched and even not understood. It is an attainment that may be described as beyond
happiness and above death” (p.106). In facing difficult life circumstances, hope can be a coping strategy that can help caregivers look beyond the current state of affairs. Hope also involves an expectation and going beyond the visible facts and may be seen as a motivating force to achieve inner goals (Saudia, Kinney, Brown, & Young, 1991). Caregivers often reflect on hope as a means of coping with their losses, as in finding connections with the beyond as a way to find meaning. Reflections on the future also seem to signify a looking forward to times of refreshment and healing.

Throughout this study, caregivers made references to the future. These reflections seemed to be directed primarily towards their own personal lives. Several participants were beginning to think about specific goals and plans for themselves. In some cases the caregivers reflected on the patients futuristic inclinations observed in sessions. In other cases the caregivers referred to thoughts pertaining to the beyond in the context of hope. Their words and comments taken from interview transcriptions describe these interests.

I think I will sing again now
Where I am going soon
I will sing
And read Whitman and
Enjoy each day
As she did
She looked forward to your coming
And now
I find hope
Knowing that she is in peace
And there will be peace
For me and all of us.
Dahlia referred to the future in a few ways. For example, she recalled moments when Mrs. S. looked forward to the music therapy sessions:

It was something that she was waiting for. She would say: “when is the next time you coming?” And, and she couldn’t wait until the next time that you were coming for the music.

She also reflected on her thoughts concerning the future in her hopes regarding Mrs. S. during the time following her death, “I am sure she is next to God. No doubt, no doubt. And we will put the words on her head stone: ‘You are the wind beneath my wings.’” She also referred to thoughts concerning her own personal future, here referring to working on healing her sadness, “I have memories of the times we had together. I am trying to leave the sadness and get the beauty from what we had... I can’t hear those songs but will soon.” Dahlia’s references to the future focused on her memories of watching Mrs. S. “looking forward” to the times in music therapy with anticipation. She also looked forward in her own life and spoke of her goals of “leaving the sadness” and returning to the “beauty” and being able to hear “those songs” again soon.

Mary also reflected on the future as she shared her personal aspirations with me in the interview. She states:

I am looking forward to doing things that I want to now. Music, yoga. I am also debating between poets to read now. I have never been able to do that easily and my mother loved “The Leaves of Grass.” I have decided to read this. She [her mother] really liked this...It is to carry on with living...To get on with the business of living. It is about living. Because the death about was about her [mother’s] life.

Mary reflected on the future, thinking about the plans she has for her life now. She refers to her mother’s death as being “about her life” and had a sense of
knowing that her mother would have wanted her to move forward. In a sense, she was acknowledging permission to “carry on with living.”

Flora also reflected on the future. Prior to the interview, she told me that she was planning to move back to her homeland, Italy, sometime in the near future. For her, this ‘moving forward’ meant taking momentous steps away from her large city apartment where she lived with her husband and going to her European homeland. While she did not directly state future plans for singing, she did allude to this as being a long-time passion of hers and mentioned it again as I was leaving her home after the interview, saying that she may find a choir to join in Italy. She refers to some of her plans:

I have a very full life. I travel a lot. I have many programs and projects. I will have to adjust to living there [Italy] again. It has been many years. The people there are very open, warm. There is more room for sentiments and feelings, not so many are scientists. A different culture.

Flora’s reflections indicated a sense of hope in her future and a shift towards a focus on taking care of herself. During Mark’s illness, Flora’s concern for herself had been superceded by her intense concern for Mark’s well-being. Thus, this shift of focus onto herself indicated a sense of hope since she was considering her wishes and aims for her future directions and next endeavors.

Miranda also made references to the future in the context of her aunt, prior to her death. She states:

She was looking forward to being with her husband, moving beyond the earthly possessions. She was looking to be with her husband, very much so.
Ruth made clear references to her sense of looking forward in her own life. She relates an incident with her son-in-law:

My son-in-law...he has a sense of humor...he said "You are a widow now." I can't even say the word. And he said "Do you want me to set you up with a date?" (Ruth laughs some). I said: "No. I can't even think about that yet."

Ruth also refers to the future as she talks about the benefits of music and her desire to promote the use of music in the world to help others. She states, "Music brings love. Music rules he world, not bullets. Start music there where the war is and bring music to the children." Ruth stressed her strong feelings regarding the positive effects of music and her desire to bring music to war-stricken places. As I was leaving the interview, she talked to me about her travel plans for the summer and thoughts about spending time with her children and grandchildren. In the interview, she also makes a clear reference to a goal for herself, "I love the music and I am going to start reading. And so that's what it is. The music is wonderful."

Each of these caregivers reflected on aspects of the future. Ruth, Maddy, and Flora conveyed specific intentions regarding personal goals. Dahlia and Miranda reflected on the patient's sense of 'looking forward.' A sense of hope was present in the interviews in these various ways. Throughout the interviews, hope seemed to portray the participants' readiness to move on with their lives, a process that signified an integration of their pasts and the present with an orientation towards the future. Reflections on the future were found across the interviews.
Summary

Spiritual themes emerged in this study through the processes of reflecting on the present, past and the future. In reflecting on the present, caregivers reported experiencing a sense of connectedness with others, themselves and with the beyond. Through actualizing this sense of connectedness, caregivers seemed to attain a deeper sense of completion in their intrapersonal (connectedness with self), interpersonal (connectedness with others) and transpersonal (connectedness with the beyond) relationships, as witnessed by their statements referring to their sense of satisfaction and gratitude for these moments of connection. Connectedness seemed to help them gain a holistic perspective of the meaning of their lives as individuals. In reflections on the past, caregivers reminisced and remembered moments in the music therapy that seemed to inspire them, providing an impetus for accepting their losses and moving forward. The process of reflecting on their pasts, a process that naturally occurred in the interviews, also seemed to help them gain perspective on their lives as a whole and enhanced their sense of life meaning. There was also a tendency to look forward, reflecting on the future through various perspectives, indicating a sense of hope. A review of the data revealed these spiritual themes as salient features of this study.
CHAPTER VII

THE CAREGIVERS' REFLECTIONS ON THE ROLES OF MUSIC AND THE MUSIC THERAPIST

Introduction

"Music is love." These words, stated by Ruth, echoed in my mind during the hours following her interview. I pondered the significance of these words and the importance of music therapy during times of loss and transition. What role did the music and the music therapist play for these caregivers? This was one of the research questions that I placed in the hands of these caregivers with whom I had witnessed such courage and valor during the end of their loved ones' lives. As I reviewed the data, I found that the caregivers viewed the role of music and the role of the music therapist to be important aspects of their overall experiences. I found recurring themes in which they portrayed the significance of music and importance of the presence of the music therapist. This chapter focuses on these themes and the transcript excerpts that describe their perceptions.

The Role of Music

"Music brings us all joy, peace and love." The caregivers described music throughout the interviews. Sometimes they referred to the longer-term
role of music in their lives as they reviewed specific times and events. Other
times they characterized prominent attributes of music as they pertained to
their reflections on the music therapy sessions. In the following is a collection
of their voices that encapsulates their views.

How can we live without music?
It is the key
That can bring joy
And serenity
During times
When really there would be no reason to have joy.
The music brought love
And transported her,
And me,
To a place where we all felt
Happy, happy.

As I recursively reviewed the reflections of the caregivers, I found four
significant qualities of music: music is a conduit; music gets inside us; the
format of music makes a difference; and music is love. These themes capture
the essence of their thoughts regarding their views of the music in the sessions
they witnessed.

Music is a Conduit

The power of music to lift, transport and to put the patients’ minds and
feelings “on a track” was described by the caregivers as being an important
aspect of the music therapy sessions. The word conduit, that is, a channel or
vehicle, describes the views of some of the participants. In a sense, this image
conveys the role that music may have played within and throughout all music
therapy sessions with the patients and caregivers, as it describes the quality of music that can bring a person ‘back to life,’ to a ‘renewal of self’ and to times of ‘connectedness,’ ‘remembrance,’ and ‘hope.’ I intend to describe this feature in the next chapter as it exemplifies the process of transcendence that I found to be the essence of the overall experiences for the caregivers in this study. Here, it is helpful to think about the perceived meaning of this quality of music, i.e., that it can be considered to play an important role in facilitating the “bringing back” and “to” that Abe poignantly describes below. He states:

The music was the conduit to bring her back to something sweet. It brought her back to something sweet and she sang and her voice got strong and she was there. These songs and words that are repeated over and over during a lifetime can take, and are bringing one back to another consciousness. It is immediately connecting to that track and she knew that that would take her to a beautiful place. The music helps lead to that place... The words and the music are the path to imaging.

Abe sees music as the “path” that helped lead Patty back to “something sweet.” Abe referred to the ‘conduit’ image as a way to explain his overall perception of music and its potential to ‘bring back’ and carry a person to a place, time and/or image of significance. He also referred to the significance of memories, that is, “the songs and words that are repeated over and over can take...to another consciousness...connecting to that track...and to a beautiful place.” Thus, according to him, music can bring a person back in touch with times and states of meaning. Patty sang “Danny Boy” every day as a child in Ireland, even to her teacher’s dismay. When she sang that song in music therapy, she always felt her mother’s presence and was taken back to her homeland. Abe
knew that Patty was in this "sweet place" when he sang this song to her and was comforted in knowing she was in a place of peace. For Abe and other caregivers, this attribute of music as a conduit was important.

Ruth also describes this quality of music. She states:

but it [the music] put him on a different track. When you came, he opened his eyes which were usually like this. He stopped opening his mouth. He closed his mouth. We found him humming. And some songs were so old that he knew the words and he would sing. It was important. And as soon as you went, I put on the music and we danced. Ruth referred to her surprise and satisfaction with this effect of the music throughout the interview, i.e., that it "put him on a different track." For her, this meant being able to ‘be with’ her husband again in meaningful moments of communication.

Toni also referred to an aspect of this "conduit" quality of music. She states, "It was so helpful to see his peace and calm. The music brought him there...it seemed to lift him and carry him, didn’t it?"

Dahlia also referred to this quality of music. Here she talks about the way that she saw Mrs. S. respond to music by being "transported." She states, "She was really happy. She was really another person. But to see her smiling and transported, to when she was listening to music and when she was singing."

Mary also referred to seeing her mother ‘go to a place’ within the music. As she reflected on observing her mother in the music, she states this: [referring to a ‘place’] “it was a place of pleasure, grace and gracefulness”
Flora referred several times to her surprise and joy in seeing the music help her husband transform. She states:

This was the first important impression of the music therapy, seeing someone who comes back to life...it was a great surprise, a great pleasure, and then more and more, as soon as you came he started...

As with Flora, music was a channel, a means by and through which their loved ones could be “transported” to other times, places or ways of being. Each of these caregivers found this attribute to have significance for them. They witnessed music helping their loved one ‘move’ out of a place of distress, as in Randy’s case, discomfort, as in Mrs. S’s case, and deterioration, as in Patty, Ruth and Flora’s cases, to places of peace, calm, communication and ‘sweetness.’ The role of music as a ‘conduit’ was an important quality to these caregivers in this study.

Music Gets Inside Us

The caregivers referred often to specific attributes of music concerning the direct influences they perceived it having on them as well as others. Often these comments focused on the physical effects of music on the body and mind.

Dahlia referred often to this image of music “getting into her heart and into her skin.” In the following she describes these thoughts about music and the way it reaches her:

The sound....Could be one song, another song, it doesn’t matter what it says. It is just, the sound that really gets into your skin. [When the
friend came over and was just playing Italian music. It was just the sound. He, nobody know what he was playing... It was just the sound, that is so, it’s so beautiful, that it gets into your heart, into your mind, into your skin, love... everything. That it really, it really, it really is unbelievable. Could be one song, another song, it doesn’t matter what it says. It just, the sound that really gets into your skin.

A significant aspect of the music for Dahlia was the sound. She found music reaching deeply inside her.

Flora also refers to the importance of the effects of music on the body and mind. She states:

Music affects very much and I understand it can affect people in a positive way. It is liberating and also what comes out is irrational. These feelings are something you cannot describe with words. You let yourself roll, and the sounds, I think the sounds are a vibration inside are also soothing. I do yoga and sometimes I have to do “om.” This vibration in the body. And in a way the singing is vibration. The body is full of vibration and it must affect you in a positive way. It goes all throughout the body.

She also refers to the effect of music on the brain:

but you know, the music is in a different part of the brain, and I read that people, who had lost the capacity to talk because of brain damage, and yet they were singing, they were using words which were in another part of the brain, and they could express in words.

Flora referred to these specific attributes and their potential to reach and influence people. For her, this was significant. Her husband had lost some of his cognitive abilities due to some neurological damages during surgery. The music helped him retrieve his abilities to talk, sing, interact, recall memories and, in essence, be himself again.

Ruth had similar comments. She referred to the potential to bring “energy”. She states:
And when they [children] are born, they are smart and it is because of the music. They wake up so early; it’s because of the music. Music is stimulating. Everything in their house is music. Did you ever see anyone in the music hall sitting around? ...The music does something to your body. It feeds your body energy...no doubt about it. It feeds your body energy. He would get up when and after you were here. You made me aware of it. There is music with the dolphins and the whales too.

Toni referred to the effect of music on Randy’s apparent physical discomfort. She states, “He had declined so much. I wasn’t sure how much pain he was feeling, though he seemed uncomfortable. He became so relaxed when we were singing and after.”

Miranda also referred to the effect of music on her aunt’s pain. She stated this:

I realize now... that particular day, she had less pain medication. She didn’t need it as much as she would have, and I think she slept more which was good. That was a significant thing for me.

Miranda was grateful for this attribute of music. As a health care provider, she had been very concerned about her aunt’s physical well-being and comfort.

The caregivers recalled these ‘getting inside us’ attributes of music as they reflected on their times in music therapy. They saw the impact of the music on them as well as their loved ones, especially in the ways it brought the physical sensations and vibrations, and the ways it helped facilitate relaxation and the diminishing of pain.
The Format of Music Makes a Difference

The caregivers sometimes referred to their thoughts concerning the presentation formats of music. The caregivers spoke about the use of songs and the benefits of live music versus recorded music. A more thorough discussion of the music therapy techniques was presented in Chapter III, outlining the use of live music and songs in music therapy sessions. Of interest here are the caregivers’ reflections pertaining to the techniques used. In the interviews, the caregivers referred to the presentation format of music, most often on their own initiative.

Miranda conveyed her impressions of the format of music as she reflected on the music therapy with her aunt. She states:

Even to this day...I believe in music therapy. It helps. And the fact that it was live music I think makes a big difference, we had radios playing, but it is the live music that has that sound that makes you want to feel calm. It’s like going to a concert. Hearing the live band is so much more exciting than hearing the records or CDs. So that was a difference.

For her, the live music was a fundamental element in her experience. Mary also reflected on the role of live music and active singing in the music therapy sessions. She states:

This [referring to the live music] was the music that we sang, we actively sang. You know, we might have sung along with the opera (Mary laughs). But these we actively sang. If we were in the car, these were the songs that we would sing ages eight and eighteen, this was the music we sat down and did together, were the songs that we sang. So it was really nice and beautiful.

Flora referred to the importance of song choices in her interview. She states:
But when he was happy he would sing "What a friend we have in Jesus". And he started singing...but between us, we sometimes sing it in the family. So also the choice of songs was important.

Flora's connections with Mark were enhanced through the songs that were familiar to Mark, as these were songs that resided deeply within him and were ways in which she could access him as he sang them with her in sessions. I return here again to Flora's comments about songs and the "lasting" effects of the music:

Knowing they [the songs] were coming after fifty years of being just inside him, and noticing he was also left more alive after singing...so the effect was lasting also.

Flora also referred to the significance of the voice. She has always loved singing and found this aspect of the music therapy to be important to her personally. She refers to this here, "So the music always affects me, especially when the voice is involved."

Ruth had similar sentiments regarding the live music and the kinds of songs in the music therapy sessions. She states this:

When someone comes in and plays the guitar, it makes a big difference... with you, he never said no. He loved the music. It is our music.

For each of these caregivers, the format of the music in the sessions that they witnessed was important. In particular, they commented on the beneficial presence of live music, the use of familiar songs and the involvement of the voice.
Music is Love

The caregivers referred to the tendency for music to inspire feelings of love. While this was not addressed directly at times, this was certainly a common sentiment throughout the interviews. They had lasting impressions of the love-filled communication that had been facilitated by music that they experienced in the music therapy sessions. In addition to their verbal comments, the caregivers expressed this theme through the passionate expressions in their faces, the stories they told and their words indicating their deep appreciation for the times spent in music therapy. The caregivers' words revealed this potential of music to touch and bring love.

Ruth stated a few times her thoughts about music and love. In relating her thoughts regarding her impressions of the music and how she feels it can help others, she states:

Then they [referring to others who are in difficult life situations] would feel happy...Music is love. How can we live without music? Make love, not war...With music, you sing and dance. There is no joy in those [war-stricken] countries. With music you sing and dance. Music brings love...and joy. There is laughter with the music. We need the laughter...The music brought love back. I felt that love when I heard the music. Music brings love...Music is love.

Ruth expanded her personal experiences with music and love into her concerns for global affairs. She felt strongly about this attribute of music. For her, this was a life-long observation, as she referred to times as a child sitting with Perry Como music, then later to times watching her brother dance, and lastly, as she sat with her husband Joe as he approached the end-of-his life.
Dahlia also referred to music and love. She states this in referring to the music:

It’s so beautiful, that it gets into your heart… into love, everything. That it really, it really, it really is unbelievable...

Dahlia noticed music getting into love. For her, music had these penetrating qualities that could, in essence, stir or activate love. Her sentiments, overall, resound with the intense feelings of love that she felt and witnessed during and after the times in music therapy. This quality of music was very important to her.

In my interview with Flora, she recalled a time when she was in Mexico working on her foundation. I return here to this story, since it is a poignant example and one which clearly impacted Flora, especially in her realizations about the power of music. The story was tragic, with many people dying at the hands of gunmen who entered a church in a small town. She was in a town nearby when orphans from this incident ran to escape into the town where she was staying. In our interview, she recalled the significance of music and the way it brought an “incredible moment of joy” to these children when there was “no reason to be joyful.” Here she states:

When this girl with her guitar showed up, there was absolute joy. They were dancing, singing; she taught them some simple songs. And then we went away and there was a song of goodbye. I had given them some candy; and there was a song about picking up what they had left behind. They were picking up and singing. These children, they had nothing to be happy about. They had no future, and that moment of music was the only moment of happiness they had during that week.
As with Ruth, Flora was very moved by the power of music to bring compassion, both in her own life as well as in the lives of others. For her, this story represented a powerful example of the potential for music to bring love and joy in extremely difficult times.

Each of these caregivers found the quality of music as love to be important to them as they reflected on the meaning of the music therapy sessions. The essence of this theme portraying ‘music as love’ was prevalent throughout the interviews, often more in the context of the overall meaning of the experiences than in verbal descriptions of music. For example, there were times in the music therapy sessions that I, as the music therapist, witnessed loving sentiments between patients and caregivers. Often there was non verbal compassion that was conveyed in the eyes, words and gestures between persons, moments that seemed to resonate in them as they conveyed their reflections of their experiences in music therapy during the interviews. Thus, music as love, in essence, describes the overall qualitative and contextual aspects of the music therapy sessions.

The role of music for the caregivers represented a range of ideas. The themes focused on the quality of music as a conduit, a channel through which people could travel to parts of themselves that were difficult to access as well as to places of beauty and happiness. The caregivers also reflected on the potential for music to “get inside us,” for example, the physical attributes of music to bring soothing vibrations, bring a sense of peace and calm and
diminish pain. They also reflected on the format of music, referring to the special meaning of live music and songs. Finally, they reflected on the unique quality of music, that ‘music is love.’ All of the caregivers found one or more aspects of music to be important to them in the sessions. Overall, music seemed to play a meaningful role in helping motivate and inspire love and beauty in each of the caregivers during the course of the music therapy and during bereavement.

**The Role of the Music Therapist**

“You Made a Difference.” The presence of the music therapist has been perceived to play an important role in music therapy. In healing relationships, it is known that the presence of the healer can be influential. When the healer emits and brings qualities such as love, kindness, surrender and peace, the healer can impact his or her surroundings (Dyer, 2001, p.100). As Magill states: “the compassion, love, empathy and energy that the therapist brings to others, along with the intangible grace of music, creates the temple within which others may safely experience their feelings, hopes, wishes, dreams, images, memories and prayers” (Magill 2005, p. 7). The caring, supportive environment that a therapist creates can help enhance feelings of acceptance and self worth and can foster a sense of peace to those in the environment.
In approaching this study, I was aware of the potential difficulty that the caregivers may have in addressing this topic since I was both the researcher and the music therapist with whom they shared the music therapy experiences. While this dynamic is more thoroughly addressed in the Chapter IV, the chapter focusing on Research Methodology, I find it important to also address here, since this was a research question of mine and also was a theme that emerged.

As I set out on the interviews, I decided to only ask questions regarding music in the interviews, if and when appropriate. I decided to let the topic of the role of the music therapist emerge naturally as a way to learn if the presence of the person in the sessions made a difference to them from their perspectives. It seemed the caregivers, in seeing me again, remembered, more acutely and more vividly, the things that I said and did in the sessions that were meaningful to them. In retrospect, it is possible that my presence in the interview facilitated deeper reflections on the role of music therapist because of this dual relationship. While this dual relationship may have prevented open, honest communication, I was careful not to introduce the topic and purposely let it emerge from them naturally.

The caregivers referred to the role of music therapist on a number of occasions. On their own initiative, they described their thoughts regarding the significance of the person bringing the music to them. Their comments surfaced during times of remembrance as they recalled special moments in
sessions, or when they reviewed global perceptions that they wished to share in their conversations with me. A collection of their voices describes their views:

You walk in and smile
His eyes come alive
And he sings
You are subtle
And your music
Meets us.
She awakes, enough,
Just right
The words and music together
The whole thing.

Ruth referred to the music therapist on a few instances in her interview.

Here she talks about the qualities she found important to her:

[Referring to her daughter]... So she said to me, gave me a whole session on the phone. Her patients call her on the phone. I said to her “The patient calls you on the phone and that’s therapy?” And she said “Yes.” She [daughter] is good. She speaks like you. She is very calming. For a half an hour she [daughter] spoke to me. I said [to daughter]: “Okay sweetheart, I feel better, I really do.” Now I can understand why people call her...you know they are in the middle of a burst of tears and they don’t know what to do.

Ruth described the feelings of helplessness she sometimes felt and the ways that healing relationships and conversations have helped her. Ruth compared me to her daughter at another point in the interview. She continues here:

You have to say something about the person that comes to the house has to have a certain quality. See, my daughter has your quality. She talks low and she talks slow and she is nothing like me. I have no patience except for the children...You are wonderful Lucanne. You are like my daughter. I don’t have the patience.

Ruth found the ‘calming’ aspect of the presence of the music therapist to be important. She spoke of her impatience and found her husband Joe’s lethargy
and quietness frustrating since she could not ‘dance and sing’ with him anymore, until music therapy entered their routine care. She also conveyed these thoughts:

    Don’t let go of the fact that the therapist has a big part of it. The therapist smiles and you can see the love in her eyes. And tolerance, there has to be tolerance involved. So all these things make it. You walk in and you are like a psychiatrist. Joe’s eyes. I see him sit there in that chair over there. You could see, even if he didn’t talk, you could see his eyes were alert, his eyes were open, not like this (Ruth closes eyes). When the physical therapist came, he [Joe] would close his eyes, he didn’t like it, and the therapist would say: “is he sleeping on me?”

Ruth also mentioned ‘smiles,’ ‘loving eyes’ and ‘tolerance’ as being attributes that she found helpful. Ruth clearly articulated the meaning of the role of music therapist for her and referred to this a few times in the interview. For her, the presence of person was especially important.

    Mary referred to the role of the music therapist as she reflected on the music in the sessions. She stated this as she shared her thoughts about her experiences:

    I was amazed at how versatile you were. These are the kinds of songs we like, and you were prepared instantaneously to sing our kind of music. I liked your flexibility and your introduction of “What a wonderful world” and “He’s got the whole world in his hands” and using different names. I thought that helped to frame the purpose. On the last time you came, you sang “My Funny Valentine” which is my mother’s favorite song, and she really responded.

Mary found the skill of the music therapist important, i.e., having versatility and being able to “frame” the purpose through song choices. I return here to one of Mary’s quotes in which she also alluded to another therapeutic skill as she describes this event:
But when my younger niece came, she hadn’t really had chance to have an exchange with my mother being somewhat alert, and while I had a hesitation about kind of bringing my mother back, I wanted to let her go, when you came and played, she came back to us enough. It didn’t seem disruptive to her leaving. It was a very gentle kind of coming back. I feel she was only back on this level of music, was aware that the younger granddaughter was present, but she didn’t have to completely wake up. We could all be there, and she could enjoy this. But she did not want to come completely back. I know that because of the last four nights when she really made an effort to leave. The hospice people said that sometimes she was sort of more active during the night than the day. It was very clear to me that she was trying to go somewhere. I kept telling her, go, go. The music was an interval; it was not an interruption. She enjoyed it. It was a familiar place that she could be, especially because we had done it once before. It wasn’t some new shock, wake up and listen to this. It allowed her to be present with her granddaughter and still not be brought back.

For Mary, the fact that the music was an “interval, not an interruption” was significant to her. She spoke about wanting her mother to gently wake up enough to be able to see her niece. This speaks to an important therapeutic skill, since, as she said, the presentation of music was gentle and merged with the mood and the needs of those present. As Mary explained, “it wasn’t some new shock, wake up and listen to this.” For Mary, this was a memorable moment in the music therapy.

Toni also referred to the role of the music therapist. She recalled the specific impression she had of her experiences in music therapy. She states:

The music did it, yes, and it was the combination of the whole thing. You were not a prominent presence, yet at the same time you were very subtle. This was important...you brought this quality to our time together, a subtleness. I wouldn’t have wanted to miss it. It was wonderful.
Toni viewed the “subtlety” of the presence of the music therapist to be important as she recalled her experiences. She believed that this was a significant part of “the whole thing,” that is, the times of sharing in the bond with Randy in the music, and the relaxation she felt and also observed in him. Again, the subtleness that Toni described refers to therapeutic skill. This was a gentle way for the music therapist to ‘be with’ the patient and family, offering them the lead while, at the same time, being a presence of support for them.

Miranda also referred to the role of the music therapist. As a nurse, she has a professional understanding of the importance of the humanness and compassion that a service like music therapy can bring and encouraged her aunt to try it. She stated this, in thinking about what “the music therapist did”:

I think you changed her mood. You changed her way of looking at things for the moment.

Her comments allude to the significance of having a person as part of the music. She views the presence of the music therapist as being interactive and helping to facilitate meaningful changes. For example, in her case, she observed her aunt focusing less on dying and more on living after the music therapy sessions. She had witnessed her aunt reminiscing and ‘traveling’ back to Scotland in the Scottish music during the music therapy sessions. After music therapy sessions, her aunt was “chatty” and talkative again. Thus, she noted the significance of the presence of the therapist, as it facilitated a meaningful verbal and musical dialogue in sessions. Miranda also conveyed her strong beliefs in the use of live music.
Dahlia referred to her impressions of the music therapy experience. For her, the music and people together comprised a whole experience. Several times, she referred to me as 'an angel' coming to soothe and bring joy. Here she shares some thoughts:

It was beautiful for Mrs. S. and for us too, all of us and the family too. Everybody was touched by that, the fact that you were coming like an angel to bring us that time where we really enjoy the music. The meaning of what the music was doing to all of us, not just to Mrs. S. She was sick and she enjoyed it.

I return here to a quote by Dahlia as she refers to the role of the therapist. She states this in reflecting on her conversation with Mrs. S.:

I said: "Mrs. S., your angel is coming to play the music, to relieve the pains physically and mentally. She is coming to play the music for us." It really meant a lot to us.

Dahlia describes the music therapist as being a conveyer of healing. For her, the presence of the music therapist was a significant component of the larger, whole experience. She often referred to her associations between 'angels' and the music therapist, referring to the healing and 'relieving' qualities of the music therapy. The presence of person is important to Dahlia in her overall life, and had played a role in her life decisions, that is, bringing her children to live with her in New York and deciding to stay at the side of Mrs. S. and not leave her alone when she became ill. The personal support she received in the music therapy seemed to be a key aspect of the total experience for her.

The caregivers described their impressions of the role of the music therapist in various ways. They referred to prominent personal attributes of the
therapist, such as the tone of voice, the eyes, and smiles. They also referred to
the significance of therapeutic skill, such as subtleness of approach and the
honoring of the needs of the patient and caregivers. They also commented on
the interactive role that they perceived to be important, such as facilitating a
change in the patients’ mood and ways of “looking at things in the moment.”
The presence of the therapist seemed to play a significant role for them, as they
viewed the personal relationship that they had with me to be an outstanding
feature of their overall experiences.

Summary

The caregivers viewed the roles of the music and the music therapist as
important elements in the music therapy experiences. They each commented
on aspects of these roles that were memorable to them. The relationship with
the music therapist was key, a human component that brought ‘loving eyes,’
‘soft tone of voice’ and a ‘gentle, subtle, healing touch’ to them at a time of
great difficulty. The skill of the music therapist was also identified as
important, with great appreciation expressed for the specific ways the music
had been delivered to them in the sessions. The music was also identified as
playing an important role. The specific attributes of music were identified,
such as the tendency for music to act as a ‘conduit,’ as something that ‘gets
inside us,’ as a medium that is beneficial in the form of live music, songs and
voice, and finally as an inspirer of love. Throughout the interviews, the
caregivers' comments clearly conveyed the impact that the music and the presence of the music therapist had on them, reaching into their hearts and minds and helping create treasured memories of times spent in joy with their loved ones.
CHAPTER VIII

TRANSCENDENCE INTO MEANING: THE LIVED EXPERIENCES OF THE CAREGIVERS

Introduction

"To bring us that, that time where we really enjoy the music. The meaning of the whole thing. The meaning of what the music was doing to all of us."

These words spoken by Dahlia offer a glimpse into the intent of this chapter, and that is to bring us to a place wherein we can attain a holistic view of the reflections that were conveyed by the caregivers. The gifts of their words have taken us on a journey into the depths of their hearts, minds and spirits, and for this I am immeasurably grateful.

In my attempt to synthesize the findings presented in the data, I contemplated all the words, sights and sounds across interviews. In listening to their voices, reading their transcripts and observing the propensities and themes across interviews, I was able to determine a totality, a holistic view of the essence of what their times in music therapy inspired in them. This totality of experience can best be described as transendence into meaning, i.e., a movement into a deepened sense of existential understanding concerning their lives and the meaning of their experiences. This trend of experience depicts the overall essence of the process that took them through their loved ones’ living
and dying, accompanied by music therapy, into rich moments of connection, remembrance and hope. These moments seemed to help carry them through the challenges of loss and uphold them in their times of bereavement.

Throughout my review and analysis of the data, an image of the ocean repeatedly appeared before me. I wish to share this image here since it played an important role in helping me integrate and organize the data into a higher-ordered conceptual framework. This image symbolically portrayed the essential characteristics of their experiences for me and assisted me in seeing a oneness as the sum total of its parts. The sea is the vast, almost infinite body of water that, for me, represents the whole, the overall trend towards *transcendence into meaning*. The sea water is comprised of a comprehensive and timeless web of diversity of life, depicting for me the *processes of reflection*, the areas of focus that helped guide the caregivers through the journeys of their lives in the present, their pasts and the future. The blue-green waves that stretch across the sandy and rocky shores of our planet are mobilized by the currents that pervade the deep and shallow waters. These currents and movements signify the joy and empowerment that the caregivers experienced, the *sustaining themes* that were the aspects that ‘drove’ the caregivers through the sometimes still and stagnant waters - the times of great difficulty. While this image changed and evolved as I deepened my comprehension of the data, it acted as a lens through and by which I could see
the myriad pieces while gaining and maintaining an ‘airplane view’
understanding of the whole.

In this chapter, I will describe, from a holistic stance, the essence of the
experiences as expressed through the words and stories of the caregivers. I will
also describe the process of transcendence into meaning that emerged as an
overarching trend in the data. As a preface to an examination of transcendence
into meaning, I will first examine the individual concepts of transcendence and
meaning and then propose a model of spiritual reorganization that attempts to
encapsulate the sum essence of the caregivers’ experiences in this study.

Transcendence

Transcendence has been described as a “‘going-beyond’ a current
awareness to another level of understanding...[and]...it is based on an innate
capacity that we have as human beings to rise above the situation” (Aldridge,
2006, p.167). Through transcendence, individuals are able to shift beyond
familiar constructs of thinking and perceiving into heightened or deepened
understandings of their life situations.

The concept of transcendence is pertinent to palliative care and to those
facing the dilemma of the threat of loss of life. When faced with the challenges
of illness and suffering, there is a tendency to search for ways to ‘go beyond’
the struggles and challenges at hand. This ability to go beyond the immediate
situation and achieve new perspectives is helpful when facing dying, since it
offers a means by which patients and caregivers may attain a sense of well-being. Transcendence occurs as a result of this search and is inspired by moments of meditation, prayer, faith and aesthetic beauty in the arts and in nature. As Aldridge states: "the main emphasis of spirituality has always been that it will help us to achieve this new consciousness by transcending the moment" (Aldridge 1995, p. 103).

Transcendence, then, may be seen as a 'lifting' into new or increased understandings and a shift into expansion of self. Aldridge (2000) states that transcendence is a process "taking us beyond our small selves, outside the everyday limitations of personality...[to] take an enlightened interest in others and the world through which we are led to a greater capacity to love" (p. 38). Transcendence is this "being transported," and is the movement along, through and within the 'conduit' that leads individuals to places and moments of actualization and fulfillment.

**Meaning**

The concept of meaning may be thought of as an existential perspective concerning one's answers to human questions such as "What is the meaning of my life," "Who am I" and "Why am I here?" There is a natural tendency to ask these questions, particularly in the face of loss, and a search for meaning is common in those contending with difficult life challenges. Meaning, or having a sense that one's life has meaning, involves the belief and understanding that
one is fulfilling a unique role and purpose in a life that is a gift, a life that comes with a responsibility to live up to one's full human potential, and by doing this, is able to achieve a sense of peace, happiness and also transcendence through being connected to something greater than oneself (Breitbart, 2001). Frankl (1959/1992) viewed suffering as a means to having a need for meaning, as in times of bleakness and distress, and for finding meaning through a reevaluation of the events surrounding the distress. Suffering may be viewed as an opportunity, then, leading to enhanced understanding of one's ultimate value as a human being. A diagnosis of cancer is an existential crisis for patients and their caregivers, potentially leading to despair as well as to opportunities for growth.

Literature refers to the role that meaning has in end-of-life care. It has been noted by some authors that in palliative care, the existential meaning of life gains importance during the dying process and the search for meaning is considered a spiritual dimension (Doyle, 1992; Ross, 1995). Other authors have emphasized the unifying aspects of spirituality that work towards bringing the person in harmony with the universe and offer answers about the infinite as a way to make sense of the meaning of life (McSherry & Draper 1997). Music therapist Bridget Hogan (1997) states: “music can symbolically connect terminally ill patients with a higher being, to past memories or peaceful images. It allows patients to reflect on their lives as they recall the past in order to contemplate the present and future. It awakens them to the
purpose of life, what life is about and what it means to them” (Hogan, 1997, p. 89). The process of reminiscence is a task that can bring individuals closer to attaining a sense of meaning in life. Gardner (1999) explains that reminiscence helps one to integrate and make sense out of the events in one’s life. She states, “Utilizing music to stimulate reminiscence provides an opportunity for life review both for the loved one…and the family caregiver (p. 82) According to her, the patient feels honored as significant memories are acknowledged and the family caregiver is empowered as she sees the meaning of these life events and reviews the unique gifts that she has gained from the patient (Gardner, 1999). The search for meaning naturally includes the process of looking back over one’s life as a way to understand meaning.

There are characteristics of music that facilitate this search since music evokes memory. As Magill (2006) states, “through music and with the accompaniment of the music therapist, patients may regain inner peace as they, through the process of life review, gain perspectives on their inner values, strengths and life accomplishments” (pp. 176-177).

Transcendence into Meaning in the Context of the Caregivers’ Experiences

Transcendence into meaning may be understood as an overall process that evolved over the course of time for the caregivers in this study. During the hours spent in music therapy and then during bereavement when they reflected on times in music therapy, the caregivers seemed to be ‘lifted’ into moments of
increased appreciation and understanding of the personal value of their relationships with others and the value of their lives as a whole. They also seemed to gain an augmented perspective of their lives and the lives of their loved ones, facilitated through reflections on the present, past and future. Through the process of transcending their circumstances in music therapy and gaining new perspectives, the caregivers attained an improved overall sense of meaning. In the following paragraphs, I will offer a synthesized analysis of the themes that were presented in Chapters V, VI and VII as a way to elucidate the essential aspects of the data and provide a conceptual framework.

As a prelude to this discussion, I present first a brief look at how I originally observed the emergence of this overarching trend towards *transcendence into meaning*. In the data collection phase, I noticed a pattern that seemed pertinent to me, i.e. the caregivers were unanimously choosing a sequence of topics in the interviews. This was fascinating to me since the caregivers initiated sharing their own life stories without prompting from me. As described in Chapter IV on Research Methodology, I decided, in the early stages of collecting data, to allow for the interviews to flow naturally without using a prescribed set and order of questions. My rationale for doing this was due primarily to the fact that I wondered if the participants would experience emotions as they reflected on their times witnessing music therapy. I knew these caregivers were in a time of bereavement. Thus, I elected to allow them the time and space they needed to recollect their experiences, if and when they
desired, and allowed them each to guide the direction of topics. I include here a journal entry that describes the trend that I saw by the time I transcribed the fifth interview. This entry was written immediately following my interview with Miranda.

I saw Miranda today and sat with her in her private office at her place of work. When I saw her, she hugged me and told me that she was glad to see me again. As we sat down, almost before I could start the tape player, she spoke about how much the times in music therapy meant to her aunt and also to her, since she had witnessed positive changes occurring in and after the sessions....I admired Miranda's ability to move into her role as a niece away from her role as nurse the way she did when we were together today. As I look back on my interview with her, I am beginning to notice a pattern that is interesting, a general pattern that is occurring within the format of the interviews themselves. The caregivers initially seem interested in reminiscing about times in music therapy following which grieving generally occurs. The caregivers then seem to focus on story telling, recalling life experiences in their own lives, with and without the patient. They then usually refer to their future directions. Finally, they offer gratitude and generalized comments regarding their overall thoughts about the music therapy sessions. This interests me because I am allowing the flow to evolve in the interviews. This may be a meaningful aspect in this study.

As I observed this pattern, I began to see a trend that each and every participant seemed to be experiencing, and that is *transcendence into meaning*. Each caregiver was finding a flow between past, present and future, inspired by their times in the music therapy, and each had seemingly perceived an ‘airplane view’ of their lives as a result of their experiences in sessions and also their reflections on times before, during and since the death. While this is a natural process that occurs during the end stages of illness and during bereavement, what was unique in these cases was the element of music, an element that is closely linked to the intricacies of feelings, images, words and
memories, and in essence, closely linked to the sentiments of love. Another unique aspect was the presence of the music therapist, the human presence that was noted to bring sentiments of compassion.

As described in Chapter VII, the caregivers noted qualities about music that were relevant for them. They described the tendency for music to act as a ‘conduit’ to ‘transport’ a person from one time, place or thought to another. For them music brought them to states of connectedness, remembrance and hope in significant ways, leading to moments of intimate sharing, improved sense of awareness and enhanced communication. It is well known that music stirs memories and is an access into the neurologically impaired mind (Aldridge, 2006). It is also known that music engages cognition, mobilizes emotion and inspires imagery (Salmon, 2001). These characteristics of music potentially describe how and why music is the ‘conduit’ that the participant Abe so astutely described.

Authors have described this trait of music that can provide a “track,” a pathway from one place of being to another. Aldridge (1995) maintains that music enables end-of-life patients to transcend, “to extend beyond the immediate context to achieve new perspectives...when they are encouraged to maintain a sense of well-being in the face of imminent biological and social loss” (p.107). Likewise, Lee (2005), states that: “the eloquence of music to provide a non-verbal path of meaning in the face of loss is a transcendental phenomenon of the greatest proportions” (p. 149). Moreover, music provides
form to what may appear chaotic and can offer an important aspect in spirituality, namely hope (Aldridge, 1995). The regularizing and stabilizing influence of music can, as we know, bring a mood of order to what otherwise may seem to be an uncontrollable time of flux and chaos. In addition, Magill (2006) states that the tendency for music to facilitate transcendence is most likely a result of the multi-dimensional nature of music and its potential to reach a multitude of domains simultaneously. She also refers to the significance of the role of the music therapist as conveyor of compassion and support, bringing a human presence that can inspire trust and facilitate communication.

The caregivers in this study vividly recalled the times spent in music therapy. They expressed being touched by seeing the notable responses in their loved ones. The music helped bring two of the patients “back to life.” The music also ‘carried’ two patients back to their Scottish and Irish homelands prior to their dying. In addition, the music helped build a “bond” between the patients and caregivers, as observed in the many examples referring to connectedness. The music also served to restore personal connection to their inner sources of faith and strength, for example through connectedness with the beyond. In these moments, they transcended, i.e. were each ‘lifted out’ of their current predicaments and were ‘lifted to’ other times and places of importance and ways of relating. This transcendence, then, was one of the primary fundamental aspects of their overall experiences, providing the means
through which they could each experience joy and empowerment and could attain some form of connectedness, remembrance and hope, all factors leading to enhanced life meaning.

From an overall perspective, the experience of transcendence provided the caregivers' with experiences that led them each to acquire a greater understanding of the meaning of their lives as they viewed their pasts, the present and their thoughts regarding the future. In some cases, the caregivers looked back on their life experiences and acknowledged the decisions they had made, seeing the ultimate reasons for and values of their choices, such as with Maddy’s decision to stay with her mother, Miranda’s decision to move her aunt to her apartment and Dahlia’s decisions to stay with Mrs. S. throughout the duration of her illness. In other cases, reconnecting to life events provided for greater appreciation for the lengthy course of relationships, such as with Ruth and Flora who had both been married to their husbands for many years and who both found joy in experiencing connections with them again in the music therapy sessions. Such moments, as those experienced in music therapy, seemed to help them each see that they each were fulfilling their inner potentials as they had each contributed to the lives of their loved ones. These moments also provided them with opportunities to regain a perspective of the meaning of the lives of their loved ones, as well as an enhanced perspective of their own personal lives. All the caregivers revealed that, for them, the times in
music therapy helped lead to unforgettable moments that brought them memories of joy and self-fulfillment, rather than memories of pain and distress.

The aspects of the music therapy experiences, that were important and meaningful to the caregivers, acted in a comprehensive manner towards transcendence into meaning. In other words, these aspects, such as joy, empowerment, connectedness, remembrance, hope and the qualities of music and the music therapist, all played roles in guiding the caregivers into transcendence and into enhanced sense of meaning. The music may be thought of as the ‘motivator,’ stirring emotions and cognitive processes, opening channels for communication and linking thoughts to images and memories. The role of the music therapist provided the supportive presence that offered encouragement and the enhancing of significant interactions and explorations. The presence of music and the music therapist played key roles in facilitating transcendence, the movement in sessions that resulted in feelings of joy and empowerment. The psycho emotional responses of joy and empowerment also acted as ‘motivators’ and ‘sustainers’, helping provide an impetus for moving forward through times of great difficulty. The processes of reflection on the present, past and future served to assist the caregivers in making sense of the course of their lives and the events therein. These reflective processes assisted them in gaining longer-term perspectives on their lives, affording them with a sense of fulfillment in knowing that their lives had and do have value and meaning.
Transcendence into meaning, then, occurred within and across the caregivers' experiences. The caregivers recalled the moments of intimacy in sessions with love, joy and feelings of empowerment, finding grounding in knowing that they helped provide for moments of peace and happiness during the days prior to death. These realizations brought them a greater sense of meaning and fulfillment, as acknowledged in their repeated words of gratitude for the 'gift' of these moments.

Transcendence into Meaning: A Proposed Model of Spiritual Reorganization

As a result of the findings in this study, I would like to offer a proposed model of spiritual reorganization that demonstrates the general process that often occurs as a result of music therapy (see Figure 1). This model exemplifies the potential stages that individuals may progress in and through as a result of participating in music therapy. With the supportive presence of music and the music therapist, caregivers generally experience transcendence, explore life events and achieve an improved sense of meaning. Thus, there is a tendency towards reorganization, i.e. a shifting from states of suffering, marked by inner turmoil and feelings of sadness and loss, to states of inner peace. This model is not intended as a step-by-step set of procedures, as there tends to be a cyclical and continual flow within and between each of these phases. This model is proposed, rather, as a generalized summary of the potential phases through which individuals may experience spiritual
Figure 1. Model of spiritual reorganization.
reorganization as a result of transcending in music therapy and attaining an enhanced sense of meaning and purpose. It has been my observation, as clinician and researcher, that spiritual reorganization occurs as patients and caregivers experience these phases in music therapy (see Figure 1).

1. Development of therapeutic trust: the caregivers acquire a trusting relationship with the therapist in which there is acceptance, understanding and an affirmation of strengths and personal attributes;

2. Reflection: with the support of the music therapist and music therapy techniques, the caregivers and those present in sessions are provided opportunities to reflect on the present (connectedness), past (remembrance) and future (hope) and transcend to places, times and thoughts of importance and meaning;

3. Expression: the caregivers are provided opportunities in music therapy techniques and verbal processing to ventilate thoughts and emotions underlying their feelings of tension, anxiety, remorse and/or guilt particularly as they pertain to thoughts about the present, the past and the future; they are also provided with opportunities in music to transcend into moments of connectedness with self, others and the beyond;

4. Activation: the caregivers and those present in sessions are provided opportunities to participate in music therapy techniques through which they may accomplish tasks aimed at restoring, healing and completing life relationship with self, others and the beyond; though such activation,
caregivers acquire improved self-efficacy, feelings of empowerment and overall sense of personal agency; and

5. Resolution: the acquisition of an enhanced sense of life meaning, resulting in feelings of accomplishment, fulfillment and inner peace.

Summary

As observed through the caregivers’ reflections, the moments in music therapy were transforming in many ways. These moments eased the distress, suffering, depression and listlessness, the disease-related conditions that were otherwise filling their days at home. As a result of the changes they witnessed and their improved interactions with their loved ones, the caregivers were affected positively as well. These experiences in music therapy facilitated transcendence, as they were able to see beyond their present circumstances and were able to have richer moments in communication, replete with love and closeness. Transcendence into meaning occurred as a result of this ‘being lifted out of’ suffering and sadness and ‘into’ these momentous experiences that were laced with feelings of joy and empowerment and times of connectedness, remembrance and hope. It was through these times that the caregivers gained deeper personal connections with the understanding the meaning of their lives.
CHAPTER IX
REFLECTIONS ON THE STUDY

This chapter intends to discuss issues concerning the methodology and scope of this study. Considerations regarding the interview process, the limitations and thoughts for future research are also addressed.

The Interview Process

Caregivers in this study were given opportunities to reflect on their experiences in music therapy with their dying loved ones within the interviews. The interview process allowed room for free-flow sharing and thus usually contained aspects of reflection, especially memories of events that occurred in music therapy sessions. The study, then, contained a retrospective approach of sorts, since the caregivers looked back on times that were meaningful for them in music therapy. As with any retrospective approach, the time that elapses between the events and the time of interview can alter one’s perceptions of the actual occurrences. While this is certainly a consideration, this was not the research focus of the study. The research study aimed instead to research the meaning of the experiences for the caregivers, specifically on how they are thinking and feeling during bereavement and if and how they construed
meaning from their experiences. This retrospective aspect of the study was a means to gaining an understanding of if and how time in music therapy helped the caregivers during bereavement and was not meant as an analysis of events as they occurred in process. The process of reflection seemed to be a way for them to describe the ways their experiences were being lived in their lives at the time of the interviews. This, in a sense, was the research focus of the study, i.e. to gather a deeper understanding of their current views on how this impacted their lives, especially from a spiritual standpoint. This open-ended interview style seemed to facilitate an integrative review as the caregivers seemed to naturally synthesize their experiences into the totality of their lives, past, present and future.

Another area of consideration in this study was the fact that I was the researcher conducting the interviews and was also the music therapist in sessions. This was an aspect that I considered in the development stages of this study. I considered the possibility that my presence could influence authentic communications in the interviews. On the contrary, it seemed that my presence instead facilitated discussions. The caregivers knew me and associated me with the times of meaning. They all seemed to feel free to share their tears and thoughts with me, as there seemed to be an inherent sense of trust in our relationships. They knew that I was intimately aware of the moments that were important to them and this seemed to help them discuss their experiences readily. It also seemed that my presence in the interview stirred reminiscence.
The caregivers and I had not met since the patient had died. Thus this was our first encounter since that time and in seeing me, the caregivers seemed to connect quickly and easily with feelings and memories of times spent together with the loved ones. Familiarity with me seemed to facilitate the process of reflection in this research study.

Reflections on the Overall Scope of this Study

As outlined throughout this document, the research focus of this study was aimed at discovering the spiritual meaning of music therapy in the caregivers post the death of their loved ones. While this was my original focus, at times themes emerged that were beyond the scope of spirituality. For example, as caregivers reflected on their overall experiences in music therapy, themes of joy and empowerment emerged. Also, there were aspects of their reflections on the roles of music and the music therapist that were not directly affiliated to spiritual themes, for example, the attention on the format of music and the interest in the specific gestures and characteristics of the music therapist. Thus, the scope of the study naturally expanded to include other areas of dimension.

While these said themes are not, in and of themselves, spiritual themes, they were parts of a greater whole, i.e., the overall trend towards transcendence into meaning that occurred in this study, as discussed in the previous chapter. In other words, for example, joy and empowerment facilitated
the caregivers in feeling comfortable enough to transcend and perceive an
‘airplane view’ of their lives as a whole, affording them a greater sense of
meaning and purpose. In addition, music, in an overall capacity, acted as a
catalyst, facilitating transcendence ‘out of’ despair and ‘into’ heightened
moments of awareness and connectedness. The presence of the music therapist
also acted to facilitate, at times, transcendence, for example, through the
initiation of meaningful techniques or with the use of supportive and reflective
listening interventions. The role of the music therapist also seemed a viable
contributor, since the depth of sharing and relating that occurred in interviews
seemed to be a direct result of the feelings of trust that these caregivers had
with the therapist. While the scope of this study shifted at times to include
other psycho emotional dimensions, there was a spiritual gestalt of experience
that occurred as the primary finding.

Implications of this Study for Music Therapy

To my knowledge, there is no qualitative research to date that has
studied the caregivers’ perceptions of the spiritual impact of home-based
palliative care music therapy on their times in bereavement. It is my hope that
this research will provide the music therapy and health care communities with
important information regarding the views of caregivers. As is documented in
literature, care of the caregivers has long lasting ramifications, providing for
healthy outcomes of grief and bereavement. This research demonstrates the
potential value of music therapy in end-of-life care to help assuage feelings of helplessness and guilt. The data revealed that the caregivers, as a result of music therapy, experienced feelings of joy and empowerment and found relief in moments of connectedness, remembrance and hope. This information affirms the importance of music therapy in this setting since joy and empowerment can sustain individuals through times of difficulty. This study also affirms the benefit of music therapy to provide for these times of pleasure and fulfillment since such memories can positively influence the grief process.

The design of this study allows for the relationship between caregivers and the music therapist to continue into bereavement. This seemed to provide the caregivers with opportunities to process grief as well as receive support from a familiar health care provider. Future music therapy researchers may want to consider the use of this methodology and refine and adapt it according to research interests.

**Limitations and Future Considerations**

This study had some limitations. It was a small study with seven participants. A larger study would allow for opportunities to learn the viewpoints of more caregivers. After seven interviews, a saturation of data occurred as emergent themes were consistently recurring. Thus, the size of this study seemed to be sufficient. Nevertheless, a larger study would allow for the possibility for other themes to emerge, such as any potential counter effects of
music therapy on caregivers, a result that did not appear in this study. Another potential limitation of this study is that the participants were at varying stages of bereavement, ranging from two months to two years post-death. While this did not seem to affect the themes since the themes were consistent across interviews, a study focusing on the meaning of the music therapy experiences at different stages of bereavement may elicit other information that would benefit health care professionals.

While the dual relationship between researcher and music therapist was found to be a beneficial aspect of this study, it is possible that it could at times be a limitation as well. Therefore, it is important for the researcher to undertake personal exploration during the course of the study in order to be able to set aside presumptions and prior determinations. This self-inquiry also affords other music therapists an understanding of the experiences of the music therapist during the bereavement stages of patients with whom they worked. Future researchers may want to consider a heuristic component in a study of this nature.

The music and experiences in sessions had different meanings for different people. The qualitative methodology allowed for personal viewpoints to emerge. The interviews allowed for open reflections by the participants on their perceived meanings of the experiences. While this study sought to examine the experiences of caregivers in bereavement, future research to look at the meanings as perceived by the patients would provide music therapists
the opportunity to understand the spiritual views of patients during end-of-life stages.

**Summary**

This study has allowed for us, as health care providers, to walk alongside the caregivers and gain glimpses through their eyes into the essence of their reflections on their times in music therapy. The importance of these moments, when considered from a whole life perspective, goes beyond the limits of human verbiage. Seeing a loved one ‘come back’ long enough to be with loved ones in moments of intimate communication again can have lasting impressions and can lead to inner healing, healing that carries on into the future. Such healing can be, and often is, passed on from generation to generation, as dying takes on new associations and meanings. We have been able to learn the value of music therapy as expressed by these caregivers, as they describe the ways in which they, along with their dying loved ones, were able to transcend their suffering and acquire sense of meaning. They live knowing that they helped prepare the path for a peaceful death in providing for moments of smiles and songs. If transcendence is the final stage of human growth, then the essence of the value of music therapy during the end-stage of life is as a gift beyond words.

Life lies before us, reminding us all of the gifts we have within us, our potentials to grasp the essence of ‘who we are’ and ‘why we are here’ as
humans on this planet. We have within our reach the sounds of music that can help lift us to heightened awareness and carry us to our inner reservoirs of strength and knowledge, reservoirs that serve to remind us to understand that we are “fulfilling a unique role and purpose in a life that is a gift” (Frankl, 1959/1992). It is my hope that this study serves to inspire the reader to find the meaning in the moments of connectedness, remembrance and hope and to resonate and live with feelings of joy and empowerment knowing the value and true meaning of one’s life.

I leave in our hands the words of a dying patient as we seek to help ourselves and others look into the life we have before us, to gather the essence of the gifts within each human being and find meaning in our moments each day.

When I am in the presence of music,
I hear the voice of God.
When I am in the presence of music,
I fly like a bird.
When I am in the presence of music,
My spirit is free and I am in peace.
REFERENCES


American Music Therapy Association. (www.musictherapy.org)


National Hospice and Palliative Care Organization (NHPCO). www.nhpco.org


APPENDIX A

OVERVIEW OF THEME STATEMENTS

This list includes all of the theme statements from Chapters V- VI

THE CAREGIVERS’ REFLECTIONS: RESPONSES TO EXPERIENCES IN MUSIC THERAPY

Joy: “These times were times of great joy and pleasure for me”

Empowerment: “I feel happy that I was able to help and give something to my loved one”

THE CAREGIVERS’ REFLECTIONS: CONNECTEDNESS, REMEMBRANCE AND HOPE

Connectedness: “In these moments, I found connection with my loved one and the greater scheme of things”

Remembrance: “My life has been a long and full journey. I am grateful for my loved one”

Hope: “I am looking forward to doing some of the things I want to do now”

THE CAREGIVERS’ REFLECTIONS ON THE ROLES OF MUSIC AND THE MUSIC THERAPIST

The Role of Music: “Music brings us all joy, peace and love”

The Role of the Music Therapist: “You Made a Difference”
APPENDIX B

CONSENT FORM
Title of research study: "The Spiritual Meaning of Music Therapy Post the Death of a Loved One: A Qualitative Study of Surviving Caregivers"

Consent Form

You have been invited to take part in a research study to learn about how music therapy sessions, held prior to the death of a loved one, impact spirituality in surviving caregivers. This study will be conducted by Lucille Anne Magill, Department of Music and Performing Arts Professions, Steinhardt School of Education, New York University, as a part of her Doctoral dissertation. Her faculty sponsor is Professor Barbara Hesser, Department of Music and Performing Arts Professions, Steinhardt School of Education, New York University.

If you agree to be in this study, you will be asked to do the following:

1. Meet with the investigator at a time of your convenience
2. Take part in an interview to answer questions regarding the impact of music therapy on you as a caregiver
3. Review the written transcription of the interview so that you can make any changes you may want to make
4. Meet with the investigator a second time so that the investigator may review her findings with you; you will be offered opportunities to provide input to these findings.

Your interviews will be audio-taped. You may review these tapes and request that all or any portion of the tapes be destroyed.

Participation in this study will take approximately 2 1/2- 3 hours of your time: 45 minutes to complete 1 interview, 1 hour to review the written transcription of the interview, and 45 minutes to meet with the investigator a second time to review the findings.

There are no known risks associated with your participation in this research beyond those of everyday life. Although you will receive no direct benefits, this research may help the investigator understand how music therapy sessions, held prior to the death of a loved one, impact spirituality in surviving caregivers.

Confidentiality of your research records will be strictly maintained by assigning pseudonyms to each participant so that data is never directly linked to individual identity.
Participation in this study is voluntary. You may refuse to participate or withdraw at anytime without penalty. For interviews, questionnaires, or surveys, you have the right to skip or not answer any questions you prefer not to answer.

Non participation or withdrawal will not affect any continuing relationship you may have with the Cabrini Hospice Bereavement Coordinator.

If there is anything about the study or your participation that is unclear or that you do not understand, if you have questions or wish to report a research-related problem, you may contact Lucille Anne Magill at (917) 434-7411, lucannem@yahoo.com, 35 West 4th Street; New York, N.Y. 10012, or the faculty sponsor, Barbara Hesser at (212) 988-5452, bh3@nyu.edu, 35 West 4th Street, New York, N.Y. 10012.

For questions about your rights as a research participant, you may contact the University Committee on Activities Involving Human Subjects, New York University, 15 Washington Place, #1-A, New York, New York, 10003, at human.subjects@nyu.edu or (212) 998-4808 or human.subjects@nyu.edu.

You have received a copy of this consent document to keep.

Agreement to Participate

Subject's Signature & Date