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Exploring Music Therapists' Experiences of Utilizing a Family-Based Approach with Children Receiving Palliative Care

Faith Anne Agolia

EXPLORING MUSIC THERAPISTS' EXPERIENCES OF UTILIZING A FAMILY-BASED APPROACH WITH CHILDREN RECEIVING PALLIATIVE CARE

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FAITH ANNE AGOLIA, MT-BC

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EXPLORING MUSIC THERAPISTS' EXPERIENCES OF UTILIZING A FAMILY-BASED APPROACH WITH CHILDREN RECEIVING PALLIATIVE CARE

Presented by: FAITH ANNE AGOLIA, MT-BC

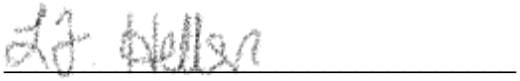
A candidate for the degree of Master of Science in Music Therapy

And hereby certify that the thesis was read and approved by committee

05/11/2024

Amanda MacRae, PhD, MT-BC

Thesis Advisor — Date



05/11/2024

Lora Heller, MS, LCAT, MT-BC

Committee Member — Date

05/09/2024

Dr. Suzanne Sorel, DA, MT-BC, LCAT — Date

Director of Graduate Music Therapy

ABSTRACT

This research study explored the experiences of three music therapists who employ a family-based approach with families whose children are receiving palliative care. Literature addressing the benefits of music therapy for people in palliative care exists, but little is known about the lived experience of music therapists who work in these settings. Music therapists were recruited through purposive sampling. Through phenomenological microanalysis, eight themes emerged: Family-based approach is natural, yet nuanced; the sacredness of the therapeutic relationship; positive memory making through legacy as a means to family connectedness; vicarious trauma; intentional self-care and coping; feeling siloed and experiencing challenges within the hospital dynamic; motivation for music therapy work with pediatric patients and their families; finding fulfillment, and a sense of purpose, and joy in the work. Some themes were further developed through sub-themes. The global distilled essence revealed that music therapists bear witness to various traumas throughout their experience. The experience of music therapists in this study revealed how the therapeutic relationship is an essential element of this work that provides significant purpose to the music therapist. Further recommendations, such as education, advocacy, and the implementation of further support systems in medical settings are suggested.

Key Words: Palliative Care, Terminal Illness, Family-Based, Music Therapy

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Chapter One: Introduction

During lengthy hospitalizations, children and families may experience depression, grief, anger, anxiety, frustration, and/or boredom (Zdun-Ryżewska et al., 2021). Particularly during palliative care, children and their families may require additional support and outlets that may aid them in releasing these emotions. According to the World Health Organization (WHO), palliative care is "an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illnesses" (WHO, 2020, para. 1). Palliative care addresses physical, mental, spiritual, and emotional needs that may arise during these long hospitalizations. Both patients and families may seek support from a variety of service providers, such as doctors, nurses, social workers, and therapists who are available to support and uplift the entire family (WHO, 2020).

Music therapy is one of many palliative care services that may help to lift patients out of depression, stimulate their creativity, and ultimately provide experiences for children and their families to feel joy and be with loved ones amidst the uncertainty of life-threatening illnesses and hospitalization (Clark et al., 2014). Music therapy provides a space for children to express themselves in a creative way, such as writing songs or singing favorite songs (Clark et al., 2014). The presence and inclusion of the family in music therapy invites family members to explore these dynamics together, rather than individually, which may enhance family functioning. While children and families are the clients in music therapy, music therapists are the facilitators who help the clients explore the various dynamics that arise. This is essential to mention, as the music therapists are holding this space to explore the dynamics. They may be affected and even brought into the family dynamics at play. It is necessary to understand the experiences of music therapists

who employ a family-based approach in palliative care, as other professionals may relate and utilize these experiences as a resource in their own work.

Music therapists working with families in palliative care may be at risk for experiencing vicarious trauma (Simard, 2020). Vicarious trauma can be defined as a cycle of change that is the result of witnessing or working with people who have experienced trauma. This can lead to lasting emotional and mental side effects. Some of these side effects may include: "cynicism, feeling sad, feeling anxious, difficulty sleeping, "zoning out", and social withdrawal" (Jeffersonc, 2023, para. #5). Learning about the experiences of music therapists who work with children and families in palliative care may benefit the profession, as this insight might provide comfort and validation to clinicians with similar experiences, as well as examples of methodology and practice for music therapists.

Through qualitative means, the researcher sought to explore the lived experiences of music therapists who work with families whose children are receiving palliative care. Many music therapists employ a family-based approach that emphasizes the family unit and addresses the ways in which family members interact with each other (Nemesh, 2017). A family-based approach in music therapy may provide a space where families can strengthen their relationship, communicate their feelings, and explore their family dynamics. Findings from this research study may be a resource to music therapists who are seeking guidance and information on family-based practice.

Background

Palliative care seeks to reduce symptoms of pain and illnesses (Mayo Clinic, 2023). Duda (2013) indicates that palliative care programs focus on improving the quality of life of the patient. Additionally, palliative care programs allow families to come together with medical

staff, such as music therapists, to collaborate in determining goals to best meet the needs of the patient (Duda, 2013), thereby offering a holistic level of care.

Terminal illness can be defined as "a life-limiting illness that cannot be cured" (*What Is a Terminal Illness? Definition of Terminal Illness, n.d.).* Music therapy can improve the quality of life for patients and families with terminal illnesses. Music therapy interventions at this stage may focus on facilitating acceptance and creating memories for the patient and their family (Lindenfelser et al., 2012). Persons with terminal illness often receive palliative care.

Music Therapy

The American Music Therapy Association defines music therapy as "the clinical and evidence-based use of music interventions to accomplish individualized goals within a therapeutic relationship by a credentialed professional who has completed an approved music therapy program" (American Music Therapy Association, 2005). Music therapists draw from four methods of music therapy: improvisation, re-creative, composition, and receptive. These four methods may be utilized to address communication, familial roles, and dynamics within the family unit (Gardstrom et al. 2017). Hibben (1992) highlighted the use of music as play when working with families. Playing music together can help families communicate and interact with one another, thereby fostering connectivity. The therapist can help facilitate this connection by exploring the various power dynamics, alliances, struggles and roles within the family that arise during session (Hibben, 1992).

Family-Based Approach in Music Therapy

Oftentimes, authors will utilize a variety of terms when discussing treating the family as a unit, rather than individuals in therapy. Kenneth Bruscia, a well-known music therapist, educator

and researcher, was one of the first music therapists to name this work*: family-centered practice*. Bruscia (1998) defined family-centered practice in music therapy as "an ecological approach where the primary focus is promoting health with and between family members" (as cited in Tuomi et al., 2021). Beth Nemesh, a family-centered therapist and board-certified music therapist termed her approach as "family-based" and "family-centered." According to Pasiali (2013) a "family-based approach utilizes music therapy interventions that emphasize the family as a unit" (as cited in Nemesh, 2017 p. 168). This approach addresses family issues through music therapy interventions. This family-based approach is relevant, as it highlights the influence of emphasizing the family as a whole in therapy, rather than focusing on one specific individual. While these authors offer various definitions, they each aim to support the family as a single unit in therapy, rather than working with individual persons. For the sake of continuity, the researcher will utilize the term "family-based" throughout this document. Family-based work facilitates an opportunity for families to explore family dynamics while a family member receives palliative care.

As addressed above, hospital visits may become more stressful for family members as care is extended over time. This stress may lead to familial conflict. Music therapy can be an effective avenue in which family members can address conflict and work through it. Moreover, the assessment process may provide insight into why conflict occurs. Miller (1994) noted that conflict is often a product of unbalanced power dynamics and newfound family roles. Understanding and exploring these power dynamics and familial roles in music therapy may help families identify their patterns of communication and learn to adjust them as needed, which may decrease familial stress and improve coping in the hospital setting.

Epistemology and Researcher's Stance

My personal epistemology resides with interpretivism, as my experience as a clinician leads me to believe that each human being has a story to share. Interpretivism is a type of research which seeks and finds the truth through individuals' lived experiences (Wheeler & Murphy, 2016). During my internship experience at Memorial Sloan Kettering Cancer Center, I had the opportunity to work with children and families undergoing cancer treatment. The experience of connecting with each child and their family was meaningful, and we grew together as a unit during music therapy sessions. Incorporating songs families shared with me into our sessions felt sacred to me, as they trusted me with sentimental songs important to them. Thus, music therapy became a place where families could bond and grow closer to one another between infusion treatments. As I worked with these families and their children, I wondered about the perspectives of other therapists who worked within a family-based approach. While I examined literature on this topic, I did not find many studies that investigated the individual, lived experiences of music therapists who work with families and children receiving palliative care. This research explored the experiences of music therapists working with families in palliative care.

Chapter Two: Literature Review

This research study focused on the lived experiences of music therapists who utilize a family-based approach when working with children and families receiving palliative care. This literature review addresses music therapy with families, needs and benefits of families receiving music therapy services, as well as summaries of music therapy experiences that music therapists may implement to address familial roles and dynamics within this setting. Furthermore, the literature includes the perspectives of parents receiving family-based music therapy, the perspective of a music therapist as she facilitates sessions for children and families, as well as the experiences of caregiver providers.

Music Therapy with Families

Tuomi et al. (2021) examined the various theoretical perspectives and approaches of music therapists who worked with families. Music therapists utilized numerous theoretical approaches, such as humanism, developmental, psychodynamic, resource-oriented, integrative, systems/ecological oriented, neurological, and behavioral when working with families to best meet their clients' needs (Tuomi et al., 2021). Moreover, music therapists incorporated a variety of music therapy experiences, such as improvisation, pre-composed songs, music and movement, vocal improvisations, songwriting, and music and listening, to address the varied needs of families. Toumi et al. (2021) highlighted the perspectives of music therapists who employ diverse methods and theoretical frameworks when working with children and families.

While there are varied approaches to working with families, this researcher was most concerned with music therapists who implement a family-based approach while working with youth in palliative care. The well-being of the family unit is essential in a palliative care setting, as each family member is a living part of the hospital experience. Family members may be

affected by the emotional and physical toll of palliative care services, such as anticipatory grief, anxiety, lack of sleep, and stress. Music therapists are trained to incorporate music experiences to assess family strengths and needs. Nemesh (2017) described how families became aware of disruptive family dynamics in the music, and sought to work through them as a family unit, thereby enhancing family functioning. Music therapy assessment is an ongoing process and is key to helping therapists and families explore family roles and dynamics. Family needs may involve emotional, physical, mental, and spiritual aspects. Some of these needs include: "physical (symptom management), psychological (coping), social (bonding, connectiveness), and spiritual (legacy)" (Knott et al., 2022, p. 14).

Benefits of Music Therapy with Families Receiving Palliative Care

The strain of being in the hospital for weeks or months at a time may be unbearable for families. Families may feel overwhelmed by hospital chaos or the amount of incoming information, and this may cause familial stress. Music therapy has been a fruitful creative arts service in palliative care within a family unit since the 1980s (Bailey, 1984; Fagen, 1982), and may facilitate communication and decrease stress within the family (Lindenfelser et al., 2012; McIntyre, 2009).

Music therapists draw from varied music therapy techniques to meet families' needs (Bailey, 1984; Duda, 2013; Pasiali, 2013). Songwriting is one method in which patients and families can express and communicate their thoughts and feelings. Children and families may write songs to facilitate closure, to honor their family member's life, and to express thoughts and feelings (Bailey, 1984; Duda, 2013; Pasiali, 2013). Duda (2013) notes that these songs may serve as lasting memories for the families, and they may also be performed at a patient's funeral. Music therapists may also implement improvisational experiences to facilitate expression and

communication (Fagen, 1982; McIntyre, 2009; Nemesh, 2017). Additionally, Lindenfelser et al. (2012) suggested that music therapy may improve the child's general physical well-being while providing a safe space for families to bond. Moreover, receptive, improvisational, and compositional music therapy interventions have been shown to "improve coping, alleviate distress, promote self-expression/communication, and support parent-child interactions" (Knott et al., 2022, p. 8).

Familial roles and communication styles may affect family functioning during this stressful time. Acknowledging the experiences of parents and caregivers who are present in music therapy sessions with their children is essential to exploring a family based-approach in palliative care. Lindenfelser et al. (2008) explored the experiences of parents receiving music therapy at home alongside their children. Parents noted that participation in music therapy resulted in improved quality of life, opportunities for connection, improved family life, and opportunities for reflection (Lindenfelser et al., 2008). This may be relevant in the hospital setting, as prolonged hospitalizations may reduce the quality of life and connection with family members. Music therapy may be an avenue in which family members can connect with one another and communicate their feelings.

Caregiver Experiences of Children Receiving Palliative Care

Caring for children receiving palliative care in-home may be emotionally taxing. Rico-Mena et al. (2023) delved into the lived experiences of healthcare providers who cared for children receiving palliative care. Home-based palliative care healthcare providers included doctors, nurses, psychologists, social workers, physiotherapists, and administrative staff. Participants shared themes of perspective, personal growth, compassion, gratitude, suffering, emotional burdens, stress, and discomfort (Rico-Mena et al., 2023). Healthcare providers were

deeply, emotionally affected by working with these pediatric palliative care patients and their families. Working in palliative care is challenging, and there may be many emotions to sift through. This study by Rico-Mena et al. (2023) was relevant to my research, as it demonstrated the need to fill the literature gap on the personal experiences of music therapists who work in palliative care.

Music Therapist Experiences in Palliative Care

Another important perspective that is not often narrated is that of the music therapist providing care. In hopes of providing a resource to other music therapists in similar settings, Rigney (2011), a music therapist, wrote an essay about her experiences of working with a terminally ill child and her family. In her essay, she shared her perspective as a young, new therapist who develops a therapeutic relationship with a young girl who had terminal cancer, and her process of navigating the experience. Rigney (2011) journaled to reflect on the decisions she made in sessions, as well as the emotions and feelings she experienced during sessions, and this supported her well-being as therapist. She also described feelings of joy, fear, and guilt during pivotal moments of her therapeutic relationship with her client. (Rigney, 2011). Rigney's descriptive phenomenology study emphasized the importance of self-care and reflection through journaling of the music therapist's experiences.

Summary of Literature and Rationale for Research

In conclusion, the literature highlights the benefits of family-based music therapy, the experiences of families receiving music therapy, as well as clinicians who facilitate music therapy sessions from a family-centered approach. Benefits of music therapy include: opportunities for connection, reduction of stress, opportunities to honor a patient's life, improved

family life, closure, and open communication. Family participation in music therapy sessions allowed opportunities for improved communication, self-expression, and bonding time with parents and children. Studies of music therapists' experiences may allow other music therapists to compare and contrast methods, experiences, and feelings that arise in session.

The researcher sought to explore the lived experiences of music therapists who use a family-based approach with families whose children are receiving palliative care. This research is necessary as limited research in this area exists. Understanding the lived experiences of music therapists who work in these situations may provide insight into the emotional, mental, physical, and spiritual effects music therapists may sustain. The research question is: What is the experience of music therapists working with families who have children receiving palliative care?

Chapter Three: Methodology

This research study sought to explore and describe the experiences of music therapists who implement a family-based approach with children receiving palliative care. Therefore, the researcher incorporated the interpretivist research method of phenomenological inquiry. According to Wheeler and Murphy (2016), phenomenology is a theoretical approach that explores the lived experience of an individual. Phenomenological inquiry features questions that investigate the life experiences and perspectives of individuals who have first-hand experience of a specific phenomenon (Wheeler & Murphy, 2016). Descriptive phenomenology focuses on describing participants' experiences, without being corrupted by one's own biases (Regent University, 2022). A phenomenological inquiry is appropriate for this study as it will explore the lived experiences of music therapists who utilize a family-based approach.

Participants and Inclusion Criteria

Three music therapists who employ a family-based approach when working with children receiving palliative care were recruited for this study. Participants were eligible for the study based on the following criteria:

1. Participants must be board-certified music therapists (MT-BCs) and have a Master's degree in Music Therapy. Master's degrees in related fields to music therapy may be considered, as long as the potential participant is implementing music therapy within a family-based framework.
2. The participants must have had their board certification for a minimum of five years. Participants in the study must be fluent in English as the researcher's primary language is English.

3. The music therapists must have worked with families and children receiving palliative care for a minimum of five years.

Recruitment Procedures

After receiving Institutional Review Board (IRB) approval for the study (see Appendix A), the researcher incorporated purposive sampling (Creswell & Creswell, 2018) and sent an invitation email to music therapists known to work in hospital settings. Purposive sampling is the process of selecting potential participants intentionally based upon their experience with the phenomenon of inquiry (Creswell & Creswell, 2018). The invitation email included a brief description of the proposed research, the rationale for the study and inclusion criteria (see Appendix B). The researcher then employed snowball sampling and asked those music therapists to share the invitation with other music therapists who may meet inclusion criteria (*Snowball Sampling,* 2017). After potential participants contacted the researcher, the researcher explained informed consent and sent participants the informed consent document.

Informed Consent Process

Potential participants received an informed consent document written in plain English and included key information about the study: time commitment, risks and discomforts, as well as benefits of participating in the research (see Appendix C). The researcher was available to discuss the informed consent document with potential participants to ensure clarity. Participants were free to leave the research at any time without consequence. Lastly, the document included the researcher's primary contact information and encouraged to reach out with any questions.

Data Collection

The researcher interviewed three music therapists in a semi-structured format. Each participant partook in one recorded audio and video interview over the Zoom platform in a private location. Interviews were no longer than one hour. The interviews featured a series of open-ended questions, in which the researcher delved into the participants' experiences of utilizing a family-based approach with children receiving palliative care. Questions explored how their experiences working with children and families impacted their work as music therapists. Approaches and methods utilized while working with children receiving palliative care were also explored. Video and audio were recorded on Zoom, as participants were not able to meet in person due to geographical locations (see Appendix D).

Data Protection Procedures

The video and audio were downloaded onto the researcher's MacBook Pro laptop as soon as the Zoom meeting concluded. This data was transferred onto one encrypted, external hard drive and permanently deleted from the original device (PCMag, 2019).

Data Analysis

Following the interview, the researcher transcribed each interview verbatim. After writing up the transcription, the researcher sent the transcripts to the participants for member checking (Candela, 2019). Participants were asked to review the verbatim transcript and make any necessary corrections or clarifications. One participant was unable to be reached to confirm the transcript.

Data analysis was guided by McFerran-Skewes and Grocke's (2007) seven-step phenomenological microanalysis. Firstly, the researcher listened to each interview and

transcribed them verbatim. Secondly, while reading over the transcript, the researcher identified key statements and concepts directly related to the phenomenon of music therapists' experiences. These statements were notated through bullet points. Next, the researcher created structural meaning units. These structural units were notated as "concrete categories" (McFerran-Skewes & Grocke, 2007, p. 278). The researcher skipped step four, the creation of experienced meaning units, because the researcher chose not to ascribe meaning to the participants' lived experiences. Also, the researcher chose to incorporate cross-case analysis and move towards developing the global distilled essence instead of individual essences, thus, the researcher skipped step five. Step six required the researcher to review the data and identify potential, emerging themes. Some of these potential themes were fully classified by the presence of common themes, significant themes, and individual themes. Lastly, step seven required the researcher to create a final statement (i.e., global distilled essence) which summarized the global meaning units (McFerran-Skewes & Grocke, 2007). The global distilled essence is a narrative statement encapsulating what it's like for music therapists to work in palliative care setting through a family-based framework.

Epoché

Epoché is a process in which a researcher can share their experience with the phenomenon in question in hopes of clearly stating their preconceived notions about an experience (Polkinghorne, 1989, as cited in McFerran-Skewes & Grocke, 2007). The researcher may refer to the epoché throughout the research process in hopes of maintaining transparency. Due to the personal nature of this section, it is written in first person.

I completed my music therapy internship at Memorial Sloan Kettering Cancer Center. This experience was so meaningful to me, and I left this clinical placement with feelings of

satisfaction and curiosity. I cherished connecting with children and their families through co-created music experiences. Using music seemed to enhance the therapeutic relationship and family connections. Music also seemed to reduce stress during medical interventions. I had several experiences where I was moved by the love, grief, joy, desperation, feelings of connection, and sadness present in hospital rooms during sessions.

Bearing witness to these feelings and emotions, becoming a part of the family unit, and setting boundaries were all part of my experience in this medical setting. It is incredibly hard to witness children dying and families experiencing anticipatory grief, but what kept me in the work was the rewarding therapeutic relationship I developed with patients and their families. It is this relationship and collaboration with families that fuels my love and passion for music therapy with patients receiving pediatric palliative care. Accordingly, I moved into this research process with the following beliefs: music is integral to family healing and the therapeutic relationship; the music therapist may experience overwhelming feelings throughout the therapeutic process, but these feelings may also be rewarding; and the relationships formed with families bring meaning to the work.

Trustworthiness

Trustworthiness is an important element of research, as it is the glue that convinces readers that they can be confident in their interpretation of the research. Without trustworthiness, readers may lack confidence in whether the findings could can be trusted (Stahl & King, 2020). In order for the researcher to demonstrate that the research process was trustworthy, the researcher consulted Lincoln and Guba's (1985) four guidelines of trustworthiness in qualitative research which include credibility, transferability, dependability, and confirmability. Per Lincoln and Guba (1985), *credibility* addresses the extent to which the results are believable,

transferability addresses the generalizability of findings to other contexts, *dependability* refers to the potential of results being repeatable should the same data be analyzed again, and *confirmability* refers to the likelihood of other researchers corroborating results. Table 1 highlights the steps to researcher took address each of these areas.

Table 1

Establishing Trustworthiness Criteria

Confirmability	• Researcher used a reflexive journal throughout the research process to notate step-by-step processes of research, her decisions, and reflections of her own feelings
Dependability	• Thesis advisor oversaw the data analysis process • Engaged in conversations with thesis advisor about recruitment and the analysis process
Credibility	• Prolonged engagement with the transcript and data analysis • Member checking (transcript was returned to participants for their review and assent that all information was accurate)
Transferability	• Thick description of participants' experiences

Note. This table presents the steps the researcher incorporated to address each area of trustworthiness as defined by Lincoln and Guba (1985).

Materials

The researcher utilized a MacBook Pro laptop and the Zoom application to facilitate the virtual space for interviews. The interviews were downloaded onto one encrypted, external hard drive. They were deleted from the original device.

Ethical Considerations

A research proposal was submitted to the Molloy IRB to ensure ethical research practice. The approved protocol number for this research project is [2142066-1]. Participants were identified as: Music Therapist A, Music Therapist B, and Music Therapist C in order to protect confidentiality.

Chapter 4: Results

This research sought to explore the lived experiences of music therapists who employ a family-based approach with children and families in palliative care settings. Data analysis revealed eight themes. Some themes were developed through sub-themes. Each theme represents a significant element of what it means to exist as a music therapist in a palliative care, hospital setting. In the results chapter, the researcher shares a brief description of the participants and then presents and defines each theme. Themes are supported by significant participant quotes. Themes are presented in no particular order. The researcher then presented the global distilled essence to illuminate the depth of participants' experiences.

Participants

This research included three music therapists: Music Therapist A (MTA), Music Therapist B (MTB) and Music Therapist C (MTC). All participants were female, had earned a Master's degree, spoke English, and had worked in a palliative care setting for at least five years.

Theme One: Family-Based Approach Is Natural, Yet Nuanced

Participants shared that working within this approach with families felt natural. In fact, not including all the family members might be detrimental to the patient and therapeutic dynamic. Participants also highlighted the importance of explaining and receiving consent from parents, caregivers, or guardians, in the event of receiving a music therapy referral for a minor. The following quotes demonstrate this theme: "It's very family-based to begin with" (MTA), "I can't see a different approach that would be as effective and helpful to the patient and family," (MTA), and "If I did other approaches, it could potentially be harmful even" (MTA). Finally, "When it comes to family-based approach therapy, I feel like it's kind of something that just

naturally feels a part of the process, you know, regardless of your education, your training." (MTC).

Participants also emphasized the nuanced nature of the approach and the importance of consent, as evidenced through the following statements: "The family-centered care, I want to say that that's nuanced, because not every individual who was admitted has a caregiver at bedside, but I will say that I will not provide treatment to anybody, anyone who is a minor, without the consent of the legal guardian," (MTB).

Sub-theme One A: The Diversity of Family Dynamics is an Integral Aspect to the Therapeutic Relationship in Family-Based Therapy Work

Families have diverse needs, and their needs dictate the music therapy interventions that may be provided by the music therapist. Every session is unique, as different family members may or may not be present each time the music therapist sees them. For example, sometimes Mom is present during sessions, while Dad is working. The music therapist also keeps in mind that while they are providing family-based work, there are family members they might not meet. The following quotes support sub-theme one A: "I think each experience I have is so different, but it continues to remind me that it's a unit and I tell people often we see 5% of this patient's life, and we don't even meet their aunts and grandmas and other things" (MTA), and "I've had situations where family members, yeah, in terms of the dynamics, don't want music therapy…" (MTB). Finally, MTC stated,

> I think it's kind of just like, yeah of course the family dynamic plays a huge role in the therapeutic process, especially when working with children, working with teenagers, even sometimes working with adults if they still have...if their family members are still present in their life, the family dynamic plays such a crucial role in someone's overall lived experiences, their life experiences, their understanding of themselves, their understanding of their perspectives of life, their values, their beliefs, and so having that family-based approach just seems so natural.

Sub-Theme One B: Collaboration with Individuals and Interdisciplinary Teams as a Means of Meeting Individualized Needs

Music therapists often collaborate with members of the interdisciplinary teams to best meet the needs of patients and families. For example, the music therapist might work with the patient to explore their individual needs through music, and a social worker might help a parent or guardian process their own experiences in the hospital setting. While utilizing a family-based approach, one-on-one time is necessary to provide a music therapy experience beneficial for the patient. Music therapists also collaborate with the patients they work with.

The following quotes support this sub-theme: "Oftentimes, we team up with our interdisciplinary teams" (MTA). MTA also stated "So, maybe I'm going to go work with the patient while the care coordinator and physician talk to Mom and Dad and answer all their questions and can give them that space to ask hard questions without the child being in the room." MTB echoed these sentiments, "No, I think I'm pretty collaborative with the individuals I work with." Lastly, MTA commented:

> Trying to use acceptance in those kinds of spaces, so we can use music for that in a sense, but I think often, back to your question of like being able to provide music therapy for siblings and parents, I find it sometimes difficult because I feel like the one on one is needed, then like a group environment.

Theme Two: The Sacredness of the Therapeutic Relationship

Each family is different and has individualized needs. The palliative care environment can be intense and unbearable for families. Participants spoke about the importance of being authentic and present in difficult moments rather than spewing fake positivity to patients and their families. Participants noted that despite the overwhelming feeling of the setting, the

significance of the therapeutic relationship propels the therapeutic process, and may help the therapist feel grounded, authentic, and present in the moment.

Participants shared the following statements about the relevance of the therapeutic relationship: "Some families may share more than others, and some may connect to music therapy on a deeper level of coping than other patients and families that I work with" (MTA). Participant MTA also said,

> So, I think that's what keeps me grounded and continuing to practice this and seeing the effects as well. It's a long therapeutic relationship, and so often I'll get...I just got an email from a family in Israel who reached out a year after their child dying.

Finally, MTC commented:

> ...here's an experience that we're doing together, that, you know, brought up so many things for us, and it kind of created this moment and this memory where that when you reflect upon your hospital experience, you are not always going to remember...you don't always have to remember the negative, you will remember the memorable and the positive, and the laughs, or the time, like, I made a fool out of myself in a session, or like the time that we like made silly noises, or we sang like "The Wheels on the Bus" 20,000 times. You know what I mean?

Some statements amplified how participants viewed their therapist role: "We're there, because we're here for the moment, and if you just keep like avoiding suppressing your feelings, it's gonna continue boiling up. It's not gonna get better" (MTC), and "Yeah, you know, so, like, and also just validate: This is really hard! This is really sad. This sucks. This sucks" (MTC).

Sub-theme Two A: Witnessing and Facilitating Family Relationships

The dynamics of the music therapy environment are changed by the family members who are present. Participants shared that bearing witness to family relationships may assist in forming interventions that help to facilitate moments of connection, bonding, and relationship between family members. For example, if the music therapist witnessed Dad being withdrawn, the music

therapist might create a goal to improve familial interaction with the aim of strengthening that relationship. Participants shared that sometimes space from parents or caregivers might be a necessary step in the family relationship as well. Music therapists also witnessed the challenges parents might have in finding stability amidst the overwhelming environment of palliative care, and these music therapy experiences may provide that. Bringing the caregiver and patient together to facilitate a moment of connection and relationship through the music was an essential aspect of the music therapists' experience.

This sentiment is demonstrated through the following statements: "So, totally, that does matter. The goals change too. If Dad's super withdrawn, maybe my goal is to have more or improved family interaction between the two" (MTA) and "Obviously, a lot of it is play. So, we'll do music games, or "Hey, buddy, why don't you challenge Dad in this music game?" Now, that is bringing Dad into the session in a very nonthreatening environment" (MTA). In the same sense, MTA stated, "So, a lot of my goals are to improve family interaction and sometimes maybe it is meaningful for them to step out of the room."

These statements describe how participants viewed their role in nurturing the family dynamic: "Then, my work is really around bringing in the caregiver and working alongside the caregiver, because you know, recognizing what that experience might be like, for the caregiver, and fostering that dialogue between them and you know, the individual and their caregiver." (MTA). And,

> There can be challenges within the family dynamic, and then we often see a lot of parents have, not marital issues, but balance. We always search for homeostasis, as a being, but oftentimes during trauma and stress that is almost impossible to have a balance (MTA).

Sub-theme Two B: Facilitating Space for Sibling Relationships and Building Trust

Participants discussed how music therapy can help facilitate sibling and patient relationships. Siblings may be resentful because the patient (their sibling) is receiving all this attention. Encouraging parents and caregivers to invite siblings to be present in the palliative care environment may promote familial interaction and providing a space for siblings to bond, connect, and witness what is happening. Participants shared that working one-on-one virtually with siblings, especially during the pandemic, may help siblings cope with this sudden change in their family dynamic.

This sub-theme is demonstrated through the following quotes: MTA stated, "There can be a lot of coping and adjustment that siblings need as well and also have that resentment towards their sibling." Participant MTA acknowledged the potential benefit of music therapy, stating,

> I think that that helps with their anxiety and their mood (Mom and Dad). If sibling is interacting with their sibling, but even if they're doing different activities or taking turns, they're practicing different dynamics of sharing and respecting one another and bonding.

Participants also shared ways they have worked within these family dynamics:

> It's appropriate to have those feelings, so music therapy, the goal can be to again to promote family interaction and positive hospital experiences outside of getting poked and taking yucky medicine and feeling crappy and providing that positive experience is helpful for coping. (MTA)

Participant MTA stated, "Because I've worked with siblings virtually to give them one-on-one space to cope through learning an instrument, through picking songs that you can tell they're connecting with on deeper levels."

Theme Three: Positive Memory Making Through Legacy as a Means to Family Connection

Participants shared that their work schedule may not have allowed them to be present in times where support is needed, such as when a patient is passing, due to the confines of eight-hour days. The family may have needed music therapy to support them in those struggling moments. Participants shared that legacy projects can begin as an anticipatory step before a patient passes. Participants also stressed the importance of creating lasting memories for the family for years to come.

The following three statements support this theme: Participant MTA said, "Oftentimes, I'm not there at the bedside. I would probably say many music therapists aren't there, you know? We work an eight-hour shift. Not everyone passes from 8 to 5, you know?" Participant MTA shared "So, it's a lot of stuff that I do preemptively. I want people to start looking at legacy as positive memory making, not when they're passing, because I think that can also be a negative form." Similarly, participant MTC said, "If I was covering, if let's say, there was an end-of-life situation, and I was, you know, to offer heartbeat recordings, or assist with hand molds and legacy items."

Sub-theme Three A: Providing Opportunities for Patient-Centered Interventions Focused on Autonomy, Family Bonding, and Connecting

Participants stressed that music therapy interventions in pediatric palliative care are patient-centered and music centered. Improvisation, active music making, and receptive listening were a few interventions that participants brought into their sessions. Participants spoke about their decisions to meet a patient where they are at, and not utilize session planning, unless there was a contraindication. Goals are individualized for the patient, and often touch upon emotional and social domains. Sometimes, the intervention may not be focused on the parent, however,

music therapists stress that it is important to invite the family into the music to contribute to the overall experience. Goal setting is transparent, as music therapists want their clients to understand the process of music therapy. Participants stressed that providing a space for the patient to have as much control and autonomy as possible is essential, particularly in a hospital setting, where they do not have abundant opportunities to do so.

In terms of not utilizing session planning, MTB stated, "I'm not a very scripted music therapist that comes in with prompts." MTA said,

> And so, even within the session though, I think we can hit on different goals, but I don't know if my intervention necessarily is focused on parents, or I try and kind of blend where like multiple goals can happen at once, while I'm still giving the patient autonomy, because it's very patient-centered in the hospital setting, where I really want to give the patient as much control and autonomy, because we kind of strip that during treatment.

Participants made the following statements about individualizing treatment:

> I think maybe I would have precautions if I were to speak of that in terms of using specified stuff with NICU babies, which sometimes are simultaneously seen by palliative care. But only because of contraindications related to their audiological development or risks for overstimulation. (MTB)

Participant MTB also said,

> And so, in that, the idea of goal setting and goal making, is very...it's a very transparent conversation that I have with either the family or caregivers present at bedside, over the phone, or with the individuals themselves, of course understanding that's individualized in terms of understanding the developmental needs and where they are developmentally.

Other statements about individualizing goals include:

> They don't have any autonomy. And developmentally, from birth, they're constantly growing in to wanting to gain more autonomy, and so, that is my approach heavily, so, yeah, I don't really gear it, but I do think that it still is beneficial if that makes sense. (MTA)

And,

> And I think normalization is a huge one, of giving your patients and even the family, I think that's a goal too, is giving the patients and families an opportunity to experience a sense of normalcy, or experience a sense of even in this very scary, heightened, anxiety environment, you are still... you still have parts of yourself that maybe you feel like are not as present now within you. (MTC)

The following statements demonstrate the importance of music: Participant MTC said, "let's use music, or use these experiences as a way to bring them forward and remind us that who we are is still here." Similarly,

> I honestly think that when working with family members present, always invite them into the music making. Regardless of which method is utilized, invite the parents into the music and creative space. This contributes to the patient's experience as well as aiding in memory making and offering opportunity for family to have opportunity for self-expression. (MTC)

Participant MTA spoke about the importance of being patient and music centered:

> Obviously, everything is patient-centered so, patient-based music centered...I don't bring a practice where I pick the song and have them process it, because in pediatrics they just might not be developmentally appropriate to even be able to lyric analysis. So, that is not very common.

Theme Four: Vicarious Trauma

Vicarious trauma can be defined as a cycle of change that is the result of witnessing or working with people who have experienced trauma (Jeffersonc, 2023). Participants shared that witnessing patients and their families who are receiving palliative care is emotionally traumatizing. Participants also said that they experience grief, burnout, and compassion fatigue due to the high intensity of supporting patients and families in their work environment. Furthermore, participants shared that ethics play a major role in palliative care, and it can be traumatic witnessing a child suffer when parents and caregivers wish to keep a child alive for as long as possible.

Music therapist participants also emphasized that desensitization and compartmentalization often occur, so they can move forward with seeing more patients. Being able to turn to spaces, such as supervision and music, to process their feelings, emotions, and experiences is such as essential piece to their work. Additionally, participants emphasized the importance of grappling with vicarious trauma through the power of community. However, they also talked about the difference between sharing these struggles with a partner and sharing them co-worker.

Participants share several statements about experiencing vicarious trauma through witnessing patient experience: Participant MTA said, “To hold someone’s hand as they’re passing can also just be traumatic as well as watching family and their various ways of coping is traumatic.” Similarly, MTC commented, “To witness all of that and trying our best to meet the needs of all of those parties involved is really hard.”

Participant MTC made the following statement about compassion fatigue:

> I think the compassion fatigue definitely caught up with me, and having to kind of move from patient to patient and not really having enough time to process the deaths and grieve or process that whole entire experience and grieve, because you never know what’s gonna happen.

Participant MTC talking about how difficult it was to witness death:

> It was the most, I don’t want to say traumatizing, but it was definitely like...I can still remember that moment very vividly, and like, you know, witnessing and seeing your patient just being dead in the room is never an image that you want to, you know, reflect upon at times.

Participants made several statements about the impact of difficult experiences: Participant MTB said, “I would experience feeling emotionally drained, feeling detached, feeling emotionally indifferent from my work, and from working with individuals.” Participant MTB

admitted, “I’m definitely feeling burnt out from this work, like right now, as we speak.” Additionally, MTB said,

> I think that, like, bearing witness to cases that were challenging, where there would be like, you know, even child abuse situations, or violence, or like, you know, the distressing nature of these situations, I think, you know, added to a level of stress.

Further, participants admitted a sense of desensitization: “I’ve been sort of desensitized to it a bit, unfortunately” (MTB), and participant MTC said,

> Also, the more patients that you experience in palliative care, there’s a lot of countertransference that emerges too, and grief, and just desensitization too, like “Why is this too easy for me to witness someone who is in severe pain?” and being able to compartmentalize that moving from patient to patient.

Despite the inherent potential for vicarious trauma, participants found value in community support. The emphasis on community support is clear in the following statements: “I think that it’s important for music therapists, especially because, oftentimes we can be siloed or the only ones in institutions.” (MTB). Participant MTB commented, “So, you know, having spaces to be able to work those out and work out the challenges that arise for me is necessary and important.: Participant MTB said, “You know, I think if you have somebody, as a music therapist, who has somebody else that you can sort of lean on at work, I think that helps a lot with mitigating a lot of things.” Similarly, MTC said, “I think also, peer support and almost like, support from your co-workers is also really, crucial.” Another relevant statement is, “Fortunately, I have an art therapist I can work alongside and process and work through things too, like on a peer basis” (MTB).

Participants also shared examples of seeking support. Such as,

> I was exhausted. I broke down and cried. I immediately reached out to my co-workers and peers, like, “Do you have a moment?” I just need to do this. I wasn’t able to do anything for the rest of the day. It literally drained me. (MTC)

And,

> Within work, I've said this to a couple of my students and new employees, I think for me, From the beginning when trauma happens or a really tough death or a tough loss within our department, I find solace and comfort within shared feelings and shared trauma, so going to my nursing staff and being able to support them, but also to just be with one another and talk about the frustrations or just talk about the patient and humor or looking back and talking about memories or different ways or just crying with a team member that gets it. (MTA)

More statements about the importance of community follow. The amount of time participants spent talking about the importance of support demonstrates its importance.

> And it's kind of like we're trauma bonded, which is messed up, but it's true, because, when you think about it, my co-workers were the only ones who I felt understood the feelings that are coming up for me, because they're the only ones that know what the work looks like, and they also experience it firsthand. (MTC)

MTC spoke at length about the significance of professional and personal community when sifting through emotional experiences.

> So, a lot of times, it was me reaching out to my coworkers and my peers and just like processing emotions and having them kind of like sit with us or even if it was us processing grief together or processing this entire experience together and being able to like have another outlet and support of people who are...that know exactly what you are going through. (MTC)

Sub-theme Four A: Call for Educational Opportunities in Preparation for Music Therapy Experiences in Palliative Care

Due to the vicarious trauma, grief, burnout, and compassion fatigue music therapists frequently experience in pediatric palliative care settings, participants articulated that there is a need for more educational opportunities in order to prepare clinicians for what they might witness in this work. Participants shared that they wished there had been more opportunities to review music therapy methods they might utilize in these spaces, as well as opportunities to

discuss the mental and emotional effects of facilitating sessions for pediatric palliative care patients and their families.

Participants clearly articulated a need for more education with the following statements. Participant MTC said, "But like I do wish that there were more opportunities in our education to mentally prepare us for the phenomenon *essentially*." (MTC). Other statements include,

> ...I think like if there were opportunities in my education where I was more mentally prepared or had more opportunities to identify interventions or even kind of like, rip the band-aid of this is palliative care. This is the stuff that you might experience. These are the things that you might witness. (MTC)

Theme Five: Intentional Self-care and Coping

The theme of self-care often arises for many music therapists, but participants in this study stressed the significance of creating intentional self-care rituals in order to process and cope with their lived experiences. Personal self-care inside and outside the work setting varies for every clinician. It may look like spending time with family, coping through exercise, spending time with animals, work-life boundaries, mantras, peer support, and journaling. Each participant stressed that it is essential to have personal and professional support in order to continue working and thrive as a clinician.

Participant MTA spoke about the importance of intention in self-care, saying "You can keep going to the gym, but remembering the intentionality behind it, of like, 'I'm going in here, because I, I need to really let off some steam, because I just saw a really bad death.'" Others talked about how helpful therapy was, "Outside, I have gone to a therapist," (MTA), and "And so, outside of the work, it's important to find professional therapy and find other coping mechanisms that allow release or just mindful distraction I think is important too" (MTA). Other supporting statement include, "Go to therapy. That's another piece. Go to therapy" (MTB), and "I also have been meeting for individual therapy" (MTC).

Participants also shared some intentional strategies for care. For example, "Within the work setting, I have my storage closet that is my prayer closet. It's the safe space that no one can enter when I need to just bawl or let things out and then move on" (MTA), and "Going for a walk during phone calls, during Zoom chats, or rounds, or whatever, because a lot of it is just going over a patient medical stuff" (MTA). Other examples include, "I think what helps is leaving work here, and going home and having a clear separation in terms of boundaries," (MTB), "I think exercise for me is another form of self-care" (MTC), and **"**I started keeping a journal entry, or I would write, and I would have a planner, and I would write just in that little section that's offered" (MTC). Participant MTC talked about the role of rituals in their work,

> I was very big on rituals, rituals as in having a ritual to start my day, to kind of like, leave personal stuff at the door and focus on work, and rituals at the end of my day to kind of close up everything at work and try to separate work from home as best as I could.

Finally, MTC spoke about how affirmations helped them get through the day.

> I would always set up affirmations or intentions for myself, and I still do that to this day, of like, you know, it's kind of like a mantra for the day, or an affirmation for the day that when I kind of take a look at it or glance at it, it always reminds me, like, "Take a deep breath", or, you know.

Sub-theme Five A: Supervision as an Essential Aspect of the Music Therapist Experience

Supervision is a crucial part of coping and processing the situations that arise in pediatric palliative care. Music therapists discussed how being supervised by a music therapist, as opposed to a manager, helps them validate and support their own practice, particularly when fueling feelings of self-doubt. Music therapists stressed the importance of locating a music therapist outside the setting they worked in to have that outside perspective. Taking the time to process, communicate one's feelings, and feel validated with their practice is an essential element of supervision.

The importance of getting supervision is evident through the following statements: “I was part of group supervisions,” (MTB), “I was part of my own individual supervision,” (MTB), “I pay for supervision for myself,” (MTB), and “So, yeah. I outsource. I use my own personal money, and during my work time, I take an hour to do my supervision. And that’s because it’s necessary and important for me...” (MTB).

Validation was an important aspect to supervision, as identified in the following statements: “It is helpful to have supervision in the sense of really just having a music therapist validate and support on a different level,” (MTA), and “It helped me feel validated, especially in an environment where I didn’t really feel that validation, or they didn’t necessarily understand my work as a music therapist and what I do provide as a music therapist.” (MTC) Similarly, “Having a music therapist who understands our practice, our scope, our ethics, all the things that are going through our brain” (MTA). Participant MTC recognized the difference between management supervision and outsourced supervision, “On top of that, my location offered supervision, but it was nice to have that additionally sort of outlet, but working with a separate music therapist for supervision was ten times more impactful for me.”

Theme Six: Feeling Siloed and Experiencing Challenges Within the Hospital Dynamic

Participants articulated the challenges of being a music therapist in a hospital setting. Music therapists shared how some hospitals included music therapists on the integrative treatment teams, so collaboration and interdisciplinary care often occurred. However, participants shared that siloed work happens frequently in other hospitals they have worked in, due to their own caseloads and misconceptions about what music therapy is. Participants shared that without professional support and understanding about music therapy from staff, it makes it incredibly difficult to be the only one advocating for music therapy.

Participants also discussed how misconception of music therapy may lead to closing down the service, because families were not interested in the music therapists' scope of practice. Additionally, it can be challenging to meet with patients receiving palliative care at the end-of-life, because some patients would rather sleep or decline services. Music therapists struggled with making contact and offering ways to support patients in these moments.

The following statements highlight participants' feelings of isolation: Participant MTA said, "I was the only music therapist in a 300 some bed hospital, where I saw every death. I mean, it was constant." Similarly, MTB said,

> So, sometimes, I'm involved in interdisciplinary treatment rounds, but it's very seldom that I am, only because where I'm located, I'm the only music therapist for the entire hospital, and we have about 200, maybe 280 beds, so it's really difficult for me to be a part of rounds and treatment team meetings, because I have my own caseload…

Another quote exemplifying the same:

> I find that my work does end up being a little bit siloed at times, where my work is just within the context or confines of me and the individuals I'm serving versus being more integrative, where in the previous hospital I was at, which where they also had palliative care, I was a more integrative treatment team member, and so, a lot of goal setting was done collaboratively and interdisciplinary, but here, that's not the case so much for me. (MTB)

The misunderstanding of music therapy practice left participants feeling a need to advocate and educate, as made clear through the following statements:

> However, I think some of the challenges that arise is that other interdisciplinary teams don't understand that, and so they have a myth or a misconception that maybe what I am doing is more recreational based or maybe entertainment based because they see me with the keyboard, and I'll be stopped by nurses or an individual who is having a difficult time experiencing depression and having a level of suffering or pain, or let's just use pain as an experience, having an acute pain crisis and you know, I am sometimes stopped by nurses to tell me, 'Hey, now's not a good time. They're not feeling well.' Right? (MTB)

And,

> I think, especially, sometimes in medical settings, our role is easily misunderstood as someone who is providing entertainment, and someone who is helping families feel happy, and helping bring a smile to their face. (MTC)

Finally,

> I do want to say I work very much in terms of having transparency, because it also helps ground and facilitate understanding of what my purpose is in the room, and sometimes clarifies a lot of myths that come with music therapy and centralizes the therapy as part of the work, because otherwise, people would view this as being recreational, being entertainment-based and not really have a full understanding of the grasp of what it is, what my work's about. (MTB)

Sub-theme Six A: Lack of Opportunities for Closure with Families Music Therapists Work With

Music therapists are not afforded the opportunity for closure with pediatric patients and their families receiving palliative care. Participants revealed how hard it can be to not have closure before patients move to hospice. Participants shared that music therapists are expected to keep interventions on the surface level, rather than delving into deeper issues, because there is not enough time. The medical setting is a fast-paced environment, and it can be challenging to continuously move on to offering sessions other patients, without pausing to reflect and process other sessions with patients.

The way a lack of closure impacted participants' experienced is shown in the following statements: "Sometimes, music therapists, especially working in a pediatric medical setting, we're not always offered the ample amount of time or the space or the opportunities to really go there with the families" (MTC), and "We are expected to pick up...to kind of leave things where they are for a second, and then, be able to move on to the next client, or next patient who has completely different situation/scenario." (MTC). Participant MTA said,

> I have found that that has been...it's hard for me sometimes to not have a sense of closure sometimes. It can be so quick that they transition to hospice, and it's weird because family and patient might not be to a place of saying goodbye to staff.

Sub-theme Six B: Feelings of Anxiety and Doubt

Feelings of anxiety and self-doubt arose for music therapists when working with patients and their families receiving palliative care. Oftentimes, participants are cautious and nervous when discussing music therapy interventions with families, out of fear of ruining the experience for the patient and their family. Music therapists expressed how they want to offer memorable experiences the families can hold on to. Moreover, participants recognized how these feelings of cautiousness may be a way in which they establish professional boundaries, so they are able to continue working in this setting.

This sub-theme is supported with the following statements: "…I think as therapists, in my experience, I always was very cautious and very mindful of the things that I was saying, the language that I was using" (MTC). Participant MTC also talked about their anxiety:

> I think there's also some anxiety, ...I've often felt like this fear of what if I mess this up and what if I make a mistake that is going to significantly impact the family's process and experience of music therapy as their child is in this palliative state?

Along the same lines, participant MTC said,

> I think being overly cautious at times, being way too mindful, and I think sometimes, it kind of...I think it's a way for me to, kind of like, separate my personal things that are coming up for me, almost like that boundary for me, of not getting too invested, or preventing that sort of connection where if something does happen for that patient and for that family, I'm still able to continue doing this work on a daily basis.

Theme Seven: Motivation for Music Therapy Work with Pediatric Patients and Their Families Receiving Palliative Care

Participants entered music therapy work with pediatric patients and their families for a variety of reasons. Participants noted the benefits of stability of healthcare music therapy positions, as well as being ready to jump into the work. Participants noted that they had little experience working in palliative care, were nervous and unprepared for the work, but ultimately decided to pursue the work, despite scary phenomena they might be exposed to.

Participants described their call to the work in the following ways: "Not necessarily because it's like I had a great passion for it. But I initially, I went in because there was a research position at a hospital, and I was interested in clinical research" (MTB). Participant MTB said,

> It's a challenging space. I think what keeps me in the practice genuinely, is that I have...There's stability in the job that I have here. It's a unionized position. So, there's a lot of great benefits that come with working in a unionized healthcare setting.

Participants also stressed their fears upon entering the work. For example, MTC said,

> I felt like I was ready to kind of just jump into it and just experience it for the first time but also, you know, recognizing, you know, the fears and you know, recognizing we're dealing with death, and I think sometimes death is a complicated and scary phenomenon that people, especially like some clinicians or people who are kind of like, they understand that this is a part of the work, but when it comes to it being actually something you will be dealing with, there's a lot of fear that comes up, and I think it's due to maybe my own insecurities, or maybe just my own misunderstanding or not really understanding what this process looks like first hand.

Similarly,

> I was actually, like really scared and kind of like nervous of approaching that, but I recognize, I think it was a part of the whole adjustment period of like getting acclimated into a medical setting of, you know, recognizing like, yeah, this is a part of the work, like this is actually a part of life. (MTC)

Theme Eight: Finding Fulfillment, a Sense of Purpose, and Joy in the Work

Participants shared that they found great joy and purpose in their work with pediatric palliative care patients and their families. Witnessing patients overcome adversity, providing a space for patients and families to bond, and being part of joyful moments are all examples of times music therapists found fulfillment in their work.

The following statements clearly show participants' joy: (The work) "I think, brought me great joy personally" (MTB), "It gave me a sense of purpose" (MTB), and "Sometimes, the patients can be so funny, during those moments, like just those interactions, and you know, it really makes the work really rewarding and fulfilling" (MTC).

Participants also shared examples of events they find rewarding. Such as:

> Yeah, when she was finally able to leave the hospital and we were able to complete something, and to bear witness to that experience, to be a part of that and see her through the other side, I would like to say brought me a great amount of joy in seeing that, seeing her come ahead and come out, which also brought me fulfillment, you know, in terms of what I was doing and why I was there. (MTB)

And,

> I think some of my favorite moments in working with families in palliative care situations is when music therapy was an opportunity to give the child and the family permission to have fun or to...I don't like saying "have fun", but like almost go back to the sense of normalcy...go back to the sense of, "Yeah, we're in a terrible situation right now, you know, you're in a lot of pain, but creating this musical improvisation was a positive experience, and enabling us to be silly, or to make mistakes. (MTC)

Finally,

> Opening their eyes for the first time for a long period of time, whereas sometimes they're constantly sleeping. You know, those are some really positive qualities of the work that we as music therapists can provide for the patient and also the family members, like recognizing that it brings a sense of hope, or just brings a sense of levity, I think. (MTC)

Global Distilled Essence

The experience of music therapists utilizing a family-based approach with children and families receiving palliative care is emotionally traumatizing. Music therapists navigate vicarious trauma, family dynamics, and challenges within hospital systems. Music therapists work and remain in these settings due to their passion for the work, as well as a means of stability. The sacredness of the therapeutic relationship plays an essential role in the therapeutic process, and music therapists find deep meaning due to the connections and relationships formed. From these results, it is evident that music therapists find solace in community, whether that be with co-workers or with peers, particularly when grappling with traumatic moments in life. Music therapists derive great purpose from their work, and they use a variety of individualized interventions to best meet the needs of their patients and families. Music therapists accentuate the importance of intentional self-care when working in this environment. They recommend that further education, advocacy, and support systems are needed to continue in this work.

Chapter 5: Discussions

This researcher explored the lived experiences of three music therapists who employ a family-based approach in palliative care settings. The research question directing this exploration was as follows: What is the experience of music therapists working with families who have children receiving palliative care? Data were analyzed according to McFerran-Skewes and Grocke's (2007) seven-step phenomenological microanalysis, and eight themes emerged. Themes are discussed in terms of participants' most salient points; the diversity of family needs, the importance of legacy, the potential for vicarious trauma, navigating isolation within the work setting, and engaging in intentional self-care practices. These points are recognized as salient due to how much participants emphasized them during their interviews.

Answering the Research Question

Being a music therapist in a palliative care setting is emotionally traumatizing. Music therapists are witnessing trauma and experiencing challenges within the hospital systems continuously. Despite these challenges, music therapists find great purpose and meaning in their work through the therapeutic relationship they create and foster with their patients and the families they work with. Participants suggest that further advocacy, education, and support systems are needed to continue in this work.

In this research study, participants articulated how every family has unique needs, and how each session can look vastly different depending on who is present. According to Knott et al. (2022) family needs may include "physical (symptom management,) psychological (coping), social (bonding, connectedness), and (spiritual) legacy" (Knott et al., 2022, para. 14). It is essential for music therapists to consistently assess and address family needs through

individualized music therapy interventions to best meet the needs of the patient and the family. Participants in this study also addressed how utilizing a family-based philosophy feels natural, yet can be nuanced. Tuomi et al. (2021) discussed how music therapists utilized a myriad of theoretical approaches and interventions to best meet the needs of their patients. In this study, the participants emphasized how the philosophical approach of family-based care is natural, and other approaches could be harmful to patients and their families. However, some participants emphasized that family-based care is nuanced, as some patients might not have family or caregivers present with them at the bedside. Some might question whether working within this setting with the patient alone, with no family members present, is truly family-based care. This researcher would argue that it is, in that the therapist remains mindful and respectful of the fact that patients' family come and go, as opposed to treating the patient without consideration of the family. Further research is needed to explore how family-based care might align or be utilized with other approaches to best meet the needs of the patient and family members present.

Participants emphasized the importance of creating memories for families through the use of legacy projects. This research study supports previous research that demonstrated how legacy is an important aspect of music therapy for families. Duda (2013) stressed how legacy projects, such as original songs, may be so significant and personal for the families, that they may even be played at a patient's funeral. In this research study, participants highlighted how legacy can be a way for families to express their anticipatory grief and create a memory with their child that will last forever. Participants also noted that legacy is especially important, because the music therapist might not be there to provide emotional support for the families when a patient passes due to the constraints of their work schedule. Participant MTA commented, "Oftentimes, I'm not

there at the bedside. I would probably say many music therapists aren't there, you know? We work an eight-hour shift. Not everyone passes from 8 to 5, you know?"

In this research study, participants discussed their lived experiences with vicarious trauma. Participants spoke about continuously bearing witness to traumas, as well as the side effects of witnessing these traumas, such as desensitization, compartmentalization, grief, stress, burnout, and compassion fatigue. Comparably, additional research discusses the emotional and mental side effects of vicarious trauma, which may include: "cynicism, feeling sad, feeling anxious, difficulty sleeping, "zoning out", and social withdrawal" (Jeffersonc, 2023, para. 5). Participants identified how consistently being exposed to traumatizing situations affected their mental health, ability to cope, and ability to function and perform as a music therapist. Future research is needed to delve into the side effects of constant experience of vicarious trauma, education about what music therapists might witness, and how to navigate being a supportive therapist when grappling with the aftereffects of vicarious trauma.

Music therapists in this study articulated their struggles with feelings of isolation, siloed practice, and challenges within the medical setting. Participants shared how their work can be siloed, depending on how they are integrated, and if they are integrated within the interdisciplinary team. Participants spoke about feeling misunderstood by medical staff, who viewed their care as recreation and not therapeutic. A research study by Meghani et al., 2020, explored nurses' perceptions of complementary therapies, including music therapy and its efficacy. 83% of nurses surveyed perceived music therapy as complementary therapy, and a majority of nurses believed music therapy could be helpful for their patients' well-being during their hospitalizations (Meghani et al., 2020). Even though music therapy may be viewed as fun by some nurses, this study demonstrated that these critical care nurses recognized how music

therapy was a legitimate therapy that provided therapeutic benefits for patients. Further studies are needed to explore the perceptions and benefits of music therapy by various members of the medical team.

This study's results demonstrated that establishing time for intentional self-care is a necessity. Participants discussed how they turned to specific and purposive self-care practices, such as journaling, supervision, peer support, exercise, work-life boundaries, mantras, and time alone to process their experiences working in these settings. Similarly, in Rigney's (2011) study, Rigney turned to journaling to express her emotions and feelings that arose during sessions. She also utilized her journal to process and reflect on her experience when working with a patient and her family. Likewise, Wilhelm and Moore's (2019) research study examined how music therapy students perceived self-care and examined what their practices were. Common self-care practices involved: spending time in music, spiritual and religious practice, creative forms of expression, watching movies or media, resting, hygiene/skin care, eating, organizing, personal therapy, and moving one's body (Wilhelm & Moore, 2019). Wilhelm and Moore (2019) noted that students engaged in these multitude of self-care practices for particular reasons, like the participants in this research study also emphasized.

Additionally, participants in this study reflected on the importance of supervision from work supervisors and outside supervisors as an integral aspect of processing one's lived experience and taking care of themselves. Trondalen (2017) underlined the importance of supervision, utilizing music individually with a supervisor, as well as group music supervision to cope and care for oneself. Participants in the study noted the importance of self-care resources inside the hospital setting, such as individual and group supervision and processing, as well as

therapy dogs. Trondalen (2017) also highlighted the variety of programs employers can offer to promote wellness to music therapy faculty.

Implications for Music Therapy Practice

The results of this research study illuminated the trauma music therapists are exposed to, and the ways in which music therapists cope and manage the trauma they experience. Participants discussed the importance of further education to prepare clinicians for what they might witness prior to working. As a result of the study findings, perhaps classes on vicarious trauma, coping, and intentional self-care practices within the medical setting may emerge within the undergraduate and graduate course curriculum to prepare future clinicians for the trauma they may witness and experience in these work environments.

Further education and advocacy about music therapy is essential for music therapists' employers. Advocating for mental and emotional health resources for clinicians may help decrease their burnout, when they feel properly cared for and appreciated. Business plans about self-care programming and opportunities, such as group processing after a death, and supervision would be fantastic ideas to incorporate into the educational setting. Recommendations for future practice might explore the success or failure rate of proposing integrated involvement in the interdisciplinary team, proposing a budget for another music therapist in the hospital, creating group spaces for therapists and clinicians to process through a variety of self-care methods, and creating time in the day for music therapists to have breaks before moving from patient to patient.

Limitations

One limitation of this research study included the inclusion criteria. The inclusion criteria for this research study required participants to have been a practicing music therapist for at least five years. Potential participants who have experience implementing a family-based approach, but not five years of experience, could not participate in the study, due to the limiting inclusion criteria. The results might have varied if these potential participants' experiences were added to the study, and they were able to discuss their lived experiences at length.

Another limitation of this study included the location and gender identity of the participants. If more potential participants entered the study from hospitals all across the United States, and if people who identified as a variety of gender identities entered the study, the results may have been more diverse. As a new researcher, the time constraints of a few months to carry out three interviews, complete the analysis process, and write up the research results felt overwhelming at times. The time constraints of a few months were limiting, as it provided a small window of scheduling interviews, writing up the transcripts, completing the analysis, and typing up the results. Moreover, though the researcher implemented strategies for trustworthiness, one researcher conducted data analysis and the potential for researcher bias exists.

Recommendations for Future Research

After examining the results, there is a great need for further research on addressing the challenges, feelings, and potential effects of isolation music therapists experience in the hospital setting, as well as ways to mitigate the music therapist's experience. Future research in this area will help show music therapists that they are not alone, and that they are supported and valued

clinicians within the medical setting. If implemented successfully, research projects regarding music therapy budgets, increased interdisciplinary team involvement, group spaces for music therapists, and breaks for processing might help music therapists feel valued by their employers. If these resources are provided, they might help sustain and protect music therapists' mental and emotional health when working in a healthcare setting. Additional research might address the overwhelming need for educational experiences within the hospital setting, classes about vicarious trauma, and practicing coping methods, so that music therapists do not feel engulfed by witnessing trauma every day. Lastly, while music did not emerge as an independent theme, participants spoke about music in many phases of treatment, such as legacy projects, improvisation, active music making, and receptive experiences. Future research might explore the impact of specific music therapy interventions utilized in family-based music therapy sessions.

Chapter 6: Conclusion

This study explored the lived experiences of music therapists who utilize a family-based approach when working with children and families receiving palliative care. The results of this study demonstrated how family-based care is ingrained within the environment of music therapy in a medical setting. Family-based music therapy is nuanced, innate, and a necessary approach to meet the diverse needs of each family. Being a music therapist in a medical setting can be emotionally draining, isolating, and traumatizing. Despite witnessing traumatizing events on the daily basis, music therapists continue to come back to this work, due to the sacred relationships formed in therapy, as well as the purpose they derive from providing music therapy services. Finally, intentional self-care, education, and advocacy are important to music therapists' health as they continue to work in this space. Seeking out supervision, community support, and creating

specific self-care rituals help music therapists cope, process their experiences, and support their well-being in this space. Further advocacy, support services, and education is needed to continue practicing in this work.

References

American Music Therapy Association (AMTA). What is music therapy? (2005). https://www.musictherapy.org/about/musictherapy/

Bailey, L. M. (1984). The use of songs in music therapy with cancer patients and their families. *Music Therapy*, *4*(1), 5–17. https://doi.org/10.1093/mt/4.1.5

Candela, A. G. (2019). Exploring the function of member checking. The Qualitative Report, 24(3), 619-628. https://nsuworks.nova.edu/tqr/vol24/iss3/14

Clark, B. A., Siden, H., & Straatman, L. (2014). An integrative approach to music therapy in pediatric palliative care. *Journal of Palliative Care, 30*(3), 179-87. https://molloy.idm.oclc.org/login?url=https://www.proquest.com/scholarly-journals/integrative-approach-music-therapy-pediatric/docview/1584940914/se-2

Creswell, J. W., & Creswell, J. D. (2018). *Research design: Qualitative, quantitative, and mixed methods approaches (5th ed.).* Los Angeles, CA: Sage Publications.

Duda. (2013). Integrating music therapy into pediatric palliative care. *Progress in Palliative Care*, *21*(2), 65–77. https://doi.org/10.1179/1743291X13Y.0000000049

Fagen, T. S. (1982). Music therapy in the treatment of anxiety and fear in terminal pediatric patients. *Music Therapy*, *2*(1), 13–23. https://doi.org/10.1093/mt/2.1.13

Gardstrom, S., & Sorel, S. (2017). Music therapy handbook. Music Therapy Methods. In B. L. Wheeler (Ed.), *The Guilford Press.*

Hibben, J. K. (1992). Music therapy in the treatment of families with young children. *Music Therapy*, *11*(1), 28–44. https://doi.org/10.1093/mt/11.1.28

Jeffersonc. (2023, August 7). *What is vicarious trauma?* Jefferson Center. https://www.jcmh.org/what-is-vicarious-trauma/

Knott, D., Krater, C., MacLean, J., Robertson, K., Stegenga, K., & Robb, S. L. (2022). Music therapy for children with oncology & hematological conditions and their families: Advancing the standards of psychosocial Care. *Journal of Pediatric Hematology/Oncology Nursing (Print)*, *39*(1), 49–59. https://doi.org/10.1177/27527530211059726

Lincoln, Y., & Guba, E. (1985). Naturalistic inquiry. London, UK: Sage Publications.

Lindenfelser, K. J., Hense, C., & McFerran, K. S. (2012). Music therapy in pediatric palliative care. *American Journal of Hospice and Palliative Medicine*, *29*(3), 219–226. https://doi.org/10.1177/1049909111429327

Lindenfelser, Grocke, D., & McFerran, K. (2008). Bereaved parents' experiences of music therapy with their terminally ill child. *The Journal of Music Therapy*, *45*(3), 330–348. https://doi.org/10.1093/jmt/45.3.330

McFerran-Skewes, K., & Grocke, D. (2007). Understanding music therapy experiences through interviewing: a phenomenological microanalysis. In Wosch T., & Wigram, T. (Eds.) *Microanalysis in music therapy: Methods, techniques and applications for clinicians, researchers, educators and students* (pp. 273-283). Jessica Kingsley Publishers.

McIntyre. (2009). Interactive family music therapy: untangling the system. *Australian and New Zealand Journal of Family Therapy*, *30*(4), 260–268. https://doi.org/10.1375/anft.30.4.260

Meghani, N., Tracy, M., O'Conner-Von, S. , Hadidi, N. , Mathiason, M. & Lindquist, R. (2020). Generating Evidence of Critical Care Nurses' Perceptions, Knowledge, Beliefs, and Use of Music Therapy, Aromatherapy, and Guided Imagery. *Dimensions of Critical Care Nursing, 39* (1), 47-57. doi: 10.1097/DCC.0000000000000391.

Miller, E. J. (1994). Musical intervention in family therapy. *Music Therapy*, *12*(2), 39–57.

https://doi.org/10.1093/mt/12.2.39

Moore, C., & Wilhelm, L. A. (2019). A Survey of Music Therapy Students' Perceived Stress and Self-Care Practices. The Journal of Music Therapy, 56(2), 174–201. https://doi.org/10.1093/jmt/thz003

Nemesh, B. (2017). Family-based music therapy: from dissonance to harmony. *Nordic Journal of Music Therapy*, 26(2), 167–184. https://doi.org/10.1080/08098131.2016.1144638

Palliative care - Mayo Clinic. (2023, June 6). https://www.mayoclinic.org/tests-procedures/palliative-care/about/pac-20384637

Pasiali. (2013). A clinical case study of family-based music therapy. *Journal of Creativity in Mental Health*, *8*(3), 249–264. https://doi.org/10.1080/15401383.2013.821925

PCMag. (2019, February 13). *ADATA HD830 External Hard Drive Review*. PCMAG. https://www.pcmag.com/reviews/adata-hd830-external-hard-drive

Regent University. (2022, July 7). *Understanding transcendental phenomenology*. https://www.regent.edu/journal/emerging-leadership-journeys/understanding-transcendental-phenomenology/

Rico-Mena, P., Güeita-Rodríguez, J., Martino-Alba, R., Castel-Sánchez, M., & Palacios-Ceña, D. (2023). The emotional experience of caring for children in pediatric palliative care: a qualitative study among a home-based interdisciplinary care team. *Children (Basel)*, *10*(4), 700-. https://doi.org/10.3390/children10040700

Rigney, M. (2011). Using reflexive tools for coping and bringing closure in pediatric palliative care: A music therapist's story of working with a terminally ill child. *Voices*, *11*(3). https://doi.org/10.15845/voices.v11i3.287

Simard, J. (2020). About caregiver suffering in hospice care. *Mortality (Abingdon, England)*, *25*(2), 125–137. https://doi.org/10.1080/13576275.2019.1572085

Snowball sampling. Division of Research and Innovation. (2017, July 8). https://research.oregonstate.edu/irb/policies-and-guidance-investigators/guidance/snowball-sampling

Stahl, N. A., & King, J. R. (2020). Expanding approaches for research: understanding and using trustworthiness in qualitative research. *Journal of Developmental Education*, *44*(1), 26–28. http://www.jstor.org/stable/45381095

Trondalen, G. (2016). Self-Care in Music Therapy: The Art of Balancing. In The Oxford Handbook of Music Therapy. Oxford University Press. https://doi.org/10.1093/oxfordhb/9780199639755.013.19

Tuomi, K., Thompson, G., Gottfried, T., & Ala-Ruona, E. (2021). Theoretical perspectives and therapeutic approaches in music therapy with families. *Voices*, *21*(2). https://doi.org/10.15845/voices.v21i2.2952

What is a terminal illness? Definition of terminal illness. (n.d.). Marie Curie. https://www.mariecurie.org.uk/who/terminal-illness-definition

Wheeler, B. L., & Murphy, K. M. (Eds.). (2016). *Music therapy research: Third edition*. Barcelona Publishers.

World Health Organization: WHO. (2020, August 5). *Palliative care*. https://www.who.int/news-room/fact-sheets/detail/palliative-care

Zdun-Ryżewska, A., Nadrowska, N., Błażek, M., Białek, K., Zach, E., & Krywda-Rybska, D. (2021). Parent's stress predictors during a child's hospitalization. *International journal of environmental research and public health*, *18*(22), 12019. https://doi.org/10.3390/ijerph182212019

Appendix A: IRB Approval Letter

MOLLOY UNIVERSITY
1000 Hempstead Ave., PO Box 5002, Rockville Center, NY 11571-5002
www.molloy.edu

Patricia A. Eckardt, PhD, RN, FAAN
Chair, Molloy University Institutional Review Board
Professor, Barbara H. Hagan School of Nursing and Health Sciences
E: peckardt@molloy.edu
T: 516.323.3711

DATE: February 1, 2024

TO: Faith Agolia
FROM: Molloy University IRB

PROJECT TITLE: [2142066-1] Exploring Music Therapists' Experiences of Utilizing a Family-Based Approach With Children and Families Receiving Palliative Care
REFERENCE #:
SUBMISSION TYPE: New Project

ACTION: DETERMINATION OF EXEMPT STATUS
DECISION DATE: January 31, 2024

REVIEW CATEGORY: Exemption category # *2*

Thank you for your submission of New Project materials for this project. The Molloy University IRB has determined this project is EXEMPT FROM IRB REVIEW according to federal regulations 45 CFR46.104(d). However, exempt research activities are subject to the same human subject protections and ethical standards as outlined in the Belmont Report.

This acknowledgment expires within three years- unless there is a change to the protocol.

Though this protocol does not require annual IRB review, the IRB requires an annual report of your exempt protocol if continuing beyond 1 year from date of IRB approval. (Expedited and Exempt Research Protocol Annual Report Form) which is available on the IRBNet webpage.

If there is a proposed change to the protocol, it is the responsibility of the Principal Investigator to inform the Molloy University IRB of any requested changes before implementation. A change in the research may change the project from EXEMPT status and requires prior communication with the IRB.

We will retain a copy of this correspondence within our records.

If you have any questions, please contact Patricia Eckardt at 516-323-3711 or peckardt@molloy.edu. Please include your project title and reference number in all correspondence with this committee.

Sincerely,

Patricia Eckardt, Ph.D., RN, FAAN
Chair, Molloy University Institutional Review Board

This letter has been issued in accordance with all applicable regulations, and a copy is retained within Molloy University IRB's records.

Appendix B: Recruitment Email

Greetings, Music Therapists!

My name is Faith Agolia, and I am a Graduate Music Therapy student at Molloy University.

You are receiving this email because you have been identified as a person who might meet the inclusion criteria, or who might know other persons who may meet inclusion criteria for this study. Inclusion criteria is in **bold** below. Please forward this request to individuals who might fit the inclusion criteria.

I am currently researching the perspectives of music therapists who utilize a family-based approach when working with families whose children are receiving palliative care. There is limited research on the perspective of music therapists who work with children and families in this manner. The purpose of this study is to understand the lived experiences of music therapists who work with children and families receiving palliative care. Additionally, the purpose of this study is to utilize these findings so that other music therapists may look to these experiences as a resource for their own work.

Participants must meet the following criteria:

1. **Participants must be board-certified music therapists for a minimum of five years.**
2. **Participants must have at least five years of experience using music therapy with children and families.**
3. **Participants must have a Master's degree in music therapy or a related profession and implement music therapy within a family-based framework.**

Participation is voluntary, and participants may withdraw from the study at any time without repercussions.

Your participation will include a recorded audio and video interview over the Zoom platform. After the researcher transcribes the interview, you will be asked to review the verbatim transcript to ensure its accuracy. If you are interested in participating in this study, please feel free to reply to this email address, and I will respond with more information about this research study.

If you have any questions regarding this study, please reach out to me at: Fagolia@lions.molloy.edu

My faculty advisor, Dr. Amanda MacRae, may also be reached at: amacrae@molloy.edu

Thank you so much for your consideration!

Sincerely,
Faith Agolia, MT-BC

(she/her/hers)
Music Therapy Graduate Student at Molloy University

Appendix C: Informed Consent Form

Graduate Music Therapy Department
Public Square 1000 Hempstead Avenue
Rockville Centre, NY 11570
516-323-3322

Title of Study: EXPLORING MUSIC THERAPISTS' EXPERIENCES OF UTILIZING A FAMILY-BASED APPROACH WITH CHILDREN RECEIVING PALLIATIVE CARE

This study is being conducted by: Faith Anne Agolia, MT-BC

Primary contact information: Fagolia@lions.molloy.edu

Thesis Advisor: Amanda MacRae, PhD, MT-BC

Contact Information: amacrae@molloy.edu

Key Information about this study:

This consent form is designed to inform you about the study you are being asked to participate in. Here you will find a brief summary about the study; however, you can find more detailed information later on in the form.

This study seeks to examine the lived experiences of music therapists who implement a family-based approach when working with children and families receiving palliative care. Music therapist participants must meet the following criteria:

1. Participants must be board-certified music therapists for a minimum of five years.

2. Participants must have at least five years of experience using music therapy with children and families.

3. Participants must have a Master's degree in music therapy or a related profession and implement music therapy within a family-based framework.

Participants' time commitment for this study should be no more than two hours. Each participant will partake in a recorded audio and video Zoom interview with the researcher, which will take up to one hour. Then the researcher will transcribe each interview. After writing up the transcription, the researcher will send the interviews to the participants. Participants will then be asked to review the verbatim transcript to ensure its accuracy.

This review will take up to one hour. The recorded audio and video interviews will be held over the Zoom platform. Participation is confidential. Participants may leave the study at any time without consequence and data will be destroyed immediately. Findings from this research will be presented in the form of a master's thesis.

Why am I being asked to take part in this study?

You are being asked to participate in the study because you have been identified as someone who may meet the inclusion criteria for this research study**.**

What will I be asked to do?

- Participants will partake in a recorded audio and video Zoom interview with the researcher.
- Participants will review the verbatim transcript to confirm its accuracy before sending it back to the researcher

Where is the study going to take place, and how long will it take?

The study will take place over the Zoom platform. The recorded audio and video Zoom interview will be approximately one hour or less. It may take up to one hour for the participant to review the transcript to confirm its accuracy before sending it back to the researcher.

What are the risks and discomforts?

It is not possible to identify all potential risks and discomforts in research. However, reasonable protective policies for this study, such as pseudonyms and the removal of identifying features, have been put into place to minimize privacy and confidentiality risks. It may be uncomfortable for music therapists to speak about their lived experiences, so the researcher will strive to create a safe, Zoom space for the participants to share their experiences.

What are the expected benefits of this research?

The expected benefits of this research are providing participants with the opportunity to share their lived experiences with others. Additionally, these lived experiences may serve as a resource to other music therapy professionals as they process their experiences of working with children and families.

Do I have to take part in this study?

Your participation in this research is voluntary. If you decide to participate in the study, you may change your mind and stop participating at any time without penalty and your data will be destroyed.

Who will have access to my information?

The researcher will have access to the transcript interviews during the study. The interviews will be downloaded onto two encrypted, external ADATA HD830 hard drives. They will be deleted from the original laptop. Findings will be published in a master's thesis.

How will my [information/biospecimens] be used?

Any private information that might identify the participant will be removed in order to preserve the confidentiality and privacy of the participant.

To ensure that this research activity is being conducted properly, Molloy University's Institutional Review Board (IRB), whose members are responsible for the protection of human subjects' rights for all Molloy-approved research protocols, have the right to review study records, but confidentiality will be maintained as allowed by law.

What if I have questions?

Before you decide whether you'd like to participate in this study, please ask any questions that come to mind now. Later, if you have questions about the study, you can contact [Faith Anne Agolia] **at** [Fagolia@lions.molloy.edu], **or** [Amanda MacRae, PhD, MT-BC] **at** [amacrae@molloy.edu].

What are my rights as a research participant?
You have rights as a research participant. All research with human participants is reviewed by a committee called the Institutional Review Board (IRB) which works to protect
your rights and welfare.
If you have questions about your rights, an unresolved question, a concern or complaint about this research you may contact the IRB contact the Molloy IRB office at irb@molloy.edu or the IRB CHAIR: Dr. Patricia A. Eckardt peckardt@molloy.edu call 516 323 3000.

Documentation of Informed Consent:

You are freely making a decision whether to be in this research study. Signing this form means that:
1. You have read and understood this consent form.
2. You have had your questions answered, and
3. After sufficient time to make your choice, you have decided to be in the study.

You will be given a copy of this consent form to keep.

_____ _____

Your signature Date:

_____ _____

Your printed name Date:

Electronic Signature Agreement:

I agree to provide an electronic signature to document my consent.

I agree to provide an electronic signature to document my consent to participate in a Zoom recording.

Your signature	Date
Your printed name	Date
Signature of researcher explaining study	Date
Printed name of researcher explaining study	Date

Appendix D: Interview Questions

1. Please tell me about your experience working with children and families receiving palliative care and utilizing a family-based framework.
2. What led you to working with children and families receiving palliative care? What has kept you in this family-based practice?
3. What methodologies do you utilize during family-based sessions? Do you stray from using any music therapy techniques? How do you view goals for the family unit?
4. What has been your happiest moment when employing a family-based framework while working with children and families in this practice?
5. How do you navigate challenging experiences (e.g., power imbalances, familial dynamics) with members of the family unit?
6. Have you experienced grief and/or vicarious trauma when working with children and families receiving palliative care? Who do you reach out to for support if needed?
7. How do you practice self-care while working with children and families under this family-based framework?