

MUSIC THERAPY WHEN DEATH IS IMMINENT:  
A PHENOMENOLOGICAL INQUIRY

A Thesis  
by  
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## **Abstract**

### **MUSIC THERAPY WHEN DEATH IS IMMINENT: A PHENOMENOLOGICAL INQUIRY**

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This phenomenological inquiry examined the experiences of music therapists who provide music therapy services to clients whose death is imminent. Music therapy during a client's final days, hours, and moments has been discussed in relation to its potential to ease pain and promote relaxation, facilitate transition, create a soothing environment, and create opportunities for relationship completion. Music therapists have reported experiences with clients whose death is imminent to be profound and spiritual. Four experienced hospice music therapists participated in the study. Each engaged in a semi-structured interview focused on their experiences providing music therapy for clients who were actively dying. Ten themes emerged from the interviews: (a) it is important to know as much information about the client as possible before providing services to them when they are actively dying; (b) assessing the client's physiological responses can suggest information about his or her internal experience; (c) the music therapist should be flexible and adaptive in the moment to serve both patient and family needs; (d) intuitive processes are extremely important; (e) countertransference is deeply influential in both the clinical process and in the music

therapist's personal life; (f) the music therapist feels a responsibility to take on a role that transforms the experience and the environment in a meaningful way; (g) The central goal is to help the patient transition meaningfully, with as little discomfort as possible; (h) when loved ones are present, the music therapist uses a dynamic and collaborative process to facilitate meaningful transition for both client and loved ones; (i) music therapy can reveal deeper meaning and beauty in the midst of pain and suffering; and (j) music therapy can transform the experience and environment. These themes were grouped into four categories: ongoing assessment, intuitive processes, countertransference, and the role of aesthetics and transformation. Due to the lack of direct client-therapist communication, ongoing assessment using diverse sources and intuitive processes is crucial to making appropriate clinical decisions. Intersubjective countertransference is a core element of the work due to its intimate nature and connection with universal concepts. Finally, music therapy revealed aesthetic experiences that transformed experiences and facilitated transition. These findings point to a need for further discussion concerning assessment for clients who are not outwardly communicative as well as an inquiry into the role of aesthetics in hospice music therapy.

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## **Dedication**

This thesis is dedicated to the clients with whom I have had the honor of sharing music in their final days, hours, and moments of living. The memories of your music are forever with me.

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## **Chapter 1**

### **Inspiration for this Research**

I provided music therapy for patients who were actively dying in an inpatient hospice facility for four to five days each week during my music therapy internship. As I developed my unique therapeutic presence and philosophy of music therapy, I noticed that my clinical decision-making in these moments had become more intuitive than prescribed. Although I initially valued a more objective stance regarding my sessions with clients who were actively dying, one patient who arrived near the end of my internship changed this view immeasurably.

I was only aware of two things about this man: first, that a sudden medical event had caused him to enter the dying process quickly; and second, that his spiritual background was extremely important to him. Although I had no contact with this patient before the session began, my intuition told me many things on that day. When I walked into the room, I felt deep sorrow. As I listened to my patient's breathing and began to focus intently on creating music to support him, I began to experience a thought in my head: I don't want to die. Over and over the thought repeated. I initially sang to this man about what joy awaited him after death as I reflected on the importance of his faith. However, somewhere in these moments, I began to understand that this did not match my sense of the energy in the room. I empathized strongly with the statement resounding in my head. I don't want to die either, I thought. I allowed this sorrow and feeling of unfairness to emerge through the music as I focused

intently on offering empathetic presence. My patient stopped breathing only minutes after this transition, at which point I moved into more peaceful, supportive music. When the nurse came in to call his time of death, she asked that I stop playing. I did, but I felt as if I was abandoning his spirit, still in transition. It was in this uncertain, poignant space that I came to respect the influence of clinical intuition and spirituality. My once objective view of the events of the session shifted dramatically, and I began to explore the profundity of my experience and how this had influenced the session's events.

### **Overview of Hospice Care**

Hospice is a philosophy of care in which the goal is not to extend life, but to improve the quality of one's final days with dignity and supportive care. The hospice philosophy was developed around three key principles: pain control, a family or community environment, and an engagement with the dying person's most deeply rooted spirituality (Coward & Stajduhar, 2012). As the vision and reach of hospice services have expanded in the United States, medical and community services have expanded to provide comprehensive care for those with terminal illness. Compassionate care by an interdisciplinary team is the guiding principle by which hospice clinicians provide services to their patients. Current Medicare regulations require that hospices provide the following services when necessary for patients: time and services of a care team including a physician, nurse, medical social worker, home-health aide, and a chaplain or spiritual advisor; medication for symptom control or pain relief; medical equipment, for example, wheelchairs, medical supplies, catheters; physical and occupational therapy; speech-language pathology services; dietary counseling; any other Medicare-covered services needed to manage pain and other symptoms of terminal illness as recommended by the hospice team; short-term inpatient care for symptom management;

short-term respite care to relieve caregivers of responsibilities; and grief and loss counseling for patient and loved ones (U.S. Department of Health and Human Services, 2013).

At the dawn of hospice services in the United States in the 1970s, the majority of patients who received hospice care were dying as a result of a terminal cancer diagnosis (Coward & Stajduhar, 2012). However, 63.1% of those individuals receiving hospice services in 2012 were adults with diagnoses other than cancer including major neurocognitive disorder, heart disease, lung disease, stroke, and renal disease (National Hospice and Palliative Care Organization, 2013, p. 7). In order to receive hospice services, a hospice physician and a second physician must certify that a patient meets specific medical eligibility criteria. Although specific admission criteria depend on the nature of the illness and its severity, generally patients who are admitted into hospice care have a prognosis of 6 months or less to live. According to the National Hospice and Palliative Care Organization, an estimated 1.5 to 1.6 million Americans received services from hospice in 2012 (NHPCO, 2013).

### **Signs and Symptoms when Death is Imminent**

The days and hours leading up to an individual's death can be challenging for the patient, family, and hospice team. The dying process remains an elusive medical and spiritual concept, even to those who have made it their life's work to study death and dying (Hui et al., 2014). Questions that have remained unanswered for millennia persist both in the medical and spiritual community: How much can be known about the dying experience? Is it possible to identify the precise moment of death? How much control does the patient have over his or her death? Can the dying person hear when spoken to?

Although each patient presents uniquely during the dying process, hospice and palliative care clinicians generally recognize a typical pattern of symptoms or signs that suggest death is imminent, that is, when the patient is actively dying. Physiologically, the body begins the process of shutting down its organs. As circulation decreases, the individual's hands and feet may begin to cool and/or mottle. As the body's metabolism decreases, wakefulness and alertness decrease while sleeping and uncommunicative resting increase. When the individual is awake, he or she may appear disoriented, confused or agitated. Emotional or spiritual experiences preceding death may include increased withdrawal from loved ones, restlessness, and even visions of persons who have already died. Urine and fecal output decrease. Generally, patients are incontinent during their last days and hours before death. Because the body no longer needs food in the same way it once did, appetite decreases and eventually disappears. As the muscles in the chest and throat relax, the individual may develop congestion and secretions in the throat and lungs. This sound, colloquially referred to as "death rattle," may be unsettling for family members; however, it is generally considered normal and poses no threat of discomfort to the patient. It is common for individuals in the last hours and moments preceding death to display irregular breathing patterns, or Cheyne-Stokes breathing. This may include shallow, pant-like breathing or five to thirty second periods of apnea (Lamers & Doka, 2005). Sometimes it is difficult for families to pinpoint the precise moment of death without confirmation from a nurse or aide (Krout, 2003). When death is recognized medically, a patient will have stopped breathing entirely. The bowels and bladder will have released, and the heart will have stopped beating. Often, the eyes and mouth relax to slightly opened positions. In order to support the natural process of dying, hospices have increased employment of music therapists (Hilliard, 2001).

## **Music Therapy**

According to the American Music Therapy Association, music therapy may be defined as,

The clinical and evidence-based use of music interventions to accomplish individualized goals within a therapeutic relationship by a credentialed professional who has completed an approved music therapy program. Music Therapy is an established health profession in which music is used within a therapeutic relationship to address physical, emotional, cognitive, and social needs of individuals. Through musical involvement in the therapeutic context, clients' abilities are strengthened and transferred to other areas of their lives. (American Music Therapy Association, 2013, para. 1)

Music therapists may use interventions including singing, song writing, improvisation, music-assisted relaxation techniques, guided imagery and music, lyric analysis, instrument playing, and music-assisted meditation to offer support and meet the diverse needs of patients and families in hospice (Bradt & Dileo, 2010).

### **Growth of Music Therapy Services in Hospice Care**

In the past two decades, the vision and reach of hospice has expanded, as well as the opportunities for employment in Complementary and Alternative Therapies (CAT) including aromatherapy, art therapy, therapeutic touch, music therapy, pet therapy, and massage therapy. In 2007, the Centers for Disease Control and Prevention (CDC) reported that 41.8% of hospice care providers in the United States offered CAT (Bercovitz, Sengupta, Jones, & Harris-Kojetin, 2011, p. 3). Data from a 2004 survey study of 300 randomly selected hospices showed that the most commonly used forms of CAT were massage therapy and

music therapy (Demmer, 2004). As a result, an increasing number of music therapists are gaining employment in facilities that offer hospice and palliative care services (Hilliard, 2001).

### **Music Therapy During the Dying Process**

Although music therapy during the dying process no longer aims to facilitate change in the traditional sense, music therapists may support or even facilitate the natural act of dying (West, 1994). Music therapy during the dying process may facilitate relationship completion or finding closure in unresolved issues in close relationships (Dileo & Loewy, 2005; Gilbert, 1977). Music therapy may also create opportunities for honoring significant aspects of the client's life and legacy (Krout, 2003). In addition, music therapy may create a structured, peaceful, and compassionate environment facilitating a "good" and/or meaningful transition from life to death (Martin, 1991; Munro, 1984). Although the dying process may not be "improved" in the traditional sense, music therapists have reported incorporating the *iso*-principle, or the manipulation of musical elements to match a client's experience, into receptive music to reduce negative symptoms including anxiety and pain (Hilliard, 2001; Hogan, 2003). In addition to offering emotional and physical support, music therapy may be used during the dying process to support the spiritual beliefs of the client and his or her loved ones (Kraut, 2003; Zabin, 2005).

### **Summary**

Hospice is a philosophy of care that places emphasis on providing holistic, supportive care to improve quality of life during the dying process. When the death of an individual receiving hospice care becomes imminent, characteristic symptoms of bodily shutdown occur. Although clinicians and caregivers acknowledge a certain degree of uncertainty about

this process, goals during this time include maintaining comfort and reducing negative symptoms. Music therapy is the clinical use of music and a client-therapist relationship to accomplish individualized goals. Although music therapy has been established as beneficial for clients in hospice (Hilliard, 2001), little evidence supports the use of music therapy for clients whose deaths are imminent. Music therapists have written about their experiences providing music therapy for clients who are actively dying, but these accounts offer no theoretical or spiritual foundation for clinical decision making (Potvin & Argue, 2014). Ultimately, the experience of providing music therapy for imminently dying clients remains esoteric. Considering the barriers in establishing empirical support for this practice along with the personal nature of the work, a phenomenological approach was selected for this research.

### **Methodology**

Phenomenology is a philosophical approach derived from the Greek word *phainómenon*, meaning “that which appears” (van Menen, 1990). Underlying this approach is the assumption that human experience can only be understood upon reflection of how we come to understand it. Phenomenological inquiry is an approach to gathering data that explores the “what” and “how” of lived experience. Phenomenological inquiry strives to understand both the “essence” of experience by gathering rich, detailed description from a small number of sources; and also how we come to perceive and understand experience (Creswell, 2013). Therefore, phenomenology is not concerned with solving problems or making vast generalizations (van Menen, 1990), but instead with allowing themes to emerge from the lived experiences of a few who have experienced the phenomenon in question. The following paragraphs will describe the process of gathering phenomenological data.

## **Epoche**

An epoche serves to contribute to the understanding of how the researcher has come to understand the phenomenon he or she is exploring. In an epoche, the researcher describes his or her feelings and experiences related to the research topic. This process reveals any biases before data collection and may be used later to inform and synthesize the data that are analyzed in the latter phase of the study. By setting aside preconceptions, the researcher hopes to approach the interview with a more open, receptive presence.

## **Phenomenological Reduction**

A phenomenological reduction may be understood as horizontalization, or the process of isolating significant statements from the interview that contribute to the understanding the phenomenon. By identifying significant statements and treating them as equally important, the researcher may begin to increase his or her understanding of the phenomenon through self-reflection (Moustakas, 1994). At this point, the researcher eliminates redundant or unrelated statements that do not contribute to the understanding of the phenomenon and organizes the statements into themes—or the “what” of the phenomenon.

## **Imaginative Variation**

Imaginative variation is a process by which the researcher uses his or her imagination to introduce polarities, reversals, varying frames of reference, and divergent approaches to understanding the phenomenon in order to reveal hidden meanings or textures (Moustakas, 1994). In this process, the researcher considers which statements contribute to the “essence” of the phenomenon by examining alternative possibilities. By expanding the scope of reference to consider what may be hidden, imaginative variation complements the eidetic process of phenomenological reduction. This contributes to the conceptualization of the

“how” of the phenomenon.

### **Synthesis**

The final step in phenomenological research is to synthesize the themes and perspectives revealed through phenomenological reduction and imaginative variation to arrive at a textural-structural description of the phenomenon. This may include isolating themes that contribute directly to understanding the phenomenon and providing data and the researcher’s written perspective in relation to the findings. What emerges during this final step may be understood as the “essence” of both the participants’ and the researcher’s lived experiences.

## **Chapter 2**

### **Review of the Literature**

This chapter will provide an overview of relevant literature that supports the need for phenomenological inquiry of this topic. It will begin with a discussion of the needs of individuals who are actively dying followed by justification for the role of music in dying, including an examination of existing models of work with imminently dying clients.

#### **Caring for the Patient Who Is Actively Dying**

The days and hours before death can produce symptoms that are quite complex and ambiguous for hospice clinicians. End-of-life care for terminally ill patients strives to alleviate symptoms and maintain comfort during a patient's final hours. As much as possible, it is important to honor patient input about the manner in which they prefer to die. An increasing number of studies have highlighted the importance of talking to both patients and family members in advance about the diagnosis of imminent death in order to give patients opportunities to express needs and desires (Ellershaw & Ward, 2003; Sullivan, Matsuyama, & Arnold, 2007; Wenrich, Curtis, Shannon, Carline, Ambrozy, & Ramsey, 2001). Tang (2003) surveyed terminally ill patients with cancer and found that 90% of respondents preferred to die at home, and all respondents identified the location of their deaths as highly important. Franck and Willems (2005) conducted interviews with patients who were dying of cancer and found that symptom control and relieving burdens on family caregivers were identified as important considerations when making care decisions during the dying process.

Ellershaw and Ward (2003) identified goals of care for patients in the dying phase. Physically, non-essential drugs and inappropriate medical interventions including blood tests and vital sign measurements should be discontinued. Because a patient may not be able to articulate his or her needs, patients should be observed for signs of pain or anxiety. Mouth care is important to keep the dying patient's mouth moist and comfortable. Psychosocially, both the patient's and family's insight surrounding death and dying should be explored and addressed appropriately. Spiritually, both the patient's and the family's religious traditions should be honored during the dying process.

At the dawn of hospice care in England and the United States, Cicely Saunders brought forward the concept of "total pain," or the acknowledgment that spiritual and psychological suffering may have deleterious effects on the body just as physical ailments do (Coward & Stajduhar, 2012). Elizabeth Kubler-Ross's (1969) five stages of dying have served as a guide for the manner in which hospice professionals consider a patient's psychosocial needs during the dying process. These stages include denial, anger, bargaining, depression, and acceptance. As a patient comes to terms with his or her own mortality, a clinician may help him or her to move through the stages toward acceptance with support and validation. However, when a client has days to hours to live, it can often be difficult to engage with the patient in order to assess his or her insight about the dying process. Indeed, it is nearly impossible to quantify what the patient is experiencing once verbal and physical communication have ceased. Renz, Mao, Bueche, Cerny, and Strasser (2012) attempted to address this ambiguity by suggesting three non-linear states of a transitional dying process as verbalized by patients who had near-death experiences. Pre-transition was defined as a state in which patients felt physical needs, pain, and emotions. Transition itself was defined as a

state of losing ego consciousness. In this state, a patient may experience physical signs of anxiety, restlessness, or disturbing imagery. Post-transition or spiritual opening was defined as a state of being beyond anxiety, pain, or powerlessness in which the patient is unable to speak but still hearing. The authors' work confirms that although we may hear subjective accounts of patient experiences and consider how to best support their needs, ultimately the experience of death remains a mystery.

### **The Sense of Hearing During the Dying Process**

Families are often encouraged to speak gently to the actively dying patient because hearing is the last sense to deteriorate. Narrative accounts written by hospice clinicians often report this belief as fact and suggest that clinicians inform families that their loved ones may still be listening in their final moments (Sheehan, Forman, Kitzes, & Anderson, 2003). There is no research-based evidence to support this claim. However, it is a widely held belief that continues to be important for families and clinicians who desire moments of connection and communication with individuals who are actively dying (Callanan & Kelley, 1992).

### **Music Therapy, Anxiety, and Pain Reduction**

A survey by Groen (2007) revealed that 97 percent of music therapy referrals made by hospice interdisciplinary teams cited anxiety reduction as a primary reason for referral. It is well documented that music therapy may facilitate anxiety reduction in hospice patients (Hilliard, 2003; Hogan, 2003; Krout, 2001). Hospice music therapists recognize that pain is a complex system that may be affected by the interaction of past experience, emotional state, social support, and sensory information (Selm, 1991). Music therapists have cited anxiety reduction as a way of facilitating pain management (Kwekkeboom, 2003; Maslar, 1986). Although markers including cortisol levels, heart rate, and blood pressure may be measured

to analyze the effect of music on stress, little research exists to support the use of music to affect physiological change in hospice patients. A pilot study by Nakayama, Kikuta, and Takeda (2009) showed a significant decrease in salivary cortisol levels in hospice patients after a small-group music therapy session; however, further studies measuring the use of music to decrease physiological variables including heart rate and blood pressure have been inconclusive (Ferrer, 2007; Pelletier, 2004).

### **Summary**

Comprehensive end-of-life care strives to address both physical and psychosocial aspects of the dying process (Coward & Stajduhar, 2012). Literature stresses the importance of honoring individual preferences of context and location of death as much as possible (Ellershaw & Ward, 2003; Tang, 2003). Although the observable physical and psychosocial experiences of dying have been explored in depth by the medical community (albeit with some ambiguity), there are few known ways to educate the living about the experience of dying once the individual has ceased external communication. A large body of evidence cites the self-reported and observed benefits of using music therapy to reduce anxiety and manage pain in hospice patients (Hilliard, 2003; Hogan, 2003; Krout, 2001); however, these results may not be generalized to patients in the dying process. Although spirituality and experience may inform our understanding of the process, no empirical evidence is available to support these claims.

### **Music Thanatology**

Music thanatology is a discipline separate from music therapy in which trained musicians play prescriptive harp music in order to provide Christian spiritual support, relaxation, and assist the dying process (Freeman, Caserta, Lund, Rossa, Dowdy, &

Partenheimer, 2006). The practice is grounded in monastic tradition dating back to 909 A.D. in which musicians kept vigil over dying individuals to offer intimacy and symptom management with music. The practice of music thanatology today is concerned with assisting a “tranquil passage” from life to death (Schroeder-Sheker, 1994). Typically, vigils last between 75 minutes and two hours. If possible, two music thanatologists sit on either side of the patient’s bed and play continuously based on the physical and intuitive cues that are observed from the patient. Although music thanatology is grounded in many of the same principles as music therapy, the practice is deeply immersed in the spiritual foundations from which it developed. Therefore, it cannot be generalized across belief systems.

### **Music Therapy for Clients Who Are Imminently Dying**

Due to the subjective and unique nature of dying, there is a dearth (and near impossibility) of empirical evidence to support the use of music therapy with clients who are actively dying (Potvin, 2015). However, an increasing number of music therapists working in hospice have written about their experiences working with imminently dying clients. Goals addressed and personal experiences vary across accounts; however, the literature suggests that music therapists consider providing music therapy for dying clients to be a personally profound and intimate experience (Munro, 1984; Zabin, 2005).

When family members are present in the room with an imminently dying client, music therapists have considered the benefits of shifting focus from client needs to family needs. Krout (2003) presented case vignettes of his work with imminently dying clients. He discussed the importance of shifting the focus to the needs of the patient’s family once the client appeared comfortable. He emphasized the importance of providing spiritual support and honoring his clients’ legacy through receptive music experiences. Gilbert (1977)

discussed the opportunities for music therapy to open family members up to discussing the death of their loved one. Martin (1991) discussed the importance of receptive music providing structure in the midst of uncertainty as well as emotional and cognitive connections to important memories during the process of awaiting a loved one's death. Hogan (2003) recounted a case in which involving the family in music therapy helped her client identify the song that he desired to be playing during his death. Munro (1984) described a session in which singing Gregorian chants helped to create a peaceful environment, honor her client's relationship with church music, and offer a sense of peace to her client's wife as she held him in his final moments. These accounts point to a sophisticated clinical process as well as powerful experiences noted by clients, family members, and music therapists.

### **The *Iso*-Principle**

Music therapists have incorporated the *iso*-principle into receptive music in order to reduce symptoms and connect with their clients during the dying process. In music therapy, the *iso*-principle may be defined as the manipulation of musical elements to match a client's emotional or physical state. Hogan (2003) presented case studies of her work with dying clients in which she emphasized the importance of using receptive music to create a familiar and relaxing environment, manage pain, and support the dying process. Hogan noted that she perceived the process of improvising and/or performing music in synchronicity with her client's respiratory rate to be helpful in reducing anxiety. Hilliard (2001) discussed a similar case in which he incorporated the *iso*-principle into receptive music to match his musical expression to his patient's pain and respiratory rate. Both Hilliard and the patient's family perceived this process to be helpful in reducing his patient's anxiety, and the patient died four

hours later surrounded by her family's compassionate presence and music. Cadesky (2005) and Weber (1999) both discussed the use of voice to match patients' moods and respiratory rate in order to serve as a vocal container for clients' emotional and physical experience of dying. The content and meaning of these experiences are often informed by the music therapist's perception of the session's events, which has necessitated the discussion of countertransference in hospice music therapy.

### **Countertransference in Hospice Music Therapy**

Countertransference is a term that emerged in the 20th century to describe the totality of a therapist's response to his or her client. Countertransference encompasses the therapist's thoughts, behaviors, clinical decision-making, and emotions in relation to the client (Bruscia, 1998). Countertransference may be positive or negative, and it may be helpful or harmful. According to both the Professional Competencies (American Music Therapy Association, 2013) and the Scope of Practice (Certification Board for Music Therapists, 2015), music therapists are responsible for acknowledging countertransference issues and addressing them in supervision when appropriate. Music therapists have acknowledged that awareness and examination of countertransference issues in end-of-life care are important as they may exert significant influence over the course of the therapeutic process.

Countertransference issues may be particularly influential for music therapists who work in hospice because experiencing death is an unavoidable part of existence. DiMaio, Wilkerson, and Sato (2015) discussed the experiences with and the influence of countertransference in hospice music therapists, identifying the following themes: facing one's own mortality, boundary issues, personal grief, exposure to pain and suffering, spiritual issues, and cultural differences. The authors noted that self-awareness, self-inquiry, and

supervision may be useful tools for coping with countertransference issues. Marom (2008) presented four vignettes of case studies in which transference and countertransference dynamics significantly affected the therapy process. Supervision and self-care were identified as important tools for developing insight about the nature of these dynamics to promote understanding and self-awareness within the therapeutic relationship. In addition, the author stressed the importance of introspection concerning the concepts of death and mortality for the hospice music therapist.

As the client nears death, observable communication often ceases. The role of the music therapist may shift to one of support, empathy, and resonance (West, 1994). In this mysterious territory, music therapists may experience a heightened awareness of their own reactions to sessions. A small number of music therapists have addressed this phenomenon. Munro (1984) reflected critically on her instinctive decision to provide music therapy for an actively dying client who did not give consent: “The music had brought calm, but had it precipitated things? Dying with music might seem “good dying” in **my** perception, but what was the significance for this woman who just lost her husband?” (p. 31). Sekeles (2007) noted that improvising for a client in the dying process necessitated increased concentration, attunement, and observation on the part of the music therapist. Although only a small number of music therapists have written about their experiences, countertransference has been identified as an influential factor in both clinical decision-making during sessions and subsequent interpretation and perception of sessions.

### **The Role of Spirituality**

Spirituality is a significant countertransference issue in hospice music therapy. Because music may become or enhance spiritual experience for hospice clients, music

therapists are often associated with providing music ministry (Potvin & Argue, 2014).

Acknowledging the spirituality of the therapist as it relates to the client-therapist relationship unleashes a tide of ethical concerns; however, a growing number of music therapists are describing and addressing this phenomenon. Runningdeer (2013) found meaning in her experiences providing music therapy for imminently dying clients within the context of ancient Native American belief systems. Kidwell (2014) and Zabin (2005) presented vignettes describing their personal experiences of spirituality when working with dying clients. Zabin (2005) reported improvising with her dying clients in a manner that emphasized the importance of spiritual connection with her clients:

As my own spirituality is important to me, I feel that I am able to access another level of intimate connection with those who are actively dying. I allow myself to sense what another is thinking/feeling/fearing and to speak about it through the music. This is essential in working with those unable to use words that depict their current moods, and I am grateful that my beliefs lead me to show my own vulnerabilities by letting my music flow forth freely from within and not be guided by intellectual decisions alone. Of course, this is not to say that I can read minds, but rather that I allow my keen sense of observation and intuition to help guide me into the realm of spirituality.

(Zabin, 2005, p. 71).

As music therapists, personal experiences of spirituality may be addressed in supervision as manifestations of countertransference (DiMaio, Wilkerson, & Sato, 2015). However, a significant number of music therapists in hospice have integrated spirituality as a grounding theoretical foundation for using music with clients in the dying process (Potvin & Argue, 2014).

Particular attention has been paid to the role of music in the experience of transcendence. Munro (1984) described the process of playing music during the final hours of a client's life to be "precious moments where music transcends emotional, physical and spiritual barriers" (p. 14). Hogan (1999) supported this idea, identifying music therapy as an aesthetic tool to support the dying process by fostering existential resolution between all of the dimensions of human experience. Lee (2003) considered the aesthetic beauty of music itself to be the primary therapeutic factor in providing comfort to imminently dying clients.

### **Summary**

Virtually no empirical evidence supports the use of music therapy with clients whose death is imminent. Although music therapists have used the *iso*-principle to address physiological symptoms (Hilliard, 2001; Hogan, 2003), these accounts remain anecdotal. Music therapists have described using music therapy as a means of facilitating release (Gilbert, 1977; Kraut, 2003), relationship completion (Dileo & Loewy, 2005), and support of the natural dying process through holding and witnessing (Cadesky, 2005; Sekeles, 2007; Weber, 1999). However, the theoretical foundations behind this work remain unclear. In addition, although countertransference issues and the spirituality of the music therapist may intimately affect the session and the interpretation of the session's events, only a small number of music therapists have discussed this realm of their work. It seems, in effect, that the "essence" of these experiences remains unclear even to those few who have experienced them.

### **Statement of Purpose**

The purpose of this study is to gain a greater understanding of the experiences of music therapists who have worked with clients who are actively dying.

The primary research questions are as follows:

- 1) How do music therapists describe their experiences providing music therapy for clients who are actively dying?
- 2) How do music therapists evaluate sessions with clients who are actively dying?

## **Chapter 3**

### **Method**

This chapter outlines the methodology utilized to conduct this research. It reviews the setting, researcher, participants, procedure, and phenomenological method for analyzing data. It includes my epoche as part of the phenomenological analysis.

#### **Research Setting**

Research was conducted and analyzed at a large university in the South. In order to communicate with music therapists from a variety of settings, I conducted interviews over telephone and Skype. Participants were encouraged to select a quiet, uninterrupted location of their choosing for the interview.

#### **Researcher**

I am a board-certified music therapist pursuing my Master of Music Therapy degree. My approach to music therapy is predominantly humanistic, but I strongly value feminist and context-oriented approaches in my work. I see music therapy as a dynamic process between client and therapist in which the music therapist benefits deeply from practicing in collaboration with the values and world views of his or her clients. I also value reflexivity and qualitative approaches to acquiring knowledge and understanding experience. For this reason, I refer to myself as “I” in this chapter, since I may not be separated from the knowledge obtained during this research.

## **Participants**

I used a purposive sample of four music therapists with at least two years of experience in hospice music therapy. I used the steps for purposive sampling outlined by Tongco (2007). After concluding that a small number of participants would contribute more effectively to the depth of understanding the phenomenon in question, I defined the qualities that the participants should have. This included at least two years of experience working with clients whose deaths were imminent. After identifying these qualities, I researched hospice music therapists with these qualifications using internet search engines and information from other music therapy colleagues about experienced hospice music therapists. I obtained e-mail addresses through participants' websites and through professional references. The final steps to using purposive sampling are to maintain awareness of bias throughout the interview and analysis processes, which I will describe later in this chapter.

Two women and two men agreed to be a part of the study. I did not ask for other identifying characteristics such as race or age, as this study did not seek to analyze the relationship between these factors and participants' experiences. The participants who responded had a significant amount of experience in hospice, with the least amount at six years, and the most at 16 years. In order to protect confidentiality, I have not listed each participant separately with his or her identifying information, as hospice music therapy is a relatively small community, and this information could easily be tied to each participant's identity. Each participant was encouraged to select a preferred name in lieu of their real name. Their names will be used as follows: Nathan, Ella, Renee, and J.C.

Participants worked in a variety of settings, including home care, skilled nursing facilities, and inpatient units. Participants also had other responsibilities besides seeing

imminently dying clients, including bereavement work, administrative tasks, serving as an internship director, and owning a private practice. Three of the participants saw clients who were actively dying on a regular basis, and one participant saw clients who were actively dying only when it occurred by chance during regularly scheduled music therapy visits.

Each participant shared a unique theoretical orientation informing their work. Some of these included person-centered, existential, humanist, Gestalt, eclectic, aesthetic, and music-centered. Three participants mentioned a variant of person-centered, including client-centered and patient-driven approaches. All participants shared that their caseloads consisted of a diverse group of individuals with unique needs, although the majority of their work was with older adults and their families.

### **Recruitment**

I contacted a purposive sample of eligible music therapists through e-mail and invited them to participate in the study. For those who responded, I sent an electronic consent form which participants then e-mailed back to me with their signatures. See Appendix A to view the informed consent document.

### **Procedure**

After consent was obtained through electronic communication, I invited participants to schedule an interview time with me through Skype or telephone. Three participants interviewed over the telephone, and one interviewed over Skype. I conducted semi-structured interviews in order to provide ample opportunities for participants to give detailed descriptions of their experiences with the phenomenon in question. The interviews were not time-limited, and they lasted between 35 and 50 minutes. See Appendix B for a list of the interview questions.

## **Epoche**

In order to reflect on my personal experience and biases, I wrote the following epoche before engaging in the recruitment and interviewing process:

When I reflect on what feels important when I am providing music therapy for someone in the dying process, I think first of considering the patient's physical needs from a medical model and planning the session accordingly. Although I trust that music may offer a relaxing and analgesic effect, ultimately I have used individuals' breathing patterns as the rhythmic foundation for improvised music to create a peaceful and supportive environment. I have found that when I truly consider the "why" and "how" of what happens, physical needs seem secondary to other, more abstract needs. Goals like "hold space" or "offer compassionate presence" come to mind. I find myself invested in the idea of easing the spiritual transition from life to death, a process with which I am, by virtue of being alive and healthy, completely unfamiliar. Communication during these sessions is unique. Some of my patients were alert and oriented until the moment of their death; others showed no physical evidence of responsiveness for weeks.

I am sensitive to ethical and spiritual dilemmas. I am a spiritual person, but I have no inclination toward any spiritual tradition in particular. I feel uncomfortable with the idea of unintentionally projecting my developing spirituality onto my clients. My greatest fear is that my spirituality ultimately informs how I perceive my experiences working with clients who are actively dying. I have asked myself, why do I want to ease their transition? Do they need help doing it? What does that say about my feelings and introspects about death and dying?

## **Data Collection**

Interviews were audio recorded using an electronic recording device both on my personal laptop and on my iPad so there would be minimal risk of technical errors resulting in a lost interview. I transcribed three of the interviews myself, and a graduate student at my university who was trained in research ethics transcribed the fourth. Participants were provided their electronic transcripts for member-checking to increase validity of results.

## **Data Analysis**

Data were analyzed using the steps for analyzing phenomenological data identified by Moustakas (1994). All themes were developed through an inductive, reflexive approach. Before analyzing the transcripts, I reviewed my epoche, or the reflective description of my experiences and perceptions of providing music therapy for clients who are actively dying. After revisiting my epoche, I reread each interview. Then, I engaged in the process of horizontalization of data, or highlighting significant statements contributing to the understanding of the participants' experiences. After highlighting significant statements in each interview, these statements were placed without identifying information into a single document. Using these statements, I created clusters of meaning to create themes and groupings for significant statements. After creating numerous meaning units, I created larger groupings and identified any emergent themes arising from the existing groupings. After identifying themes, I returned to the interviews and connected each code with the participant who relayed it. At this point, I engaged in the process of imaginative variation to consider which themes contributed or did not contribute to understanding the "essence" of all four participants' experiences. Ten emergent themes were distilled using this process. Once the themes were identified, I created a textural description of the participants' experiences

organized by each emergent theme. These results may be found in Chapter 4. As I engaged in this analysis, I maintained awareness of the final steps of Tongco's (2007) steps for purposive sampling, remaining mindful of potential bias in the results due to my selection of participants. In addition, I maintained communication with participants during the analysis process to offer opportunities for them to add their perspectives on the results.

## **Chapter 4**

### **Results**

Included in this chapter are textural descriptions of themes and subthemes that emerged from the synthetic analysis of all participants' interviews. Predetermined information including participants' amount of experience and theoretical background may be found in Chapter 3. The themes presented in this chapter emerged after engaging in the processes of horizontalization and distillation of major themes. See Figure 1 for a table of major themes and subthemes. Nine themes were present in all four interviews: (a) it is important to know as much information about the client as possible before providing services to them when they are actively dying; (b) assessing the client's physiological responses can suggest information about his or her internal experience; (c) the central goal is to help the patient transition meaningfully, with as little discomfort as possible; (d) when loved ones are present, the music therapist uses a dynamic and collaborative process to facilitate meaningful transition for both client and loved ones; (e) the music therapist needs to be flexible and adaptive in the moment; (f) countertransference is deeply influential in both the clinical process and in one's personal life; (g) music therapy can reveal deeper meaning and beauty in the midst of pain and suffering; (h) music therapy can transform the experience and environment; and (i) the music therapist feels a responsibility to take on a role that

Category	Ongoing Assessment			Ongoing Assessment			
Themes	It is important to know as much information about the clients as possible before providing services to them when they are actively dying.		Assessing client's physical state can suggest information about internal experience.				
Sub Themes			It is rare for there to be verbal communication with the client.	Participants observed respiration and other visible physiological responses to assess their clients' internal experiences.			
Category	Intuitive Processes			Intuitive Processes			
Themes	The music therapist must be flexible and adaptive in the moment to serve both patient and family needs.		Intuitive processes are extremely important.				
Category	Countertransference			Countertransference			
Themes	Countertransference is deeply influential in both the clinical process and in the music therapist's personal life.		The music therapist feels a responsibility to take on a role that transforms the experience and environment in a meaningful way.				
Sub Themes	Countertransference influenced the clinical process.	Countertransference influenced personal and spiritual revelations	Supervision and self-care are extremely important.				
Category	Aesthetics, Transition, and Transformation			Aesthetics, Transition, and Transformation			Aesthetics, Transition, and Transformation
Themes	The central goal is to help the patient transition meaningfully, with as little discomfort as possible.		When loved ones are present, the music therapist uses a dynamic and collaborative process to facilitate meaningful transition for both client and his or her loved ones.		Music therapy can reveal deeper meaning in the midst of pain and suffering.		Music therapy can transform the experience and environment.
Sub Themes					The dying process can be musical.		

Figure 1. Themes and Subthemes

transforms the experience and environment in a meaningful way. One theme was present in only three interviews but was included as an emergent theme due to its stated importance in the interviews in which it appeared: (j) intuitive processes are extremely important. After reflecting on the relationship between themes, I have organized them into four categories to be further discussed in Chapter 5: ongoing assessment, intuitive processes, countertransference, and the role of aesthetics and transformation.

### **Ongoing Assessment**

#### **1. It is important to know as much information about the clients as possible before providing services to them when they are actively dying.**

All four participants made a distinction between providing services for a client with whom they had a preexisting relationship and providing services to a client with whom they had no relationship. When a preexisting relationship did exist, participants reported using information that they already knew about the client to create an appropriate music therapy experience during the client's final days and hours.

J.C.: If it's a regular patient who has been seen in music therapy, we already have an understanding of their symptoms, specific issues and musical preferences, which enables us to better target the interventions.

Nathan: Usually one of the first things I think about is "do I have a pre-existing relationship with the individual or not?" If I have a pre-existing relationship with them, I can draw from our past sessions to understand their needs in that moment.

Renee: I draw on what I know about the client basically...in the past and what we've been working on in our sessions together.

Ella noted that during her assessment procedures for all hospice clients, she included space for a conversation about the role of music during the dying process:

Ella: Um, I would say if it's a client that I do know, that if I'm on my game, these are the discussions I've had with them beforehand. Like, it's on our assessment to talk about the dying process and music and the role that they want music to play.

For clients with whom participants did not have a preexisting relationship, all four participants stressed the importance of a thorough assessment. Ella shared that she often invited family members into the session in order to gain more information about the client; however, she considered a here-and-now approach to assessment as the most important:

Ella: For people I don't know, the most important thing is... what is their experience right now? Are they suffering?

The other three participants highlighted the role of consultation with family and the interdisciplinary team as an important source of information to meet the client's needs. J.C. acknowledged that there wasn't always time for this; however, when possible, consultation provided the music therapist more tools for providing appropriate services.

J.C. I will say that sometimes you don't have the opportunity of looking through the chart and calling team members if you are asked to intervene immediately with a dying patient.

J.C. If we haven't seen the patient before and are called in to offer music therapy, if there is time, we try to review the chart, talk to the social worker, chaplain, and family to gain some information on the patient and family.

Renee and J.C. also shared their sense that consultation provided a more contextualized picture of the client's needs:

J.C. Sometimes one piece of critical information from the hospice team or family member can make the difference in our approach. It might be information about a relationship or a special song or a last wish that we can integrate into our session.

Renee: I try to support people's processes, wherever those are, whether that means consulting with spiritual care people from the hospice or otherwise.

Nathan suggested that the music therapist may both gain information from and act as a support for the context of the goals of the interdisciplinary team:

Nathan: So we needed to – it wasn't choreographed as much as we would need to consult with one another as to what we felt was going to be the best approach for the family at the time. So I think a big part of practice and decision making also had to do with the context of the team.

J.C. supported this idea:

J.C.: So in a sense we mirror the entire team's interventions in our approach, and goal areas may overlap where we can clinically support the goals of the chaplain or social worker but have a unique approach through music therapy

## **2. Assessing the client's physical state can suggest information about his or her internal experience.**

**It is rare for there to be verbal communication with the client.** All four participants shared their sense that it was rare for clients to verbally or physically communicate their needs.

Ella: Most people I've worked with who are actively dying can't talk – not all of them, some people can – but most of them can't. So it's not like I can say, what do you need right now?

Nathan: The majority of cases, the person has been in their own internal experience at the time.

Renee noted that even when verbal or physical communication was present, the dying process created an overwhelming amount of need that perhaps couldn't be expressed outwardly through words.

Renee: Even if they are verbal and there are family members... and they are physically aware... they are overwhelmed, so they can't say, "This is what I want to hear, and this is what I need right now."

**Participants observed respiration and other visible physiological responses to assess their clients' internal experiences.** In the absence of verbal communication, all four participants shared that they observed their clients' breathing patterns and other physiological responses in order to evaluate their clients' comfort level. Ella shared that in her work setting, these physiological responses were given numerical values in order to better shape the assessment process:

Ella: In our hospice, we use the PAINAD scale to give a number and a quality to that experience. But you can hear it and see it, you know, like what kind of sound? Are they moaning? Is it distressing? Are they extremely restless – that terminal agitation? Because that becomes a priority to me.

Respiration was the most commonly mentioned physiological response across all four interviews. J.C. and Renee noted that observing breathing patterns can impart crucial information about a client's experience of pain or anxiety.

J.C.: They may be fighting the dying process and their breathing may be labored.

Renee: If they're very tense or breathing very quickly... or having some restlessness versus relaxed... or maybe not breathing... when they don't seem to be struggling as much, maybe breaths come less often. They get to a point where breaths are coming less often.

Nathan noted that rarely, physiological responses can also suggest whether or not the client is experiencing change in the context of the music therapy experience.

Nathan: Sometimes they will give you some sort of external response; their breathing will change, they'll have turned their head towards the music or they'll have given me a squeeze of their hand, so those moments you know that you've at least reached them. In my experience, that is more the minority.

### **Intuitive Processes**

**3. The music therapist should be flexible and adaptive in the moment to serve both patient and family needs.**

Adaptability and flexibility were identified as important aspects of working with clients and their families during the dying process. All four participants noted that it was important to engage in continuous assessment, allowing the music therapy experience to reflect the needs of the moment accordingly.

Renee: ...continuously observing and changing and assessing because, you know, I might try something a particular song or particular style and it's not working, and then you have to do something else.

J.C. stressed that although information about the client was important, pre-planning an experience would not lead to a successful music therapy intervention:

J.C.: Sometimes everything you might have read about this patient may be non-applicable when you walk in the room. You still need to have the ability to make clinical decisions based on what's presenting in the moment. And sometimes you may have to set aside what you have read or been told.

When asked about changes in their practice over the years, Ella and Nathan noted that over time, they experienced an improvement in their clinical skills as they embraced a more flexible approach.

Ella: I'm not as rigid, I think, is what it comes down to. Being able to say well this is what I think or what I thought of that approach... and well, that's changing... and that doesn't fit, so I need to change.

Nathan: Initially I was thinking of myself as "there's the patient, there's the family, there's the medical team, there's the music therapist, there's the hospice team," I was compartmentalizing everybody and all the roles that were present, and what I came to realize is that there's not really, unless that boundary is being explicitly set by the family or by the patient, those compartments didn't really exist.

**4. Intuitive processes are extremely important.** Nathan, J.C., and Renee noted that intuitive processes were an important part of assessing and meeting the client and family's needs in the moment. I have included this as an emergent theme because of the weight placed on this theme by those who expressed it, as well as my own sense that intuitive processes are

embedded in much of the language relayed in describing the assessment of imminently dying clients. Nathan highlighted the importance of using focused intuitive processes to assess physical and energetic responses when alone with a client who was actively dying:

Nathan: I have to say that if it's just me and the clients, more or less, I feel like I really just try to check with my intuition. I feel like if I spend 2 hours with a very active client, I leave those sessions much less tired than the 15 minutes I spend with my unresponsive client because the challenge there is for me to open up all my empathic sensors; all of my antennas, all my intuition, put all my energy into that, because the most subtle movement can communicate so much: an eyebrow shift, a fluttering of the eyelid, the slight movement of a hand. So I try to be as receptive and as aware and as sensitive to those small responses as I can be, and then I contextualize it.

J.C. and Renee suggested that tapping into one's intuition can impart information about the environment and needs of those who are present in the session:

J.C.: You still need to be in the present and respond appropriately and intuitively to the moment by moment flow of the session. Sometimes I will put my knowledge of a patient/family in the back of my awareness and respond spontaneously but can draw from this information as needed.

Renee: I'm really also trying to feel what it's like in the room... like feel, you know, what their distress level is. Or if there's family, what's the feeling in there? There's a lot of intuition and clinical judgment that is part of the time in that setting.

J.C. shared his sense that developing intuition and deep listening were, in some ways, at the core of what it means to improve as a music therapist in this setting:

J.C: I like to think that I've developed a strong clinical sense that will guide me in a good direction with different patients that offers what they need at that moment. I think you develop a deeper level of listening skills and can "hear" between the lines with your patients. Deeper listening and empathy combined with music is a most powerful medicine! It may very well be the essence of this work. Being able to tap into what a person really needs during this critical time is essential.

### **Countertransference**

**5. Countertransference is deeply influential in both the clinical process and in the music therapist's personal life.**

All four participants recounted experiences of countertransference during significant music therapy sessions. In addition, all four participants highlighted the influence of countertransference in both the clinical process and in the context of their own lives.

**Countertransference influenced the clinical process.** The participants' belief systems around the use of music therapy with clients who are actively dying significantly contributed to their clinical decisions. Ella acknowledged that this extended beyond her theoretical orientation and belief system:

Ella: My experience has been that absolutely everything about me influences my relationships with my clients.

Ella also recounted an example in which a countertransferential reaction to a song influenced the music therapy experience in a positive manner:

Ella: I happen to love that Beatles song "In my Life," and so I knew it really well. And because I knew it well, it could really reflect and be what it needed to be to be helpful and therapeutic in that moment. It was like all the stars aligned looking back on it.

Nathan and Renee identified countertransferential reactions to sessions as not only influential, but potentially important to inform the assessment and interaction the environment. Nathan identified this shift in perspective as a significant change in his practice over the years:

Nathan: So now I think that I'm much more accepting of any sort of emotions I might have. I mean, there are times where you're going to cry with the family because that's the most appropriate response. If everyone's crying and you're not crying... in some contexts, that's just weird.

Renee shared her belief that countertransference can influence intuitive processes:

Renee: I've heard people use the phrase using your countertransference as a guide for what you're doing so I think about that as a way that I can work in that setting.

All four participants were aware of their countertransference when it brought up uncomfortable emotions. They acknowledged this as a regular and noteworthy aspect of working with clients whose deaths were imminent. Nathan expressed his awareness of how countertransference could potentially influence his conception of his role as a music therapist with a client who was actively dying:

Nathan: I think the people who are actively dying, when they're hanging on for that long, they're working stuff out for themselves. I always feel a bit awkward about not wanting to be an uninvited guest in that process. I want to be helpful, but I take whatever cues I can take that indicate if my presence is not desired at the time because they're doing their own work

J.C. acknowledged that personal grief may be triggered as well:

J.C.: A patient's death may also trigger emotions around personal losses we've had in our own lives.

**Countertransference influenced personal and spiritual revelations.** Participants were invited to share a significant experience providing music therapy for a client who was actively dying. Although all four participants stressed that all music therapy sessions were uniquely meaningful, these experiences in particular revealed personal and spiritual revelations about universal concepts. Renee shared an experience in which one of her clients with whom she had a previous relationship died during their time together. This revealed to her a new experience of knowledge regarding the processes of life and death, particularly in relation to her spirituality:

Renee: That was the first time I had been with a patient by myself that they died... You know, life begins and life ends in a moment. And it just felt so holy. She and I had connected previously, and her faith is very similar to my faith, so I was conscious of that. So I had an idea of what she may have been thinking or feeling about the end of life.

She then contextualized this revelation in relationship to her experience at the time:

Renee: I mean, if I think about it longer, that happened a couple months after I came back from maternity leave... so I had just given birth to new life.

J.C. expressed a sense of validation in response to a music therapy session in which his client responded to significant lyrics of an important song in her life by making eye contact with her daughter and then taking her last breath. He reflected,

J.C.: Needless to say, that experience was very powerful and intense, and it moved me deeply. It reminded me how hearing is often intact till the very end with patients and that even when a patient is seemingly non-responsive, they are still able to hear the music. That was very affirming to know that this patient, who was not responding in any overt way, was actively listening to the song. I wondered if it was a coincidence that she chose that precise moment to open her eyes and have that last moment with her daughter. I don't think so! The session was an emotionally transcendent experience that stays with me to this day.

For J.C., the experience not only validated his beliefs about his clients' abilities to share in music experiences at the end of life, but it also resonated with his spirituality in its transcendent qualities. Nathan and Ella mirrored this sentiment. They expressed that their experiences with actively dying clients both interacted with and informed their spirituality:

Nathan: I don't have a dogmatic belief system, so I find it's very fluid, and it's very much been shaped by my experiences in hospice, so I absolutely do draw from ideas of transitioning, from ideas of integrating into some sort of larger framework, some sort of larger fold.

Ella: With the dying process I would say personally it's affected me and my spirituality because I don't have a set of core beliefs around spirituality. I find myself super influenced by what's going on in my work and then going home thinking, how does that fit in?

**Supervision and self-care are extremely important.** J.C., Ella, and Renee stressed the importance of supervision and self-care when doing this work. J.C. shared his sense that this was especially important in hospice work due to the significant energetic requirements:

J.C.: This work requires a great deal of energy and when you're giving that level of output all day you need to do self-care and things that will renew your energy. There is nothing unique in this message and we've all heard the importance of caring for oneself, but in this work, I think it is an absolute necessity!

Renee and Ella identified two ways in which supervision and self-care were important for their experiences. Renee described a significant clinical experience that necessitated further processing time than she had available. Although she was able to push her next group session back one hour, this presented a challenge for her:

Renee: I said, I'm with a hospice patient, and I can't leave right now, so I pushed the session back. Then, I had to do this upbeat, wake everybody up, interactive kind of thing. That was a really, really hard transition for me.

Ella described a gradual process of using supervision and self-care as tools for learning how to authentically appreciate belief systems that were contradictory from her own:

Ella: I would say that because my spirituality tends to be the opposite of most of my clients, I've gotten really good at being able to sing about things I disagree with over the years, which has been a change—and reason why I've had to seek therapy myself and supervision.

## **6. The music therapist feels a responsibility to take on a role that transforms the experience and the environment in a meaningful way.**

This theme emerged when I revisited each interview after having already organized significant statement by theme. I noticed that embedded within countertransference to sessions was a common sentiment: all four participants expressed a sort of calling to this work; at the core of their experiences was the sense that it was their responsibility react appropriately to important elements of sessions and to provide music therapy experiences in a meaningful way. Renee shared a clear example of this when she noted a significant polarity in her work: on one hand, she felt called to be a hospice music therapist in her own spiritual life; but on the other, she felt it was important to put her beliefs aside to support her clients in their belief systems.

Renee: I feel very strongly at the core of my being that I'm called to the work that I'm doing, and I'm particularly called to be with people in their final years of life. So

clinically, I've worked very hard to support my clients' beliefs and to not put myself on them.

When she reflected back on her experience sitting with a client who died in their session, she shared her sense that she had a responsibility to stay with the client until the family arrived.

Renee: And I was there about another hour after that because I didn't want to leave her alone... I didn't want to have the family show up and nobody be there with her.

Nathan shared a similar view to Renee in relation to becoming more flexible in the work in order to support clients' various belief systems and unique dying processes. He shared that the process of both examining and blurring the boundaries and roles of his process made him a more effective vessel of the music and clinical process:

Nathan: I try to think of how I fit within not my framework so much as what their framework is. I balance that out with knowing what my scope of focus is, knowing what's ethical and what's unethical.

J.C. directly addressed what he saw as his responsibilities in the moment:

J.C.: As a music therapist, I feel a sense of responsibility to try my best to make the most of their dying experience and bring the joy of music and a feeling of comfort and support to the patient and family.

Ella addressed an idea similar to that of Nathan's. She questioned the roles of the music and of herself during a significant music therapy session, highlighting her sense of responsibility to create a "good" death environment:

Ella: I felt like, this is what music therapy is when someone's dying; this is great. And other times I thought, God, am I an intruder? Does he blame me that she died while I was there? All my core issues came up. But I really felt like it was a good session and a good death, and I was really, really honored to be a part of it.

It might be concluded that all participants expressed, either on a clinical or personal level, a desire and responsibility to transform the experience of dying for their clients in a meaningful way for the client and his or her loved ones.

## **Aesthetics, Transition, and Transformation**

### **7. The central goal is to help the patient transition meaningfully, with as little discomfort as possible.**

All four participants shared a sense that their central goal in providing music therapy for clients who were imminently dying was to facilitate a shift from any visible suffering, anxiety, or pain to a place of minimal discomfort across several dimensions of the dying experience. Nathan and J.C. summarized what they acknowledged as this assumption of the work:

Nathan: There's an assumption that you're going to help somebody transition; you're going to help somebody be more comfortable. You want to ease whatever sort of physiological discomfort they may have. You're going to try to ease whatever sort of emotional or spiritual discomfort they may have.

J.C.: Our goal is to provide support, comfort and validation through the process of music therapy to help our patients and families better deal with their loved ones' illness and death.

J.C. and Ella shared their sense of the music serving as a support to this goal:

J.C.: So, your music is always focused on serving the patient and what they need in that moment to bring as much comfort and relaxation as possible.

Ella: ... it's really a matter of letting my fingers and my voice meet them where they are and seeing how my music influences their music. And hopefully that can bring some relief, some shift, some change from what I'm hearing from them.

Although all four participants agreed that it was ideal to facilitate increased comfort and relaxation, all four acknowledged that discomfort and pain were sometimes inescapable aspects of the dying experience. In these cases, participants noted that supporting a client's unique process was important.

Renee: You're supporting somebody through the end of life rather than helping somebody work toward a goal.

Nathan addressed this further, highlighting the importance of context in facilitating a meaningful experience for the client who is actively dying:

Nathan: I think often times you encounter people who aren't ready to go yet. They, in fact, might be actively dying, but they are not in a place yet where they are ready to let go or say goodbye and move on to whatever they're going to be moving on to. I try to gather information around those contexts. For instance, they may be waiting for their daughter to come in from out of town. There may have been some sort of emotional spike of energy prior to them moving into this space. So in that moment I'm thinking, "I'm not going to help this person transition if they're not ready to move." Instead, what I want to be focusing on is, "How can I help hold them in this space? How can I hold both of them in this space together in a way that can help fuel this interaction that ultimately can lead to successfully dying in a way that feels rich and meaningful and with value?"

**8. When loved ones are present, the music therapist uses a dynamic and collaborative process to facilitate meaningful transition for both client and his or her loved ones.**

Participants agreed that when loved ones were present in music therapy sessions, their needs became equally as important in the therapeutic process. Ella described this shift in focus:

Ella: When I walk into a room and there's family and the client is dying, it's managing a group. How's my client? How's my other clients, and are they coping well?

There was a shared sense that if the family's grief was significantly affecting the environment in a negative way, the patient might experience more difficulty transitioning without discomfort. Therefore, addressing the family's experience was important in considering the needs of the client.

J.C.: A lot of times too, the individual who's dying is okay; it's the people around the person who's dying who need the most kind of support... Based on that I'm going to be constructing different sorts of music experiences, some that might challenge them [family] to consider what transition is going to be like for the individual, or challenge them to consider what life is going to be like when they are not assuming the role of caregiver, or when they're relationship with the dying person is going to be changed.

Nathan: I'm going to support you, but I'm really going to be more present for your family because if they're in a place of giving you permission, you're going to be in a better place yourself to be able to transition and to die.

Renee: If there are people in the room, I watch what's going on with them too, so whether people are turning away from the person who is dying or if they're turning toward them. If they're... sometimes people cry... well, sometimes they're tears of release and letting go, or the fact that they're upset by that ... there are so many layers to everything; it's hard to pin it down to one thing.

J.C. introduced the idea that the family's experience was sometimes incongruent with that of the client's. In this case, he conceptualized the therapeutic process as dynamic: a balancing act between serving both patient and client. He explained that involving loved ones in the session became a way of facilitating this dynamic process:

J.C.: Sometimes family might request seemingly inappropriate songs that are up tempo and lively when a patient may need something relaxing and comforting. So you work to best serve both the patient and family needs. You're always trying to find a way of integrating, adapting and finding a balance where you can best serve the patient and the family. It's an active, collaborative process that we do in music therapy with actively dying patients where you're involving everybody in the process.

Renee shared that another important aspect of the family's involvement was the sense that their memories would continue for a long time. Participants considered the family's experience of the death to be equally as important as they may carry the meaning of the experience with them.

Renee: ...if there's family there, then they're very much part of the care as well. I'm conscious of families remembering the end of this person's life and what's happening right now. It's gonna stick with them for a long time, so their comfort is also very important.

J.C. shared how one family's memory of the death was significantly influenced by the music therapy session during which the client died:

J.C.: I can't even describe to you how appreciative the daughter and family were to have had that experience. It was such a powerful moment and it provided a great deal of comfort for the patient's daughter to know that she had that her mother died in her arms.

Ella, Nathan, and J.C. shared experiences in which the family was actively involved in the music-making experience through playing instruments, singing, active listening, or other forms of musical engagement. This added an element of dynamic exchange within sessions between music therapist, client, and his or her loved ones. T highlighted the interactive nature of this process:

J.C.: Our music therapists primarily use live interactive music and try to involve the patient and family in the music therapy process as much as possible to meet their needs.

Ella described her clinical process when facilitating this interaction, highlighting the role that familiar songs may play when loved ones are present:

Ella: My way to involve them in the session becomes what can you tell me about this person and music? What song do you think they would want to hear? What song would they want you to hear in this moment? Songs become so much more important because that's how they can participate usually.

Nathan described the various forms that this process could take, acknowledging both the importance of the music and the importance of other forms of interaction:

Nathan: You walk into that room and the family's all just kind of sitting there like this, not saying anything, and the moment a familiar song comes on, the moment a familiar spiritual begins to be introduced into the environment, that's when the emotions start to come... I pay really careful attention to the emotions, too. Sometimes I see cycles occur where they move from laughter and stories to tears to silence and then they move back and they keep moving around. Other times people are just in this really great place of gratitude. They are just sharing stories and there are tears but it's an acceptance of what is eventually going to come.

## **9. Music therapy can reveal deeper meaning and beauty in the midst of pain and suffering.**

All four participants used the word “beauty” or “beautiful” when describing a significant experience providing music therapy for a client who was actively dying. The aesthetic quality of experiences in this setting were described as important for the overall

effect of the session on both clients and loved ones. Renee, Ella, and Nathan shared their sense of why their shared experiences remained significant over the years:

Renee: It was beautiful all the way around. I wish it could be that way for everybody for every single person. That their life would end in that kind of peace.

Ella: I think part of the reason why it influenced me and why it was so special too is because there were parts that were so beautiful.

Nathan: It ended up being a very beautiful experience because she died almost immediately after they took her off the meds, but we weren't really aware of that.

In exploring this phenomenon more deeply, all four participants shared a sense that music therapy can facilitate a sense of meaning and beauty in relation to the full spectrum of human experience. Ella shared this as motivation for working in this setting:

Ella: Wanting to go into this work for the desire to help be a part of something that can be beautiful. And realizing that there's great suffering in this world and how you find beauty in their suffering.

J.C., Ella, and Nathan expanded on the function of meaning-making in the midst of human suffering. J.C. shared his sense that no matter what occurred during sessions, the end of someone's life approaching gave the work inherent meaning:

J.C.: I find it meaningful to work with all sorts of patients and families, and because this is a time when they're actively dying, it takes on an importance and significance. To me it has an inherent meaning. I also feel that it's an incredible honor and privilege to be with our patients at this time in their lives, in their final hours.

Ella shared her realization that although music therapy had the potential to create beauty in the midst of suffering, this was not always what occurred:

Ella: Man, we're supposed to make these moments beautiful in hospice, and they're just not. It was really a shocking discovery about this work.

She continued her reflection, wondering about beauty in a larger context of meaning-making:

Ella: Bruscia talked about being beauty-centered. And Lee. How do you find aesthetic in something that is unaesthetic? I think that's just how my existential self has made

meaning of witnessing suffering and great acts of suffering and great moments of suffering and beauty. And sometimes it's both in the same session.

Nathan expanded on this concept, providing examples for the role of unaesthetic experiences and the importance of framing them in a larger context:

Nathan: Drawing upon not thinking of the active dying experience as an isolated experience, but really understanding it as the culmination of a much larger and extensive process. I think that's what was helpful for me was not thinking "Oh we ran out of time" or thinking of it as "we didn't do enough", but just thinking "this is okay; this is the process, we are at where we're at. How can we help to facilitate a sense of meaningful resolution that is within the context of the larger process that came before it?"

Nathan: I've found that working with people who are actively dying with borderline personality disorder, they fight at the end; they're not ready to go. These people with borderline personality disorder tend to live in chaos, so they're going to die in chaos too. So I try to think about that as well... The way that we live is the way that we die, so what is going to make the most sense for this person during this chapter?

For Nathan, the role of aesthetic experiences took on equal importance as unaesthetic experiences when framed in the context of how an individual died in relationship to their life experiences.

**The dying process can be musical.** Nathan, Ella, and J.C. considered the idea that a patient's physiological experience can be integrated within the larger experience of music in the environment. Ella acknowledged this directly, sharing her sense that her clients' dying processes were inherently musical:

Ella: The dying process can be obviously physical but it's also musical. There are sounds people make when they're dying that can become music.

Nathan shared a similar sense that the patient's physiological responses became recreative, contributing to the experience of the music.

Nathan: I don't really make distinctions between receptive or recreative music experiences anymore because I don't feel like you're ever truly just listening. If you're actively listening, then you're breathing differently, you're moving differently,

you're thinking differently, so in some way you are contributing to the aesthetic environment, you are putting something out there.

J.C. addressed this indirectly, noting that the client's breathing patterns—more specifically, the tempo of the client's breathing patterns—necessarily became a part of the music if the music therapist used advanced techniques to change the client's internal experience.

J.C.: You might use different entrainment/iso principal techniques that can slow the respiration and offer gentle guitar picking supporting the breath and gradually slowing in tempo.

### **10. Music therapy can transform the experience and environment.**

All four participants shared a sense that music therapy had the potential to transform the experience of actively dying for both patients and their families. Nathan described an experience in which a music experience brought both his and the family's attention away from some of the uncomfortable aspects of his client's death and toward a meaningful, shared experience of music.

Nathan: It ended up being a very beautiful experience because she died almost immediately after they took her off the meds, but we weren't really aware of that. They were really embraced within the music, I think we were all really embraced within the music.

Ella shared an experience in which her client's loved ones moved into a space of deep connection through active music making:

Ella: The daughter was doing a great job playing really soft waves [with the ocean drum], and I was talking to the client during the intro also; moments of reflecting back what I was noticing about this room and these people who loved her, and my guesses about her. And then I moved into the lyrics, changing the lyrics. I think I made up a few verses and found a short phrase that became a part of the song. It was something to the effect of, "You are in my life, you are loved," over and over. I expanded that music, watching the client the whole time. And she stopped breathing during the song and died. And it was... that moment was beautiful; she was so surrounded by people who love her.

Nathan also shared a story in which a music therapy experience between father and son widened the son's perspective of his father, allowing their relationship to come to meaningful closure. Nathan highlighted the role of music therapy in facilitating these meaningful connections between clients and their loved ones:

Nathan: Understanding the music relationship and adjusting the little qualities to facilitate that connection between family and patient is really important.

J.C. noted that although it was not guaranteed to occur, he noticed mostly positive changes in the environment as a result of music therapy:

J.C.: Unfortunately, some deaths are very difficult and problematic and as hard as we try, we are not always able to bring the comfort and ease that we strive for to certain patients. But in my experience and with most of the patients that I have seen who are actively dying, music therapy has had a profoundly positive effect in their final hours.

Renee shared this view, pointing out that music had the potential to support a variety of environments depending on the needs of the client and his or her loved ones:

Renee: Sometimes, people need to leave. Sometimes they need to be there. Sometimes they need it quiet. Sometimes they need it soothing... relaxing with hymns... and there's sometimes something more conversational and upbeat. It's different every time.

## **Chapter 5**

### **Discussion**

The purpose of this study was to understand the experiences of music therapists who work with clients who are actively dying. Specifically, this study posed the following research questions: “How do music therapists describe their experiences working with clients who are actively dying?” and “How do music therapists evaluate their experiences working with clients who are actively dying?” A phenomenological analysis revealed nine emergent themes present in all four interviews and one emergent theme present in three of the interviews. These themes were presented individually in Chapter 4. In Chapter 5, I have grouped the ten emergent themes into four broader ideas to be discussed in relation to existing music therapy literature: ongoing assessment, countertransference, the role of aesthetics and transformation, and intuitive processes.

#### **Ongoing Assessment**

In all four interviews, participants noted some form of ongoing assessment as a significant feature in the clinical process. All four participants made the initial distinction between providing music therapy for a client with whom they had a preexisting relationship and providing music therapy for a new client in the dying process. In the introduction to this research, I shared a significant music therapy session with a client whose death was imminent. I, too, described the hastened process of assessment with this client, noting that I did not have a relationship with him before providing music therapy. I assessed his needs

through a brief consultation with the interdisciplinary team and ongoing assessment of his responses and the environment during our time together.

Existing music therapy literature has extensively explored the features of a music therapy assessment for hospice clients; however, there is little emphasis on the role of assessment in caring for the actively dying patient. In some cases, this is because the music therapist has already had a chance to have an assessment session prior to the patient entering the dying process (West, 1994). The majority of assessment tools are designed to measure a client's behaviors—either musical or communicative—and to use the assessment to create music therapy experiences geared toward growth and healing (Hintz, 2000; Thompson, Arnold, & Murray, 1990). In addition, there is an assumption that assessment tools should contribute to objective, generalizable information informing treatment goals (Lipe & York, 2000). However, the behaviors displayed by actively dying clients are often quite subtle. In addition, many of the factors informing the music therapists' assessment processes in this study were quite abstract: Renee described using her intuition to assess the “energy” in a patient's room. Considering these factors and the unique experiences of hospice patients in the dying process, one might wonder if a formal assessment could ever be generalizable depending on the needs of the client in his or her immediate context.

All four participants agreed that assessing global pain and/or anxiety was a primary consideration before providing music therapy. Ella mentioned the Pain Assessment in Advanced Dementia (PAINAD) scale as a tool in assessing her clients' pain levels. A survey by Groen (2007) revealed that hospice music therapists use a variety of numerical tools to assess pain, including the Numeric Pain Rating Scale (NRS) and Faces (FPS) scales. It is notable, however, that spiritual support was listed in this study as the primary reason for

referral in music therapists. Although pain and anxiety are often the primary experiences assessed before providing treatment, a total understanding of pain and anxiety requires an assessment taking other global factors that influence the experience pain into account (Coward & Stajduhar, 2012). Understanding the importance of global assessment, one might wonder: how does a numerical rating help music therapists address the factors contributing to the experience of pain? Maue-Johnson and Tanguay (2006) created a global assessment tool that addressed several aspects of the hospice patient's experience, including physical state, psychological, social, and spiritual domains. Although the assessment was geared toward assessing hospice patients before they reached imminent status, the tool in many ways mirrors the information that was sought by study participants. All four participants mentioned using the interdisciplinary team including social workers, chaplains, and other providers as a resource for seeking this information. In addition, interactions with families and loved ones provided a dynamic exchange of information through their sharing and the features of their presence and relationships with the client in the dying process.

In the absence of consultation with family or the interdisciplinary team, participants reported assessing the session moment by moment using the client's minimal physical responses and intuitive and musical processes. A few studies explore the phenomenon of assessment when clients are minimally responsive. McFerran and Shanahan (2011) described an assessment procedure with a child in hospice care that, instead of assessing for future goals and objectives, focused on meeting the child in the moment with the music in order to provide presence and focused listening. Lichtensztejn, Macchi, and Lischinsky (2014) discussed the features of assessing clients who were minimally conscious, noting the parallels between creative music therapy and engagement in receptive experiences providing

information and communication with the patient. This resonated with me, as I observed this phenomenon in my work with dying clients. In addition, all four research participants in this study indicated small physical and energetic responses as evidence that there was some level of communication occurring with each client, even in his or her final moments.

### **Intuitive Processes**

Bruscia (1998) defined intuition as an “inner knowing,” a spontaneous process of deriving whole meaning from a seemingly illogical process. In returning to my epoche, I noticed that intuition was one of the first words I mentioned in relation to my spontaneous experience of inner understanding of my client’s experience. Intuition has been identified as a tool that may inform both the clinical and musical process (Forinash, 1992). Three participants indicated intuitive processes as extremely important in the dynamic clinical process. In addition, references to intuition were often included in the literature describing vignettes and experiences of providing music therapy with clients who were actively dying (Cadesky, 2005; Sekeles, 2007; Zabin, 2005).

It is noteworthy that Brescia (2005) was inspired to conduct a qualitative study examining the role of intuition after her experiences providing music therapy with children in palliative care who were actively dying. In her interviews with music therapists, she found that music therapists experienced physical, visual, spiritual, emotional, and auditory manifestations of intuition. Her results suggested that intuition may be a product of the interaction between deep listening, self-awareness, and previous experience and education. All four of the participants in this study noted the importance of deep listening and self-awareness along with the importance of knowledge in the clinical process. J.C. shared that he felt this was the “essence” of the work. Brescia also noted the role of intuition in the

therapeutic relationship as informing the shift from tension to release, which will be discussed further in this chapter. Brescia created a poem in order to share the voices and experiences of her study participants in discussing the role of intuition in their music therapy practices. I include it here firstly, because of its similarity to the experiences relayed by my participants; and secondly, because reframing their responses with the role of intuition in mind offers a significant shift in perspective.

Intuition Informs . . . the Music Informs . . . Intuition  
I Open myself to receive what is there,  
To receive the client,  
To receive the music  
To Receive I Breathe in and out, I let go of everything  
Express what Is In the music  
I create  
I am the vehicle  
For the music  
The music flows through me  
I am fluid, like a river  
I am in sync, connected with the client  
Connected to all beings  
There is easiness in this place  
And yet, there is paradox,  
Clarity and ambiguity  
Form but not predictable  
I am open to what comes  
From this creative source  
I am open to my intuition, my intuition opens the music. (pp. 99-100)

In essence, intuitive processes may play a very large role in music therapists' experiences of assessing client and family dynamics and providing music therapy with clients whose death is imminent, even if their elements are not conceptualized as such. Indeed, the significant role of countertransference in this work may speak to the large role of intuitive processes in the music therapist's experience.

## **Countertransference**

All four participants confirmed that they experienced rich and influential countertransference while providing music therapy for imminently dying clients. This finding was consistent with both research suggesting that a music therapist working in hospice may be forced to examine existential issues related to death (DiMaio, Wilkerson, & Sato, 2015) and also that music therapist's countertransference may significantly influence the clinical process (West, 1994).

An unexpected finding related to countertransference was the dynamic exchange of meaning that participants experienced. Countertransference to significant sessions influenced their worldviews and became material to be integrated into their spirituality. Scheiby (2005) discussed the phenomenon of intersubjective countertransference, or that which influences the process of the therapist in relationship to the therapeutic process. In the process of being fully "with" and "for" the client in music, the music therapist may experience personal revelations as a result. Birnbaum (2014) distinguished between countertransference, transference, and intersubjectivity. Intersubjectivity may be conceptualized as the therapist's experiences of transformation and healing as a result of his or her therapeutic relationship with a client. Traditional views of countertransference generally accept that acknowledging this phenomenon is important in order to differentiate between the client's and therapist's experiences in order to be present with the client. Intersubjectivity does not negate this reasoning; it suggests, however, that it is highly unlikely that a music therapist will enter into an intimate therapeutic relationship with a client without experiencing some aspect of personal transformation as a result (and in my experience, the majority of therapeutic relationships in hospice music therapy can be quickly and powerfully intimate).

The last emergent theme—something that was distilled from both countertransference in sessions and also the discussion of the various roles a music therapist might take on during the clinical process—was the participants’ experiences of feeling a responsibility to transform the environment in a meaningful way. In returning to the literature, Marom (2008) discussed a countertransference issue in hospice music therapists as a feeling of responsibility to make something beautiful out of something painful. This reaction in particular has been discussed in further research: DiMaio (2010) identified a “desire to fix” as a countertransferential reaction to her work providing entrainment to address pain in hospice patients. Indeed, the participants I interviewed identified the process of transforming painful experiences into beautiful ones as a core element of the work. Lecourt (1998) suggested the frightening possibility that what might be conceived as the purpose of providing hospice music therapy was a result of countertransference: He asked, “Is our use of aesthetic concerns a defense against anxiety, distress, or aggressiveness? What is the nature of our need to immediately transform something painful into something beautiful?” (p. 142). Perhaps this even reflects our American unwillingness to welcome or acknowledge that dying is a natural, and sometimes unfair, aspect of living despite the advances of modern medicine (Webb, 1999). This is a key question, and it suggests without a doubt that the experiences of hospice music therapy and countertransference are inseparable. My sense from the participants in this study was that although the transformation of painful experiences into beautiful ones was indeed personally moving, they received far more satisfaction in the knowledge that loved ones of the dying patient were able to contextualize the suffering in relation to something larger.

## **Aesthetics, Transition, and Transformation**

“Beautiful” was a frequently used and important word in this study. All four participants expressed their sense that music therapy in the dying process could be a profoundly beautiful experience. This stemmed from the beauty of the music and the transformation of the environment and the dying process into a connected, intimate space. E. Thayer Gaston, often considered the founder of modern music therapy, addressed the role of aesthetic experiences in music therapy early in his writings, noting that music was inextricable from the experience of man, as both shared the quality of being a “part of the cosmos and subject to all the laws of nature” (Gaston, 1964, p. 1). The role of aesthetic experience lost some traction for a significant period of time as music therapists shifted to a focus on using music to address nonmusical goals (Aigen, 2007). However, the role of aesthetic experiences in music therapy has received slightly increased attention in research in the past few decades.

Beauty may be conceived as a universal concept of the human experience (Kenny, 2006). Salas (1990) defined beauty as “the quality or integrity of form that echoes, to a greater or lesser degree, the grace and elegance of the patterns of existence” (p. 4). Support for this assertion is outlined by Stern (2001), in which he suggested that beautiful music reflects integral dynamics of vitality and existence occurring in physical motion that connect us to universal concepts. Aesthetic experiences in this sense may extend beyond traditional definitions of music and toward the sounds of our clients as they die or the hum of their family members as they prepare, willingly or unwillingly, for their loved one to transition (Abrams, 2011). Three participants in this study viewed their clients as an integral part of music creation, broadening their definition of music to include environmental aesthetic

considerations. Salas (1990) supported this idea, suggesting that beauty is always an interdependent process: “Beauty is perceived when the conviction of the creator meets the conviction of the perceiver” (p. 7). Perhaps aesthetic or beautiful experiences serve the purpose of providing evidence of order, affirming both the client’s process and the music therapist’s role and place in their lives.

Aigen (2007) introduced the idea of aesthetic experiences as transformational. All four participants spoke about the power of music therapy to transform the environment and facilitate meaning making. In some cases, music therapy mirrored preexisting goals. In other vignettes, music therapy provided a transformation of how to perceive the environment. Transformation may be considered in the context of personal growth; however, there is inherent mystery and spiritual consideration in the process of transformation. It is often difficult to pinpoint the exact moment or process behind transformation. In the dying process, it is sometimes difficult to confirm that death has occurred. Supporting this transition, the transformation from living being to whatever awaits after death, has become the overarching focus of providing music therapy for hospice patients (Krout, 2003). Aigen (2007) noted that the aspects of tension and release in music mirror a client’s process of tension and release. The participants in the current study and other music therapists have noted that facilitating release for both clients and family members is a central goal of providing music therapy when clients are actively dying (Krout, 2001).

There has been some critique of aesthetic experiences in music therapy, as it is somewhat difficult to note the therapeutic effect of beauty across music therapy experiences and theoretical orientations (Aigen, 2008). All four participants in this study mirrored this sentiment somewhat: although they recognized the power in aesthetic experiences, they also

noted that unaesthetic experiences were equally important as they ascribed meaning to each person's unique process. Nathan expressed a thought echoed by Sheiby (2005): The way that we live is the way that we die; and in this sense, every death is unique and meaningful. Nathan noted this in his description of how his patients with borderline personality disorder seemed more likely to die in a state of chaos. Many music therapists value the unaesthetic, non-musical aspects of sessions as equally important, as did the participants in this study. This may not be entirely incompatible, however, with aesthetic theory. Salas (1990) described a broader conceptualization of aesthetics, noting that all artistic creation was full of merit because of its potential ontological affirmations of meaning. West (1994) offered this perspective in her sharing of a clinical vignette. Concerning interaction between music, meaning, and metaphor, she wrote, "Changes in the music used and the progression of her art and imagery paralleled her movement through phases and tasks of dying" (p. 123). Therefore, an experience may be aesthetic or unaesthetic and still hold meaning in relation to the client's lived experience. In addition, this may provide a meaningful experience for the music therapist as he or she has shared in this process.

### **Implications for Clinical Practice**

The results of this study shed light on both the multitudes of experiences for clients in the dying process as well as the unique experiences of the music therapist. In order for a music therapist to provide services to a client who is actively dying, he or she would benefit from having increased understanding of advanced music therapy concepts including various types of countertransference, pain management and anxiety reduction techniques, and intuitive processes, as these contribute significantly to the essence of the work. Further, the music therapist needs fully-developed musical and clinical skills to engage in a flexible and

dynamic approach with clients and their families. Although many of these skills emerge with experience, internship supervisors might note these qualities of the work and provide resources accordingly. In addition, educators might note these principles as they relate to hospice music therapy when teaching hospice coursework. These research findings speak to the importance of supervision and self-care in hospice work. The dynamic role of countertransference in both the clinical process and in participants' lives necessitates effective and meaningful processing of these interactions.

### **Limitations**

This was a qualitative, phenomenological inquiry seeking to form a greater understanding of the experiences of four experienced hospice music therapists in their work with imminently dying clients. Due to the qualitative nature of this study, a small participant sample was used, and the emergent themes that were uncovered cannot be generalized across the experiences of other music therapists. Personally, I see this as reflective of the content of this research: very little can be generalized in the experience of dying and working with those who are living and dying in unique ways. However, a mixed-methods research design might incorporate these results plus a survey of music therapists or clients' loved ones that may contribute to generalization of this study's findings.

Another embedded limitation to this research design is my perspective in designing, implementing, and analyzing the interviews. It is certain that my experiences and interpretations of the interviews were highly influential in their analysis. However, I added validity to my findings by engaging in the creation of an epoche. In addition, I submitted the transcribed interviews to each participant for member checking. One participant elected to provide changes and additional information to his interview, and the other three participants

elected to keep their interview transcripts as written. I offered, as much as possible, to create an ongoing relationship with participants during the analysis process to honor their voices and experiences. It is perhaps notable that data came only from one source: the four music therapists in this study. In the future, interviews with family members who have experienced a music therapy session during their loved one's active dying process might shed light on further dimensions of the global experience of music therapy services when a client's death is imminent.

### **Implications for Further Research**

The results of this study highlight the need for music therapists to discuss the role of assessment for clients who are not outwardly responsive. The participants in this study revealed an ongoing assessment process supported by consultation with significant persons in the client's life and treatment team. My exploration of this in the discussion section uncovered a range of conceptions of the assessment process from a variety of theoretical traditions. I see a need for discourse surrounding the intention, purpose, role, and process of assessment when a music therapist may be providing only receptive experiences with the intention of responding to minimal feedback from clients.

I also see a need for further inquiry into the role of aesthetic experiences in hospice music therapy. I have been told more than once, "If the client is not responding, then that's not music therapy!" by well-meaning hospice volunteers and experienced music therapists alike. The fact remains that although we are trained to invite our clients into music-making as much as possible, many of our sessions will be based in receptive music. What, then, is the role of aesthetic and receptive experiences? What can we learn from them, and how do they relate to the work that we do? Are they even truly receptive experiences if we are taking

environmental factors into account as we create the music? Further inquiry in this area may help to illuminate the processes that have been described by the participants in this study.

## **Conclusion**

To summarize, this study sought to understand the experiences of music therapists who provide music therapy for clients whose death is imminent. Four experienced hospice music therapists described their diverse experiences through semi-structured interviews. I identified ten emergent themes through a process of phenomenological analysis of the interviews. Major themes in this research included the role and scope of ongoing assessment of both objective and subjective qualities of this work, the role of intuitive processes, the intersubjective nature of countertransference in participants' experiences, and the role of aesthetics in facilitating transitional and transformational experiences through music therapy. Further inquiry into the features of these concepts as they relate to hospice music therapy may shed more light on why we pursue this work and how it may (or may not) generalize across experience. Much of what we know about this work is veiled in spiritual and esoteric concepts; and ultimately, as each participant expressed, it is impossible to know the experiences of our clients with absolute certainty. Perhaps understanding more about loved ones' experiences as well as our own will help shed more light on the gray areas in the space between ourselves and our clients as we move, with them and for them in music, toward transition and transformation.

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## Appendix A

### Informed Consent Document

#### Consent to Participate in Research *Information to Consider About this Research*

I agree to participate as an interviewee in this research project, which concerns the experience of music therapists who provide music therapy for clients whose death is imminent. The interview will take place in a location of my choosing via telephone or Skype for approximately one hour. I understand the interview will be about my personal experiences providing music therapy for clients whose death is imminent.

I understand that there are no foreseeable risks associated with my participation. I also know that this study may benefit music therapists and hospice music therapy programs by offering a greater understanding of music therapists' experiences serving clients who are actively dying.

I understand that the interview will be audio and may be published. I understand that the audio recordings of my interview may be stored in a password-protected laptop if I sign the authorization below.

I give Alexa Dorris ownership of the tapes, transcripts, recordings and/or photographs from the interview she conducts with me and understand that tapes and transcripts will be kept in a password-protected laptop. I understand that information or quotations from my transcripts will be sent to me electronically for member-checking and review before they will be published. I understand I will not receive compensation for the interview.

I understand that the interview is voluntary and there are no consequences if I choose not to participate. I also understand that I do not have to answer any questions and can end the interview at any time with no consequences.

If I have questions about this research project, I can call Alexa Dorris or Christine Leist at 828-262-6663 or the Appalachian Institutional Review Board Administrator at 828-262-2692(days), through email at irb@appstate.edu or at Appalachian State University, Office of Research Protections, IRB Administrator, Boone, NC 28608.

This research project has been approved on \_\_\_\_ (date) by the Institutional Review Board (IRB) at Appalachian State University. This approval will expire on [Expiration Date] unless the IRB renews the approval of this research.

I request that my name **not** be used in connection with tapes, transcripts, photographs or publications resulting from this interview.

I request that my name **be used** in connection with tapes, transcripts, photographs or publications resulting from this interview.

By signing this form, I acknowledge that I have read this form, had the opportunity to ask questions about the research and received satisfactory answers, and want to participate. I understand I can keep a copy for my records.

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Participant's Name (PRINT)

Signature

Date

#### **Authorization**

I hereby release, discharge and agree to save harmless Appalachian State University, its successors, assigns, officers, employees or agents, any person(s) or corporation(s) for whom it might be acting, and any firm publishing and/or distributing any photograph or video footage produced as part of this research, in whole or in part, as a finished product, from and against any liability as a result of any distortion, blurring, alteration, visual or auditory illusion, or use in composite form, either intentionally or otherwise, that may occur or be produced in the recording, processing, reproduction, publication or distribution of any photograph, videotape, or interview, even should the same subject me to ridicule, scandal, reproach, scorn or indignity. I hereby agree that the photographs and video footage may be used under the conditions stated herein without blurring my identifying characteristics.

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Participant's Name (PRINT)

Signature

Date

## **Appendix B**

### **Interview Questions**

1. How many years of experience do you have working as a music therapist in hospice care?
2. Please describe your current job, including number of clients that you see, setting, characteristics of clients, and anything else that feels important.
3. Describe your clinical and/or philosophical approach to music therapy in hospice.
4. Describe your clinical decision making process when clients are actively dying.
5. Please describe a memorable music therapy session with a client who was actively dying.
6. What feels important to you about that session?
7. Describe your approach now compared to when you first began practicing as a music therapist.
8. What else would you like to discuss regarding music therapy for clients who are imminent?

## **Vita**

Alexa Kathryn Dorris was born in Indianapolis, Indiana, to Allison Dorris. She graduated from Lawrence Central High School in Indianapolis in May 2008. The following autumn, she entered Denison University to study Vocal Performance and Psychology; and in May 2012, she was awarded the Bachelor of Arts degree. In the fall of 2012, she accepted a Graduate Research Associate Mentor (GRAM) position at Appalachian State University with Dr. Christine Leist and began study toward the Equivalency/Master of Music Therapy program. She completed her clinical internship in music therapy at CarePartners Hospice in Asheville, North Carolina, with Lauren DiMaio. In January 2015, she was board-certified as a music therapist and returned to Appalachian to complete her graduate work in music therapy. She received her Master of Music Therapy degree in December 2015.

In addition to her music therapy work, Alexa owns Hoosier Sugar Cookies, a web-based custom sugar cookie decorating business. In January 2016, she is relocating to the Columbus, OH, area where she will work as a full time music therapist at The Learning Spectrum.