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A PHENOMENOLOGICAL INVESTIGATION OF  
MUSIC THERAPISTS' LIVED EXPERIENCES WHEN  
WORKING WITH HOSPICE PATIENTS WHO WERE  
ACTIVELY DYING: AN ANALYSIS OF WORDS,  
MANDALAS, AND MUSIC

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ABSTRACT

This phenomenological study was an exploration of the lived experiences of three music therapists who worked with hospice patients who were very close to death and in an active process of dying. The participants spoke of their experiences, drew mandalas, and improvised music. Through the lens of Interpretive Phenomenological Analysis (IPA) two primary themes emerged: clinical experiences and personal experiences. Subthemes under clinical experiences included use of ongoing assessment, clinical reasoning, importance of presence, clinical use of music to meet patient needs, roles as music therapist, awareness of countertransference, family presence and influence, and working with patients' spirituality. Subthemes under personal experiences included awareness of needs for self-care, emotions and new awareness from the work, a deepened understanding of death, and the work as spiritual on a personal level. Emotional and spiritual experiences were present in both clinical and personal experiences. The mandalas and music improvisation served as arts-based modalities of data collection and helped the participants reveal more, especially about their personal experiences.

## INTRODUCTION

*The greatest mystery in life is not life itself, but death.*  
-Rajneesh

“What is death?” is an existential question that has persistently crossed the minds of humankind for centuries. Reflective thoughts, theories, guidance, and beliefs around the experience of death continue to surface in fields such as medicine, philosophy, sociology, psychology, and theology (Aiken, 2001, Kagan, 2012, Kung, 2003). What it means and feels like to be present to the dying also leaves one with much to grapple. Those present with a dying person are faced with exceptional challenges and feelings, such as grief, existential questioning, or even enlightenment.

My interest in this study stems from my own challenges, reflections, and wonderings about my experiences of working with hospice patients who were actively dying. Along my educational and career path I did not receive training in how to approach a music therapy session with a dying person. In addition, I personally grappled with feelings about death and my own mortality. Admittedly, I entered the hospice setting with a sense of uncertainty. Learning through experience and supervision over the past seven years I have developed an understanding of my role and responsibilities as a clinician, realizing both the music and my presence have the potential to hold a sacred space for the patient and others present. My experiences with death and dying and music have been profound and have affected me deeply.

I often tell people that I really love my work. In turn I am usually asked “How do you work with dying people? Isn’t that difficult?” It is challenging for me to articulate why I am drawn to this work because the paradoxes I experience are difficult to describe. Holding both sorrow and love in the music, being the supportive presence in the room when others are struggling or even overcome with grief, and managing my own feelings as I relate and respond to the as-yet-unknown unfolding moments are some of the experiences I have had. To me these paradoxes bring a sense of beauty and wonder to the work. I feel a sense of reverence.

Through this research I sought to illuminate an understanding of the music therapist’s experience when working with hospice patients who are actively dying. I wanted to come to a deeper understanding of this experience through both verbal and creative means of exploration, and in turn help others understand it. This work is different from any other type of music therapy practice, and I entered into this research with wonder about how we can more accurately describe this experience.

## REVIEW OF THE LITERATURE

The hospice approach involves a team of professionals who attend to the patient’s physical, emotional, and spiritual well-being to preserve dignity and comfort at the end of

life (National Hospice and Palliative Care Organization [NHPCO], 2016). About 1.3 million people received hospice services in 2013 and there were at least 4,000 hospice care agencies in 2014 in the United States (Centers for Disease Control and Prevention, 2016). There has been a steady increase in number of patients served and number of hospice agencies per year according to the NHPCO (2016), and accordingly, the prevalence of non-required referral-based services, such as music therapy, have increased in the hospice setting (Silverman & Furman, 2014).

Hospice philosophy recognizes the patient as a whole person with end-of-life needs within physical, emotional, psychosocial, and spiritual domains, and support is also provided to the caregivers, family members, and other loved ones by an interdisciplinary team. Required disciplines under the Medicare benefit (primary hospice insurer) are nurses, social workers, spiritual care providers, physicians, home health aides, volunteer coordinators, and grief counselors. Non-required disciplines include referral-based services, such as music therapists, massage therapists, physical therapists, respiratory therapists, art therapists, etc. (Hilliard, 2005). Each discipline uses its area of expertise to attend to the needs of hospice patients and families, and the team meets on a regular basis to coordinate plans of care for each patient.

The music therapist serves on the interdisciplinary hospice team and receives referrals from team members based on their assessments of needs for services. Referral reasons may include pain and discomfort, anxiety, fear, dyspnea, disorientation, confusion, nausea, coping difficulty, depression, withdrawal, isolation, difficulty expressing or communicating thoughts and feelings, difficulties exploring spirituality or spiritual issues, and cultural language barriers. Following the referral, the music therapist assesses the patient and notes significant responses. The most pressing needs are addressed first, and upon symptom stabilization other aspects of the patient's personhood can be explored in music (Clements-Cortéz, 2013). If family is present the music therapist attends to their emotional needs and invites active or passive participation in meaningful music experiences (Krout, 2003).

## The Dying Process

When the person begins to show indications that end of life is near there are signs and symptoms that accompany the "pre-active" and "active" phases of dying. It should be noted that each person's dying process is unique, and none, one, some, or all of the following symptoms may be experienced. In the pre-active phase, which is about one to three months prior to death, the person may exhibit increased weakness and lethargy, increased dependence on caregivers, withdrawal from interactions with others, decreased food and fluid intake, difficulty swallowing, disorientation, seeing and speaking to others who have already died, restlessness, and incontinence (Strada, 2013; Karnes, 2014). One to two weeks prior to death there may be an increase in disorientation and physical changes that include lowered blood pressure, changes in pulse, fluctuations in body temperature, breathing changes, and changes in skin color, hands, feet, and nail beds (Karnes, 2014).

The person then transitions to the active dying phase, which is one to two days, or hours prior to death. Some people may experience a brief surge of energy where they become alert, talkative, and may even ask for a meal. Additional symptoms in this phase include restlessness and increased confusion, and eventually the person becomes unresponsive. Physical signs of imminent death include breathing pattern changes with apnea (pauses in breathing) or rapid and shallow breathing, congestion, open eyes with a glassy stare, and decreased circulation causing mottling (purplish tones) to the knees, ankles, and elbows (Strada, 2013; Karnes, 2014).

As mentioned before, the dying process is unique to each individual. The timelines mentioned in this section are not always the case; for example, some people remain in the active dying stage for several days (Karnes, 2014). A team of hospice professionals continually assess pain, shortness of breath, confusion and agitation, terminal congestion, as well as other physical symptoms, and adjust interventions as needed. In addition, the changes experienced in the pre-active and active phases are often difficult for family and loved ones to watch, and the hospice team attends to their needs for emotional and spiritual support (Reith & Payne, 2009).

As a member of the interdisciplinary team the music therapist assesses needs of the patient and family if present, and offers music experiences that would help both (Gallagher et al., 2017; Krout, 2003). Krout (2003) described how the music therapist provides original or familiar music to promote the patient's comfort and reduce pain and anxiety, and invites family to actively or passively participate in the music. Family may request songs and share memories, and a receptive experience of listening affords the opportunity to feel and release emotions. The music therapist's role is to attend to the unique needs of both patient and family.

## Music Therapy Research Evidence: Objectivist Studies

There has been an increasing amount of research and discussion in the literature on music therapy in hospice and researchers have empirically studied the effects of music on symptoms associated with end-of-life. While these studies are helpful for justifying the effectiveness of music therapy interventions, the focus of interventions has been on needs and symptoms during earlier phases of disease progression when the patients are relatively stable and able to consent to participate. I was unable to find quantitative studies of music therapy with hospice patients who were actively dying, and this may be due to ethical concerns. Ethical concerns in research have been identified as not being able to gain consent from a person who is unresponsive, inability of a participant to change their mind once consciousness shifts, and respect for the dying process (Lawton, 2001).

Nevertheless, findings from the existing objectivist studies are helpful in guiding the music therapist when working with patients who are actively dying. One of the first objectivist studies was implemented by Curtis in 1986. She found that music therapy positively affected pain perception, physical comfort, relaxation, and contentment in hospice patients prior to the active dying phase. Whitall's (1989) results showed decreased heart rate and blood pressure following music therapy sessions with eight

stable terminally ill patients. In a later study Krout (2001) found that active and passive music therapy experiences were effective in pain control, physical comfort, and relaxation from pre- to post-test in a single session. Using the Hospice Quality of Life Index-Revised, Hilliard (2003) found that the experimental group of participants with terminal cancer who received a variety of music therapy interventions scored significantly higher in measures of quality of life.

Gallagher, Lagman, Walsh, Davis, and LeGrand (2006) found that song choice was effective in providing enjoyment, decreasing anxiety and depression, decreasing pain perception, developing coping skills, improving mood, and providing distraction. Significant effects on anxiety were found in another study (Horne-Thompson & Grocke, 2007) where live familiar music, singing, music and relaxation, music and imagery improvisation, music assisted counseling, reminiscence, and listening to recorded music were implemented based on the patients' presenting needs. Włodarczyk (2007) studied the effects of music therapy on spirituality. Music interventions included singing and playing guitar using familiar songs, song choice, improvisation, songwriting, life review, song dedications, and sing-alongs with family and friends. Another study found that live music was found to be more effective than recorded music on pain reduction and comfort (Clements-Cortés, 2011). These objectivist studies point toward the benefits and effectiveness of music therapy with hospice patients who are not yet actively dying. While these studies can be useful to draw from there needs to be more research available to music therapists to guide their practice when the end of life draws near.

## Music Therapy Research Evidence: Case Studies

There are many case examples of music therapy in hospice and palliative care (see Aldridge, 1999; see Bruscia, 1991; see Bruscia, 2012; see Dileo & Loewy, 2005; DiMaio, 2010; see Meadows, 2011) and like the objectivist research most describe a therapeutic process that occurs during the period of stability before the active dying process. There are only a handful of descriptions and accounts of music therapy with hospice patients who are actively dying.

Hogan (1999) described her work with a hospice patient that included pain and anxiety reduction, emotional support, relaxation, reminiscing, family support, and comfort during a period of stability and at end-of-life. She helped compile a tape of songs that were meaningful to the patient, which was used at night when he became restless. On the day the patient died she sat with him and his wife and they listened to the tape. As the song *Danny Boy* played the patient died. As the tape continued family arrived and, supported by the music, they shared meaningful moments in their grief and sorrow. Several songs from the tape were played at the funeral, and the wife said listening to the tape was helpful in her time of bereavement.

Dileo and Parker (2005) discussed how music therapy offers space and time for "profound transformation when death is imminent" (p. 43). They shared cases of hospice patients who experienced relationship completion with self, God, and loved ones through the sharing of meaningful songs. In another case, Loewy, Altillo, and Dietrich (2005) told the story of a hospice patient who engaged in imagery, drumming, and vocalizing just before slipping into an unresponsive state. This experience was described as a "rite of

passage.” Additionally, Hartley (2005) described a patient who moved into a place of peace just before his death with the support of his music therapist, who provided music that aligned with his faith beliefs.

Potvin (2015) described a case within a context of ritual drama with a hospice patient who was actively dying. He described the role of ritual drama, which involved the family’s exploration of new roles in a process of separation, liminality, and reintegration. He acknowledged each person’s role as the patient transitioned to an unresponsive state, and supported a transformational process with music. Potvin, mindful of cultural and spiritual traditions, supported the patient and family in processing, connecting, celebrating, grieving, and discovering how to move forward. He “used the music to facilitate a meaningful interpersonal connectivity...[with] expressions of love, stories of remembrance, and physical affection that expressed more than any words could” (p. 59). Self-examination of his own countertransference was a critical part of his understanding of the process as it unfolded. While these case studies are helpful in developing an understanding of how music therapy provides support to hospice patients when actively dying, formal research approaches, such as phenomenological research, could provide more clarity on this area of music therapy practice.

## Music Therapy Research Evidence: A Literature Review on Spirituality

Spiritual issues and concerns often become paramount in hospice care, and music holds the capacity to support spiritual beliefs and experiences within personalized and cultural contexts. A recent literature review by Hong (2016) listed spiritual needs addressed by music therapists with hospice patients. These included the need to transcend one’s current situation, need to find meaning, need to restore or affirm one’s sense of hope and faith, loss of spiritual/personal connection with others, loss of identity and lack of connection to oneself, need for resolution or closure, and feelings of anxiety, worry, fear, and denial. Interventions found within the studies included music entrainment, musical life review, chanting for the patient, music listening for relaxation, music and imagery, music listening to support prayer and worship, lyric analysis with songs containing spiritual themes, and song choice.

The sources in this literature review provide a helpful and informative framework for music therapists on spiritual needs of hospice patients and music therapy interventions to address those needs. However, spiritual needs specific to patients who are actively dying and their families were not addressed in isolation, thus further pointing toward the need for investigative attention to music therapy during the active dying phase.

## Caregivers’ Experiences of Music Therapy

It is not only the patient who receives music therapy in a hospice setting, but also the caregivers, family members, and other loved ones. Two studies explicated the experiences of caregivers who were family member of terminally patients. Through a

research method of naturalistic inquiry, Magill (2009) interviewed seven bereaved caregivers about their experiences in music therapy. Data analysis included coding for themes, which revealed that the caregivers experienced joy in seeing their loved one benefit from a meaningful experience. They also reported feelings of empowerment by being able to contribute to the music therapy sessions. Spiritual themes emerged as they reflected on past/remembrance, present/connectedness, and future/hope. The overarching theme that emerged was “meaning through transcendence” as they were able to connect with the love, joy, and peace they felt with their loved one during music therapy.

Potvin, Bradt, and Ghetti (2018) explored caregivers’ experiences through grounded theory methodology with results depicting a resource-oriented model of music therapy that promoted resilience. They found that during music therapy with their loved ones the caregivers were able to connect with their identities as they experienced them before their loved ones became ill. This resource provided them the strength and energy they needed to step back into the caregiving role. These studies show that music therapy for adult hospice patients is valuable and beneficial for caregivers.

## The Music Therapist’s Experience of Working with Hospice Patients

There are two research studies that explored the music therapist’s experience of working with the actively dying. An aspect of the music therapist’s experience was present in Forinash and Gonzalez’s (1989) phenomenological exploration of a music therapy session with a hospice patient who was actively dying. They found that the music therapist’s clinical assessment of the relationship between the client’s breathing and the music, and personal experience of imagery that was influenced by the music were important elements for the music therapist’s awareness. Essentially, the music therapist relied on both clinical observations and personal experiences in their provision of music therapy.

Economos’ (2018) study was most influential to my project because it directly investigated music therapists’ experiences with patients who were actively dying through phenomenological inquiry. She interviewed four music therapists and found themes of ongoing assessment, intuitive processes, countertransference, and the role of aesthetics and transformation. Within these themes the following sub-themes emerged:

- Importance of knowing the client’s background
- Physiological responses can indicate internal experiences
- The music therapist should be flexible and adaptive in the moment
- Intuitive processes are important
- Influence of countertransference
- Responsibility to take on a role that transforms the experience in a meaningful way
- The central goal is to help the patient transition meaningfully and without discomfort
- The music therapist engages in a collaborative process with loved ones and provides a meaningful experience for them as well

- Music therapy can reveal beauty and meaning in the midst of pain and suffering
- Music therapy can transform the experience and environment

Our research questions and methodologies neared facsimile. Economos' method of data collection was phone interviews, so the main differences in our studies were my conduction of in-person interviews and my addition of arts-based data collection. It was interesting to discover the overlaps in our results (see Discussion section).

Other literature has included the music therapist's personal reactions and responses, though not within a phenomenological research context and not isolated to working with patients who are actively dying. DiMaio (2010) included personal responses of her experiences using Music Therapy Entrainment with hospice patients who were in pain. She wrote that she made personal discoveries in her connections with the patients, she was able to respond authentically, she realized she could ask fewer questions, she was aware of her countertransferences, and she was sensitive to the effect of her presence and focus on her ability to read nonverbal cues. She also reported feeling anxious about the patients' pain and felt a responsibility for their pain. She realized she needed to trust herself and the process and to allow the interaction with the patient and the music to unfold. While helpful to know what she was experiencing, these reactions were not in response to hospice patients who were actively dying.

Potvin (2015) disclosed his personally felt connections to the patient and her family in the epoché section of his article. He revealed that his religious beliefs and history with his mother surviving cancer manifested in countertransference, and acknowledged the overlap of his own spiritual and cultural practices with those of the family's. This information was provided to help the reader understand how his role developed with the patient and family, how he understood their situation, and what was involved in his approaches and thought process as the patient's health declined.

## Related Studies on Intuition, Spirituality, and Presence

Several researchers have explored lived experiences of music therapists that relate to the present study, and these include intuition, spirituality, and presence. Through naturalistic and hermeneutic inquiry, Brescia (2005) found that the music therapists she interviewed (some who had experience in hospice) used intuition and did so through the receipt of physical messages, emotional messages, auditory messages, and visual messages. They also described their intuition coming from a spiritual realm. Conditions involved in using intuition were trust, deep listening, self-awareness, previous experience, and relationship with the client.

Marom (2004), in a phenomenological study, found that the music therapists interviewed had spiritual experiences that included witnessing the client's spiritual experience, sharing a spiritual experience with the client, or having a personal spiritual experience. The music served to enter into the spiritual experience, hold it, intensify it, and process it. The participants described the need for self-awareness and maintenance of professional boundaries, the experience of a strong sense of empathy for the client(s),

remaining open and supportive of the client's experience, and holding a safe space for the clients to have a spiritual experience.

Muller (2008) explored the experience of therapeutic presence through phenomenological methodology. He found that both intention and openness to the "as yet unknown" are involved in feeling fully present. Additionally, the music therapist must effectively work with emotion, which involves identifying and using them in the process. Finally, the music therapist must maintain a balance of being in the client's world, being in the music, and being self-aware. I have found intuition, spirituality, and presence as important aspects of my work with hospice patients who are actively dying, and I anticipated these topics to emerge in the data of this study.

While researchers have evaluated music therapy for needs associated with end-of-life (symptoms, etc.) the bulk of this literature is focused on patients in the period of stability prior to the active dying phase. There are few sources of literature that address music therapy with hospice patients who are actively dying, and even fewer that evaluate the work within a research methodology. Many music therapists work in the hospice setting and providing music therapy at this final stage is a recurrent and important part of the job. Given the profundity of being with a person who is actively dying it seems worthwhile to explore and analyze how music therapists experience their work. For these reasons, the research questions guiding this study were:

1. What do music therapists experience when working with patients who are actively dying?
2. How do music therapists prepare for these visits, and then process their experiences afterward?

## METHOD

### Epistemology and Methodology

Phenomenology "seeks to discover and describe the structure and meaning of a phenomenon that makes it intrinsically what it 'is'—its essence" (Jackson, 2016, p. 441). It is an appropriate methodology for research questions that are subjective and non-positivistic, where rather than finding a conclusion, a human experience is more deeply understood (Marom, 2004). My research questions for this study warranted a phenomenological methodology because I was seeking to understand the nature of a human experience. My aim was to gain a deepened understanding of the parts and the whole of the experience from pre-session to post-session. The only way I could gather information to explore this topic was from music therapists who have conducted this work.

### Interpretive Phenomenological Analysis

The phenomenological approach that guided the process of this research was Interpretive Phenomenological Analysis (IPA). IPA involves a detailed examination of the participant's life-world and an exploration of perceptions and meanings of life events or experiences. As a contextual approach it recognizes that people's lives are embedded in social and cultural environments, and people make sense of their experiences through self-reflection and self-interpretation. As a researcher adhering to this methodology, I also employed reflection and interpretation when attempting to make sense of the participants' experiences, thus resulting in a dual interpretive process. IPA also involves a dual analytic process wherein I endeavored to take an "insider stance" to understand the experiences true to the participants' perspectives, as well as an "outsider stance" to understand how the participants were making sense of their experiences (Braun & Clarke, 2013). In other words, I attempted to understand the participants' experiences from their point of view, and also step back and critically analyze and question their perceptions (Smith and Osborn, 2007).

## Data Collection

I chose three modalities data collection on the experiences of working with patients who were actively dying: a verbal discussion, drawing a mandala, and music improvisation. A mandala is a piece of paper with a circle already drawn on it that is used by art therapists and often by practitioners of the Bonny Method of Guided Imagery and Music (GIM). It is believed that drawing in a reflective way brings new awareness and insights (Bonny & Kellogg, 2002/1977). As a practitioner of GIM I have had training in their use and I have an understanding of how new awareness emerges through shape and color and use of the circle. Similarly, music improvisation lends itself to emerging awareness through expression of sound. It is a method commonly employed by music therapy clinicians for the purposes of psychological growth and promotion of awareness and insight (Bruscia, 2014).

Because of my own struggle to verbally articulate what it is like to provide music therapy to a person who is actively dying, I was drawn to using creative modalities as components of data collection. I wondered if expressions in art and music would reveal aspects of the work that would be difficult to express in words.

## Trustworthiness

Because I also have experience with this phenomenon I made a significant effort to maintain awareness of my own experiences and possible influence of myself on the research (Smith & Osborne, 2007). Triangulation, a process of cross-checking, is used by qualitative researchers to promote the integrity of data collection and analysis (Jackson, 2016). I engaged in a practice of triangulation to ensure the trustworthiness of this study, which involved journaling, bracketing, member checking, and supervision and consultation.

I kept a journal where I recorded what I considered in each step of the study. I also made notes on Economos' (2018) study, and noticing the similarities and differences of our studies helped me solidify necessary steps in the method. I also jotted my personal reactions, thoughts, questions, and feelings as they arose. Keeping these in my awareness helped me remain open to understanding the research process as it unfolded.

I used bracketing during the interviews, which proved to be challenging. Bracketing involves setting aside personal thoughts, beliefs, values, and feelings in order to best understand the information from the other person's perspective (Jackson, 2016). As the participants spoke sometimes my own thoughts, feelings, and memories of patients would surface, and I recognized that my own experiences and emotions were distracting me from what they were sharing. I made every effort to clear them away and remain open to what the participants were saying to ensure the interview remained focused on the participants' experiences.

Member checking involved the participants again. I sent their transcripts to them so they could clarify, change, or modify what they shared, which was meant to ensure I had the information exactly how they wanted it expressed. I received two of the transcripts back with no changes, and the third was not sent back by the participant so it was used in its original form.

My research was supervised by a doctoral-level music therapist with expertise in phenomenology. We met periodically to review my questions and discuss issues within the process. I also consulted with a doctoral-level music therapist who is an expert in research as well as mandala and music analysis. My primary question for him regarded the process of data analysis, and considerations of the arts-based data collection. This conversation resulted in a clearer vision of how to analyze the participants' creative expressions, which was to use the participants' verbal descriptions of them as well as my observations.

## Participants

Following IRB approval from Augsburg University and completing CITI (Collaborative Institutional Training Initiative) training I moved forward with recruiting participants. Criteria for participation in this study were (1) board-certification in music therapy, (2) at least five years of full-time (or equivalent) experience in the hospice setting, and (3) currently working in hospice. The criteria of length of experience was chosen to ensure a significant number of experiences with hospice patients who were actively dying, and ample time to process these experiences and develop perspectives from them. In addition, I hoped that because the participants would be currently working in hospice the experiences they would share would be freshly present to them, thereby providing depth and richness to the data that would be collected. (I later modified the criteria of "currently working in hospice" for one participant, Phyllis, explained below.)

Three music therapists participated in this study. They were recruited from a notice I posted on a closed-group internet forum for hospice and palliative care music therapists. No compensation was provided for participation. The participants would be speaking about their experiences within their professional roles, so there was little risk to the study.

*Barbara*

Barbara described her approach to hospice music therapy as eclectic, but mostly humanistic. She had worked in hospice for nine years, and had been a music therapist for a total of 33 years, working in other settings that included schools, adult day care, psychiatric facilities, and medical/hospital. She also had a background in GIM. She described her caseload of hospice patients as located in the rural south, with economic and cultural diversity. She reported working with patients who were actively dying at least one to two times per week.

*Phyllis*

A participant who was originally recruited cancelled the day before the scheduled interview due to a family emergency. This person contacted another music therapist (Phyllis) in her area who was able to participate in the study. Phyllis was board-certified with twelve years of full-time experience in hospice and palliative care, however she had not worked for six months following the birth of a child. I decided to waive the criterion of “currently working in hospice” because she had a significant amount of experience with a comparatively short time away from the field.

Phyllis described her approach to hospice music therapy as influenced by humanistic and Jungian theory, with special attention to the emotional and cathartic shape to the session. She had a background in GIM training, and this was also influential in her work. She described the patients she served as being mostly elderly, white, in the rural south, and economically diverse. She reported she had worked with patients who were actively dying about five times per week.

*Tova*

Tova had ten years of full-time experience in hospice, and 17 years of experience overall as a music therapist, working also in special education and early intervention. She described her approach to hospice music therapy as eclectic, and influenced by humanistic and existential theories, Buddhist psychology, and feminist theory (relational-cultural theory). She described her caseload as over 50% Catholic, many patients of Irish and Italian descent, and the majority in the middle class economic bracket, although representative all ends of the economic spectrum. She said about 40% of her caseload was quite diverse, and included Vietnamese, Greek, Armenian, African American, and Latino ethnic groups. About half her caseload were patients in private homes, and the other half lived in care facilities. She also had a small pediatric caseload. She reported working with patients who were actively dying four to five times a week, with a majority of those patients residing at her company’s 20-bed hospice residence.

## Data Collection

### *Interviews*

Interviews were conducted at locations convenient to the participants since I had to travel to their area of the country; these included a classroom at a church, a conference room at a hotel, and a participant's living room in her apartment. Interviews lasted 90-120 minutes. I used an iPad with the application "Recorder," as well as an iPhone with the application "Voice Memos" to record the interviews. Both devices were password protected. I turned off the WiFi connections and used the "do not disturb" function to prevent unwanted noises.

I asked them to pick a preferred name to be used as a pseudonym for the study, and then asked several demographic questions. The first part of the interview involved questions about their experiences with patients who were actively dying. As a semi-structured interview, I allowed the discussions to take shape as naturally directed by the participants, and sometimes I asked follow up questions for clarification. The questions I asked each participant were:

- Please share any general thoughts that come to mind as you think about what it is like for you to work with hospice patients who are actively dying.
- Are there any experiences that stand out in your memory?
- What are some important factors you keep in mind?
- What are your aims, intentions, or goals?
- Do you do anything to prepare for working with actively dying patients?
- Do you do anything to process your feelings afterward?
- What are your feelings in the moment?
- What is your experience of the music?

### *Mandalas*

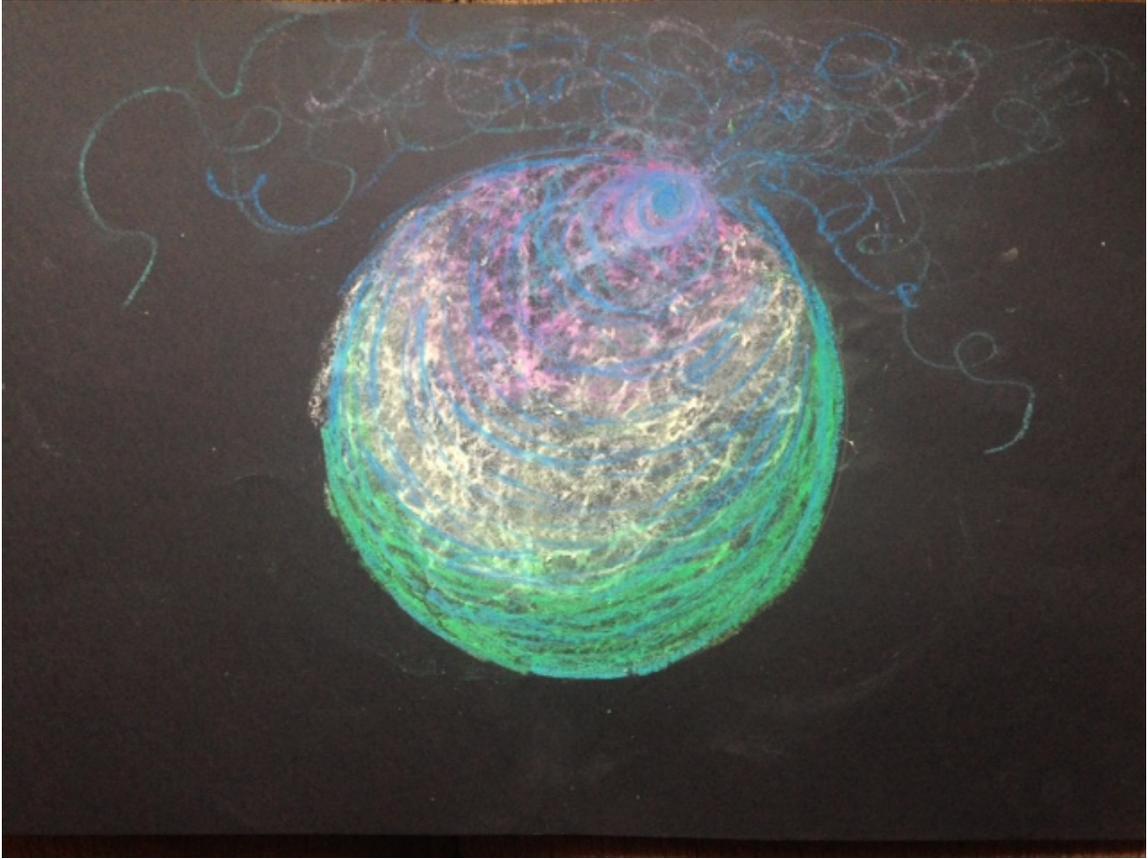
Following this part of the interview I gave them the option of drawing a mandala or making music next. Each chose to draw a mandala and each reported having drawn mandalas before. They were provided a set of oil pastels and given a choice of black or white paper. Interestingly, each chose black paper and each said they had never drawn a mandala on black paper before. I provided the following prompt:

*As you reflect on the experiences you just shared, continue your reflection on working with hospice patients who are actively dying as you choose colors to come onto the paper. Allow your experiences, thoughts, and feelings to guide you.*

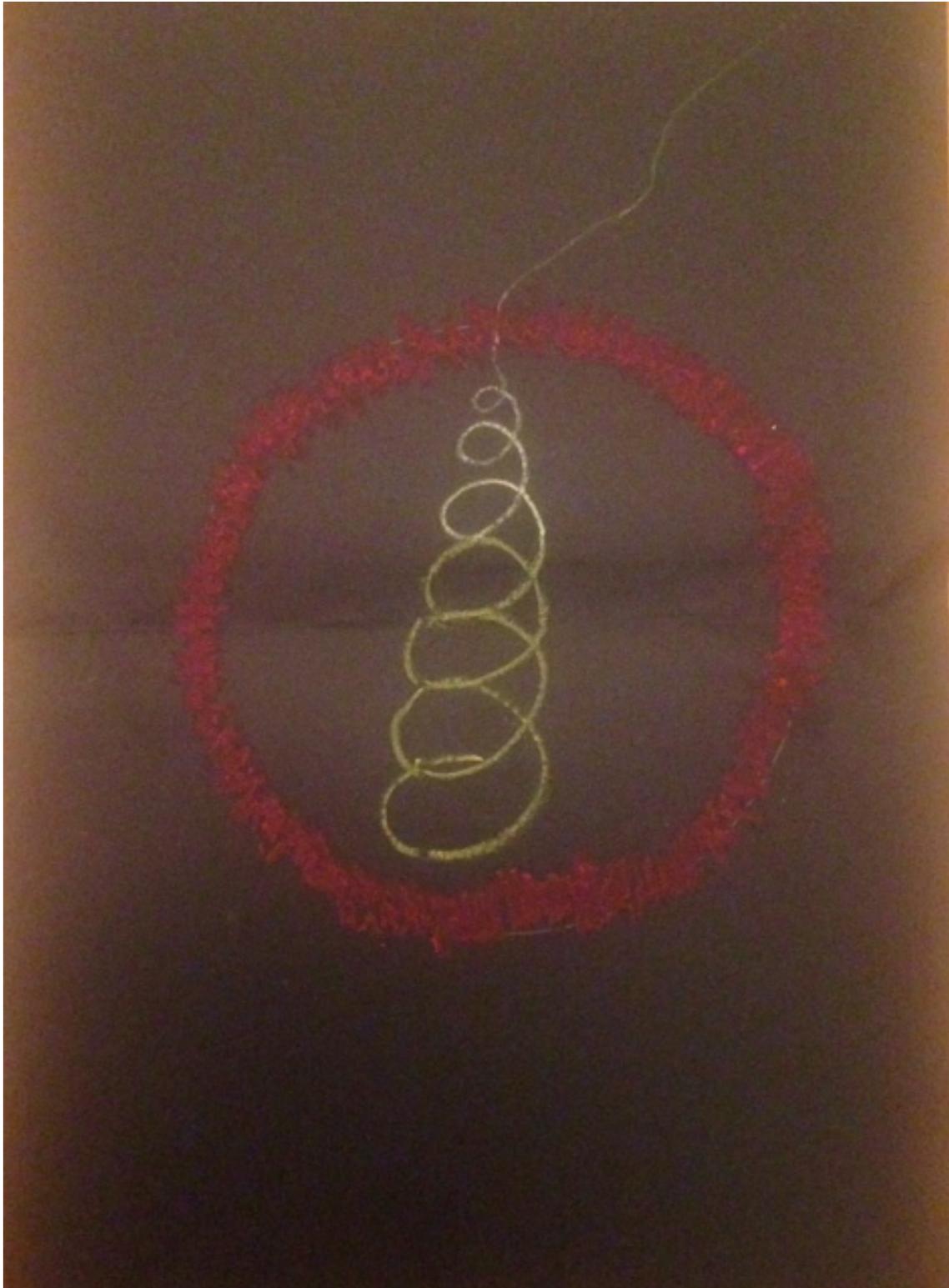
The participants drew in silence, taking about 10-15 minutes. Afterward they shared what stood out to them about their mandalas. The mandalas are shown below in Figures 1-3.



*Figure 1.* Barbara's mandala



*Figure 2.* Phyllis' mandala



*Figure 3.* Tova's mandala

Then each participant made music. I brought a selection of instruments and laid them on a table before the participants: Reverie Harp, Native American flute, chime eggs, ocean drum, medium hand drum, small hand drum, two maracas, plastic hand-held jam block (similar to a cowbell) with mallet, tambourine, bells, rain stick, and vibratone bar (middle C). I asked each participant to bring any instruments they would like for this portion of the interview. Phyllis brought a guitar, Barbara brought a Native American flute and a guitar, and Tova had available hand held chimes and a set of Free Tones (similar to a pentatonic metallaphone). I provided the following prompt:

*As you continue to reflect on the experiences you have shared, continue your reflection now in sound and music. Notice what instruments you are drawn to and allow the sounds and music to come into the room. Allow your experiences, thoughts, and feelings to guide to you.*

Each person improvised on the instruments for 5-10 minutes, and my role during the music remained as observer and listener. Afterward they shared their thoughts on their music. I have transcribed into words a description of the music each person made. Audio clips of the improvisations are available on the Barcelona Qualitative Inquiries in Music Therapy website.

#### *Barbara's Music*

Barbara struck the vibratone moderately three times, letting the sound ring and fade. Then she picked up the ocean drum and let the beads roll around slowly, and lifted it so the beads would fall quickly and loudly. She lifted and turned the drum so the beads were continuously rolling, creating a swirling sound, with an ebb and flow of loud and soft. She did this for about one minute and 45 seconds. Then she played her Native American flute, which was in the key of E-minor pentatonic. She used the entire range of the notes, ascending and descending, using simple rhythmic and melodically-shaped phrases and occasional articulation with trills. The tone was warm with vibrato on notes that were held. The tempo was andante. She played for about two and half minutes, ending on a held and fading tonic note of E. Finally she played the vibratone again in the same way as before, striking it with the mallet three times, and letting the sound ring and fade.

[See website for Barbara's music.](#)

#### *Phyllis' Music*

Phyllis picked up a maraca and shook it side to side with a loose eighth-note rhythm at about 120 beats per minute (bpm), slowing just slightly sometimes, and for about eighteen seconds. Then she played a steady quarter note rhythm at about 60 bpm for about 30 seconds, then returned to the first rhythm for about 20 seconds, and then played the final shakes slower and slower. She grasped the chime eggs, shaking them so they rang consistently for about ten seconds, and then shook the shaker again a few more times.

She picked up her guitar, playing 9<sup>th</sup> chords with a steady strum at about 75 bpm. Her progression used suspended A major, E minor, and F-sharp minor chords. She began to vocally hum “mmm” on an A (above middle C) and down a fourth to E, then back up to A. Her vocal sound opened to an “ahh” on the same A and E and moved downward to a melody with D, C-sharp, and A. She repeated this melody, staying on C-sharp. Then she moved to C-natural, to D, and resolving to E. She then continued strumming on an A9 chord and hummed on A, descending to G-sharp and E, and back up again. She played the chords a few more times, and then the tempo slowed and the sound faded. She put down the guitar and picked up the jam block, “tocking it” two tocks at a time like a heartbeat, and did this seven times. Then she let the beads of the rain stick descend one time.

[See website for Phyllis’ music.](#)

### *Tova’s Music*

Tova began with the Native American flute. She explored different notes, letting her entire breath out on some, and allowing the sound to fade. She explored different sounds on the flute, sometimes arrhythmic and sometimes playing rhythmically and melodically. After two minutes she began to play her Free Notes. She again seemed to be exploring, playing high notes, then low notes in an arrhythmic manner. Then she played an interval of a second, repeating it and going to a third. She continued playing in this way. The volume was soft. She then moved to higher notes, playing seemingly random melodic and harmonic intervals. Then she played one note, slowly. She very softly and quickly played upper notes, alternating, then together. The exploratory quality of playing continued. She played upper notes quickly, which had an effect of a “sprinkling” of pitches. Then she moved to the middle register, playing one note at a time, wandering up and down. She ended with a repeated high note.

She picked up her chimes and rang them in an upward motion for about 30 seconds. Then she played the Reverie Harp, plucking a few strings, and then strumming the entire range of strings. Her playing became quick, short strums randomly over the instrument, and briefly vocally “ooh”-ed for about ten seconds before letting the sound fade to the ending.

[See website for Tova’s music.](#)

## Data Analysis

In preparation for transcribing the interviews and coding the data, I read selected chapters from Braun and Clarke’s (2013) *Successful Qualitative Research: A Practical Guide for Beginners*. Also, taking guidance from the concepts of IPA (Smith & Osborn, 2007) I engaged in the following data analysis process:

1. Transcription of interviews with member checking
2. Coding: Underlined and concisely described significant phrases

3. Assignment of preliminary themes to codes
4. Collation of preliminary themes to groups
5. Organization and assignment of themes and sub-themes

*Data Preparation*

In preparation for coding I changed the right-hand side margin of the transcripts to four inches, printed the documents, and hand-wrote codes next to the text. Then I interpretively assigned the codes a descriptive preliminary theme in parentheses. See Appendix A for a visual example of this step in the process of analysis.

At first I strived to understand their experiences from their perspectives. For example, next to Barbara’s statement of “I think the number one thing is it’s an honor to be able to be with people at that point,” I assigned the code “It’s an honor to be with the dying.” I then thought about what possible theme this code could fall under (my interpretation of the statement) and I designated the preliminary theme to be “feelings about the work.” I used the term “preliminary theme” to allow for changes and modifications as data analysis continued. The resultant preliminary themes for each participant are tabled below, listing same and similar themes next to each other. What stood out to me at this point was that some of the preliminary themes emerged from information shared after the mandala drawing and music making. The preliminary themes in italics indicate that additional information around that topic was shared after the mandala drawing and/or music making, and the preliminary themes in bold emerged only after the mandala drawing and/or music making. See Table 1 below.

BARBARA	PHYLLIS	TOVA
<i>Feelings about the work</i>	Feelings about the work	Feelings about the work
Role as music therapist	Role as music therapist	Role as music therapist
Factors influencing decisions	Factors influencing decisions	Factors influencing decisions
Countertransference	Countertransference	Countertransference
Presence	Presence	<i>Presence</i>
Approach and clinical decisions	Approach and clinical decisions	Approach and clinical decision
<i>Music (considerations and effects)</i>	Music (interventions and effects of)	<i>Music (role, effects of, metaphors)</i>
Assessment	Assessment	Assessment
Personal time for reflection	Personal time for reflection	<i>Personal time for reflection</i>
Patients (background)	Patients (symptoms)	Patients (symptoms)
Personal experience and feelings	<i>Personal experience and feelings</i>	<i>Personal experience and feelings</i>
Intuition	Intuition	<i>Intuition and awareness</i>
Working with family (challenges)	Working with family	Working with family (challenges)
Work as spiritual	<b>Work as spiritual</b>	Spiritual realm
Self-care	<b>Self-care</b>	Self-care, humor
<b>Understanding of death</b>	<b>Understanding of death</b>	<i>Understanding of death</i>
	Therapeutic process	<i>Therapeutic process</i>
New awareness from the work		<b>New awareness from the work</b>
		Reflected on what it was like to share during the interview

		Interdisciplinary team Being present at time of death
<i>Italics:</i> Themes talked about more after the mandalas and music	<b>Bold:</b> Themes talked about only after the mandalas and music	

*Table 1. Preliminary themes for each participant  
Grouping the Themes*

I put each of these preliminary themes on a piece of paper and began taping them to a wall, grouping them as I went. I made groups of the preliminary themes and put them by related groups of preliminary themes. When I found I could not think of any more ways to move and relate the groups I stepped back and noticed two main groupings of preliminary themes: clinical experiences and personal experiences. A small group of “spiritual” preliminary themes was located between these two groups, and I realized the participants described spiritual aspects of both their clinical and personal experiences.

I then outlined the sub-themes from this array of groupings, noting that spirituality was shared between the two groups. As I sorted through the participants’ words it became clear that countertransference, particularly in regard to emotions, was also experienced in both personal and clinical realms.

## RESULTS

The results of my analysis revealed that these music therapists’ experiences when working with hospice patients who were actively dying were of two types: clinical experiences and personal experiences. They experienced spirituality and emotions both clinically and personally. Clinical experiences included (1) Use of ongoing assessment; (2) Clinical reasoning (clinical approaches, factors that influence clinical decisions, and use of intuition), (3) Importance of presence; (4) Clinical use of music to meet patient

needs; (5) Roles as music therapist; (6) Awareness of countertransference, (7) Family presence and influence; and (8) Working with patients' spirituality. Personal experiences included (1) Awareness of needs for self-care; (2) Emotions and new awareness from the work; (3) A deepened understanding of death; and (4) The work as spiritual on a personal level.

As depicted in Table 2, the participants had clinical experiences in their professional role and personal experiences that included their own emotions, understandings, and perspectives. The middle column represents the incidence of spiritual and emotional aspects in both the clinical and personal experiences. The lines at the bottom of the column have been removed to show the shared space between the two types of experiences.

**THREE MUSIC THERAPISTS' LIVED EXPERIENCES WHEN WORKING  
WITH HOSPICE PATIENTS WHO WERE ACTIVELY DYING**

**Clinical Experiences**

**Personal Experiences**

<ol style="list-style-type: none"> <li>1. Use of ongoing assessment</li> <li>2. Clinical reasoning             <ol style="list-style-type: none"> <li>a. Clinical approaches</li> <li>b. Factors that influence clinical decisions</li> <li>c. Use of intuition</li> </ol> </li> <li>3. Importance of presence</li> <li>4. Clinical use of the music to meet patient needs</li> <li>5. Roles as music therapist</li> <li>6. Awareness of countertransference</li> <li>7. Family presence and influence</li> <li>8. Working with patients' spirituality</li> </ol>	<p>Spiritual</p> <p>Emotional</p>	<ol style="list-style-type: none"> <li>1. Awareness of needs for self-care</li> <li>2. Emotions and new awareness from the work</li> <li>3. A deepened understanding of death</li> <li>4. The work is spiritual on a personal level</li> </ol>
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Table 2. Final analysis of themes

## Clinical Experiences

### *Use of ongoing assessment*

Barbara, Phyllis, and Tova each spoke about the importance of ongoing assessment when working with patients who are actively dying. Assessment of the patient occurs the entire time they are with the patient, and they adjust their approach accordingly at any given moment. They noted that they observe the patient closely for any signs that would help them provide music for comfort and support. Typically the patient is unable to respond, so they look for physical signs. The participants described the patients' breathing as particularly important in their assessment. They also explained how they use the music as part of assessment to help notice signs of changes in breathing:

Phyllis: [I observe] definitely breathing, definitely what their face is doing, if I see eyebrow movements, facial movements, if they're conscious they can be agitated or whatnot...And that's such an in-the-moment process, rather than one you can plan...I think just paying attention is so important, paying close attention.

Barbara: I watch the person's chest more than their face, to match their breathing [with the music], especially toward the end sometimes the breathing's erratic, and

that's another thing I'm watching for, the final breath, sometimes you can really tell through the music.

Phyllis noted that assessing the patient's spiritual background is essential to the provision of music, as well as her general sense of what is happening in the moment:

Phyllis: I think with an actively dying person, knowing their spiritual background is really important...a lot of very southern people, they need their gospel songs, I mean it's just their language! How I play them, again, really depends on the feelings in the room, also on my goal, what needs to happen in the moment.

Tova said her assessment includes looking for signs of distress caused by the music. She said she is very careful about not causing harm because the patient cannot verbally respond:

Tova: It's like, observing in as many ways as you can, but without having any sense of anybody giving anything back, or necessarily plugging into the fact that I'm there...I think part of the observation is about, just wanting to make very sure that I can't see any signs of causing distress. And for me mostly that comes right here, this spot right between the eyes (Tova pointed to her forehead, where wrinkles form when grimacing).

#### *Clinical reasoning*

Clinical reasoning is the process by which music therapists consider all information available in order to make clinical decisions (University of Newcastle, 2009). The participants discussed clinical approaches, factors that influence clinical decisions, and use of intuition.

Each participant described their clinical approaches, and Phyllis described hers as non-directive:

Phyllis: Meeting them where they are, starting where they are, is important I think. And then just, following them wherever they need to go.

Barbara described her approach as patient-centered:

Barbara: It's all about them. It's not about me at all. It's kinda like I'm the vessel to provide that for them.

Tova said she approaches patients with a sense of curiosity:

Tova: I think at the base of it is this just really intense curiosity. I'm really curious of what somebody's experience is.

In addition to the participants' approaches there were factors that guide their clinical decisions. Barbara noted that the length of time knowing the patient before they went into the dying process influenced her decisions:

Barbara: This was a case where I had seen the patient numerous times so I knew what her preferences were and I knew how she responded when she was able to, to the music, so I was able to talk to the family about that and they were open to me playing.

Clinically, the participants indicated intuition as a source of information within their approach and provision of music therapy services. Phyllis spoke of her intuitive sense combined with her knowledge of the patient's religious background as influencing her clinical decisions:

Phyllis: I had a patient who was very religious...Baptist...He was moaning so much, and I just felt like I needed to play songs about heaven, and I wouldn't normally choose that on my own, but my intuitive sense was that he needed that, and he needed that comfort.

Tova spoke of her intuitive sense as a sensory experience:

Tova: I feel like it's like this super sensory opening process that happens where I feel like I go into a, a sensory place really, where I feel like I'm listening or experiencing everything in the room out of all sides of me, it's not just out of my face and ears and eyes, it feels like a very open kind of taking in.

#### *Importance of presence*

Presence refers to the demeanor of the therapist in his or her interaction with clients (Schneider & Krug, 2010). Phyllis described the importance of presence within her work:

Phyllis: I think that it's just so important for the music therapist to be that strong presence, to be that grounding, create that grounding space...I think it's so crucial to be like just *so present* with them and follow them really well.

Barbara spoke to the importance of presence and she noted when it is challenging to be present:

Barbara: That I need to be the strong person for them and that I am there kind of as visitor, not to invade, not to take over, but to just be that support and that I need to remain calm and let them guide the way...I do get sometimes with patients if they're not real responsive I'll find myself, my mind wandering. I guess that's pretty normal, but usually I'm able to bring it back and say "This is what I'm here for."

#### *Clinical uses of music to meet patient needs*

The participants noted uses and purposes of the music, including examples of interventions, observed effects, and clinical considerations. Phyllis discussed symptom management and shared what she thinks about as far as the elements of music and interventions to meet patient needs:

Phyllis: What's the tempo that needs to happen? What's the rhythm that needs to happen? And what song feels that way? Just meeting their breath, and using entrainment is just so helpful, with people who are anxious or agitated.

Barbara spoke of the calming effects of the music:

Barbara: To use the music and see someone go from angst to calm, to know that the music has that power.

The participants often talked about indications for using familiar songs, unfamiliar songs, and improvised music. Phyllis and Tova described their thoughts on using familiar or unfamiliar music:

Phyllis: Sometimes it's a familiar song will help, and sometimes it's really not helpful, because it's waking them up more, where you want to kind of help them get sleepier, so sometimes things that they're not familiar with are more helpful, or improvisation.

Tova: I always wonder if for some people all that familiarity is like a tether, and for some, definitely hymns are very comforting.

Tova talked about when providing music with a less detectable rhythm is indicated and what has influenced her thinking on this:

Tova: You can sometimes read accounts of people who've had near death experiences and they talk about sound sometimes, and they remark on the fact that there is no rhythm, that it's not rhythmically oriented, that it's sound, but not rhythm, which makes total sense to me, because rhythm is about life and life moving forward, and it's motion, and the kind of motion that they're in is very swirly to me...And so there's a way that I'm trying to do that with my music.

After the music making portion of the interview Barbara talked about how certain instruments, and use of timbre, can be effective in reducing symptoms. As she played her Native American flute memories emerged of playing this instrument for a patient who was in a great deal of pain from stomach cancer:

Barbara: I pulled this out and played it for about fifteen minutes...and he was just calm and his pain had decreased significantly.

*Roles as a music therapist*

Each person discussed roles they identified with as a music therapist on the hospice team. Barbara spoke of roles of comforter, a source of strength, a source of support, and a vessel. Phyllis spoke of her role as a provider of support. Tova indicated her role as being an active and participatory witness, as well as a source of information and reassurance. She also spoke of her role as a comforting and grounding presence:

Tova: And so they're so freaked out and ask "what happens when I actually die?" And I can talk about it, and I can really talk about it, and I'm not freaked out and that's comforting to them.

*Awareness of countertransference*

Each participant discussed countertransference and indicated it was important to be aware of and address in a way that benefits the patient. Sometimes this meant totally bracketing their inner responses and sometimes it became useful information to be used in their approaches and clinical decisions. Barbara spoke to the use of bracketing:

Barbara: Sometimes depending on my relationship with the patient I have to compartmentalize my emotions and push my own thoughts aside so I can be fully present for the patient and family.

Phyllis said she has "triggers" in her countertransference, which are things she needs to recognize as either being most appropriately addressed in personal reflection, or as a source of information about the patient:

Phyllis: If I'm feeling a lot of my own emotions, I'm noticing that's a trigger for me, and I think as we work we get to know our triggers better and better, and know how to work with that trigger. Because there's nothing wrong with that, it may mean that I have a sense of what they're feeling if it's in me too. But if my own feelings are coming up a lot then that means I need to go do some work afterwards [personal reflection], as far as what this is and what I need to do with it...it can be very unhelpful, but it can be very helpful too...in fact it can actually be some information about what's going on there, but it's a fine line.

Barbara shared how her personal life experiences have manifested in countertransference and how she needed to be aware of how her reactions influenced her approach, as well as how her experiences have left her with a deepened understanding of what families are going through:

Barbara: I think the hardest was when my dad died two and half years ago...I had to be very careful not to project my emotions onto whatever situation I was walking into. Basically I put dad in this little compartment up here. It felt like that helped me be more empathetic and understand that this is a family member, this is somebody's parent or spouse, and just to think how would I want somebody treating my parent in this situation? That really put it on the front of how to approach these families and know that I have felt that grief that they are feeling.

Tova also talked about factors that determine the emergence of countertransference:

Tova: I don't get a lot of countertransference around the person dying where it's exactly what this person needs to be doing. It feels pretty clear to me. Then the spectrum starts to get much muddier, as I move into people I know better, people who are younger, people who have been active for a really long time. And if the family's there and they're really broken up, they're really sobbing, then it gets hard not to kind of take that in.

#### *Family presence and influence*

Each participant shared that family presence makes a difference, and they aim to help both the patient and family. Phyllis described how music therapy helps the family:

Phyllis: A lot of times it's about the family if they're there. Sometimes it's about just helping them to feel like they have something to do, or that they can be present with that person because I think it can just be awkward for them sometimes, they're just sitting there, it helps them to connect with that person and have something to do, to reach them, or to feel like they're helping in some way too. Sometimes it's about helping them express what they need to express to that person, very gently.

Some families have complex dynamics and the music therapist is challenged in managing these situations. Barbara talked about a family of four siblings who were present with their mother who was actively dying. Barbara said "one of the daughters...her grief was the anger type" and there seemed to be a fair amount of tension in the room. She told the family about their mother's previous responses to music and asked if she could play her favorite music. The family agreed and Barbara said the music "kind of diffused the situation for that time." During the music the daughter's anger gradually lessened and she was able to grieve with her siblings.

Tova described challenges in considering the needs of both the patient and families:

Tova: If the family's there and they're anxious or they weren't able to be clear with me before I started playing, what they wanted, and so I'm feeling a need to stop and check in and maybe start playing some more. Those are much harder for me, to just tune in and stay.

The most difficult situations for Tova were responding to family members who requested she play religious songs when she knew those types of songs opposed with the patient's religious and/or spiritual beliefs. She was adamant about respecting the dying person's beliefs and wishes:

Tova: I think, sometimes I feel conflicted, if the family's asking me to do particular hymns and stuff...but the patient I have had interactions with they were very clear they did not want anything religious, and to have the chaplain tell me "well it's about the family now" and I'm like ooh conflict right? No, the person is still here. Once the person is gone I will sing any hymns you want me to sing. When the person is dead no problem. Active? No, I'll take you next door to the chapel and sing hymns for you. I'm not doing it.

#### *Working with patients' spirituality*

The participants all noted that the patient's spiritual background is important to the provision of music therapy. For example, I previously reported Phyllis' consideration of a patient's religious beliefs when she provided songs about heaven for a patient. Songs that are spiritually meaningful might be indicated, and the primary clinical goal may be of spiritual nature.

Barbara: Some of the goals are just to keep them in the sacred space, to help them get there and stay in the calm space and not to pull them out of it. One of our interventions we have on our care plans is "a creation of sacred space."

Clinically, Barbara was aware of her patients' needs for spiritual support. She described "sacred space" as a meaningful connection with the patient where the patient appears to be experiencing peace.

## Personal Experiences

#### *Awareness of needs for self-care*

Each participant spoke of self-care as mandatory. Phyllis spoke to the importance of personal reflection and processing for staying emotionally healthy as a music therapist and maintaining the ability to be fully present. Barbara reflected on how she uses music for self-care:

Barbara: I love to play [music] and it's a good way to just internalize, or let what's internal to come out.

The participants each talked about actions for self-care taken before and after visits. Each reported taking time to prepare before the visit, and taking time to process after the visit.

Phyllis: If I walk into a nursing home or something I definitely feel my feet on the ground and just be present, remind myself to be present. Sometimes I need to stand outside for a minute and take a breath...I think sometimes you know, we need that [processing afterward] and sometimes we don't. Sometimes I needed to not see another person, not to go see my next person if it felt like I needed to pull

a short break. Sometimes taking a walk...sometimes I have to cry, and sometimes I'm good, good to go.

Tova described avenues of self-care she has taken to regain a sense of balance:

Tova: There's a need in the next while to just absolutely know I'm among the living (laughs), like I need to hug people and reinvest in being here, like this is my time here...I might go outside and, and really walk, or just super snuggle my kids. If I can see my partner that would be great...I might play [piano], I have a couple pieces I really like to play sometimes...I mean I think there's such a sense of awe, and, an honor, and sort of humbleness that comes with being there, and then there's some kind of balance for me that needs to happen, like sometimes I'll get raucous!

Tova also spoke to the importance of humor in staying balanced and healthy:

Tova: If the chaplain or the social worker are there who I know really well, we kind of do that for each other, you know we tell jokes. [She shared a story of a joke told by a nurse.] ...I think I laughed until the tears rolled down, because I think it was just so, it was just a release.

#### *Emotions and new awareness from the work*

Emotions felt during hospice visits were discussed. These emotions can be considered within the realm of countertransference however they did not seem to be activated by the music therapist's past or current life situation and/or relationships; instead, they seemed to be primordial in nature and actuated from the authentic human interaction with the dying person, and sometimes the family. In addition, these emotions seemed more personal to the music therapist and the meaning they found in their own lives. Phyllis recalled working with a couple whose love story was quite poignant, and Tova said that she was moved to tears when present at the death of patient:

Phyllis: Or, you know that person's love story is just too much and I can't take it! I probably could have wept for them that day.

Tova: I'll often have to stop vocalizing at that point because I get so, I got so, in the two that come to mind, where I was so choked up, there was no way, I mean I was probably crying, not sobbing-sobbing but tears, and I can't sing while I'm crying, it's just not possible.

Tova also said she feels compassion toward her patients and families:

Tova: I have a ton of compassion for people who are on this journey not of their own volition thank you very much. I'm choosing to be there, and almost nobody else is choosing to be there.

After making music Barbara remarked how she feels especially close with some patients, and experiences with them in the music have touched her. She remembered one patient in particular:

Barbara: Some patients just kind of stand out in your mind. It's usually the ones that you've spent the most time with or had the longest...he was a very unique person.

After making music Tova continued to reflect on what it is like for her to leave a dying person and re-enter her life:

Tova: When I stopped playing the Reverie Harp it was like after I stop being with a person who is actively dying, like it was kind of my coming back to, there's something about looking at the word Reverie in there, and it was just like oh that's a celebratory come back to life word to me, like revitalize, re-engage and re-invigorate.

Barbara also described how her experiences have brought new awareness and shaped perspectives on life:

Barbara: I have such a diverse culture that I work with...when they get to the point of dying they're in the same place, it doesn't matter. I don't know how to put this, it gives me a lot of perspective on end of life, is that you don't need all this stuff....it gives life a lot of perspective, especially if things aren't going well.

#### *A deepened understanding of death*

This sub-theme emerged most prominently for all the participants after the mandala drawing and music making portions of the interview. I used the participants' descriptions of their mandalas and music, my interpretations of their mandalas and music, and their explicit words about their deepened understanding of death as evidence of this sub-theme.

Barbara described the lines of her mandala as the hospice patients she has worked with. They begin with a full life at the top and the motion is downward, representing the life span. The lives "trail off" and the patients die. The darkness the lines have trailed off into is the space the spirit goes after death. See Figure 1 on page 15.

Phyllis said she drew spirit within the orb, with the blue encircling the orb and holding it together, connecting all of us as spiritual beings. The blue circle allows the spirit to exit at the top. This is the spirit departing the body. See Figure 2 on page 16.

Tova's mandala shows a spiky maroon border, which she identified as her presence as a human. She said it includes her life energy as well as her music, and it is warm and loving. It is holding the life of the patient, which is the yellow spiral. The dying patient's energy is swirling and moving upward, finally exiting the top as the person dies. The energy continues and dissipates. See Figure 3 on page 17.

Tova: It just goes and trails off. So there's a way that this is the boundary of life. So like the whole world of that person's being has come down to just what's inside that circle and then it's just gone.

The end of each participant's music was a gradual fading to silence, which I interpreted as a metaphor for death, similar to the images of dissipation in the mandalas. Their words provided evidence for this interpretation. Phyllis talked about the jam block she played as a heartbeat:

Phyllis: ...and then I wanted a (makes three clicking sounds with her tongue) for some reason. It felt like maybe it needed some sort of ending, or some sort of like we're coming back to the heartbeat, or something that reminds us that we're here... And at the end was a "sphew," like disperse the energy.

Tova described the last instrument she played also as a release of energy:

Tova: And these have always sort of reminded me of (plays chimes) spirit without substance, whatever that is... very ethereal.

*The work is spiritual on a personal level*

As can already be seen in the mandalas and music, the participants have been influenced spiritually by their work, and they reported having had spiritual experiences when working with hospice patients who were actively dying. Barbara described her experience:

Barbara: And I really feel that sacred space, that bond between me and the patient sometimes, and that's just so powerful, it's like, we're connecting on some other level... Very, very spiritual!

Barbara also described her spiritual experiences as an altered state of consciousness:

Barbara: Sometimes in the moment, you get these, it's almost like, not out of body, but the altered state of consciousness, it's like, something else is taking over to get me through this.

Tova spiritually prepares for work with an actively dying patient by using a meditation mantra:

Tova: So I'm a meditator and I have been for a long time. I have kind of a little meditation mantra that I say as I'm walking into a facility that I work in or house or whatever.... But I actually do it again, specifically before I know I'm going into somebody who's active.

Phyllis and Tova shared their thoughts on spiritual experiences after the mandala drawing and music making. It was as if the modalities for creative expression allowed the

participants to reach deeper levels of understanding these experiences. Phyllis described her spiritual beliefs within the work:

Phyllis: I believe that everything has sort of an order, yin and yang, that everything happens for a reason at a certain time, and like all of it is supported, whether we feel grounded or whether we're letting ourselves get into this misty stuff, this spiritual stuff that we're all, all of it is connected, we are all connected.

After making music Tova shared reflections on the spiritual nature of life and death:

Tova: What is the animating presence? What is the animating presence that blazes through me that's not there anymore? And if it's not there anymore, does it just vanish? I love that we don't know. I love that we don't know. It's so great. (Erin: It's the greatest mystery) Tova: It is.

## DISCUSSION

I explored the experiences of music therapists when working with hospice patients who were actively dying. My initial research questions were (1) What do music therapists experience when working with hospice patients who are actively dying? and (2) How do music therapists prepare for these visits, and then process their experiences afterward? The first question was answered by the emergence of the two main themes of clinical experiences and personal experiences, and corresponding sub-themes. The second question was answered within the theme of personal experience and sub-theme of awareness of needs for self-care. The emergence of the two primary themes aligns with the findings of Forinash and Gonzalez (1989), who found that both clinical assessment and personal experiences help guide the hospice music therapist when working with a patient who is dying. There were also significant overlaps with Economos' (2018) results in her study of music therapists' experiences when working with hospice patients when death was imminent.

Because of the profound nature of this work, and my own difficulties expressing my experiences, I included creative modalities of mandalas and music making. I hoped that more information would emerge that would not otherwise in a strictly verbal conversation. The mandalas and music did indeed serve as means to further discussion and materialization of new information, notably that the participants experienced a deepened understanding of death. In this section I discuss the function of the mandalas and music, the shared themes of spiritual and emotional experiences, and the remaining sub-themes and their significance.

### Function of the Mandalas and Music

Arts-based research promotes the use of creative modalities to explore research questions and reveal new or deepened understandings (Aigen, 2015; Viega, 2016; Viega & Forinash, 2016). The mandalas and music in this study functioned as adjunctive means in data collection, which resulted in more information that was included in the data analysis. While the participants mostly discussed their clinical experiences in the first part of the interview, it was during and after the mandala drawing and music making that deeper levels of their experiences were uncovered. The experience of drawing and making music within the interview seemed to have helped the participants more closely connect to their experiences, thus resulting in additional data.

New material that had not been shared prior to the mandalas and music included (a) understanding of death, (b) self-care, (c) work as spiritual, and (d) new awareness from the work. Further information around topics already discussed also emerged and included (a) new awareness of the work, (b) music (considerations and effects of, role, metaphors), (c) personal experience and feelings, (d) personal time for reflection, (e) personal experience and feelings, (f) intuition and awareness, (g) understanding of death, and (h) therapeutic process. Much of this information speaks to their personal experiences, and the experience of making art and music may have made connections that were more personal in nature. For example, making music in the interview reminded Barbara how important her own music was to her self-care. See Tables 3 and 4.

BARBARA	PHYLLIS	TOVA
Understanding of death	Work as spiritual Self-care Understanding of death	New awareness from the work

*Table 3.* New preliminary themes from participants’ words after the mandalas and music

BARBARA	PHYLLIS	TOVA
Feelings about the work Music (considerations and effects of)	Personal experience and feelings	Understanding of death Music (role, effects of, considerations, metaphors) Personal time for reflection Personal experiences and feelings Intuition and awareness Therapeutic process

*Table 4.* Preliminary themes further discussed after the mandalas and music

After the interviews, I noticed that the mandalas depicted each participants’ understanding of death. As stated in the method section, I did not ask them to draw their understanding of death specifically, and instead I provided an open directive to “continue your reflection of working with hospice patients who are actively dying as you choose colors to come onto the paper.” It was also remarkable that their mandalas had similar qualities, such as all on black paper with a rounded, upward-shaped movement ending in dissipation of the colors. The mandalas led me to more questions, such as do these qualities reflect a shared cultural understanding of death?

The participants’ music also had similar qualities compared to one another. They each had clear beginnings, middles, and ending sections. The beginnings were loose, rhythmic (and in Tova’s case melodic) explorations of sound before moving into fuller,

more active expressions. Each ended their music with a gradual fade into silence. Phyllis and Tova described their music as a dissolution of energy, indicating that their music reflected their patients' transition from life into death.

As stated earlier, the participants spoke a good deal about their clinical experiences, which makes sense because they are functioning in a professional role on the hospice team. More reflection on their personal experiences came after making the mandalas and music, and I wondered if their clinical and personal experiences were connected in their conscious experience. Two reasons for possible disconnect with their personal experiences are (1) their focus on their clinical role and (2) limited opportunities to talk about and reflect on the personal side of their work. In fact, Tova remarked several times in her interview, "it's funny, I've never talked about this." The modalities of creative expression helped further uncover and connect with these personal experiences.

Increased awareness of personal feelings and their impact on clinical work is an important ethical responsibility of music therapists (American Music Therapy Association [AMTA], 2019). Hospice music therapists may be well-served by supervision from a seasoned professional in order to come into a deeper understanding of the intersections between clinical and personal facets of the work (Wilkerson, DiMaio, & Sato, 2017). Supervision appears to be underutilized by hospice music therapists, however, with only one third of respondents in a study reported to have received supervision (Jackson, 2008). Wilkerson et al. (2017) encouraged hospice music therapists to seek supervision and promoted it as one of the most effective ways of developing self-awareness, processing personal feelings, and integrating those into clinical practice. Given the utility of the mandalas and music improvisation in this study, creative modalities within supervision may be effective in increasing awareness of personal experiences and feelings, and exploring how those experiences intersect with clinical responsibilities.

## Spirituality and Emotions

Spiritual and emotional experiences occurred in both clinical experiences and personal experiences. Clinically, the participants worked with the patient's religious and spiritual beliefs, and personally, the music therapists had spiritual experiences. In the same vein, emotions were experienced as countertransference that impacted clinical decisions, as well as enhanced meaningful personal experiences. Sometimes these spiritual and emotional experiences felt shared, as in the case of Barbara who said "it's just so powerful, it's like, we're connecting on some other level."

The participants said they address spiritual needs with hospice patients who are actively dying, which agreed with the literature (Hilliard & Justice, 2011; Hong, 2016; Włodarczyk, 2007.) The participants in this study discussed similar spiritual themes that were found by Magill (2005), such as faith, meaning and purpose, and peace. For example, Phyllis' described how she provided songs of a patient's faith which helped ease his agitation and helped him arrive at a place of peace and relaxation.

Music therapists' accounts of personal spiritual experiences have also been discussed in the literature. Forinash and Gonzalez (1989) described images they

experienced during a session with a hospice patient who was actively dying, which included visualizing the patient reaching her hands toward God. These personal experiences were included in their phenomenological analysis. Marom (2004) conceptualized the music therapist's spiritual experiences as witnessing the client's spiritual experience, sharing a spiritual experience with the client, or having a personal spiritual experience. There is agreement between my study and Marom's study in that music therapists have spiritual experiences that lie in both clinical and personal domains.

The participants in this study identified experiences of countertransference in their clinical work. Countertransference can be defined as any feelings, reactions, and responses to the client (Katz & Johnson, 2016). Experiences in hospice can tap into the music therapist's beliefs, fears, grief, and anxieties, and the music therapist may step into a "role" and play out a past relationship (Wilkerson et al., 2017). Participants in this study said it was important to recognize what to do with these types of responses, such as whether to set them aside or to use them in the therapeutic process. Barbara talked about the importance of bracketing the feelings she had around her father's death, and Phyllis noted countertransference to sometimes be useful information. She explained that it can provide insight into how the patient or family member is feeling, which in turn informs the music therapist's clinical decisions. This type of awareness was outlined by Potvin (2015), who described his process of examining his countertransference and studying how it was influencing and shaping his approach.

The participants also reported personal emotional experiences that impacted them in meaningful ways. This type of countertransference was also found by Economos (2018), and emerged as a central theme to her study. Similar to the present study, she found that countertransference is acutely influential in both the clinical process and the music therapist's personal life. A sub-theme of her study states "countertransference influenced personal and spiritual revelations" (p. 318). Emotions and new awareness from the work were discussed by the present participants, mostly in the verbal parts of the interviews, and with a bit more information after the mandala drawing and music making. For example, Phyllis shared a time when she was deeply moved by the love story of a patient and their spouse, and Tova was moved to tears when present at a death and witnessing the raw grief experienced by the family. Also, Barbara spoke to her work with patients who were actively dying as helping to shift her perspective on life with a deepened understanding what is truly important.

## Clinical Experiences

The remaining sub-themes of use of ongoing assessment, clinical reasoning, importance of presence, roles as music therapist, family presence and influence, and clinical use of music to meet patient needs are discussed below.

The participants spoke extensively on their clinical experiences. They reported the need for ongoing assessment throughout their visits. This theme is shared with Economos' (2018) study, and one of the primary themes she found was also ongoing assessment, with sub-themes of assessment of the patient's background, and assessment

of physical state to help gain a sense of the patient's internal state. The participants in this study noted that they had observed breathing as a primary indicator of the patient's condition, which was also found as a primary theme by Forinash and Gonzalez (1989) and discussed by the participants in Economos' (2018) study. The participants in the present study also noted that because their patients were usually non-responsive they tried to obtain information from others, including religious/spiritual information and preferred/familiar music.

Several components of clinical reasoning emerged, including clinical approaches, factors that influence clinical decisions, and use of intuition. Clinical approaches in hospice music therapy have been described by Hilliard (2005) as a mix of cognitive-behavioral and humanistic orientation, and DiMaio (2010) as humanistic. At the beginning of the interviews the participants described their theoretical approaches, with each reporting use of aspects of humanism, and none reporting the use of cognitive-behavioral tenets. Within the interview they described their approaches informally as "non-directive," "patient-centered," and "curiosity-driven." Factors that influence clinical decisions were found to be length of time knowing a patient, the goal of the session, and family presence, and these align with Krout's (2003) discussion of the role of the music therapist. Descriptions of these types of considerations have been discussed (though rarely) as part of the process within case examples in the literature; for example, in DiMaio's (2010) descriptions of using Music Therapy Entrainment with hospice patients.

Intuition was also included within the sub-theme of Clinical Reasoning and this was another similarity to Economos' study. Her participants described intuition as important in assessment of the patient, family, and environment. Brescia (2005) explored the music therapist's experience of intuition and found that it involves physical messages, emotional messages, auditory messages, and visual messages. In this study the participants described their intuition as a "knowing" or a "sense" of the patient or situation, although they did not specify how these received this information. Phyllis described her intuitive sense with a patient who was actively dying, and taking into consideration his spiritual background, she had a "knowing" that songs about heaven would be comforting. Phyllis also noted that she often had a knack for choosing "just the right songs" as confirmed by the family. Tova described her experience of intuition as taking in information from all of her senses.

The importance of presence was another finding that is supported by the literature. Muller's (2008) phenomenological investigation of music therapists' experiences of presence revealed that both intention and openness to the as-yet-unknown are involved in being present with clients. Along these lines, the participants in this study noted that it is of utmost importance to be fully present when patients are dying in order to support their needs and the needs of the family.

Barbara, Phyllis, and Tova each spoke to what they believe are their roles as the music therapist. Phrases such as "it's an honor" and "active and participatory witness" were shared. These phrases align with reflections of music therapists within hospice music therapy literature (see Dileo & Loewy, 2005).

All participants noted that their clinical approaches shift to include the family when they are present, which agrees with Economos' (2018) findings. Her participants spoke of music therapy as a collaborative and meaningful process with the patient's

family. Interestingly, family presence was noted as a challenge by two out of three of my participants, which is in contrast to Economos' findings.

The literature contains studies and discussions of clinical uses of music to meet patient needs. Quantitative researchers have supported music therapy's effectiveness for a number of symptoms (Clements-Cortés, 2011; Gallagher et. al, 2006; Hilliard, 2003; Horne-Thompson & Grocke, 2007; Krout, 2001; Whittall, 1989; Wlodarczyk, 2007) and music therapists have described case examples of music therapy interventions and client responses (see Aldridge, 1999; see Bruscia, 1991; see Bruscia, 2012; see Dileo & Loewy, 2005, DiMaio, 2010, see Meadows, 2011). The patients involved in these studies were stable and not actively dying. The participants in this study described interventions they have implemented that are also found in the literature such as receptive experiences, attendance to breathing, and relaxation experiences. The participants' uses of music also align with West's (1994) non-research based descriptions of the use of music with the dying, such as using improvisation and attention to the music elements to support the dying process. Additional attention to research on the implementation of music therapy specific to hospice patients who are actively dying is needed.

## Personal Experiences

The remaining sub-theme of personal experiences is awareness of needs for self-care. The participants described self-care practices, particularly when preparing before and processing after a visit with a hospice patient who was actively dying. They described ways they prepare before visits by taking time to breathe or pray, as well as taking time after visits to process by being in nature or connecting "with the living" as Tova said. Scheer's (2013) qualitative investigation of self-care by hospice music therapists revealed similar rituals and self-care practices.

## Implications for Clinical Practice

As music therapists, we have an ethical responsibility to continue to learn and grow throughout our careers (AMTA, 2019), and this includes broadening our understanding of issues and skills in clinical practice. The outcomes of this study provide insight into similar lived experiences of three music therapists who worked with hospice patients who were actively dying. By learning about their experiences we can come into a deepened understanding of our own work with new or more awareness of the clinical and personal components of it, as well as the intersections of these experiences.

Music therapists who work in hospice may be well-served to understand that working with hospice patients who are actively dying involves many types of experiences within both clinical and personal realms. The results of this study indicate it is common for the music therapist to be focused on their professional role while also having personal experiences. The music therapists in this study were aware of clinical processes, factors, and roles, as well as their own needs, emotions, and experiences. Shared spiritual and

emotional experiences with patients and families could be quite powerful for the music therapist, so awareness of countertransference is very important in maintaining therapeutic presence.

Having spiritual and emotional experiences while providing therapy are associated with an area of advanced practice. Hospice music therapy has actually been considered advanced clinical practice and some have argued that bachelor's level training may not provide the depth of training needed (Dileo & Loewy, 2005). As academic programs continue to develop advanced music therapy training this study and others like it could help our students and emerging professionals develop a base of evidence for growth and improvement.

## Limitations and Recommendations

Once I completed this study I realized my interaction with the participants was limited to the interview (member checking resulted in no changes made by the participants to their transcripts). More involvement with the participants may have impacted the outcomes, such as having one or more follow-up interviews or sending them preliminary results of the data analysis to ask for their feedback. Involving participants throughout the research process has been employed by researchers to promote reliable results (Min Kim, 2016). Additional follow up requires more time and effort on the part of the participants, so monetary compensation should be a consideration in future studies.

Another limitation was demographic similarities of the participants. All were white adult women with about the same years of experience in hospice (nine to twelve). Two lived in the same southern state and one lived in a northeastern state of the United States. While there were differences in religious and spiritual beliefs, they stated similar theoretical frameworks and approaches to hospice care. Increased diversity in gender, theoretical orientations, geographies, etc., among participants may reveal different types of experiences.

Topics recommended in future research are shared spiritual and emotional experiences of music therapists and hospice patients and families, interventions and approaches specific to hospice patients who are actively dying, personal perceptions and awareness influenced by the work, and cultural factors in death and dying. Similar to Marom's (2004) study, the participants talked about moments when both patient and therapist had spiritual and emotional experiences, and further inquiry would help music therapists understand how to manage those moments and support the patient. Interventions and approaches with patients who are actively dying are difficult to research due to the ethical concerns of gaining consent when consciousness is variable. Further qualitative studies of the music therapist's experiences would lend to increased information that would be impossible or unethical to obtain from patients themselves. Because the mandalas and music served to deepen reflection on personal experiences, personal perceptions and awareness influenced by the work could be further explored through arts-based research. It is also recommended this type of study be conducted with music therapists and hospice patients from other cultures to examine this phenomenon within contexts of the practicing music therapist of diverse areas of the world.

## Conclusion

I hope this study helps others understand what it is like for a music therapist to work with hospice patients who are actively dying. In the process of this research I was able to see the work as an intersection of both the clinical role and the personal self. The potential for art and music to uncover layers of human experience was realized as the participants explored deeper layers of their work in their creative expressions.

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## Appendix A

### Example of Coding Process: One Page from Barbara's Transcript

BARBARA

Verbal Interview

Erin: As you sit with thinking about your experiences working with actively dying patients can you share a little about what that's like for you as a music therapist?

Barbara: I think the number one thing is it's an honor to be able to be with people at that point. Usually there's family around, so in addition to comfort to the patient it's comfort to the family. Sometimes depending on my relationship with the patient I have to compartmentalize my emotions and push my own thoughts aside so I can be fully present for the patient and family.

Erin: Yeah. How do you find that, is that easy, is it difficult?

Barbara: I think when I first started with hospice patients or with dying patients when I was working in the hospital, it was kind of hard, just the transference of you know. This could be my family member. But I think just the experience of doing it I've gotten to where I can push that aside.

Erin: What do you keep in mind as you enter the space?

Barbara: That I need to be the strong person for them and that I am there kind of as visitor, not to invade, not to take over, but to

*It's an honor to be with the dying [feelings about the work]*

*Be a source of comfort [you] / Type of relationship is a consideration [relationship]*

*Compartmentalize emotions [Er]*

*Being fully present is important / success [presence]*

*Years of experience has helped w/ it [variability]*

*Ability to bracket thoughts + feelings w/ 40 years of exp [Er/Bar]*

*Be a source of strength [you]*

*Be a source of support [you]*