Music Therapy and Dynamics in Families of Terminally Ill Mothers

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Music Therapy and Dynamics
in Families of Terminally Ill Mothers

by

Kimberly Light Febres

A Master's Thesis Submitted to the Faculty of
Montclair State University
In Partial Fulfillment of the Requirements
For the Degree of
Master of Arts in Music, concentration in music therapy

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MUSIC THERAPY AND DYNAMICS
IN FAMILIES OF TERMINALLY ILL MOTHERS

A THESIS

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Montclair State University
Montclair, NJ
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Abstract

This thesis focuses on aspects and interactions related to communication and music therapy in family units with a terminally ill mother. Post-treatment analysis of music therapy with four terminally ill female patients and their families was used to study patterns in communication and explore how music therapy may serve to facilitate interaction amongst family members. All patients were mothers and familial issues pertaining to this role were explored.

In order to better support this population, it is important for music therapists to understand the various needs and dynamics of terminally ill patients and their families. In this thesis, physical and psychosocial needs are discussed, along with music therapy interventions that may be effective in communicating and meeting those needs. Through case examples, the stories of four families are presented in the hope of broadening understanding of family-centered music therapy with terminally ill mothers. The case examples present patients of different ages and stages of life, all with children. In two of the cases, the children were adults and in two of the cases the children were under eighteen. The special needs relating to both situations were explored.

In all cases, music therapy appeared to have a positive effect on the communication issues and family dynamics. Through interpretation and study of post-treatment session notes, common themes in treatment of terminally ill mothers were found. These themes included safety in the music therapy sessions, enhanced awareness of emotions, increased acceptance of the terminal diagnoses, release and re-allocation of roles within the family unit, and openness in communication. Through the case examples,
the writer explores these themes and discusses their implication for work with terminally ill patients and their families.
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Review of the Literature

One of the difficulties a terminally ill patient must face is dealing with familial issues. Communication in families is often hindered during the terminal phase of an illness, though this is the time when patients may need the most support from their family members. Openness helps the family to function under the stress of an illness (Hockley, 2000). Most patients desire this openness so they can work towards being reconciled with their families and telling their loved ones their feelings about their illness and impending death. Research shows that differences in the dynamics of family communication occur as a result of age, stage of life, and stage of the illness (Hockley, 2000). It is important to consider the mental, emotional, and physical needs of the individual patient in conjunction with the family unit as a whole. When the patient is the mother, very specific issues arise related to family dynamics, due to her role within the family unit. For this reason, I will be discussing the needs of terminally ill mothers and a family-centered approach to music therapy in working with the patients and their families. I will also illustrate the benefits of music therapy for family communication through four case studies with terminally ill mothers.

General Needs of the Patient

Aldridge (1996) outlines some of the mental, emotional, and physical changes terminally ill patients experience. Patients must cope with physical changes such as anticipation and management of pain, changes in physical appearance, and management of the physical side effects of the treatment and medication they are receiving. They must also cope with personal changes, including loss of hope and identity, anxiety and depression about the future, loss of role in their family, loss of occupation, and feelings of
helplessness. Relationship changes and spiritual changes such as social isolation, accepting dependency, and discussing death also result from a diagnosis of terminal illness. Patients may experience spiritual issues such as doubts, faith questions, and existential questions.

Patients with terminal diagnoses have a strong desire for a peaceful death (Aldridge, 1999). In order to achieve this, it is important that they remember past events and friends, enhance their awareness of their being-in-the-world, and learn how to cope with their disease. This allows patients to reconcile difficult issues that might prevent them from gaining peace. Fears and uncertainty about the future are also concerns which hinder patients from attaining the peace they hope for. For example, some terminal patients fear amputation and pain, uncertainty about the success of the treatment, recurrence of the disease, deterioration of health, death, social stigma and discrimination associated with the illness (Aldridge, 1996). Other worries that may prevent patients from achieving a sense of peace are related to their social and professional life as well as financial implications of the illness and impending death. In order to attend to these problems, patients often neglect their own personal needs. In other words, patients may focus more on environmental concerns and worries related to other people in their lives than on preparation for their own death. This preoccupation seems especially germane in the case of mothers.

A central theme in the care of terminally ill patients is the importance of fostering hope. Terminally ill patients often need the help of their family to find hope, even though death may be imminent (Bascom & Tolle, 1995). A study by Aldridge (1996) was geared at identifying various facets of hope and how to foster it. Seven hope-fostering categories
were found including interpersonal connectedness, attainable aims, spiritual base, personal attributes, light-heartedness, uplifting memories, and affirmation of worth. Three hope-hindering categories are abandonment and isolation, uncontrollable pain and discomfort, and devaluation of personhood. Music therapy interventions can foster hope in these categories due to their emphasis on emotional expression, exploration and enhancement of the patient’s creativity and productivity, musical and nonmusical relatedness to others, nurturance, and validation of the Self. Music and hope are alike in that both are dynamic and involve the use thoughts, feelings, experiences, and actions (Aldridge, 1996).

Family Roles

A terminal illness almost always results in role reallocations, and even role reversals, within the family unit, especially if the patient has been the caregiver. Berardo and Berardo (1992) point out that families who heavily relied on certain roles before the onset of the illness are prone to be less flexible and less able to cope with role reallocation. Previous levels of independence and increasing levels of dependency will affect the structure of the family unit.

The current study focused on the mother as the patient and the way family dynamics are affected by her illness. Due to her role and presence within the family structure, the mother often has a significant effect on the dynamics of the family and the development of the children. Many of the family members may take on the same reactions experienced by the mother, such as fear, anxiety, and uncertainty. Terminal illness “can potentially be even more traumatic for patients’ children than it is for the patients themselves” (Harvey & Miller, 2000, p.167). Young children may be unsure of
how to express their pain and grief and are confused about what is happening to their mother. Adults should be open and honest with their children in order to help them understand, and should speak to them in terms appropriate for their developmental level (Becvar, 2001). Many children of various ages will struggle with wanting to help their mother by taking on the caregiver role but, at the same time, wanting to go on with their own lives and activities (Harvey & Miller, 2000). Young adults may feel like they are being abandoned and may need to communicate their sadness at planning for a future without their parent. They may face the realization that their mother will not be there for important goals and milestones such as graduation, marriage, and parenthood (Becvar, 2001). In families with multiple siblings, the eldest often feels obligated to take on a parental role. For older adults, the loss of their mother is usually felt with great emotional distress because they may have achieved an improved sense of acceptance and understanding of their mother’s role in their lives (Bouvard & Gladu, 1998, in Becvar, 2001). One of life’s most difficult trials is losing a mother, no matter at what the age. When a mother is suffering from a painful disease like cancer, children of any age may endure intense grief, feelings of helplessness, and confusion. In general, it is distressing for children to watch their parent age, but when a mother’s life is ended prematurely due to a disease it can be even more upsetting.

Husbands also have a difficult time coping, especially if they were not previously the primary caregiver of the children. Although in today’s society there are many households in which both husband and wife have full-time professions and equally share the task of raising children and caring for the home, there are still many homes in which the wife is the primary homemaker. In these cases, the husband may have trouble
adjusting to the role reversal in the home. For example, he may not be used to waiting on
his family (Kubler-Ross, 1969). Out of this role-reorganization often come feelings of
guilt, confusion, and resentment. Studies have also found that children may begin to have
negative feelings and resentment towards the healthy parent as a result of the father’s
degree of emotional reaction and demands placed on the child (Harvey & Miller, 2000).

Communication

Besides having profound effects on established roles and dynamics within a
family unit, the presence of a major stressor, such as confrontation with terminal illness,
also affects familial communication patterns. Although the physical stresses and changes
may be vast, psychosocial and spiritual needs may be far more complex and disturbing
for the patients to deal with and for their family to witness (Aldridge, 1999). And it is
these psychosocial and spiritual needs that may most profoundly affect communication
amongst family members.

Terminally ill patients often have a strong desire to be reconciled with their
families and a need to share their feelings with their loved ones. It is often important for
the patient to be able to discuss the illness and threat of loss with the family. However,
not all family members may be ready to engage in an advanced level of discourse. In
many cases, the patient and/or the other members of the family will use emotional
distance to avoid communication of feelings of fear or loss. Avoidance of discussion of
death and the subsequent interactions between the family members during hospital visits
and at home may contribute to stress and anxiety levels of the patient and other family
members.
Terminally ill patients are often burdened by the need to protect their loved ones from the physical pain as well as the emotional burdens they are feeling (Gilbar & Ben-Zur, 2002). Especially in the case of mothers who are accustomed to being caregivers, there is a need to protect the family from witnessing their physical suffering. Therefore, dying mothers often suppress expression of their feelings and reactions. Berardo and Berardo (1992) state that good communication patterns in the family aid in dealing with a terminal illness. Bascom and Tolle (1995) discuss the support patients and their families need related to guidance and planning for future decisions. They also discuss the emotional burdens of the family, especially when they choose to have their loved one come home to die. They must learn new caregiver skills, including helping their loved one prepare for death.

Nadeau (1998) studied communication patterns of family members related to death of a loved one and found that family members use simple conversation methods to make sense of death and their grief. In her study, Nadeau found that family members communicate by means of several methods, which she calls family speak. “Family speak includes agreeing/disagreeing, referencing, interrupting, echoing, finishing sentences, elaborating, and questioning” (Nadeau, 1998, p.148). These methods allow different family members to have a voice in the conversation and also to support each other. For example, echoing and elaborating indicate that family members are listening to each other, and suggest a feeling of speaking in one voice. Disagreeing and questioning allow family members to differentiate themselves from one another. These methods of communication contribute to the process of the family’s meaning-making of the illness and impending death. As will become clear in the case studies provided, music therapy
can play a significant role in strengthening the voice of each family member, including
the patient.

Aldridge (1996) refers to a study in which family adaptation to terminal illness
was measured by looking at the number of stressful events after the diagnosis, as well as
role flexibility. Results showed that families dealing with terminal illness experience
higher stress levels, reduced emotional expression, and reduced levels of trust. Kubler-
Ross (1969) suggests that the dying person may model sharing thoughts and feelings in
order to let other family members know that it is acceptable to do so.

One should not ignore the importance of non-verbal communication between
family members as an effective way to communicate both positive and negative
sentiments. Family members become particularly skilled in reading each other’s body
language. For this reason, a non-verbal medium for expression can be a powerful tool.
Work in creative arts therapies other than music has proven to be effective in helping
patients and families cope with illness. For example, art therapy has been used to help
terminally ill patients with self-expression and to communicate feelings of vulnerability
and concern (Teufel, 1995).

Musik Therapy at the End-of-Life

In the field of music therapy, many different interventions have been used to meet
the needs of terminally ill patients. Music therapy encourages exploration of “new modes
of expression and, in the context of the musical relationship, allowing a new identity to
emerge” (Aldridge, 1996, p.221). Patients are given back their individuality during music
therapy, as well as a level of independence. They can make decisions and have an
influence over the direction of the session. This is contrary to the way they may feel
about what is happening to their bodies. Taking this role in therapy gives the patient the opportunity to take the initiative in coping with the disease and become an active partner in their own care. In addition, music therapy can provide intimacy for the patients with his or her body. This is of crucial importance as individuals with a terminal illness often become disconnected from their body (Gilbar & Ben-Zur, 2002). This disconnect is often a result of an attempt to escape the reality of a degenerating body and increasing physical pain. Moreover, such disconnect helps to sustain a suppression of awareness of inner emotions. Therefore, an important function of music therapy is to help to re-establish a relatedness and awareness at a bodily and an emotional level.

Hogan (as cited in Aldridge, 1999) describes several music therapy techniques suitable for use in palliative care. Techniques may include song choice, recordings, life review, song writing, and planning music for the funeral. Song choice involves offering the patient or family a list of songs and lyrics to choose from, usually songs with a variety of styles and themes. As many patients and their family members frequently choose to deny the need to process their feelings about dying, song choice may be very helpful in offering a non-threatening way to experience current feelings, communicate with loved ones, and experience positive memories. This technique is extremely useful in music therapy sessions for several other reasons. First, it allows patients and families to exercise some control over the direction and depth of the session. A song often serves as a jumping board for discussion of difficult topics, as will be presented in the following case studies. Song choice also allows people to express their feelings through the lyrics in the songs, rather than directly with words. This process may be conscious or unconscious and still accomplish self-expression and possibly awareness of feelings. Lastly, song choice is
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an effective assessment tool. The therapist may note which songs a patient chooses and which ones are avoided. The types of songs a patient and family members avoid may be reflective of some emotional and communicative roadblocks. The therapist can also take the opportunity to observe the patients’ verbal and nonverbal reactions to songs. It is important to involve the family in the process as much as possible, as this may help with redistribution of roles, and adaptation thereof, in the family unit. Asking family members to choose songs provides support and reflects the moods of the family members.

Life review is another useful intervention. In this technique, patients recall past events through singing, listening to, and playing music that was important during different parts of their lives. Patients discuss associations and memories triggered by the music with the therapist. Music can be chosen to represent important family events or memories during the patient’s life. Patients often make tapes of the songs they chose for their life review and listen to them during times of severe pain, fear, and loneliness. These tapes can also be passed on to families as a comfort during bereavement. A recorded life review can be a wonderful gift for family and friends to keep in remembrance of their lost loved one. It is also a safe way for the dying patient to communicate special messages to their family, which they can listen to later.

Song writing is also a viable way for terminally ill patients to explore and express their feelings. O’Callaghan (1997) discusses this method in her article, describing song writing as a way to access repressed feelings, enhance insight into personal problems, develop cohesion when done in a group, and enhance feelings of belonging, cooperation, and pride. Song writing can be done by creating original melodies and lyrics or by substituting new words to existing songs. Songs can be presented as gifts to the family.
from the patient. Common themes that emerge during song writing were analyzed by O’Callaghan. Most songs composed by patients are meant to express important messages to people in their lives. Themes of the songs are varied, but include reflections on aspects of themselves, compliments to others, memories, reflections on the patient’s loved ones, self-expression of pain, imagery, and prayers. Many patients with degenerative illnesses suffer cognitive impairment, but can still benefit from song writing, according to O’Callaghan. Therapists can help them create songs by providing structure and encouraging their responses.

O’Callaghan describes the many therapeutic benefits associated with song writing, such as the chance for the patient to express himself creatively through lyrics and music and the promotion of physical and social well-being, such as singing to use more of the lung capacity of the patient. Song writing also allows patients to make creative choices, offers opportunities for counseling, the melodies may offer comfort for the patient, and it validates emotional expression.

*Family-centered Music Therapy*

In order to explicate my philosophy in working with families, I will briefly discuss the family-centered model of music therapy. Families have specific needs that may be addressed through group therapy. The therapist must be aware of the complex relationships and intricate interactions between each family member. The interactions are complex due to equifinality, the idea that there are many ways to get to the same destination. Family-centered therapy addresses the family as a unit and treatment is designed to bring about change within the family structure that leads to stability (Scharf, 2004). It may help families who struggle with communication and unity when they face
difficult relational issues or life events, in this case illness and impending death. Family therapy helps to promote agency and communion within the family. Other goals of this model are to promote awareness of patterns and imbalance that exist within the family unit, differentiation of self, and developing appropriate boundaries. This approach may eventually allow families to engage in freer verbal communication, better interactions, enhanced emotional awareness, and greater tolerance for each other. The use of music experiences in family therapy enhances the potential for active engagement of all family members (Decuir, 1991).

According to Patterson and Dorfman (2002), family members provide instrumental support for their terminally ill loved one. It is important for caregivers such as music therapists to provide them with the tools and support they will need in order to help their loved one. When used in conjunction with music therapy, the music serves as a bridge between each family member’s thought processes and interaction with other family members. The use of music therapy allows the expression of feelings to occur in the here-and-now, without much premeditation or rehearsal. Clients bring their fears, pain, as well as joys and love into the music therapy sessions. These different emotions are often played out in their musical interactions with each other and with the music therapist. Music therapy sessions provide a space for clients to explore and discover themselves, finding meaning in their musical interactions with each other.

Rationale

Although there is some literature available about how to include the family in the music therapy sessions of a terminally ill patient, there is limited information available specifically related to the dynamics and process of communication. For this reason,
additional studies are needed to assist clinicians in enhancing their effectiveness in working with the families of this population. I decided it would be most helpful to report on my personal experiences in working with terminally ill mothers and their families to further understanding of this topic. Although this thesis does not claim to provide a standardized method for working with this population, it does demonstrate real life examples of four families struggling to cope with impending death. It is my hope that through these examples, other clinicians may gain insight into the various needs of families facing terminal illness and the potential benefits of music therapy for working through family dynamics.
Method

Design

This thesis resulted from a growing interest in communication patterns as I was working with patients at my internship setting. I used a retrospective case study design to enhance understanding of family communication conflicts and resolutions in the context of music therapy treatment. Four case studies are presented. Through descriptive narrative, in-the-moment interactions and music making in the music therapy sessions, communication patterns amongst family members and the patients, and changes thereof are explored. Each case is discussed in terms of implication for music therapy work with this population. Each case describes a detailed background of the patient and family, including medical history, a description of session events, and a discussion of the effect of the music on family communication.

The case studies provide detailed descriptions of the music therapy sessions as they occurred; no alteration of treatment took place in any way. During the course of my internship training, I kept detailed notes on all of my patients and music therapy sessions. Any session notes taken or patient information collected was common practice for interns at this setting. Those notes were subsequently examined post-facto for potential use as case examples once my thesis topic was developed. The four families selected for the cases presented in this thesis were selected after their treatment was complete. They were selected partly because my notes about these sessions were comprehensive throughout the treatment. However, the major disadvantage for using past notes for these case studies was that, at times, my notes were not as detailed as I would have wanted them to be.
Participants

The patients in the case studies were hospitalized in a major hospital on the East Coast, where I completed my music therapy internship. They were mothers who had been diagnosed with terminal cancer. In the case studies, fictitious names are used for the patients and their family members and no identifying information is revealed to protect patient’s privacy rights.

Contextualizing

I have chosen to explore this topic because of a personal interest in working with terminally ill patients in a palliative care program. The primary goal in palliative care is to help the patient die in the best way possible, integrating physical, psychological, social, and spiritual dimensions of the patient (Aldridge, 1999). Such a program serves to alleviate the symptoms of a disease and does not strive for a cure (Bruscia, 1991). Rather, the philosophy is geared towards improving the quality of life, providing comfort and symptom management. In this context, the familial issues play a major role in the emotional and psychological well-being of the patient because the family dynamics may affect how the patient experiences their illness. With this writing, I hoped to explore and report how music therapy may be used to help the patient die more comfortably and with more dignity as well. Likewise, I experienced that through music therapy sessions, the family members were able to resolve issues with the dying patient, thus being a better support for the patients and being better prepared themselves for the death and the consequent grieving process.

I worked with this population during a 9-month music therapy internship and it is work I hope to do professionally now that my internship is completed. This process has
helped me to better understand the issues related to working in palliative care and working with families. It was also extremely relevant and meaningful to the lives of the families in the case examples as they dealt with difficult issues.

I chose these four families as examples because I had a strong reaction to the circumstances in each of their cases and felt connected to each of them in a powerful way. However, this was true for many of the patients I worked with during my internship. Above all, I felt that these four women represented four different family units with different issues and different dynamics.

Data Collection through Journaling

All sessions were conducted during my internship training. Session notes on families who met the criteria for the case studies were examined after their treatment was complete: the patients had regular visits from their families in which music therapy sessions occurred. Detailed information regarding the medical and social history of the patients was gathered from medical charts at the start of treatment with each of the patients as a routine procedure. Self-reports from the patient and family regarding their current status were obtained at various points before, during, and after music therapy sessions as a part of treatment and ongoing assessments of psychosocial and physical status. Session notes were geared at describing any events that took place during the sessions, so that they could be analyzed later for significance during supervision sessions and self-work. In addition, the therapist’s personal reflections such as interpretation of events and emotional reactions were recorded immediately following the session. Due to restrictions at my internship site, post-facto analysis was the only form of reporting available to me for a thesis project.
Analysis

Following my internship, all session notes were reviewed to determine which families could best represent various aspects of communication enhancement through music therapy. Once the cases were selected, an inventory of all gathered data was taken. After studying the session notes in detail, I conducted a content analysis of the session notes to identify significant events and themes related to family dynamics. The following guiding questions were considered during the content analysis:

- What significance did music therapy have for communication issues in these families as interpreted by the music therapist?
- What did the patient/family share during the sessions regarding the significance of music therapy concerning family dynamics?
- What did the music therapist notice about family communication issues during music therapy sessions?
- What personal reactions did the music therapist experience related to communication issues and family dynamics she observed?

It is important to note that these questions served as a guide only during post-session analysis. After performing the content analysis, I organized recurring themes and patterns from the different studies into condensed versions. I then assigned labels to each of the recurring themes so that I was able to trace them throughout the four case examples as they transpired.

After labeling recurring themes throughout the four cases, I was able to synthesize the data to compare similarities between the cases in terms of the families’ communication needs and interventions that were effective in meeting those needs.
During the analysis process, I collaborated with my thesis advisor to check the accuracy of the case summaries. A descriptive case study format was used to present the most pertinent data within each case, followed by a conclusions section to tie the four cases together. Common themes between cases were identified and discussed in depth in this section.
Case Study 1: Marie

What a Wonderful World: Remember Me with Music

This case discusses the grief faced by an adult child and her mother’s last gift to her family. In this case, I will reflect on the relational dynamics and communication between a mother and a daughter at the end of the mother’s life. I will also describe the role of the spouse in bringing the family together through music therapy. The specific technique of life review played a central role in the music therapy process, and this technique will be discussed within the context of work with this family. My own countertransferences and grief reactions will also be explored.

Background Information

Medical history.

Marie was a 66 year old female with uterine carcinosarcoma. She was diagnosed in December of 2003 and underwent surgery in January of 2004. Doctors were not able to remove the entire tumor, so she received chemotherapy and radiation treatments throughout 2004 in an attempt to reduce the tumor. Late in 2004, the cancer spread to the tissue surrounding the uterus and was inoperable. Marie continued to receive radiation therapy as supportive treatment. She was admitted to the hospital in early June 2005 with abdominal pain, fatigue, and nausea. Shortly after her admission, she declared herself a Do Not Resuscitate (DNR) case.

Disease information.

Uterine carcinosarcoma is an infrequent form of uterine cancer, although it is the most common type of uterine sarcoma. Tumors contain malignant cells transformed from cells normally found in the uterus. It can spread to the tissue surrounding the uterus and
cervix, to the bladder, groin, pelvic lymph nodes, and also to the liver, lung, and brain. Exact cause is unknown, but age has been found to be a factor, as well as previous pelvic radiation.

Family information.

Marie is married and lives with her husband Douglas. Marie is a warm person with a sweet disposition. She has pale skin and reddish brown hair which is always nicely curled. She and her husband have four grown children and three grandchildren. Three of their children are married and they live out of state with the grandchildren. Their youngest daughter, Karen, is 28 years old, is single, and lives about twenty minutes away from them. She provides support and help for her parents when they need it. According to Marie, their family is close knit, even though some of the children live far away. She talks to her children and grandchildren over the phone several times per week and they fly or drive out to see her and her husband three to four times a year. Douglas is a retired police officer and Marie is a retired teacher.

Treatment Process

Music takes me away.

Marie was referred by the hospital social worker for psychosocial needs related to end-of-life care, as well as pain management. I worked with Marie during the summer months of my internship and she was one of the first patients I went to see on my own. The first time I went to see Marie, both her husband Douglas and her daughter Karen were present. Marie was lying reclined in her bed and had a very peaceful and pleasant expression on her face. I was immediately struck by the bright lighting in the room, the many “Get Well Soon” cards posted on her bulletin board, flowers and balloons on the
window sill, and pictures up on the walls. Even though she had only been in the hospital for a couple of days at that point, it seemed that she and her family had tried to make the room homey. The cards and flowers showed evidence of support from friends and family.

I explained to Marie and her family what music therapy was and the different ways she could use music, such as for pain management, sensory stimulation, music listening and relaxation, and active participation. They immediately seemed pleased that she had been referred for music therapy services, especially Douglas. He said their family had always loved music and constantly enjoyed music together. He said none of them were musicians, but they had always experienced music socially, singing together at family functions, going to the symphony or to plays, and listening to music frequently at home. Marie mentioned that they listened to music far more than they ever watched television. I asked her if she had any favorite styles or singers. She said her tastes were diverse, but she loved Simon and Garfunkel, Neil Diamond, and Bette Midler. Karen also mentioned that she and her mother had always loved to sing in community or church choirs.

I began by using song choice as a way to assess not only the family’s musical preference, but also the type of songs and song lyrics they were willing to choose. Marie looked at the book and immediately chose *What a Wonderful World*. She said it was one of her favorite songs and was one of her other daughter’s wedding songs. I told her she could join me in singing, but she said she just wanted to listen. Karen said she would sing along, so I gave her a copy of the songbook with lyrics. As we sang the song, Marie began to cry – not sobbing or even crying out loud, but just allowing tears to run down her face. She closed her eyes as she listened to the music and seemed to have such a
peaceful way of letting the music surround her. I mentioned this to her when the music was over, and asked her what was going on for her as she listened to the music. She said she has often found that music takes her away to another place, reminding her of good times. I asked if she was thinking about her daughter’s wedding. She said yes, she felt like she was right back at the reception hall, watching her daughter and her new son-in-law have their first dance together. While she was describing this image, I could almost see her vision, and I felt tightness in my throat as she shared the details. She pointed out a picture of the daughter she was talking about on her bulletin board.

She then asked me if I knew *Sweet Caroline* because it reminded her of one of her grandchildren. This session was one of my first experiences as a music therapist in seeing the power of song choice and how people often choose songs that remind them of people or places. Using music to remember people or go to another place in life can be comforting and soothing for patients, especially when they can not be with their whole families. I did not know the song, but promised her I would look for it for the next time.

Douglas looked through the songbook and chose *Blowing in the Wind*. Karen sang with me as Marie and Douglas listened together. Douglas began reminiscing about times they had sat in their living room singing together when all of the children still lived at home. He told me he used to play the guitar while everyone sang. According to Douglas, they sang everything from the popular music of the time to show tunes to hymns and spirituals. I offered my guitar to him, but he said he had not played in years and did not think he would remember. Still, he expressed some of his fond memories of having music in their home and having the whole family together. For both him and Marie, the songs prompted reminiscence of times past. Since they had been so connected to music during
their lives, it seemed natural to reflect on music-related memories. After that song, I asked Karen if she would like to choose a song as well. She chose *From a Distance*, which we sang together for Marie. Karen mentioned that it felt good to get back to singing again and that she had not realized that she missed it. We closed the session at that time with *He’s Got the Whole World in His Hands* and put in the names of each of Marie’s children and grandchildren.

I felt almost immediately that music therapy would be beneficial for Marie and her family. It seemed that she had many life associations with music that she would be reminded of during our sessions. I realized after I left that no one had mentioned her illness, her pain, or her disease progression. It seemed like the family wanted to just be in the music together without clouding it with talk of death and dying. Since they had so many positive musical memories, I was not sure if any issues would come up relating to the end of Marie’s life in the music. However, I was hoping that the beauty of the music would provide them with the strength and courage to discuss the impending loss.

*Tearful moments.*

The next time I saw Marie, her husband and daughter were present again. Karen mentioned that Marie was in a lot of pain and they had just called the nurse for medication. However, Marie said she would love to hear music and asked her daughter to look at the list and select songs. I offered *Sweet Caroline*, which she had requested in the previous session and she agreed. This song began a discussion about her grandchildren. She showed the pictures of each of the grandchildren on her wall and told me their ages, what they liked to do, and how they each had a different name for her. Marie looked directly at me and said that her family’s support is important to her and it is difficult to be
far away from them. I empathized with her and she asked me if I also had a big family. I said I did and that we were also very close. She asked if I could sing *What a Wonderful World* again and she closed her eyes to listen, saying she wanted to go back to that place with her daughter. I encouraged her to do this, saying that one of the beautiful things about music is that it could take her almost anywhere she wanted to go. Douglas cried during the song as he watched his wife. After this song I felt that it was important to include him, so I said I could see how much he loved her and the rest of their family. They smiled at each other and that brief moment of nonverbal communication seemed to brighten Marie’s affect a bit.

Karen requested *Bridge over Troubled Water*, and Marie emphatically agreed. I asked if this song had a special meaning for her since it was the first time I had seen such a decisive response from her. She said the song reminded her that there were people there for her during troubled times. As I sang the song, Karen and Douglas cried. I mentioned to them that by being there for Marie they fit the description of the support offered in the song. Marie agreed that she loved having them with her to keep her company. At that point, I had the idea to use life review with Marie and her family, since she seemed to think of songs that reminded her of different people and places in her life. I suggested making a tape with her during my next visit, for which she could select special songs for her family as a way to honor them and share something with them. Marie thought this was a good idea and said she wanted to think about it so that she could choose the right songs for the tape. After this, the nurse came for routine care so I said I would be back the following week. She and her family smiled and thanked me for the music. Her
husband followed me out the door and asked me to make sure I recorded the tape with her next week, as it would be very important for them to have.

During the session, themes of family, support, and memories were present. Marie seemed to rely heavily on her family for support, although I sensed that it was difficult for her to allow them to see her in pain. According to her stories and her family’s reports, she seemed to be the matriarch of a big and close knit family. For this reason, she may have been having some difficulty feeling incapacitated and not able to be there for them. Perhaps in *Bridge over Troubled Water* she hoped to still be bridge for her family as much as she felt her loved ones providing that bridge for her. On the other hand, she seemed comfortable with allowing them to be there to support her instead. Since she had been sick for about eighteen months already, perhaps this was a role change she had become accustomed to. Her family’s support was a significant coping mechanism for her. Her eyes lit up when she talked about her children and grandchildren, and she looked over at her husband with tenderness and love. Her song choices were very significant and meaningful, and although some of the selections made her and her family cry, she seemed to want to choose songs that were important to them.

While I was with Marie and her family, I was often vividly reminded of my own family. We are also very close knit and have used music as a way to bond over the years. She was also pretty close to my mother’s age, and I think her very loving and caring nature made her like a mother figure to many people she met. For this reason, I experienced strong countertransferences towards her and her daughter, who is close to my age. I wondered what it would be like for me to know that my mother, who I am very close to, was dying. I imagine there would be feelings of helplessness and extreme loss.
There was a part of me that could not help being glad that it was not me in that situation. In a way I felt specially blessed, even though my mother is getting older and is not in the best of health, but she is not imminently dying. On the other hand, I felt that Karen was lucky that she was given the opportunity to prepare herself for the loss and to provide closure. Still, there was not much Karen could do for her mother beyond being there for her and keeping her company. Fortunately, that seemed to be something that caused Marie to feel loved, so it was healthy for both of them in this case. I knew at that point that it would be important for me to separate my feelings about fear of my own mother’s death with what I was observing and sensing in Karen.

Although we only had two sessions together up to that point, I felt that Marie was comfortable being open with me. I was curious to see what might be different if I had a session alone with her, without any family members present. She seemed comfortable expressing emotions during the music, and I felt a connection with her through the songs. As our relationship was growing, I hoped to continue to be able to offer her support through connection to her family and to the music.

One for each special moment.

For our next session, I went prepared with a tape recorder, several blank tapes, and several songbooks to give Marie many choices. Douglas was in the room and Marie was awake and alert. Since our last session, she had thought about and looked forward to creating a recording of special songs and had written out a list of possibilities. She said she wanted to pick a song for each special moment in her life. We discussed different ways she could make the recording. She could make one recording that covered all of the special songs she wanted to share, or she could make a recording for each of her children
and for her husband, with songs especially for them. She decided to make one recording that they could copy for everyone because she had such a big family. Before we started, she asked Douglas to leave for a little while because she wanted the final project to be a surprise.

I suggested that Marie say a few words before each song to explain why it was special to her or any special memories she had associated with the song. I welcomed her to sing with me as well, but she was not comfortable doing that. The first song on her list was *You Are My Sunshine*, which she remembered from when she was younger. On the tape she talked about how her mother had sung to her as a little girl and how she had grown up as a very happy and friendly child. Then she chose *It’s Now or Never* which reminded her of love songs that were popular when she and her husband got married. She talked about how they had met in church after her family moved to a new area and how she fell in love with him right away. She then chose *Que Sera Sera* for her children when they were younger, as she remembered how much hope she had for each of them. She talked about how each child was different and special in their own way, but they all had such promise when they were small. On the tape she said she was very proud of how far they all had come and how much they had accomplished. For the next part of the tape she chose a song for each of her four children. She chose *What a Wonderful World* for her daughter who had chosen it as her wedding song, because of the wonderful images in the song and how her daughter helped to make the world an even more beautiful place just by being who she was. *Can’t Help Falling in Love* was the wedding song of one of her sons, and she chose it because she was inspired and encouraged by the wonderful husband and father he was. She picked *Because You Loved Me* for her eldest son because she felt like...
he was always the strong one in the family. He had also dedicated this song to her at his wedding so she wanted to give it back to him as a gift. Finally, she chose *The Rose* for Karen. She said she thought of Karen as a beautiful flower who was blossoming every day and also as someone who had taught her important lessons about love and kindness.

At this point, Douglas returned and Marie said she needed a break. I agreed to return the following day to help her finish the project.

Throughout the taping, Marie often became emotional and cried as she spoke to each of her children. Several times I asked if she was okay to continue because I could sense so much raw emotion coming from her. At times, I also felt choked up because she was allowing me to join her on this intimate journey of special moments in her life with her family. It was an honor and a wonderful learning experience to see how Marie used the music to remember times that were precious to her.

I was not able to connect with Marie for the next few days due to medical procedures and scheduling conflicts. Finally, we got together to finish the tape. Marie wanted to choose a song that all of her grandchildren would like instead of choosing a song for each of them. I suggested *He's Got the Whole World in His Hands* because children love hearing their names in songs and this would be a way to include all of them. I sang the song and she filled in each of their names. Then she chose *Wind beneath My Wings* for Douglas, as a thank you for all of the support he had offered her through the years and the love he continued to show her. In her message to him, she said she felt that without him, she would not have lived such a full and happy life and she looked fondly on all of the memories they shared. Next, she chose *Bridge over Troubled Water* for all of her other friends and family who had been there for her through the years. Marie wanted
Amazing Grace to be the last song in her life review, saying that she truly felt blessed in her life as she had experienced the grace of God and all of the other people she had been in contact with. Marie sang a little bit with me for this song, especially in the third verse, “When we’ve been there ten thousand years…” After we were finished, she took my hand and squeezed it, thanking me for the idea of the tape. She told me she was expecting to go home in a few days and that this would be a special gift she could share with her family.

Marie really took this project on for herself, deciding what songs she wanted and how to organize the tape. My role in the process was as a facilitator, one who guided the process and provided the music. Since she reminded me so strongly of my own mother, I often found that I had to step back into myself and try not to identify with her too much. I was sad for Marie and the pain she had to endure, but out of all of the patients I worked with in my internship, she seemed to be one of the most accepting of her circumstances. Her family also seemed to be accepting, although I did not realize that their attitude of acceptance was for her benefit when they were in her presence, not necessarily a reflection of their true feelings.

Feeling lost.

A couple of days later, I met Karen in the hallway, looking upset. She told me her mother was sleeping and asked if I could come back. I said I could but said she looked like she might need a listening ear. She nodded and said she would like someone to talk to. We went to the patient lounge on the floor, which happened to be empty at the time. I asked her what was going on and she told me Marie was scheduled to go home the next day. Instead of looking pleased, she appeared very distraught. I asked her how she felt
about that and she responded that she was glad for her mom, but also very sad. She said that the doctors were thinking of putting her on hospice care, which she knew meant her mother would have six months or less left to live. She said, “I know she is sick, I know there’s no cure, but now they’re telling me this is really the end. I don’t even know what to do. I feel lost.” I asked her what she meant by feeling lost. She told me that she was closer to her mother than any of her other siblings were and even though she knew her mom was getting older, she hoped they would still have a long time left together. Now she knew that that was not going to happen. She wanted her mother to be around to see her get married and have children. It saddened her that her children would never know their maternal grandmother.

I strongly resonated with Karen during this conversation. I had always feared losing my mother at a young age, mostly because she is older than the mothers of most of my friends. I know that age does not always matter, but the fact remained that my mother would be elderly while I was still fairly young. Since she has a long history of heart disease and cancer in her family, I always worried that illness would claim her life too early for me to be without her. I went through my life hoping my mother would make each milestone I achieved: getting married, my college graduation, getting my Master’s degree, buying my first home, possibly having children some day. For me, those fears were normal thoughts that crossed my mind every so often, my own form of denial of her mortality. Now there I was, sitting with a young woman at about the same age and stage of life as me who was living my fears. I did not know what to say, except that I could not imagine what she was going through. I told her that her mom and I had been putting together a tape of songs that reminded her of special times in her life and asked Karen if
there was something she wanted to do to help her say goodbye to her mom. She said she was not sure if she was ready for that yet or if she ever would be, but she would like to have a chance to sing for her mom again with me before she left the hospital. I could tell her grief was intense. I told her I knew it would not be easy to hear, but time does help to heal our pain, as does support from others. I pointed out that she has a large support system in her family and that it might be helpful for her to rely on them during this difficult time, as they are also closely connected to her mother in their own ways. She agreed, but said it would be a long time before she was ready to lose her mother, even though she knew she might not have a long time. She said the one thing she felt like she had learned too late was that she should have been showing her mother all along how much she loved and appreciated her. She told me to make sure I did the same for my mother. That night on the train on my way home, I called my mother to tell her I loved her and thanked her for all she does.

The next day I visited Marie as she was preparing for discharge. Douglas and Karen were there and Karen asked her mom if she could sing a song for her. She chose *The Rose*. Marie looked at her and asked her if she had heard the tape yet. Karen said no, it was still in the hospital with the things they were packing to bring home. Marie looked tearful and told her that was a special song she had chosen for her as well. Karen looked surprised and I said, “I think your mom really understands how much you love her.” They both cried and hugged each other. I knew from conversations with Karen and Douglas that Marie’s discharge from the hospital was emotional for her family because it was one more hurdle that she had overcome in her disease progression. They also reported that they loved having her at home because they could be with her more often. I
gave Karen a copy of the lyrics to *The Rose* and we began singing it together. In the last verse, I sang a harmony part to allow Karen to have the main voice in the song. She sang the song strongly, often smiling at her mother. Marie and Douglas clapped at the end and said they loved it. They all thanked me for the music therapy and the opportunities it had given them to be in the music together. I presented them with a copy of the hospital songbook because they had loved so many of the songs from it. I told them I hoped they would continue to use music together as it seemed to bring them so much joy and peace.

*Therapist Reactions*

This was a difficult case for me in some ways because of my own feelings about losing my mother. Since it was one of the first women I worked with and she resembled my mother in so many ways, I was compelled to face my fears about losing my mother very early in my internship. Although I had done much reading and reflection about death and dying in preparation for my internship, this was the first time I was confronted with it face to face. I identified deeply with Karen and all she was going through. I also empathized with the other siblings who could not be with Marie as much. They must have also been having a hard time dealing with the loss of their mother, even though they were already physically separated from her. It is different not to be able to pick up the phone at any time to hear your mother’s voice. This is something I will never take for granted again. Although sometimes I am still sad when I think about losing my mother eventually, I have come to terms with her mortality. Instead of worrying about how much time she has left, I want to enjoy and be grateful for the time we have to spend together.
Discussion

Marie was such a strong woman and she inspired me to value life as she had, so that I will not have any regrets. She had a tender and gentle way about her that made it pleasant to be around her. I imagine that this was one of the things her family would miss about her. Although they were emotional at times during the treatment process, they seemed to understand that illness was sometimes part of life’s course and must be accepted, even though it was hard to do so. As I mentioned previously, Marie had a sense of peace and acceptance about her, and I believe that contributed to her family’s feelings of acceptance. Although in Karen’s case, she did not seem to be at the same level of acceptance as her father and mother, she appeared to have an understanding of the finality of her mother’s condition and was working on finding ways to cope.

One of the things music therapy was able to help with was in giving the family something concrete to have as a memory of Marie. The life review recording offered them a glimpse into different moments of Marie’s life when she was happy and content. It provided Marie with the means to communicate to each of her family members through the songs she chose for them. She carefully considered songs that were important to her and chose to share them with her family through the recording. Marie did not include any sad moments of her life on the recording, but this fit with the way she previously used the music in our sessions, which was to reminisce on happy moments. Marie used the music to go to a place where she felt safe, was content and often surrounded by family.

Although Marie did not discuss her impending death directly through music therapy, she had the opportunity to reflect on her life and important memories, which may have helped her to have closure and communicate her intense love for each of them.
For the family, she had something to leave behind to show her appreciation and gratitude for their roles in her life. They would have the gift of her special messages they can go back to whenever they want to hear her voice and the music that was special to her. This gift would also grant them an enhanced awareness of her feelings about them. The music therapy also prompted communication in the form of reminiscence during the sessions, allowing the family to reflect on enjoyable times. These reflections and group processing of memories had the potential to serve as comfort for the family as Marie’s disease progressed. Without music therapy to bring up these memories, the family may not have had the opportunity to share their reminiscences.
Case Study 2: Diana

*Over the Rainbow: A Mother’s Decision to Let Go*

This case study presents the journey of a woman with a difficult choice to make related to how she says goodbye to her children. It may be one of the hardest things a parent ever has to do in life. I will discuss this young mother’s process in dealing with her own death and learning how to leave her two children and husband. Different music therapy techniques that are effective in dealing with anticipatory grief will be discussed, as well as my role in the process, and the specific needs of a woman facing terminal illness and the needs of children anticipating the death of their mother.

**Background Information**

*Medical history.*

Diana was a 40 year old female with stage IV metastatic cervical cancer. She was diagnosed with advanced cervical cancer in March of the year 2004 after she visited the doctor for lower abdominal pain. At that time she received radiation and chemotherapy. The treatments prolonged her life a bit, but did not remove the cancer. The cancer spread to her liver, lungs, and rectovaginal fistula and was in the end stage by July 2005 when she was admitted to the hospital for relief of pain in her lower back and pelvis. Diana was receiving supportive care from the pain and palliative care services to help manage her pain. She also had a history of depression and had taken anti-depressants in the past to control it. At the time of her admission, Diana’s symptoms also included poor appetite, difficulty sleeping, fatigue, mouth pain, and fever. She had also received a diverting colostomy for her rectovaginal fistula. She and her family were investigating hospice options.
**Disease information.**

Cervical cancer can be detected early by a Pap smear and can be treated, but many cases go undetected. Prognosis depends on stage, size of tumor, lymphatic spread, and vascular invasion. There are typically no symptoms, which is why early detection is key; however, some secondary symptoms may be unusual discharge, bleeding, or pain. In stage IV of the disease, radiation therapy is often used to relieve pain.

**Family information.**

Diana lives with her husband David and 2 daughters, Melissa and Britney, ages 18 and 8 years. Diana and David had been married for 19 years and Diana had stayed home with both of her children during their early childhood years. Prior to her illness, Diana worked as a public relations manager for a small company. David worked as an accountant for a large corporation. Her husband and daughters spent a lot of time in the hospital with Diana and appeared to be very supportive and caring of her. Melissa had just finished high school in June of 2005 and was planning to attend college in September, and Britney was going to be starting the 4th grade in the fall. Diana also had a sister she who was very close to named Barbara. Barbara lived on the same street as Diana and her family and visited often. Barbara’s daughter Tiffany was the same age as Melissa and the two girls were very close. Diana described her family as being very close and caring. Diana and her sister often spent time together and helped each other with childcare when needed.
Treatment Process

*She wants to cry.*

I was in the hallway on Diana’s floor where I was stopped by one of the hospital’s chaplains. He looked concerned and told me that he had just come from visiting Diana. He mentioned that she was in the end stage of her disease and was having trouble dealing with her emotions. He said he could see that she wanted to cry but could not, possibly would not allow herself to cry for some reason. The chaplain asked if she could receive music therapy, as he thought the music might assist her in connecting to her emotions and allow her to express herself more freely.

I wondered what the obstacle was that was preventing Diana from crying the tears she was holding in. In my experience so far with patients at the end of life, I knew it could be a variety of issues. Diana could be trying to hide her emotions from others in an effort to appear strong and in control of her feelings. Not allowing herself to cry might be the small way she was able to retain control over what was happening to her. Another reason she may not express her emotions in an obvious way could be that she was not connected to her emotional pain. In an effort to cope with the anguish of dying, people often withdraw from their feelings. This is a form of avoidance of dealing with grief. Diana may also have been having trouble distinguishing the physical pain she was in related to her disease and her emotions. Perhaps she did not feel that it was acceptable to cry about physical pain and tried to hold her tears back, not realizing that emotional pain may have been causing her such great sadness.

After reading her case history I went to see Diana the following day. Her eyes were closed and she appeared to be sleeping, but she had a grimace on her face. I spoke
with her nurse to see if it would be okay to wake her or if she should be left to sleep. The nurse said she thought Diana was just resting as she had just woken up from a long nap not too long ago. I went back into the room and called Diana’s name softly. She opened her eyes, but her face remained twisted as if she was in pain. I could see immediately what the chaplain had been referring to. She looked like someone just seconds away from sobbing, but was stuck at that intense point just before tears are released. Her body also looked very tense, especially in her shoulders, arms, and hands. I told Diana who I was and explained that I could provide relaxing music for her if she felt like resting. She did not say anything, but nodded her head and closed her eyes again.

I began to play softly on my guitar, improvising a chord progression to create a soothing and restful environment. Since Diana appeared to need to rest and relax, I did not expect her to participate in any active way, rather just to allow the music to surround her in a comforting way. The flexibility and wide variety of available techniques allows music therapists to meet the individual needs of each patient. In this case, I used music listening to work with Diana and help her to relax. Music therapy relaxation techniques including music listening have been found to be effective in reducing anxiety, perceived stress and tension, and pain (Robb, 2000). In order to provide a calming environment for Diana, I played the guitar softly and steadily, allowing the music to fill the room. I did not use songs that she might have a strong association to, but just improvised with my voice, humming softly or singing on a neutral syllable. I watched Diana carefully for any sign that she might be uncomfortable, or on the other hand, that her tension might be lessening a little. She relaxed slightly into the music, releasing her shoulders a bit, but did not respond in any other way.
While I was playing, a man entered the room. He did not say anything, but signaled to me to keep playing for Diana. His brow was furrowed and he looked sad as he watched Diana. She did not open her eyes or acknowledge any awareness that someone had entered the room. I immediately felt compassion for this man, as he was obviously very distressed. At that point I wondered what my relationship would become to these people and if I would end up learning their story or not. We come in contact with so many people at the hospital and are not always sure how long we will work with each family. Since I had read in Diana’s chart that her family was looking into hospice care, I was not sure how long her admission would be. I felt a strong desire to help them in some way, if only for a brief time.

After a little while I heard Diana breathing very easily and sensed that she had fallen asleep. I quietly prepared to leave the room and the man followed me out. He introduced himself as Diana’s husband. He had a kind yet concerned face. I introduced myself and explained music therapy services to him. I explained that I had come in while Diana was resting and she had agreed to let me play for her to help her relax. He looked surprised that she had agreed to music therapy and remarked that she had been refusing visitors lately because she had been in so much pain. He thanked me for the visit and asked if I would continue to come and see her to help her with her pain and trouble sleeping. He said if anyone deserved to be comfortable and have some relief from pain it was Diana, as she was a wonderful person. I told him I would be back the next day to see her. I could see how much care and tenderness David felt for Diana and how determined he was that she should have the best care possible at the hospital. It seemed that this was one way he could show his love for her.
Opening closed doors and windows.

The next time I saw Diana for a music therapy session, her husband and youngest daughter Britney were present. David was in the hallway as I approached the room and I asked if it was a good time for me to visit. He mentioned that Britney and Diana were watching a movie together and that I might try to come back later. Diana must have heard my voice outside because she asked Britney to open the door to her room and ask me to come in right away. I said hello to Diana and she said she wanted to have music therapy with her daughter present, that they could finish the movie another time. She was much more responsive than the previous session, but appeared tired. She smiled when she saw me and proudly introduced her daughter, who was eight years old.

When I went back into the hall to unpack my guitar, I noticed that David was tearful. I asked him what was wrong and he said Diana rarely opens the door to any optional services, except chaplaincy. He said it was nice to see her interacting with others because it reminded him of how friendly and sociable she had always been before she became sick. As in the previous session, I felt strong pangs of empathy for David and wondered what it must be like to watch a spouse die, especially in so much pain, as Diana was. I construed the comments he had made thus far about Diana to be evidence that her personality and moods had drastically changed during the course of her illness. These changes would likely have an effect on the dynamics in the family and how Diana would interact with her husband and children. I felt sad that I might not get to know Diana as she was before, but also understood that terminal illness changes lives and can transform hearts, bodies, and relationships beyond recovery. Since I had seen in other experiences
that changes in relationships can often be for the better, such as people becoming reconciled to each other, I hoped that this might be the case for Diana and her family.

At the same time, I marveled at the fact that Diana wanted to share some of her precious time with her daughter and husband with me. She seemed excited to share the music with them since she was more alert than the last time I had seen her. Still, I wondered what it was that stimulated her to open the door for music therapy above other services offered to her. I wondered if she had a previous connection to music that caused an intrigue for music therapy. I wondered how this related to her inability to cry when she needed to. It seemed Diana was making a choice, whether it was conscious or subconscious I can not say for sure, to open a window to her heart for me to see in for a while.

Diana was lying in her bed when I entered the room and David sat in a chair at the right of the bedside, holding her hand. Britney was sitting in another chair on the left of the bed, a few feet away. She did not make eye contact with me when I came in, but looked down at the floor and hugged a stuffed animal on her lap. I spent a little time talking to Britney, as I observed that she seemed a little nervous or shy. I asked her about the toy she had and her face lit up as she talked about who it was, a character from the Pokemon cartoon. She showed me some of the other characters she had brought with her as well. I told Britney I did not know any songs from the Pokemon show, but we could make one up if she wanted. She shook her head, so I asked her if she liked music and had a favorite song. Diana watched Britney closely with a big smile on her face. Britney said she liked singing songs in her class at school, but she could not remember the names of any of them. Diana said, "Don't you remember, Britney? You sing the song about the
sunshine! I bet Kim knows how to sing that song.” I checked with Diana and Britney and determined that it was *You Are My Sunshine*. I sang the song and Britney sang some of the words along with me, very quietly. Diana was trying to sit up in her bed to see Britney better, which I could tell was an effort for her. Regardless, she looked happier than I had ever seen her. It was interesting to see how much energy she seemed to obtain just by being in the same room as her daughter.

I then asked Diana if she would like to choose some songs to hear during the session. I suggested that she choose a song for herself, one for her daughter, and one for David. As discussed in the literature review, song choice can often be a very safe way for patients to express messages to their loved ones. Since Britney seemed a little shy, I also thought this would be a way to include her as well as David in the session. I handed Diana the songbook and while she was looking through it, she nodded off a couple of times. I helped hold the book for her because she was very weak, and I gave her a lot of time. She finally chose *Bridge over Troubled Water* for herself, *Someone to Watch over Me* for David, and *I'm a Believer* for Britney. *Bridge over Troubled Water* can be a very emotional song for many patients, so it was intriguing that Diana had chosen it. It caused me to question whether she was more open than I initially thought. I thought that her inability to cry might be a resistance of sorts, but perhaps she just needed an opportunity or to be asked to express her emotions. Also, not every patient needs to cry to be connected to their emotions. Perhaps Diana was someone with a quiet strength who did not typically express her emotions with tears. As I was getting to know her, I saw beauty in her composure. As I sang the song for her, she closed her eyes to listen. At the end of the song, she looked thoughtful and said she loved that song. I asked her what she loved
about it and she replied that it has a comforting message. I asked her if she felt comforted by it herself or if it was a comforting message she could give to others. She smiled, looked at her husband, and said it was both.

I moved on to the song for David, *Someone to Watch over Me*. Again, Diana had chosen a very poignant song for her husband, one with a clear message of love and appreciation. After the song I asked Diana what she was thinking about when she chose that song for David and she answered that he was always there for her when she needed him. I wondered if it had always been that way or if they had begun spending more time together when she became ill. I decided not to ask them, but had a sense that they had always been close and that David was a very loving husband. It is fascinating to work with families facing terminal illness because in a way the therapist is just seeing a snapshot of an entire life, whole family history and collection of events, relationships, and memories.

I saw that Britney was looking a little uncomfortable, possibly feeling left out. I asked her if she had ever seen Shrek and she nodded. I asked if she remembered the song the donkey sang and she did. I said her mom had picked that song out just for her. I started singing *I’m a Believer* and Diana mouthed the words with me, actively participating in the music with me for the first time. I knew it must be difficult because she had a lot of mouth pain. She also tried to sit up in bed again so she could see her daughter’s face during the song. David helped her sit up to see better. It was a moment of tenderness and sweetness as the energy of the upbeat song filled the room and opened the window into Diana’s heart even further. I no longer saw a woman consumed by pain, but caught a glimpse of the amiable woman David had told me she was.
After this, I offered the songbook to Britney to choose a song for her mom. She looked through the book and chose *Puff the Magic Dragon* because the picture of Puff in the songbook looked like one of her Pokemon characters. She danced the toy around as we sang just the chorus of the song and we changed the words to put the character’s name in the song. We added more verses for her other Pokemon characters and she sang to each one of them. Diana laughed as Britney danced around the room. After the song, Britney approached her mom for the first time during the session and kissed her on the hand, then laughed and went back to her chair.

Diana said David had to choose a song for her too, before we finished for the day. He looked through the songbook very carefully and chose *What a Wonderful World* saying it was one of his favorites. As they listened to the song he gently stroked his wife’s arm and she closed her eyes to listen. After the song I asked why it was his favorite song, to give him an opportunity to share something with his wife that may have been important for him. David answered that the song reminds him that there is still so much beauty in the world, even in the face of suffering. I looked at Diana, but she did not respond in any overt way. There was a brief silence in the room and then she sighed and said she was tired. She smiled weakly at me and asked if I could come back another day. She thanked me in a very small voice and I left the room.

At the end of the session I felt a peace in the room that had not been there at the beginning of the session. There were some very special moments during the session between Diana and her daughter and also with her husband. It seemed that Diana was trying to find ways to connect with her daughter, even though she was weak and tired. I thought Britney seemed a little scared and uncertain about being in the hospital, but
Diana was reaching out to her. The songs Diana chose appeared to give a voice to the things she wanted to say to her husband and daughter and helped her to come out of herself during the session. The same may be true for David, whose choice also suggested that he is looking for an outlet for self-expression.

As I was getting to know Diana and her family better, I determined that some of their primary needs were anticipatory grief, resolution of any issues within their relationships, and closure between Diana and her husband and daughters. The music therapy would likely play a powerful role in helping them to communicate with each other and develop a deeper understanding of each other’s needs and feelings. Although the family seemed open with choosing music they felt strong associations with, the sound of the music would probably also be significant. In this session for example, Diana seemed to respond well to upbeat music, for she seemed to gain energy from lilting melodies and rhythms. In future sessions, it would be interesting to see how she would respond to different styles of music.

This was a difficult case for me in some ways because Diana was so young and I could see how hard it was for her to let go. It became even clearer when I met her daughter and saw how much Diana loved her family. I felt a great deal of empathy for her and all that she was leaving behind. I cannot imagine having to face the reality of not being there to see my children grow into adulthood. I felt a sense of urgency when I reflected on Diana and her family because I knew she probably did not have much time. Perhaps she or her family was projecting that sense of urgency onto me. For this reason, I knew I needed to stay very open to the underlying emotions and energy in the room during sessions.
Holding on.

About two weeks into my time with Diana, I had the opportunity to have a session with both of her daughters present. The two daughters were sitting on Diana’s bed watching the television together. I noticed that Diana was beginning to look more drawn and weak than she had in previous sessions. However, Diana had an expression of contentment on her face and was stroking Britney’s hair. I asked her how her day was going and she smiled and said she was feeling just fine. I knew Diana had been having problems with pain management and wondered whether she was covering up her pain for the sake of her daughters. On the other hand, perhaps the pain truly was lessened as a result of the presence of her children with her. This was the second time I had seen Diana look comfortable and content in her expression, and both times her daughters were with her. The power of a mother’s love for her children appears to be extremely significant in the coping process of a terminally ill patient. However, I wondered how much or if she had talked with her daughters about her death at all. There still seemed to be a part of her that was closed off to looking toward the future; she seemed to be staying in the moment most of the time, whether it was in pain or a joyful moment. The implications of this coping strategy for herself and her family were yet to be seen. My plan was to provide opportunities for her to be in the music with her daughters and provide support should she be moved to express her true emotions. As in the previous session with her, I still had a sense that there were feelings lying just under the surface of her façade and that they would either be released and result in catharsis for her, or she would keep them buried until she died.
Diana said she was glad I came because I had not yet met Melissa. Melissa was a friendly teenager, a very pretty girl who looked a lot like her mother, slender with short blond hair. I wondered what she must be going through, for eighteen is a very young age to lose a mother. My empathy for her was strong and at times like these in my work with Diana I found myself thinking about my own mother and developing an ever greater love and appreciation for her. My awareness of these countertransferences towards Diana and her family was helpful, because I believe it aided me in being receptive to their needs and not imposing my own values or decisions about what I would do if I were in their situation.

I talked to Melissa for a while, congratulating her on finishing high school and asking her what she wanted to study in college. She said she was interested in elementary education, but that she might take a year off to work first. Diana attended to that comment and said, "No, you can’t do that! We already talked about this. I told you if you do that it will be hard to go back." Melissa was looking down at the floor and my heart jumped a little, as I could see that I had opened a can of worms. Melissa answered that she just needed a little time before starting college, that she was not ready yet. Diana looked sad and said she knew that was not true. She said she knew Melissa was taking the break because of her and that it was not necessary. She said, "Please Melissa, I want to see you go to college." I could sense the urgency in her voice, the voice of a woman who knew that starting college might be the last milestone she would see her daughter achieve. Melissa became tearful and said, "I just don’t think I could concentrate on school right now. Can we talk about this later?" Diana mumbled something under her breath that I could not completely hear, but it sounded something like she did not have
too many “laters” to talk. During this exchange Britney appeared to be ignoring them and focusing on the television, but she had to have heard and understood in some way. I felt very guilty for mentioning Melissa’s future plans when I did not know that they were not resolved. I said I could see that this was a difficult issue for both of them and I apologized for bringing it up at that time. Melissa said it was okay, she knew she had to tell her mother soon anyway. Diana looked very sad and remarked that sometimes things get really hard for them, but certain things can not be ignored. For a while there was a silence in the room that felt weighty. I had not yet brought my guitar in because I wanted to check first and see what they wanted to do and I felt a little lost without it. As an inexperienced therapist, I felt that I had made a mistake and said the wrong thing, not knowing how to smooth it over.

I went out into the hallway and grabbed my guitar. When I came back in I said, “People say it is sometimes hard to talk about what will happen in the future. No one really knows what will happen.” Diana and Melissa nodded and Britney continued watching the television. I started playing Que Será Será on the guitar. They listened quietly and did not sing along during the song. After the song, Britney asked if she could have a drink and Melissa took her to the pantry down the hall for juice. When they had left the room, Diana said knowing the future is unclear does not make facing it any easier. I asked what would make it easier and she answered that she would need some assurance that everything was going to be okay. She said she felt like her job as a mother was not over yet. I told her I could not claim to understand what that was like for her, but that she could be encouraged to see how beautiful and special her daughters already were. I told her I could see that she had already set them on the right track and that her love and
nurturing ways would continue to guide them. I said I had heard once that a mother’s love is written on her child’s heart, no matter what happens. Diana smiled weakly and said she would love to believe that, but believing it would be like letting go of her girls.

I felt at that moment that Diana wanted to hold on to her role as a mother for all she was worth. It seemed like deep inside she knew they would be fine, but she implied that it was hard for her to accept that they would be fine without her. I think she may have felt a little left out of their futures and the family’s decisions and I wondered how they could work as a family to communicate more openly about each other’s plans. Diana seemed to be making an effort to be open with them in some ways, but perhaps did not feel that openness being returned from her daughters and husband.

When her daughters returned to the room, Britney saw the percussion instruments in my cart in the hallway. She said, “You have a drum out there!” Since she was attracted to the instruments I thought incorporating them into the session would be a nice way to involve her. I asked them if they would like to play some improvised music together and they agreed. Improvisation is a valuable music therapy method because it provides an opportunity to explore hidden feelings. The non-verbal interaction that occurs during improvisation often gives clients a safe venue for exploring and expressing their emotions. Clients bring their fears, pain, as well as joys and love into the music therapy sessions. These different emotions are often played out in their musical interactions with each other and with the music therapist. Improvisational music therapy sessions provide a space for clients to explore and discover themselves, finding meaning in their musical interactions during the improvisation.
The use of improvisation allows the expression of feelings to occur in the moment, without much premeditation or rehearsal. It is through this method that hidden feelings come to the forefront of awareness. The therapist must consider the musical aspects of the improvisation such as rhythm, melody, harmony, and the amount of structure. The clients may need the therapist to provide some structure or grounding for the group at times. In other instances the therapist may give the group more freedom so as not to “inhibit the expression of feelings” (Bruscia, 1987, p.129). Since this was our first time improvising together I thought I would give them some structure and just wait and see what would transpire.

When I brought the instruments in, Britney immediately reached for the bongos. I also had a small hand drum, a tambourine, and a maraca. Melissa took the tambourine and Diana chose the maraca. We improvised for a while with me playing on the guitar, providing a grounding rhythm. The three of them were smiling at each other, especially Britney who loved the bongos. After a couple of minutes, Diana asked if she could try the hand drum instead because she was getting tired quickly from shaking the maraca. We placed the drum right under her hand so that she would not have to move much to tap it with her fingers. I suggested that we take turns starting the improvisation so that each person would have a chance to give the rest of us the beat to start with. Britney asked if she could go first and she drummed very quickly on the bongos with both hands. Melissa shook the tambourine quickly and I joined them on the guitar. Diana laughed and said she could not keep up. Britney said, “Yes you can, Mommy, try it!” Diana used all of her fingers to tap on the drum. It sounded a little like rain to me. Overall, the music was somewhat chaotic and lacked a clear pulse, but it was playful, reflective of Britney’s
youth and character. We each took a turn having a solo, which Britney seemed to really enjoy; she put her whole body into playing the bongos. I brought the improvisation to a close and asked Melissa if she wanted to take a turn. She said no, she liked just joining in when someone else started it. She said she was not that good at music. I reassured her that she was doing great, but she seemed embarrassed about starting the improvisation herself. She had also been shy in the previous improvisation about her solo on the tambourine. I wondered if the shyness was part of her personality or if it was a resistance to being exposed in some way in the music.

I asked Diana to start instead and she tapped very softly and lightly on the drum. We joined her very quietly and I found myself playing a more tender chord progression on the guitar, using finger-picking to play softer and sweetly. Melissa and Britney joined in. Britney was very expressive about playing quietly. With the addition of our three instruments we could barely hear Diana. I noticed that she stopped playing and I asked her if she was okay. She said she was a little tired, but it was okay because she was enjoying listening to her girls. I asked her to join us one more time if she was okay physically to do so. I stopped playing but signaled for the three of them to continue. Diana stopped playing again after a moment and just watched Melissa and Britney. They had spontaneously moved into a call and response game with the instruments. Finally, Britney seemed to want to do away with the structure because she began drumming very quickly and loudly as she had in the beginning. When she finished she flopped down on the bed with a big sigh. We all laughed together. I asked them what it was like to play together like that. Melissa said it was fun; they had not made music like that before. Diana said even though they had not done that before, it reminded her of old times, how
they would play together and how much she loved to watch her daughters play with each other. It was interesting to me how Diana stopped playing to watch them during the improvisation. It was symbolic in a way because she would be leaving them soon. I wondered if Melissa would take on a mothering role for Britney since she was ten years older. Perhaps she was already doing so when they were at home without Diana.

We put the instruments away and I suggested one more song to close our time together. I offered *He's Got the Whole World in His Hands* to them as a way to include each of them in the song. This song is a great closing song for people of many different faiths because it provides them with a sense of support and peace, as well as a sense that there is something bigger than we are taking care of us and our loved ones. Diana asked her daughters to come closer to her on the bed and the three of them lied down together as I sang the song. I sang each of their names and well as “Dad,” and asked them who else they would like to put in the song. Britney put their cat in the song and then we sang to “Mom” one more time. They thanked me for the time and we ended the session.

Many things happened during this session that gave me some more clues to the intra and interpersonal processes of the family members. I could see the conflict Melissa was experiencing between her mother’s wishes for her and her own needs regarding going to college. I got the impression that Diana placed a lot of expectation on Melissa and wanted her to be successful. It seemed that Diana may have been feeling like she was a burden to the family at that point and was getting in the way of their plans for the future. When I first began working with Diana I thought she might be holding emotions back. However, in this session she was open with me about her desire for reconciliation of her family’s needs. I reflected back on my feeling of being lost and not knowing what
to do at certain points in the session and wondered whether I was picking up on some of
Diana’s emotions as well. I imagined she must have felt out of the loop while she was in
the hospital because her condition did not allow her to play an active role in the daily care
of her family and in the decisions that were made at home. Although I felt we began to
open up the lines of communication in this session, there was still a long way to go before
Diana would be ready to let go of her daughters.

*Tough decision.*

The next time I saw Diana she was with her husband in the room. They both
welcomed me warmly, but I noticed that David’s face was tense. I asked them how things
were going and they said they had been having a difficult day. They were investigating
hospice options for Diana and were having a hard time deciding what to do. Diana
wanted home hospice care so that she could be with her family as much as possible
during the time she had left. David was worried that taking her home would be too hard
on the family. He was worried that the care would be too difficult and that it would be
traumatic for their daughters to have their mother die at home. I could see what a struggle
they were having trying to make the best decision for Diana and the rest of the family.
Diana felt it was a burden for the family to have to come visit her at a hospice location.
The underlying concern might have been that she would not get to see them as often as
she wanted to and would be left alone quite a bit. David worried that as Diana was
decurring, their daughters (especially Britney) would become depressed and anxious in
witnessing this on a daily basis. He also worried that they would then associate grief and
sadness with their home after she died. Although he mentioned the daughters when
voicing these concerns, I suspected that he shared those worries for himself as well.
They asked me what I would do in their situation. This request for help in their decision making process floored me. I am young and inexperienced and was not sure that any advice I had to offer would be of use to them. Rather, I felt that what they were really asking for was empathy and support. Diana said that pretty soon she would be far away from her family and she did not want to rush the separation by going to a hospice. I said I could understand both sides and that this was a big decision for them. I tried to reflect what they were saying instead of giving my opinion. I knew from talking to the case manager that this decision-making had been going on for several weeks and they were now being asked to make a final choice. The case manager and the family agreed that Diana would be better off with hospice care then staying at the hospital for a number of reasons, one of them being the distance from their home. I felt that David should honor Diana's wishes and take her home. I realized that he was trying to protect his daughters and possibly himself from seeing Diana die at home, but I also felt that openness about her death might help them to attain an enhanced acceptance and understanding. I encouraged them to talk to their daughters and see how they would feel about each of the options. I mentioned the importance of making the decision together so that no one would feel like they were overlooked or did not matter.

David said no matter what they chose, someone was going to have to compromise. Diana said that saying goodbye to her family was incredibly painful and she wanted to do it in the best way possible. She felt the best way was in the comfort of their home, not in a facility full of strangers. I asked her if she felt ready to say goodbye and how that was affecting her decision. She said she would never be completely ready, but she felt her body changing and failing on her. Diana said she felt that time was running
out and she knew she could never get back lost time. She did not want to waste a moment that she had left. I validated her point of view because I sincerely felt that she was reaching a deeper level of acceptance of her own death. Although it was still difficult for her to face her loss, a part of her seemed to be ready to go. It was interesting to note her sense of separation from her body. As a result of the disease she did not seem to feel connected to her body, but felt it was out of her control.

Diana said she did not want to talk about it anymore and asked if I would sing for her. I offered her the songbook and she chose *Over the Rainbow.* The lyrics of this song reflect a desire to be somewhere else, somewhere more beautiful and peaceful than where one currently is. I thought this choice was a very clear expression of Diana’s desire for a peaceful death. She was already in so much pain that I wondered if she was afraid it would get worse and she would lose even more control over her body. During the song, she cried for the first time in her treatment process with me. She said the song always made her cry and I asked her why. She said the singer wants to go to a better place, but she does not know how good she has it. She said it can be hard to decide whether to move on or hold on to what you have. I told her I thought those were very wise words and asked her what that meant for her personally. She said she did not want to have to make that choice, but she knew she had to go away soon. David stayed quiet through this exchange, but I noticed that his eyes were teary as well. At that moment we unfortunately were interrupted by a doctor who needed to see her, so we could not continue our processing. I told Diana I would return as soon as possible.

As our treatment progressed, I saw Diana becoming more and more open and direct with her feelings about her death. She seemed to really be trying to communicate to
her family how difficult it was for her to leave them, but that she knew somehow it would be okay for her on the other side. I think she wanted reassurance for herself as well as her family as to the outcome of this tough time in their lives. Her honesty about her trouble with letting go was touching. As I reflected and processed this case on my own, I found myself grieving for her as if I were one of her family members. I too wanted her to have a peaceful end, but felt her fear of the physical and emotional pain that could not be avoided at the end. I knew that if she felt comfortable letting go, her death would be less of a struggle for her and her family. For this reason, I hoped that they would opt for home hospice care, but I knew that many factors would come into play with their decision.

Letting go.

In my last session with Diana, I found out that they had chosen home hospice care. Diana was glad to be going home the next day so she could be with her family a little while longer. David seemed to feel okay with the decision as well. They had some intervention from the case manager and the social worker to help them make their decision. I felt that the music therapy session in which we discussed this also played a role in their decision. David had pulled me aside in the hallway a few days after that session to thank me for encouraging them to be open with their daughters. He told me he learned that they were much stronger than he gave them credit for and were adamant about having their mom come home. He also mentioned that he had noticed a change in Diana since she had begun music therapy. He felt that he understood her feelings better and that she was willing to be more open with him. The music therapy provided them with a space in which they could freely explore their emotions in more than just words.
Although we did do quite a bit of verbal processing, it was usually prompted by songs or musical improvisations.

In this last session, Diana appeared relaxed, but her affect was flat. She also seemed very tired, which may have been due to a new pain medication they were trying for her. Her sister Barbara was present, as well as her daughter Tiffany, Diana’s daughter Melissa, and David. Diana asked Barbara to choose the songs because she was too tired. Barbara looked through the book and chose *Lean on Me*. She said it seemed appropriate for the moment. While I sang the song she smiled and held Diana’s hand. Diana nodded at some of the lyrics, but did not look directly at anyone. After the song Barbara smiled and said that song fit them very well. I asked why and she said they had always been there for each other and she would be there for her in her hardest times. She said it was also nice to be neighbors because they could help each other out in many ways. Barbara then picked *I Can See Clearly Now* because she wanted to do something upbeat. Tiffany and Melissa did not sing along, but both smiled and moved their bodies to the music a little. I could tell that everyone was trying to keep the mood light and keep the energy flowing in the room. Diana then asked for *Someone to Watch over Me*, which I sang while the others looked on and David held her hand. Although Diana chose this song she did not talk at all during the rest of the session. Barbara and David became teary eyed at times during the music. There was such a change in Diana from the last time I saw her. Although part of it may have been the medication, I also wondered if she was beginning to let go and release herself from the worries she had faced, now that she knew her final wish to die at home would be granted. It was as if she had fought for something important
to her and now was ready to just let the rest of her life unfold before her. This was the last time I saw Diana.

Therapist Reactions

When I began working with Diana, I had a false impression of who she really was. For some reason, I perceived her as being emotionally distant and closed off to expression. I was continually surprised that she accepted music therapy because I was afraid it was too invasive for her. I was humbled when I realized my initial assessment of her level of openness was faulty. I realized that there was probably something within me that wanted to distance myself from her in the beginning. Perhaps it was because she was so young and it reminded me of my own mortality. Even more so, I think I felt inadequate as a therapist and was not sure I had the tools to meet the many needs of a young mother losing her life. I think my own inexperience as a music therapist as well as in life in general caused me to be afraid that I could not do and say the right things for Diana. There was often so much below the surface of what was verbally expressed that I sometimes felt like I was putting the pieces of a puzzle together. Working with Diana and her family taught me that the needs of the dying are multi-faceted and not always obvious. As I would consider her needs, my own fears about losing loved ones were in the back of my mind. Through supervision and personal reflection I was able to deal with these fears as well as my grief for Diana. I tried to maintain awareness of my countertransferences and reactions to her illness during the treatment process so that they would not cloud my actions during sessions.
Discussion

In my work with Diana and her family, I saw the difficulty a mother experiences when letting go of her children. The internal conflict between the role of a mother and the reality of having to release that role can be heartbreaking. Diana’s way of moving back and forth between openness and distance was her way of coping with her resistance to saying goodbye and her knowledge that she had to. Her need for support and empathy was clearly expressed from the beginning of our time together. In the beginning of our time together, she seemed to be experiencing her pain of the current moment and refusing to consider what could happen in the future. This initial refusal may be seen as a defense mechanism that she needed in order to cope. The use of song choice and musical improvisation during the treatment process assisted Diana in communicating her concerns about the future as well as hearing her family’s concerns. Diana looked more readily at decisions that needed to be made, such as regarding hospice care.

During our time together, themes of protection of the children also emerged. Diana would hide her physical pain from the children in order to guard them from sadness, fear, or worry about her. In this way, she was putting her own needs aside to care for the children. I believe this is a natural thing for a mother to try to do; however, it may become more challenging as the disease progresses. The less control she has over her body and the way she expresses pain may cause her to worry about how the children would react. This was an especially important issue for Diana since she chose home hospice care. Although hiding her pain may have once served a protective function, openness about her disease progression may have been important to help her children cope. I felt that this issue was also related to her level of acceptance of her death. In the
music therapy sessions, particularly in the improvisation, she did allow her children to see that she was tired and weak. Diana’s statement that she enjoyed watching them instead of being a more active participant was a way for her to communicate the changes in her role in their relationship. This may not have been accomplished without the music therapy.

Another theme was the effect of the children’s presence on Diana. She seemed so energized when they were present, and I felt that I was seeing more of her personality. Her love for her children seemed to give her strength and joy, which gave her decision to die at home more meaning. It seems that the energy and happiness a mother receives from our children may have to do with how much of herself is defined by being a mother. Many mothers also define themselves as career-women, wives, friends, daughters, and more. Depending on where a woman is in her life, she may relate more to her role as a mother and therefore be emotionally fed by her children. It appeared that this may have been the case for Diana.

The music therapy provided an avenue for Diana to explore her feelings about dying, give those feelings a voice, and begin to communicate more openly with her family. She was able to use the music for herself either for relaxation, to send a message, or to reflect on her life as she did with the improvisation. The music brought the family together by allowing each of them a space to express their needs. It also helped Diana to be more open and honest about her thoughts and feelings.
Case Study 3: Ellen

*I Hope You Dance: A Family’s Journey towards Acceptance of Terminal Illness*

This case describes music therapy with a woman dying of cancer and her interactions with her family. I will share the journey that she and her family took to move towards a deeper understanding of each other. The case study will focus on the family dynamics throughout the music therapy work, especially communication issues. I will also describe the music therapy techniques used with this family and how these techniques facilitated and enhanced communications.

*Background Information*

*Medical history.*

Ellen is a 65 year old Caucasian woman diagnosed with peritoneal ovarian cancer. She was originally diagnosed with ovarian cancer in December 2004 when she was experiencing abdominal pain and vomiting. Immediately following the diagnosis she was admitted to the hospital for treatment, including a hysterectomy and chemotherapy. Since this initial treatment, Ellen has had several readmissions to deal with various issues related to the advancement of her disease. She has had multiple setbacks in the last year including an obstruction that was preventing her from eating and required surgery, several bouts of infections, and poor healing of her wounds. Most recently, she was admitted for fluid build up in one of her lungs. A procedure was conducted to drain the fluid, which she then would be able to do herself at home as needed. Ellen suffers from pain related to the cancer and is receiving palliative care to make her comfortable. Cancer may run in Ellen’s family, as her mother had breast cancer and her father had lung cancer.
Disease information.

Ovarian cancer is the rapid growth of abnormal cells in the ovaries. Seventy-five to eighty percent of cases are undetected because there are no symptoms in the early stages. Some of the symptoms that develop as the disease progresses are persistent abdominal or lower back pain, bloating, change in bowel or bladder habits, nausea, loss of appetite, and abnormal vaginal bleeding. Peritoneal cancer occurs when the abnormal cells spread to the abdominal cavity and implant in the peritoneal lining.

Family information.

Ellen lives alone with her husband John. She is a slight woman with a kind, grandmotherly demeanor and wise eyes. She was a stay at home wife and John was the primary breadwinner until he retired two years ago. They have three adult children, one daughter and two sons. Her daughter and one of her sons are married and live out of state. Her other son James and her sister Carole live close to Ellen and visit frequently during her hospital admissions. John recently had some heart problems and hypertension requiring a hospital admission. The family is supportive and helps Ellen and John by caring for them in various ways such as rides to the hospital, cleaning their home, and providing meals. Ellen has indicated that faith and spirituality is important to her family and they are active in their local church.

Treatment Process

Unexpected encounter.

I began working with Ellen about two months into my internship. I had been seeing patients on my own for a little over a month and had experiences with people in various stages of disease. My work with some other patients including Marie had sparked
my interest in women’s health and wellness and I enjoyed seeing patients on the floor
dedicated to cancers typically contracted by women.

Music therapists at my internship setting see patients on a referral basis. I was
referred to Ellen’s roommate at the time, and when I went to see the roommate, Ellen
asked if she could participate as well. Since the roommate was open to this, we pulled
back the curtain between the beds and began the session as a small group. The primary
music therapy technique I used at this time was song choice.

During this session, Ellen and her roommate chose several songs with themes of
hope and being uplifted such as I Can See Clearly Now, You Raise Me Up, and Climb
Every Mountain. When it was time to close the session, the roommate chose the closing
song, I Hope You Dance. While I was singing this song, Ellen began to cry. After the
song I asked her what was going on for her during the music. She said she had never
heard the song before, but was struck by the lyrics. Ellen said the song made her realize
that everyone has choices, no matter what their situation. She said in her case, she could
give up, lie down, and die, or make the best of the time she has left. We talked a little bit
more about this theme. Ellen pointed out that when choices are taken away from us we
sometimes want to give up on everything we have left. This session was my first window
into some of the struggles that Ellen was dealing with relating to her illness. Ellen and her
roommate were being discharged the next day, so when we closed the session I wished
them well, thinking I would not see them again. I wished that I had more time with Ellen,
as I thought the music would be beneficial in helping her to express the feelings she was
having.
Meeting the family.

Ellen was readmitted several weeks later with complications due to an obstruction in her abdomen. I was making rounds on her floor to gather participants for a group I was holding when I found her. She was too weak to attend the group, but I made plans to begin seeing her for individual sessions. In the first session I had with her during this admission I found her surrounded by family when I entered the room. Ellen wanted to have her family members participate in the music therapy, so she asked them to stay with her while I was there. Her husband John, sister Carole and her husband Gary, and her son James were present. She and her family were very welcoming, but some of her family members seemed slightly skeptical of music therapy. I explained to them that music therapy is a service of the hospital’s integrative medicine department and how it can help patients with relaxation, expression, and any other needs they may have. The family agreed to have a session together with Ellen.

Ellen immediately asked for *I Hope You Dance*, saying that it felt like her theme song. It is important to note at this point that I sang *I Hope You Dance* at Ellen’s request in every future session we had. She became teary-eyed as I sang the song, and began expressing her thoughts right after the song finished. She said that the song means so much to her because she has lived a good life and wants to be strong and hopeful now that her life has taken an unexpected turn. At this point, John walked out of the room. Ellen said that dealing with her illness has been very difficult for her husband. I did not make any attempts to try to keep John in the room because I wanted to allow him space and the opportunity to choose whether or not he wanted to talk about these difficult issues.
Ellen began talking about how difficult it has been to deal with her physical pain and how she was looking forward to going to heaven when things would be so beautiful and perfect. I suggested singing *Way beyond the Blue* as a way to tie in Ellen’s joy in anticipating what heaven would be like. Everyone sang together and clapped their hands along to the music. I asked Ellen, Carole, James, and Gary to think of things that would be in heaven and we put them into the song. This is a technique called word substitution in which patients and families change the words to familiar songs to personalize the music for them. This technique helps people to feel more connected to the music and provides another level of participation in the session. I felt that it helped bring the family into the activity together, after Ellen had been describing her feelings. It also gave them a way to support her in her desire to go to heaven and not be in pain any longer. They seemed to want to support Ellen and be there for her without outwardly accepting that she was dying. At the stage the family was at, it was helpful to have the music to allow them to do this. No other family member had verbalized their own reactions to Ellen’s illness at this point, but were all (except John) able to acknowledge her impending death through the music.

Ellen mentioned at that point that her son James was getting married in about six weeks and she was hoping to be able to make the wedding. I talked to James a little while about his impending marriage. I had assessed that he might want to talk because his eyes also became teary up during the music, indicating that he was having some emotional reactions. He seemed open to discuss and share with his family how it is difficult to plan for such a happy event when he is worried about his mom. He explained that she has always done so much for the family and he wants to be available to help her now. At that
point John returned and showed me a picture of James's fiancé. He seemed a little more comfortable discussing the wedding than his wife's illness.

To bring the music back in, I asked John if there was a special song he and Ellen had when they got married. He could not remember, but said that it was a very spiritual ceremony and asked if I knew *Just a Closer Walk with Thee*. I started the song and John, Ellen, and Carole sang along with me. This was significant because it suggested that he was making an effort to participate in a way that was comfortable for him. This song was also significant because the lyrics speak to the fact that we are weak and need to rely on God for strength and help. I wondered if this was a message John was sharing about himself, or one that he wanted for his wife, but I did not have the opportunity to ask him.

To close this session, we sang *He's Got the Whole World in His Hands*, putting the names of each family member in the song. I thought this would be a nice way to tie in the themes in the session of God being in control of what was happening in their lives and to reinforce the fact that he was watching not just over Ellen, but the whole family. Everyone sang along loudly and clapped their hands again. This outward participation in the music was evidence for the fact that the family felt comfortable using music as a form of emotional expression. This was important for me to know when preparing for future sessions with the family. Songs that are engaging seem to be best in helping the family members get involved in the discussion and the music.

I noticed that the personalities of various family members sometimes affected the level of communication that took place within the family. Ellen was very open and willing to share her thoughts and feelings, so she did not hesitate in doing so. Her husband appeared to need more time to warm up and also seemed to be at a different
stage of acceptance of Ellen’s prognosis. When working with families, it is important to consider the unique contributions of each member of the family and how each person affects the dynamics of the family. I wanted to meet Ellen’s need to explore her feelings without alienating other members of the family who may not have been ready to address those issues. Since the family members seemed to be at different stages of the grief process, it was important to consider each of their needs.

*Getting closer to Ellen.*

During Ellen’s various hospital admissions I had several sessions alone with her. Although the primary purpose of this case study is to discuss the family sessions, there were some important moments in our individual work that are relevant to her communications with her family. Two sessions in particular provided some significant progress in Ellen’s own understanding of her illness, which eventually translated to enhanced interaction with her family.

In one session, Ellen was requesting many songs of faith including *One Day at a Time, In Moments like These*, and *I Can Only Imagine*. This led to a discussion of how her faith was helping her cope with her illness. Ellen felt that her faith allowed her to accept her illness and death as part of life. She also felt that dying was the end of her life on earth, but the beginning of her eternal life in heaven. Ellen explained that her family did not completely agree with her; she thought they were afraid that her acceptance of her death meant that she was giving up on life. This was a struggle for Ellen. Her family’s feelings caused her to doubt herself and her acceptance of the end of her life on earth. She wondered if she should be seeking more treatment or hope for a miracle. She was not angry at God for being sick and was having difficulty bridging the gap between her own
acceptance and her family’s various stages of denial, anger, and bargaining. We discussed how she could talk to them about these feelings, explaining that she was not giving up on life; she was just turning the control of her life and her future over to God. I introduced a song called *If You Want Me To*, in which the lyrics talk about how life is filled with trials and can be difficult; however, we know that we are not alone if we trust God. Ellen felt she could resonate with this song, given her current feelings. We recorded the song for her to share with her family when she talked to them again. Recording songs is a technique often used with hospitalized patients. It provides them with a concrete representation of what happened in the therapy session that they can come back to when they need to, or share with loved ones. I found out later that the family had begun praying together specifically to reach a deeper acceptance and understanding of God’s purpose for Ellen.

Several sessions later, Ellen talked about her feelings of regret about getting sick. As her son’s wedding was drawing closer, she began to worry that she might not get out of the hospital in time to make it. She expressed several “What if” questions she had been having: What if they had caught the cancer sooner? What if there was another treatment that could have helped her? What if she had not had so many setbacks? Ellen told me a story of how she had read about ovarian cancer in a magazine before she was diagnosed and how ringworm can be a symptom. She developed ringworm and asked her doctor if it could be cancer, but he said no. Ellen said that while she still felt she could accept the reality of her situation, it did not stop her from wondering what would have been if things were different. I wondered at this point if Ellen was really moving into a different stage of coping with her illness or if she was only identifying with her family’s worries and
fears about her. Believing in God did not stop her from asking “Why?” It seemed important for her to work through her doubts so that she could be okay with them. In this session we talked a lot about inner strength and how she could access it when she was feeling doubts coming on. Ellen chose songs with themes of hope and inner strength such as *Hero, The Greatest Love of All,* and *I Believe I Can Fly.* Her admission of doubt and realization that it was common to have doubts and fears helped her to understand her family’s doubts. After this session, Ellen said she was beginning to understand why her family was having such a hard time. They were trying to be strong for her; however, they were used to relying on her for strength and hope. I saw that the family was dealing with role reorganization at this point in their mother’s illness. Since she had always been the one to nurture them, they did not seem to know how to become the nurturers. This uncertainty was manifesting itself in their denial of the seriousness of her illness.

*Staying close.*

In subsequent sessions with Ellen’s family members, they began to allow themselves to talk more openly about Ellen’s illness. Through the use of song choice, they were able to share their love and support with Ellen. An important turning point occurred when John called the music therapy office as soon as Ellen was admitted, a couple of weeks before their son’s wedding. He said he knows how much the music therapy means to her and he wanted to make sure I knew she was there and would come to see her. Now John was welcoming music therapy and staying in the room during the music, openly sharing his thoughts and feelings. He was also showing more physical affection for Marianne, often holding her hand or hugging her. It was as if her modeling
of not taking time for granted and making the best of difficult situations had helped John become more accepting of their situation.

During this session, Ellen’s sister Carole found *Wind beneath My Wings* in the songbook and asked if we could sing it. As the song progressed, Carole was singing the chorus louder and louder, looking at Ellen as she sang. After the song, Carole went over to Ellen’s bed, hugged her and told her she loves her and the two of them cried together. Ellen and her sister agreed that it was the perfect song for the moment. I said that I could see that her family has a lot of love and support for her and that Ellen’s sister was really letting her know this by choosing *Wind beneath My Wings*. Ellen agreed, and said it has been a long haul for her whole family. She said she has had many struggles, but also many blessings and has taken one day at a time. Ellen told me that she decided to have a DNR order. She said if something happens and they resuscitate her, what will it be for? She said it is not worth coming back to live the way she is living now, in pain. I asked her family how they felt about that. Her husband said Ellen is a strong gal and when she’s ready to go, she’ll go. He said we can not say what the Lord’s will is for the length of a life. Ellen’s sister said she thinks Ellen has chosen that because she has peace and wants to go to heaven. I looked at Ellen to see if she had any response and she smiled and said she has a wonderful family. This open acceptance was a big change from her family’s previous reactions.

*Finally able to dance.*

About a month after her son’s wedding, Ellen was admitted for fluid in her lungs. I had a session with her, John, Carole, and James. When I went to see her, she looked very weak. She had made it to James’s wedding and they brought some pictures to show
me. Ellen was very pleased that it had worked out for her to go, saying she had wanted to go to that wedding if it was the last thing she did. Carole and James pointed out that it was a hard day for her physically. Ellen said her family had to carry her around all day, but she would not have missed it for the world. They told me the highlight of the day was when it was time for the groom and his mother to dance in the reception. James surprised her by choosing *I Hope You Dance* and dedicating it to her for their dance. Ellen said he practically had to hold her up as they danced together because she was so weak. They all said there was not a dry eye in the whole place. She asked me to sing the song for her while they looked at the pictures again. They all became teary-eyed. After the song I pointed out that it has really come to have a special meaning for Ellen. Carole agreed and said “For all of us.” I said that the song had always seemed to speak to Ellen in a very personal way. Ellen said that it reflects how she feels about living life, that we should not take it for granted while we are here and we should encourage others to do the same. She said it is also her wish for her loved ones. She said that our time together has been a blessing to her and her family because she feels more connected to them and they understand her feelings about dying. I said I could see how much they support her and her son said he would like us to sing *Lean on Me*. We sang the song together and the lyrics were very fitting for the moment. During the session I had a strong feeling that it might be my last time with the family. Ellen was being discharged the next day and she was growing very weak. I had a feeling that her time left was limited. We closed the session with *Just a Closer Walk with Thee* and said good-bye.
**Therapist Reactions**

Ellen and I developed a special bond in our work together. Because she was very open and honest about her feelings, she shared a lot with me and I felt like I was sharing her burdens and joys. There were times when I felt I could really put myself in her shoes, especially because I could resonate with some of the spiritual challenges she was experiencing. One of the challenges for me as a therapist was reconciling the hope I had for her with the reality of her declining condition. Although I was glad that she had a sense of peace and acceptance about her death, I had high hopes for her. I hoped that she would make the wedding, that she would not be in too much pain, that she would feel okay about leaving her family. These were personal reactions I explored on my own during my work with her. It is important for people working in end of life care to become aware that many times the hopes we have for our patients are never realized. In Ellen’s case there were many successes, but they did not change the fact that she would soon die or that I would miss her. I learned so much from her about acceptance, walking with God, and living each day as a gift. I was touched by the things she shared with me in our sessions. I was often in awe of the faith she had and of her ability to verbalize it as well as her doubts. I felt lucky to have spent so much time with her, as I had learned many important things about what it is like to live with cancer and stay strong in the face of it.

**Discussion**

The music helped Ellen and her family to express their thoughts and connect with their emotions. It felt like a safe place for them to meet and be together with the issues that were too difficult to talk about with words. Music therapy provided them with the opportunity to have an enhanced awareness of their emotions related to Ellen’s illness.
and to be more expressive. I noticed during our time together that she would choose to share different things when different family members were present. It seemed that she had a sense of where each family member was in their acceptance of her illness and wanted to grow with them. For example, she tended to be more open with her sister than with her husband until he became more comfortable discussing those difficult issues. The music allowed her to communicate important issues to her family while at the same time protect them from some things they were not ready to accept yet. Towards the end of the treatment process, she seemed to feel she could release that need and be more open with all of her family.

I had numerous music therapy sessions with the patient and various members of her family over a period of about six months. Ellen enjoyed choosing songs that related to how she felt and she used the music as a jumping board for discussing her emotions related to her illness and her future. Some sessions were very emotional with her family present, and others were more quiet discussions and sharing of music with just the two of us. Ellen was open and shared many things with me, including her acceptance of her illness, her struggles with faith, the conflict between her acceptance and her family’s hope for her, her fears and doubts about the future, and her hopes to go to heaven. Her theme song, *I Hope You Dance*, was an important tool for her to communicate her wishes for herself and her family and for them to accept and support her. Listening to her and reflecting her thoughts with words and music helped her to become more aware of her feelings and know how to express them.

After working with her family for a while, they became more open as well. Over time, they trusted that the music would comfort her and they welcomed it as therapy
progressed. John became an active part of sessions. I think that the music, as well as
Ellen’s acceptance of her situation, played a part in helping him become more
comfortable in sharing the sessions with her. The music was also important for Ellen
because it transcended where she was at with her pain and physical suffering. It brought
her to a place of peace and beauty where she could be with her feelings and experience
support. In past sessions, Ellen often struggled with being in a place of acceptance, while
others were not. This was difficult for her because other people had the impression that
she was giving up. I had the impression at the end of the treatment process that her family
had a better understanding of Ellen’s feelings, which enhanced Ellen’s sense of peace.
Case Study 4: Cheryl

You are My Sunshine: a Mother’s Last Wish for her Daughter

This case discusses a single mother who is faced with leaving her daughter in someone else’s care. Although I only worked with this family for a couple of weeks, I felt it was an important case to include because of the special circumstances. Sadly, this is a scenario that probably occurs far too frequently in single parent homes when the parent becomes ill. The dying mother faces the prospect of having to choose the person who will raise her child or children, which can often be heartrending. This case will explore some of the mother’s needs in the last days of her life including support and opportunity for self-expression, the need for a sense of control, and the desire to stay connected to her daughter. It will demonstrate how music therapy was used to aid in meeting these needs and helping the family have a sense of closure.

Background Information

Medical history.

Cheryl was a 35 year old African-American female with stage IV breast cancer including bone, lung, liver, and skin metastases. She was originally diagnosed in 2003 with a lump in her right breast. She had a lumpectomy and modified radical mastectomy, followed by chemotherapy. She went into remission in 2004, but developed a rash on her breast in 2005. Cancerous nodules were found, along with bone lesions, liver lesions, and pleurae effusions, which is an escape of fluids from the membrane of the lungs into the lungs or other surrounding body cavities. Cheryl was admitted to the hospital through the emergency care unit in January 2006 for abdominal pain, nausea, vomiting, and palpitations. She was on morphine for pain and oxygen treatments for shortness of breath.
Disease information.

Breast cancer is a disease in which malignant cells form in the tissues of the breast. It is the most common malignancy in women in Western society. Risk factors include older age, family history of cancer, hormone use, and alcohol use. Breast cancer is most treatable in the early stages, which is why early detection is critical. It may take several years for a lump to appear after the cancer has started. Treatment options include lumpectomy, mastectomy, radiation, chemo, and hormone therapies. In stage IV of breast cancer, the cancer has spread to distant organs and is not curable, although some people can live a normal life with metastases for a long time.

Family information.

Cheryl was single and lived with her eight year old daughter named Briana. Briana’s father was estranged and had not had any contact with them since before Briana was born. Cheryl worked full-time as a dental hygienist to support herself and Briana. Her mother died of a heart attack when Cheryl was in her early twenties. Her father was still living and had dementia. He lived in the south with his sister and her family. Cheryl had one sister named Janine with whom she was extremely close. She described Janine as her best friend and the two women were very supportive of each other. Janine was 32 years old, single and had no children of her own.

Treatment Process

Staying connected.

I was referred to see Cheryl for music therapy during a multidisciplinary team meeting on her floor, towards the end of my internship. The nurse manager working on her case remarked that she did not think that Cheryl would make it out of the hospital.
Cheryl was referred for psychosocial issues related to end of life care as well as social work issues related to her daughter. Cheryl had not yet made any definitive arrangements for the care of her daughter, believing she had more time left.

When I entered the room Cheryl was sitting on the side of her bed, with her sister Janine sitting in a chair at her bedside. Her affect was flat, but Janine had a pleasant face with a friendly expression. I introduced myself to Cheryl and Janine and explained what music therapy was. I told her she had been referred by a nurse and that there were many ways she could use the music. I told her that music often helps people with pain and can be used for relaxation. I also mentioned that people often use music to increase their energy and lift their spirits. She looked a little skeptical while I was explaining all of this to her. Janine had a big smile on her face and was watching Cheryl. She said, “That sounds great! You should do it, Cheryl.” Cheryl asked me how long the music would last. I told her it was up to her and that she could tell me when she wanted to finish for the day. I said that some people just like to hear a couple of songs, while others like to spend more time. She looked at her sister and said, “Briana would love this, she loves music.” I asked who Briana was and she told me it was her daughter. I said that if she wanted, we could make a tape of some songs for Briana that she could send home to her. Cheryl asked if she would have to sing on the tape. I said she could if she wanted to, or she could just say a message for her. She said she would think about it. Then she said she thought she would just like one song.

I offered her the songbook to choose from, but she said I should choose the song. I played *Here Comes the Sun* for her because it is simple but pretty and I have found in past experiences that it is often a good song to start with. People often interpret the lyrics
in different ways, depending on how they are feeling and what they may want to get out of the music. For example, the song can be very hopeful, but can also be reassuring for someone in a place of acceptance. About halfway through the song Cheryl started moving her body to the music. She said, “That sounds nice,” and lay back in bed to listen. She began smiling and looked pleased with the music.

After the song was over she said, “I think I would like to make that tape. Do you have time today?” I said yes, brought in my tape recorder and set it up. Janine asked to see the songbook to check what songs I had. While she was looking, I asked Cheryl if there were any special songs she sings to Briana. She said they liked to sing *You Are My Sunshine* together. I turned the tape on and she said hi to Briana and that she missed her. She said to listen to a special song just for her. I started singing the song and both Cheryl and Janine joined in right away. Cheryl seemed to feel safer once the music started, despite her earlier hesitation about singing. After that song, Janine suggested *I Can See Clearly Now* for the tape. Cheryl said Janine should say something on the tape too since she was picking a song for Briana. Janine said a simple hello to her from her Aunt Janine and we started the song. Cheryl sang even louder this time and she and her sister clapped along to the music. They both moved their bodies and seemed like they were really getting into the music. They were both smiling and looked content after the song. We turned off the tape to decide what to do next and I mentioned how much they seemed to enjoy that song. Cheryl said she loved the song because it is so uplifting. She said it reminded her that things were never as bad as they seemed. Janine looked surprised by Cheryl’s response and said, “That’s really deep, Cheryl!” They both laughed and Cheryl
said she did not mean to get profound. I pointed out that music often brings up deep
thoughts and feelings. They both agreed that music was powerful.

I suggested singing *He's Got the Whole World in His Hands* and singing Briana’s
name. They thought it was a good choice and sang and clapped enthusiastically during
the song. After the song was over Cheryl spoke into the tape recorder, saying “I hope you
liked that, Briana! I’ll see you soon and I love you!” She was smiling as she spoke. It was
interesting to see how Cheryl’s affect changed when she spoke to her daughter through
the recorder. It became brighter and more energized. Her posture and tone of voice also
changed and immediately became very gentle and nurturing. It was almost as if her
daughter was sitting in the room with us. I suggested that she send the tape home to
Briana and ask her to record a message or a song at home in response and then to send it
back for Cheryl to hear and add to. She said that was a good idea and thought Briana
would like to do that. At that point a patient escort came to take her down for a test so we
had to finish our time. She thanked me and said she was glad I had come by. I told her I
was glad to meet her and Janine and would come back in a couple of days to see her
again.

I saw a transformation in Cheryl during the session. At the beginning she seemed
skeptical about music therapy and wanted me to stay just for one song. Once the music
began, it seemed to help her open up and become more comfortable. I think it also helped
her to be able to make some choices about what happened in the session. She seemed to
feel more comfortable to know that I did not have any expectations for her during the
session (i.e. that she had to actively participate in some way, such as singing with me).
The music had a powerful effect on her mood. Her sister was also very supportive and
willing to show that she was enjoying the music through singing and moving her body. I think this may have also helped Cheryl feel comfortable. I got the impression that she was a quiet person – not shy, but a little reserved. The music seemed to help her come out of her shell a little, especially once she agreed to use the music to connect with her daughter at home.

When I first came into the room, I was unsure of how Cheryl felt about music therapy. Once the music started, I think I was able to relax and become more open with her, as she was with me. The music is something I can always rely on to be there when I am unsure of what to say. I felt a lot of empathy for her because she is very young to be facing such a serious disease. I felt that she has a strong spirit and I was encouraged to see her uplifted by the music. I was pleased that she allowed me to be a part of her recording when we had just met. I thought we connected during our first meeting and I looked forward to having more sessions with her.

*Don’t let her forget*

The next time I visited Cheryl, just a few days later, her condition had declined quite a bit. Her breathing was labored and the nurse had given her an oxygen tank to help her breathe if she needed it. Janine was with her and welcomed me with a friendly smile, but I sensed that she was worried about Cheryl. Even though I could tell she was not feeling well, Cheryl waved me into the room anyway. I let her know that she could just relax, that she would not have to talk or sing much or at all if it was difficult for her. She smiled a “thank you” at me.

I asked how Briana had liked the tape and Cheryl’s face lit up. Janine said Briana had loved it and they had a great time recording a message for Cheryl to hear. They
played a part of it back for me and I heard the little voice of an eight year old child asking her mother when she would be coming home. She said Aunt Janine had bought her a new doll that she wanted her mom to see. Briana talked a little about her school and her friends as prompted by Janine in the background. Then Janine helped her sing *You Are My Sunshine* to finish the message. Cheryl was beaming while she listened. As in the previous session, I noticed an immediate change in her when her daughter was brought into the conversation and when she heard her voice. As in Diana’s case, she seemed to receive energy when she was placed back in her role of mother.

I mentioned that is was very nice of Janine to help Briana make the tape. Janine said it was easy since Briana was staying with her anyway. I asked her how that was working out for them and Janine replied that she loved having her niece with her. I noticed that she looked pointedly at Cheryl when she said this and Cheryl just shook her head. Cheryl said in a soft voice that she just wanted to make the best decision for everyone. I was not exactly sure what was transpiring between the sisters, but I had an idea from the social worker’s notes in the chart that it had something to do with Briana’s care should anything happen to Cheryl. I was not surprised that this had come up during the session because it was a big issue for Cheryl and Janine at the time. Apparently her aunt in the south had volunteered to take Briana and Cheryl thought this was a good idea because they were financially stable and there were many family members in the area that could help out. Janine wanted Briana to stay with her because it was familiar to her already and because Janine loved Briana so much. Cheryl was worried that Briana might be a burden on Janine because she was single and had many possibilities open to her in the future as far as getting married and having children of her own. Cheryl did not want
to get in the way of Janine’s plans or take the chance that Briana might ever feel out of place. In addition, Janine would be the only one left in the family who lived in the area and would not have the benefit of the support of aunts, uncles, and cousins. It was a tough decision because each side had advantages and disadvantages.

At that point, Janine suggested adding a little more to the tape, in a seeming attempt to change the subject. Cheryl nodded and I asked them if they wanted to look at the songbook or if they had any ideas of their own for songs to add. Cheryl suggested *This Little Light of Mine*, a song Briana knew from the children’s class at the church they attended. We turned the tape on and Cheryl said hello to Briana, that she missed her and wanted her to keep shining her light all over the place. I noticed the theme of sunshine and light recurring in the different songs she chose in music therapy sessions. I wondered if the light could be equated to the hope she had for recovery and for her daughter’s future. We sang the song and substituted many different lyrics for the verses to show all of the places where Briana could let her light shine, such as “When I go to school,” “At my Aunt Janine’s house,” and “All around my neighborhood.” It seemed to be Cheryl’s way of reminding Briana to be a good girl even though she could not be there to parent her. Janine clapped during the song, giving it a lively and energetic feel. Cheryl did not sing along much, but helped with the lyric substitution. Lyric substitution is a way for patients to be actively involved in the music therapy session by personalizing songs for their unique situations.

After that song, Cheryl said on the tape, “Don’t forget how much mommy loves you! Remember all the nice things we did together for Christmas and your birthday? You can think about those things whenever you miss mommy.” This was a very poignant
moment in the session because it was a clear effort on Cheryl’s part to let Briana know that they might not always be together. She looked at me and simply said, “I’m afraid one day she won’t remember me anymore. Right now I’m all she has, but she has her whole life ahead of her.” I could see that Cheryl felt her place in her child’s life slipping away, and at that moment it made sense to me why she had not yet decided who would care for Briana after she died. Making that decision would be like giving up her role as a mother too soon.

I asked her and Janine if Briana understood what was happening to her mother. Janine said she knew her mother was very sick and might not be able to come home. Cheryl said she was worried that Briana might feel abandoned by her. I pointed out that the tape was a gift Briana would always have as a memory of her mother and that Cheryl had been expressing her love on the tape so that Briana would always remember it. Cheryl answered that she just did not know what to do. I sensed that she was referring to more than just leaving Briana without a mother and asked if she was also feeling worried about Briana’s care. She nodded and said, “All the time.” I asked her what was most important to her concerning Briana’s care. She said she wanted Briana to be well-loved and well taken care of. Most importantly, she wanted Briana to remember her memory always. Janine took Cheryl’s hand and said “I will do all of that! You know that. Don’t worry about me – God put me here for a reason and maybe this is it.” Cheryl said quietly, “Don’t let her forget me or why I left – that it wasn’t my choice.”

I felt that something very important was happening between the sisters and suddenly felt unsure of my role there. They seemed to be coming to a turning point on their own and I was not sure if my presence would be invasive. I looked at Janine and
said it seemed like they had some things to plan. I asked if she wanted me to leave the
two of them alone to talk for a while. She said yes, she thought they needed some time to
work things out. Cheryl asked if she could choose one more song for Briana’s tape and
asked for the songbook. She looked at the book very carefully and chose *What a
Wonderful World*. I suggested that she record a message saying why she had chosen that
song. Cheryl said, “Briana, I want you to remember me in the beautiful things you see in
the world. Don’t be sad because I can’t be with you anymore. Just remember how much I
love you and that Aunt Janine will take good care of you for me.” Janine sang along with
me, but Cheryl was quiet. It seemed that the talking had worn her out, or perhaps the
content of the conversation. After the song, I quietly packed up and left the sisters alone
to work things out together.

*Saying goodbye.*

I had one more session with Cheryl before she passed away. Several days after the
last session we had, I arrived at Cheryl’s room to find it filled with family and friends.
Janine met me out in the hallway and explained that Cheryl was quickly getting worse
and was having a lot of trouble breathing. She could not talk because it was too difficult,
but was still aware and could hear what was going on. The staff had recommended that
family should be invited in to say their goodbyes to her, so some family had flown in
from out of state to see her one last time. I asked Janine if Briana had come yet and she
said she planned on bringing her later that day. Although she was facing the imminent
death of her sister she seemed to be composed. I guessed that settling Briana’s future was
a burden that had been lifted for both sisters.
Janine invited me to come in and play for them for a while because she knew Cheryl would want it. I went into the room and introduced myself to the family members in the room. I said hello to Cheryl and she looked up at me from under her oxygen mask. Her eyes looked pained and her breathing was very shallow. I squeezed her hand gently and said, “We’re here with you.” She nodded and closed her eyes. There was a nurse in the room who encouraged Cheryl to try to take slower breaths. I began to play softly on the guitar. I asked Cheryl to listen to the music in the room, to allow it to surround her. I matched the rhythm to her breathing and asked her if she could try to breath with the music. Using this principle she was able to slow down her breathing gradually until she looked a little less uncomfortable.

Janine asked if the family could sing for her together. She chose Lean on Me from the songbook and everyone joined in singing. It was a song that helped the family show their support and love for Cheryl and for each other. After that, I suggested He’s Got the Whole World in His Hands, during which we included everyone’s name who was in the room, as well as other family members who could not be there that day. Cheryl just listened with her eyes closed while her family stood around her and sang. When we got to Briana’s name in the song her eyes flew open and she looked at Janine and nodded, then closed her eyes again. It was heartbreaking to witness how hard it was for her to let her daughter go. Cheryl died the next morning.

**Therapist Reactions**

I had the impression that Cheryl felt out of control of what was happening to her. Although I had tried to give her opportunities for control in the music therapy sessions, they were only brief moments and could not compare to the magnitude of what she was
facing. I wondered how successful my interventions really were with Cheryl and regretted not having more time with her. She had to make a difficult decision about the care of her daughter and I think she felt rushed. She did not have time to consider all of the pros and cons of each option and was probably feeling pressure on both sides. I had a sense of the unfairness of the situation, that such a young mother should have to feel like she was giving up her child. I could not imagine being in her shoes. It made me realize the importance of thinking about tough issues before illness or tragedy strikes, so that hard decisions will already have been made. Although I never met Briana in person, I could see her in Cheryl and the way she talked to her on the tape and talked about her in sessions. I felt heavy and weighed down after leaving her room, like I had taken on some of her burden.

In this case it was important for me to be aware of space Cheryl and Janine needed to go over important details like Briana’s care. I did not want to intrude on their time because every minute is important when a person only has a few days left on earth. Consequently I was very cautious in my approach with Cheryl, giving her the opportunity to be honest about what she wanted to do with the time and to take the direction in the sessions when she was able to. It was sometimes hard for me to stay composed and collected when I was listening to her messages to her daughter on the tape recording. I could hear the anguish and pain in her voice and sometimes I felt helpless as to how to help her. My awareness of these feelings of not knowing what to do helped me to better understand Cheryl’s feelings of helplessness and powerlessness over her disease.
Discussion

Music therapy helped to open the lines of communication between Cheryl and Janine, as well as Cheryl and Briana. In the sessions, Cheryl was given the chance to share things with her daughter that she wanted her to be able to keep with her. Since Cheryl did not have the strength to speak the last time she saw Briana, it was important for her to have her words recorded in our sessions. The emotions expressed in the music therapy sessions through the recording of her messages to Briana and the songs that were chosen also enhanced Janine’s awareness of Cheryl’s pain and helped her to offer her the support Cheryl needed.

Cheryl did not seem to ever reach an acceptance of her death, at least not that she had a chance to express. However, she was able to be open about her fears and feelings related to releasing her role as a mother. Song choice and recorded messages for her daughter afforded Cheryl with the opportunity to be expressive and develop an enhanced awareness of her own feelings about dying.
Conclusions

Each of the four families in the case studies were very different and had their own set of unique needs to be addressed. However, many of the themes recurred throughout the four cases and the way the families dealt with terminal illness. The five themes that seemed to be most salient for the four families were feelings of safety, enhanced awareness, increased acceptance, openness, and feelings of release.

Many of the patients and family members who may have had a hard time expressing themselves often felt safe doing so in the context of music therapy. Song choice, improvisation, or recording music helped individuals to have a safe outlet for their thoughts and feelings about death and related issues. In all four of the cases, certain songs prompted the families to discuss issues related to the mother’s death. The two mothers of younger children seemed to try to create an environment of safety for their children so that the children would not have to witness more pain and suffering than was necessary. The music therapy often assisted mothers in doing this by providing them with opportunities to connect with their children in the music.

Music therapy also helped the families achieve an enhanced awareness of their emotions. Through the use of music therapy techniques, feelings were brought into consciousness that the patients and families either did not recognize or were avoiding as a form of denial. For example, in the case of Ellen, she became aware of her doubts through the use of certain song lyrics and was able to reconcile the internal conflict she felt as a result of the doubts. In Marie’s case, her daughter Karen became aware of her need to show more love and appreciation for her mother so that she would not have any regrets after her mother died. In all of the cases, an enhanced awareness of her own
feelings as well as those of her family was critical for the dying mother in order for her to attain a sense of peace about her death. Enhanced awareness also helped families make difficult decisions, such as in the case of Diana when David realized that she and the children both wanted her to come home to die. In Cheryl’s case, her family realized an enhanced awareness of her last wishes for Briana.

Once families reached an enhanced awareness of each other’s feelings and thought processes, many of them were able to arrive at an increased acceptance of death. What I witnessed in each case was that different family members were at various stages of acceptance of the terminal illness. If the patient was accepting and the rest of the family was not, such as in Ellen’s and Marie’s cases, tension often resulted in the family dynamics. If the patient was not accepting of her own death, it also made decision-making difficult, such as in Diana’s and Cheryl’s cases. What often led to increased acceptance of the prognosis was openness in communication.

Music therapy helped to open communication by allowing patients and family members to give a voice to anything they wanted to share with each other. Patients and families were often very open with me, which I think was a way from them to practice sharing things with their family members. Having an objective person to listen to concerns without judgment helped many of the families a great deal. At the end of life, patients want their voice to be heard; they still want to play an active role in what is happening within the family unit. Openness in communication allows them to have this opportunity and to share meaningful last words and wishes with the family. Music therapy accomplished this through life review and recorded messages in Marie’s and
Cheryl’s cases. It also helped Diana to communicate more freely with her daughters and Ellen to share her feelings about her death with her family.

Finally, release is very significant for patients at the end of life and their families. Patients may experience a release of many things: control, roles, responsibilities, pain, fear, anxiety, and unhealthy coping mechanisms. For Diana and Cheryl, mothers of young children, it was difficult for them to release their roles as mothers. They were both faced with the reality of having to miss out on their children’s futures and no longer be able to be mothers to them. This was a release that was painful for both of them as they experienced a sense of not being in control. Adult children of dying mothers also experience a release of sorts, as for Marie’s daughter Karen. Karen felt a loss of a sense of self because she knew she would no longer be able to identify herself as Marie’s daughter, a member of a complete two-parent household. Once Marie died she felt she would identify only as one who had lost a parent. She feared this release of her relationship with her mother, but found ways to stay connected to her through the music therapy sessions. For patients with strong spiritual connections such as Ellen, it was possible to experience a positive release of control, putting the rest of her life in God’s hand and asking Him to care for her and her family.

Working with these families changed my life. It was an amazing experience to walk with these mothers on the last bit of their journeys through life. Although their experiences were painful in some ways, I saw beauty and strength in each of them that touched me deeply. I am changed because of them, now having a deeper appreciation of their suffering, a deeper love of life, and a greater appreciation for my own mother. When I first chose the topic for this thesis, I hoped that I would grow personally as I was
helping families to grow closer. I feel that I achieved both aims, although many of the endings to their stories were sad. I grieved for these women all over again as I wrote this thesis, but have a hope that my experiences with these mothers and their families will aid other clinicians working with this population. My work with these families was not always easy and I made some mistakes. I hope people will learn from my mistakes as well as my successes in these cases. The intimacy of their stories is a testament to the mystery of death and disease, who gets chosen when and why. I can not pretend to understand it, even after having been faced with many families in the throes of it. However, I can say that I have seen the power of music therapy work to their benefit, alleviating some of the pain and suffering and giving them precious memories and moments of relief. Writing on this topic has truly been an amazing and worthwhile passage, an experience not soon to be forgotten.
References


