

Parents' Experiences of Music Therapy with Pediatric Palliative Care Patients

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## **Abstract**

Over 8,600 children are eligible to receive pediatric palliative care services every day (Freibert & Williams, 2015). Due to the wide range of diagnoses and complicated medical treatment required for these patients, adequate pediatric palliative must serve patients using a holistic, interdisciplinary team approach. Research has shown that music therapy with pediatric palliative care patients and their parents can facilitate bonding, provide meaningful experiences, enhance communication, and relieve stress (Lindenfelser, Grocke, & McFerran, 2008). Therefore, the researcher sought information about how parents are impacted by music therapy when observing or participating in music therapy sessions with their child on palliative care services. The research questions included: (a) what are parental experiences of music therapy with children on pediatric palliative care services? And, (b) how are parents impacted by music therapy when observing or participating in music therapy sessions with their child in palliative care services? Seven participants participated in this study. Each participant was audio-recorded in a semi-structured interview. Data were then analyzed upon completion of the study and global themes were discovered among the participants. Results from the study showed that music therapy had positive primary and secondary impacts on parents of children receiving palliative care.

## **Introduction**

Approximately 8,600 children are eligible to receive pediatric palliative care services every day (Freibert & Williams, 2015). These are children suffering from a multitude of diagnoses, ranging from congenital malformations to cardiovascular disease, neuromuscular disorders, traumas, genetic conditions, and more. Due to the wide range of diagnoses and complicated medical treatment required for these patients, adequate pediatric palliative care must serve patients using a holistic, interdisciplinary team approach.

About 75% of pediatric deaths were patients who were receiving pediatric palliative care or met the criteria for receiving such services (Freibert & Williams, 2015). Due to medical advancement, children with life-limiting conditions receiving pediatric palliative care services are living longer. As these children continue to grow, and the amount of children living with life-limiting, chronic conditions increase, so does the need for a greater understanding of how to treat these patients and their families effectively.

### **Statement of Problem**

Limited research exists for the pediatric palliative care population, especially regarding the impact of music therapy with this population. The limited published research, focuses on pediatric patients that have already passed, patients at end of life, or patients with cancer, rather than pediatric patients suffering from life-limiting conditions who are still alive (Clark, Siden, & Straatman, 2014; Daveson & Kenelly, 2000; Hynson & Sawyer, 2001; Sheetz & Bowman, 2012; Verberne et al., 2017).

The American Academy of Pediatrics reports that pediatric palliative care must involve an integrated, interdisciplinary approach for both the patient and family that

focuses on physical, emotional, psychosocial, and spiritual domains (Committee on Bioethics and Committee on Hospital Care, 2000). As parents are often the primary caregivers to pediatric patients, the World Health Organization (2017), states, “effective palliative care requires a broad multidisciplinary approach that includes the family” (p. 1). Research shows that parents of pediatric patients in a critical care setting experience higher levels of stress and anxiety, and may not be able to fully comprehend information or make appropriate decisions. These parental effects are exacerbated when treating pediatric patients with life-limiting conditions (LLC) that are receiving palliative care. (Foster, Whitehead, & Maybee, 2016).

Music therapy has the ability to address the aforementioned domains of care within an interdisciplinary palliative care team. Research shows that music therapy can address goals detailed by the World health Organization for PPC. These include reducing anxiety, reducing pain, increasing emotional expression, and improving family interactions (Lindenfelser et al., 2008). However, there is a lack of research regarding parent satisfaction with pediatric palliative care programs and parental experiences of music therapy with their children on palliative care.

### **Need for the Study**

Pediatric palliative care programs have the responsibility of treating both the pediatric patient and their family. Research demonstrates a need for various supportive and psychosocial treatment modalities, including expressive therapies, for parents of pediatric palliative care patients. However, in addition to providing one-to-one parent support, it is vital to understand how parents are impacted by the services their child is receiving. Research has shown that music therapy with pediatric palliative care patients

and their parents can facilitate bonding, provide meaningful experiences, enhance communication, and relieve stress (Lindenfelser et al., 2008). Therefore, it is important to investigate how parents are impacted by music therapy when observing or participating in music therapy sessions with their child on palliative care services.

### **Purpose of the Study**

This researcher seeks to examine parents' experiences when observing or participating in music therapy sessions with their child.

### **Terminology**

For clarification purposes, the following terms are defined as follows:

- Music therapy: “Music therapy is 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 profession” (American Music Therapy Association, 2017, p. 1).
- Parent: For purposes of this study, a parent will be defined as synonymous with legal guardian.
  - Person authorized under state law to consent on behalf of the child for general medical care (University of Pittsburgh Human Research Protection Office, 2017, p. 1)
- Pediatric Palliative Care: “Palliative care for children is that active total care of the child’s body, mind, and spirit, and also involves giving support to the family” (World Health Organization, 2017, p. 1)



## **Review of Related Literature**

There are limited published studies regarding the interaction between pediatric palliative care, music therapy, and family-centered care. Research demonstrates a need for supportive treatment modalities, including music therapy, to treat the patient and the family (Lindenfelser et al., 2008). Through an exploration of music therapy's impact on parents of children receiving palliative care, the researcher seeks to understand how parents and families of pediatric palliative care patients can be best served in the hospital setting.

### **Pediatric Palliative Care**

Palliative care is defined by the World Health Organization (2017) as “an approach that improves the quality of life of patients and families facing the problem associated with life-threatening illness, through the prevention and relief of suffering” (p. 1). The World Health Organization defines palliative care for children in a similar way, but includes the role of family even more. It states, “palliative care for children is that active total care of the child’s body, mind, and spirit, and also involves giving support to the family...effective palliative care requires a broad multidisciplinary approach that includes the family” (World Health Organization, 2017, p. 1). More so, “pediatric palliative care begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease” (World Health Organization, 2017, p. 1).

The National Hospice and Palliative Care Organization (NHPCO) recognizes that significant differences exist in providing adequate palliative care for children versus adult patients. This includes differences in the course of illness, effective care interventions,

and family support (Freibert & Williams, 2015). Adult and pediatric palliative care differs, for reasons including age, diagnosis, prognosis, and goals of care. Therefore, the standards of palliative care for children and adults must differ as well (American Academy of Pediatrics, 2000; Bergstraesser, 2013; Clark et al., 2014).

The American Academy of Pediatrics defines the goal of palliative care as “the achievement of the best quality of life for patients and their families, consistent with their values, regardless of the location of the patient” (American Academy of Pediatrics, 2000, p. 1). Still, unlike adult palliative care, limited research exists for the pediatric palliative care population (Clark et al., 2014; Daveson & Kenelly, 2000; Hynson & Sawyer, 2001; Sheetz & Bowman, 2012; Verberne et al., 2017). What little research does exist usually surrounds pediatric patients that have passed away, rather than pediatric patients with life-limiting conditions (LLC) who are still alive and receiving support. More so, it is important to recognize the palliative care and end-of-life support are not equivalent, and while end-of-life care may be included in palliative support, it is one component within palliative care (Bergstraesser, 2013; Hays et al., 2006).

With the advancement of medical strategies, children with life-threatening conditions (LTC) are living longer. The Children’s International Project on Palliative/Hospice Services (ChiPPS) report that at least 8,600 children may be eligible for palliative care services on any given day. While a reported 69% of children’s hospitals currently have palliative care programs, this population is still underserved and understudied (Freibert & Williams, 2015). As Lindenfelser, Hense and McFerran (2010) stated, “Families with children accessing PPC are one of the most at-risk populations within the palliative care field, making this kind of research a priority” (p. 223).

## **Pediatric Palliative Care and the Family System**

The admission of a child into the hospital, especially a child suffering from a life-limiting illness, often causes an overwhelming amount of stress and anxiety in parents and those negative impacts may be observed in decision-making, comprehension, and overall care (Foster et al., 2016; Horne-Thompson & Grocke, 2008).

The unpredictable nature of pediatric palliative care in the hospital can often exacerbate these negative effects, and anticipatory grief, an inability to cope, and post-traumatic stress disorder (PTSD) are often seen among parents (Lane & Mason, 2014; Verberne et al., 2017). More so, the loss of a child increases parental risk for developing psychological issues including anxiety, depression, prolonged grief, and substance abuse (Knapp, Madden, Curtis, Sloyer, & Shenkman, 2010; Lane & Mason, 2014; van der Geest et al., 2014; Kreicbergs, Valdimarsdottir, Onelov, Henter, & Steineck, 2004; Verberne et al., 2017).

Working with children suffering from life-limiting conditions has an impact on the entire family unit. From parents, to siblings and extended family, it is important to provide care for everyone involved. Therefore, research demonstrates a need for family-centered care (Daverson, 2000; Hays et al., 2006; Hyson & Sawyer, 2001; Knapp et al., 2010; Lane & Mason, 2014; Maguire & Price, 2007; Verberne et al., 2017; Zimmermann et al., 2016).

Family-Centered Care may be defined as “professional support for the child and family through a process of involvement, participation and partnership, underpinned by negotiation and empowerment” (Maguire & Price, 2007, p. 36). Research demonstrates

that family-centered care is vital in pediatric palliative care, with respite care, supportive counseling, bereavement, and expressive therapies among the needed services for families (Knapp et al., 2010). Following the need for family-centered care, The American Academy of Pediatrics (2000) has outlined five minimum standards and necessary principles for providing an integrated model for palliative care.

The first principle of providing integrative palliative care is *respect for the dignity of patients and families* (American Academy of Pediatrics, 2000). This encompasses providing services for pediatric palliative care patients and the patients' families, both during the patients' illness and after the patients' death. Equally as important is *access to competent and compassionate palliative care*. In addition to goals such as pain and symptom management, an interdisciplinary team should be providing therapies that enhance quality of life, including music therapy.

Research into bereaved parents' experiences with palliative care has resulted in a collection of repeatedly stated themes: parents need sincere relations, compassionate support, genuine communication, coordination and accessibility to care, and bereavement support (Zimmermann et al., 2016). In a 2017 qualitative study, researchers investigated the impact of caregiving for pediatric palliative care patients by interviewing 42 parents of 24 different children receiving palliative care (Verberne et al., 2017). Interviews lasted from 30 minutes to two hours, as researchers asked questions about parenting, caregiving, and family life. An inductive thematic analysis was used to analyze the data and three aims emerged: controlling the disease and its symptoms, providing a "life worth living" (p. 347) for their child, and maintaining family balance (Verberne et al., 2017).

Parents consistently reported that controlling symptoms of the disease was not just for prolonging their child's life, but also for helping to prevent further loss of their child's abilities. This related to parents' sentiments about providing a "life worth living" for their child. Verberne et al. (2017) stated, "Most parents felt challenged to create a life worth living for their child. Especially when their child... deteriorated and lost his/her abilities for life fulfillment, parents put even more efforts toward creating a life worth living" (pp. 347-348).

In a 2012 study on bereaved parental perception of a pediatric palliative care program, 65 parents were anonymously surveyed regarding parental satisfaction with palliative care goals (Sheetz & Bowman, 2012). Results were separated into six categories: medical decision-making, support for families, management of symptoms, communication, satisfaction with palliative care services, and parental perception of what helped and what could be improved. Researchers reported that the primary reason for referral to this service was for family support and help with decision-making. Results supported existing literature, as 97% of parents reported that they were both emotionally supported and supported in their decision-making process. Therefore, the authors purported the need to focus on family support.

Research clearly demonstrates the importance of parental caregiving within pediatric palliative care. More so, there is the need for family-centered care, and the ability to create meaningful experiences that incorporate both the pediatric patient and their parent (Hays et al., 2006). Music therapy, a flexible, expressive treatment modality often used in interdisciplinary palliative care programs, has the ability to create these

meaningful life experiences and enhance the quality of life in both pediatric palliative care patients and their parents (Lindenfelser et al., 2008; Magill, 2009).

### **Music Therapy and Palliative Care: An Overview**

Goals of palliative care treatment may include, but are not limited to, pain and symptom management, emotional, spiritual and psychological support for patient and family, support in decision-making, coordination of care, and bereavement support (Hays et al., 2006; Hilliard, 2003a; Sheetz & Bowman, 2012). Music therapy may be used to address these goals from various domains, including physical, emotional, cognitive, and spiritual, thus complementing the interdisciplinary team approach (Amadoru & McFerran, 2007; Hilliard, 2001; Hilliard, 2003a; Magill, 2009). Still, existing literature indicates a need for further research into music therapy and its effect in palliative care treatment. More specifically, there is a need for research regarding music therapy's impact within pediatric palliative care using a family-centered care model (Hilliard, 2001; Lindenfelser et al., 2010).

### **Music Therapy and Parents of Pediatric Palliative Care Patients**

Research has revealed an over-arching theme of parental desire to maintain or enhance the quality of life for their children on palliative care and many music therapy studies support this need (Clark et al., 2014; Daveson & Kennely, 2000; Hilliard, 2003a; Knapp et al., 2009; Verberne et al., 2017). In one study on music therapy in pediatric palliative care, researchers used phenomenological strategies to analyze open-ended questions on the role of music therapy (Amadoru & McFerran, 2007). Researchers found that music therapy was beneficial not only to the patient, but to the entire family. Families reported that they had better communication, were able to “enjoy their

experiences unhindered by the limitations of the child's illness or disability" (p. 126) (Amadoru & McFerran, 2007). One staff member stated, "Music therapy allows children and families to just forget for a moment, and do things that they subconsciously want to do like laughing and enjoying a moment when they feel like they should be incredible sad, and they're not" (Amadoru & McFerran, 2007, p. 126).

A separate study sought, via a survey tool, to discover the pediatric patients' use of, and parental satisfaction with, music therapy services (Knapp et al., 2009). Participants included parents of pediatric patients who were enrolled in a pediatric palliative care program. Ninety-eight percent of parents reported being *very satisfied* or *satisfied* with music therapy services and 60% reported that their child had not received music therapy services but they would like these services for their child (Knapp et al., 2009). Results from the study demonstrate that the inclusion of music therapy services was the "greatest predictor of parent-reported satisfaction" with the pediatric palliative care program (p. 454). These findings demonstrate a need for more music therapy services within pediatric palliative care, and demonstrate the positive effects of music therapy with the patient and their caregivers.

In a study on music therapy and family quality of life, researchers discovered numerous positive impacts of music therapy on mothers of children with Autism (Thompson, 2017). One hundred percent of participants reported that music therapy offered new opportunities to connect with their child and 50% reported that they were able to "see a different side to their children's character through their participation in music therapy (p. 445). In addition, 88% of participants reported an increase of confidence and knowledge in how to interact and bond with their child through using

music. Although this study was not specific to palliative care patients, the results demonstrate a significant impact on parent-child relationships and an overall positive influence of music therapy on mothers' of children receiving music therapy.

Music therapists may employ various music therapy techniques when working in hospice or palliative care, including receptive listening, playing preferred music, improvisation, songwriting, lyric analysis, or guided imagery. Although treatment approaches and interventions used may vary, music therapists have the unique capability of enhancing the patients' quality of life, giving opportunities for choice and control, and helping to provide an outlet for self-expression (Hilliard, 2003a; Magill, 2009). Magill's 2009 study sought to discover caregiver perceptions of music within music therapy sessions within a home-based hospice program. Participants included caregivers who had been present in at least one music therapy session with their child suffering from advanced cancer. Interviews resulted in four themes: music is a conduit, music gets inside us, live music makes a difference, and music is love (Magill, 2009). *Music is a conduit*, described the ability of music to engage and positively affect patients. Caregivers described music as having the ability to *bring back* or reveal meaningful moments or memories with loved ones. *Music gets inside us*, referred to caregivers' recognition that music was able to directly influence the patient and therefore, impact the caregiver. Caregivers described this feeling as having a wide range, from being "energized" to feeling "soothe and relaxed" (Magill, 2009, p. 36).

Results indicated themes of music therapy being used to "enhance feelings of joy, empowerment, connectedness, remembrance, and hope" (Magill, 2009, p. 35). This study



provides an important discussion into pre-loss music therapy sessions with bereaved caregivers. Magill (2009) stated:

the relevance of these sentiments is profound when considered in the context of bereavement, as caregivers are generally left with images and thoughts reminiscent to *life* and *living* again in lieu of suffering and remorse....supportive ? are administered to caregivers prior to loss can have far-reaching and long-lasting effects. These findings affirm the potential contribution of music therapy services to caregiver populations in that therapy offered prior to death could possibly serve to positively affect grief and transform time in bereavement. (p. 37)

Hilliard (2003a) outlined case examples of music therapy within an interdisciplinary team of pediatric palliative care services, and described music therapy's impact on both patient and family. In one example of a young girl with terminal cancer, the music therapy session is described as facilitating positive family interactions and "providing opportunities for the family to feel as though they were making a difference in the quality of life for their daughter" (p. 130). Other case studies contained similar notions, with parents describing the sense of normalcy that music therapy provided, as well as the opportunity for the parent to engage with their child (Hilliard, 2003a).

### **Music Therapy & Quality of Life within Pediatric Palliative Care**

In a 2010 study, researchers investigated the impact of music therapy on quality of life of families of pediatric palliative care patients (Lindenfelser et al., 2010). Fourteen parents completed the PedsQL Family Impact Module before the first music therapy session and after music therapy treatment was completed. This survey contained

questions relating to self-perceived level of physical, emotional and cognitive functioning.

Using a phenomenological approach to analysis, three global themes emerged from the data: music therapy improved the child's physical state, music therapy fostered positive experiences, and music therapy fostered family (Lindenfelser et al., 2010). Nine parents reported the ability to observe music therapy increasing their child's overall comfort, reducing distress, and providing emotional and cognitive stimulation to their child. Two parents also reported that they were physically relaxed during the sessions, showing a secondary impact of music therapy on caregivers. Ten parents described specific, positive experiences within the music therapy sessions, and six parents reported an improved quality of life from music therapy services. For example, authors quoted parents: "Music therapy helps us to focus on the main things, gets us back in family mode, and brings some smiles"; "It's something we can do together" (p. 222). Six parents reported observing their child's connection to music, including physical and emotional responses. Lastly, four parents described how music therapy allowed the family to communicate with each other more effectively, within different mediums. This study demonstrates how "parental involvement in the sessions allowed the therapeutic benefits of music therapy to extend beyond the child for some families, to include both mothers and fathers" (p. 222). Authors stated,

Parents in this study reported experiencing family-centered care with opportunities for choice and control during music therapy sessions and collaborative processes that strengthened families' own capacities...Parents reported that opportunities for choices within PPC makes a significant difference

to their experience of quality of life and these opportunities were provided during music therapy as one parent stated, ‘making choices and decision in music therapy meant a lot...and gave us some control over our environment. (p. 224)

The authors support the need for family-centered, strength-oriented music therapy when working with pediatric palliative care patients and families (Lindenfelser et al., 2010). More so, this study validates the critical role of music therapy within the palliative care interdisciplinary team, as it is a service that can provide support to the patient, parents, siblings, and other family members through flexibility and creativity.

### **Summary of the Literature Review**

The review of relevant literature reveals a need for pediatric palliative care research, music therapy, and family support. Numerous studies revealed positive outcomes for both pediatric palliative patients and caregivers when receiving music therapy services. However, many of these studies focused on bereaved caregivers or on caregivers of patients currently at end of life. Therefore, the author sought to examine parents’ experiences when observing or participating in music therapy sessions with their child.

## **Method**

Pediatric palliative care programs have the responsibility of treating both the pediatric patient and their family. Research demonstrates a need for various treatment modalities, such as music therapy, that can practice from a model of family-centered care. Research has shown that music therapy can facilitate bonding, enhance communication, and relieve stress with this population (Lindenfelser et al., 2008). Still, more information is needed regarding parental experiences of music therapy with their children. Therefore, the purpose of this study was to examine parents' experiences when observing or participating in music therapy sessions with their child.

### **Research Questions**

1. What are parental experiences of music therapy with children on pediatric palliative care services?
2. How are parents impacted by music therapy when observing or participating in music therapy sessions with their child in palliative care services?

### **Design**

As this research is designed to understand parental experiences of music therapy with pediatric palliative care patients, a qualitative design was used. Phenomenological analysis, based upon a systematic, quantitative description of organized text, was used to analyze data. When categorized, phrases of interviews are condensed into meaning units that can be organized and displayed through graphic visuals (Kvale & Brinkmann, 2009).

### **Participants**

Participants (see Table 1) in this study included parents of living children receiving pediatric palliative care. Inclusion criteria for consideration included:

- The participant's child must have received music therapy within the past five years at Primary Children's Hospital
- The participant's child must be receiving pediatric palliative care services when admitted to Primary Children's Hospital
- The participant must have been present for at least three music therapy sessions with their child
- The participant must be fluent in English

Upon meeting the participant inclusion criteria as outlined above, participants were chosen via purposive sampling (Jackson, 2016). The researcher, along with the team of two other music therapists at the hospital, decided upon families that met inclusion criteria for the study. After creating this list as a team, the researcher utilized iCentra, the electronic healthcare record at the researcher's workplace. Using this established documentation system, the researcher located identifying information of potential participants, including names and contact information. Participants were then contacted via phone call or email by the researcher, depending upon which contact information was provided. While a phone call was the preferred method of contact, email was used if no phone number was provided within the medical chart. The researcher obtained informed consent and ensured that participants understood the purpose and details of participating in the study before conducting the research (Creswell, 2014).

A total of 16 participants were contacted for inclusion in this research. Seven participants completed this study, five potential participants did not respond to the

researcher's inquiry, while four potential participants were unable to schedule an interview with researcher after verbalizing interest.

Participants of this study included seven mothers of children receiving pediatric palliative care. It is important to understand background information on each pediatric patient, as to recognize that the global themes of this study do not necessarily correlate to age or diagnosis of the patient. The pediatric patients ranged in age from two-years old to twenty-one years old, and have all received music therapy services while inpatient at a pediatric hospital. Each pediatric patient has been diagnosed with different medical conditions. Each diagnosis, as well as other pertinent medical information, is listed below, in no particular order:

Table 1

*Pediatric Palliative Care Patient Information*

Age (yrs)	Diagnosis	Symptoms/Surgeries
7	Trisomy 21	Pontine cerebellar hypotonia with progressive loss of function
11	Spastic quadriplegic Cerebral Palsy	Epilepsy; GJ and tracheostomy dependent; severe global developmental delay; scoliosis
10	Hypoplastic right heart with pulmonary atresia	Has undergone two heart transplants
2	Osteogenesis Imperfecta Type II-III	Bone fractures; respiratory insufficiencies; bilateral club feet; enteral feeding dependency
14	Neurofibromatosis Type II	Bilateral acoustic neuromas; bilateral hearing loss; cognitive deficits
9	Infantile Leukodystrophy	Spastic quadriplegia; respiratory distress; neuromuscular scoliosis; chronic static encephalopathy
21	Fetal Valproate Syndrome & Spastic Quadriplegic Cerebral Palsy	Dysarthria; muscle weakness; hydrocephalus; epilepsy; chronic lung disease; global developmental delays

**Ethical Considerations**

This study involved the participation of human subjects and thus, great consideration was taken to ensure safety of all participants. The researcher followed the American Music Therapy Association's code of ethics and the American Counseling Association's (ACA) five principles to ethical decision-making during the research

process. These included autonomy, justice, beneficence, non-maleficence, and fidelity (AMTA, 2015; Forester-Miller & Davis, 1995).

### **Recruitment Procedures**

Before beginning the study, the researcher obtained permission from two Institutional Review Boards (IRB). IRB permission was given from the researcher's workplace at a children's hospital and from Saint Mary-of-the Woods College. The researcher obtained informed consent from all participants before allowing individuals to participate in the study. This consent form included the following:

1. Title of the study
2. Description of the study and its purpose
3. Description of what participants will be asked to do
4. Description of potential risks and benefits to the participant
5. Statement ensuring that the participant may withdraw from the study at any time
6. Description of how data will remain confidential and be stored securely
7. Place for participant and researcher to sign and date the form

Participants were sent a copy of the consent form before agreeing to the research or meeting for an interview. This was to ensure that participants had adequate time to look over the consent form prior to meeting with the researcher. More so, this allowed at least two opportunities, prior to the research beginning, for every participant to voice any questions or concerns. Still, both the researcher and participant reviewed the consent form together before any research took place.

In each consent form, participants were able to indicate if they would like to be contacted for future research, and if their interviews could be securely stored to be used



for future research. All participants answered, “yes” to both of these questions. Therefore, the participants’ interviews will remain securely stored on an encrypted password-protected drive at the researcher’s workplace.

The researcher continued to monitor ethical practices to minimize the risk of harm to participants throughout all stages of the study (Cone & Foster, 2006). Additionally, all identifiable information was securely stored on a password-protected, encrypted drive. Only the researcher had access to this drive and it was stored in a locked cabinet when not in use.

### **Data Collection**

Data collection took place using a semi-structured, in-depth interview with parents of living, terminally ill children who had experienced at least three music therapy sessions with their child within the past five years. Data were collected during the interview process, as the interview was audio-recorded on two devices. The researcher transcribed each interview and offered these transcriptions them to the participants once finalized. All data and identifying information were stored on an encrypted, password-protected drive that was only accessible by the researcher (Creswell, 2014; Moustakas, 1994).

**Interviews.** A semi-structured, in-depth, and open-ended qualitative interview was conducted at the participant’s home, over the phone, or at the researcher’s workplace. The participant chose the interview location in this study, as it was important for the participant to feel comfortable and safe within the interview environment. Interviews will be audio-recorded and transcribed upon completion.

The researcher utilized an open-ended, semi-structured interview process. Therefore, the researcher was able to follow a set of relevant questions while having the freedom to let the research participant guide the discussion. Each interview lasted between 75 to 120 minutes and breaks were utilized as needed. A list of the approved questions used in these interviews is listed in Appendix A.

### **Data Analysis**

Data analysis occurred upon completion of the interview process. A phenomenological methodology based upon Giorgi (1975), Colaizzi (1978), and Moustakas (1994), as outlined in Wheeler and Murphy (2016) was used for the analysis. These steps are outlined below:

1. The researcher read and analyzed each interview transcript separately. Interviews were read through at least three times, with key phrases highlighted.
2. Key statements and phrases from each transcript were categorized into groupings, known as meaning units. These meaning units provided greater insight into the meaning of the participants' experiences.
3. Headings were assigned to each meaning unit that accurately described the meaning of the category. Sentences and phrases quoted from participants were used to demonstrate meaning units.
4. The essences of participants' experiences were highlighted through the meaning units.

A general outline of the qualitative data analysis steps, as detailed by Creswell (2014), may be found in Appendix B.

**Reliability and Validity**

Peer debriefing with the music therapy team at the hospital was used to help reduce bias. Music therapy team members were included in reading the transcripts of participant interviews and findings were shared with team members to discuss any possible bias or misinterpretation of information. In addition, as this research was completed in partial fulfillment of a master's thesis, the advisor of the study supervised the process of the researcher's data analysis via email and phone calls. This advisor challenged the researcher to enhance her data analysis until the final themes were regarded as the most accurate reflection of parental experiences of music therapy.

## Results

### Themes and Meaning Units

Although not categorized as themes, each participant detailed a difficult medical and personal journey upon the onset of their child's diagnosis. In each case, the diagnosis was unexpected, occurring either prenatally, at birth, or later in the child's life.

Participants described having to "fight" for their child – including fighting for medical answers, advocating for medical and therapeutic services, and feelings of being ignored by medical staff. Parents described their journey as one of continuous research and pushing for answers and seeking a desire to be heard by medical staff. Lastly, each parent described how their child's prognosis is unknown and unanswered. Each parent described at least one instance in which they "were not given hope" about their child and do not know what the future holds.

**Theme 1: Music therapy offered an emotional and physical reprieve to child and family.** The global meaning units from which this theme was derived were that music therapy (a) gave parents a physical break to leave their child's room; (b) provided an emotional reprieve for parents inundated with medical information; (c) offered flexibility to parent and child; (d) provided new opportunities and experiences to parent and child, and; (e) has filled a gap in the parent and child's life.

In regard to a physical break and emotional reprieve, one parent stated, "When music therapy came in, it was a break for me. I didn't have to entertain my child. I knew that he was happy. I knew that it was what he needed. And sometimes I could even leave the room because he got to the point where he trusted music therapy and I could go down the hall. I literally never left

because he just got a lot of anxiety if I would leave his room. So it was really good for music therapy to come and to have that emotional break for me.

Because emotionally, it was so nice for me to just let you guys take over for a few minutes.

Another parent stated,

To have someone else that can come in and do what I can't do, it just takes a lot of stress off of me and helps with the whole process of just dealing with what you have with your child being sick. It's almost a chance where I can take a deep breath and I'm not the one, for a moment, that has to worry. I have that time where it's not on me for a little while. And it's still in the back of my mind, I'm obviously thinking about it, but it's a stress relief. It's kind of, it's just a big, deep breath moment is the best way to describe it.

The global meaning unit of music therapy offering flexibility appeared to reflect the music therapy term, "iso-principle", defined as a "technique by which music is matched with the mood of a client, then gradually altered to affect the desired mood state. This technique can also be used to affect physiological responses such as heart rate and blood pressure" (Davis, Gfeller, & Thaut, 2008, p. 547). Numerous participants reflected upon music therapy's ability to "meet the child where they were at" – physically, emotionally, and musically. One participant stated,

The great thing about music therapy is wherever you're at, you come to us.

There were times in the hospital where my child was able to tinker around on the piano and other times where she was throwing up during music therapy. You've seen it all!

The global meaning unit of music therapy filling a gap was discovered through parent sentiments of music therapy offering a needed service for the child that could not be re-created by parents or other medical professionals. One parent stated,

Before we realized that music therapy was something we could access or something she would enjoy, it was hard. It was hard to find what could help her to calm down and not be so anxious about everything going on.

Table 2.0 in Appendix C provides a list of all quotes that represent this global theme and corresponding meaning units.

**Theme 2: Music therapy alters the child and family's perception of their situation and experience.** The global meaning units from which this theme was derived were that music therapy (a) offered re-direction from negative stimuli; (b) provided an opportunity for enjoyment; (c) provided an opportunity for self-expression and creativity; (d) helped children reach important milestones and; (e) provided the child and family with quality of life and coping.

Many participants expressed the meaning unit of music therapy offering a re-direction from negative stimuli. One parent stated,

Music therapy helps my son away from his pain, to forget the IV's that he's getting, the shunts in his head, and being stuck in a bed. I think it takes him to a place other than right there in the hospital room. It makes him think that he's important and the music takes things away.

Another parent expressed a similar sentiment, stating, "music therapy distracts him from those tough moments and gets his brain switched over to something else.

Whenever anyone from music therapy would come in, it was always like, ‘pew – maybe he’ll finally have some peace and settle down’.

In regards to music therapy offering an opportunity for enjoyment, self-expression, and creativity, one parent stated,

I loved when she started creating her own music. I think that was kind of a turning point for her too, where she wasn’t just singing lyrics to songs that brought her comfort, but she was trying to express what she was feeling inside, too. And that has proven to be a great, great coping mechanism for her.

Another parent commented,

When I think of music therapy, I think of happy memories of hard times. I think of music therapy like a ray of sunshine. It was a ray of sunshine when there are storm clouds. Like little rays of sunshine poking through.

Expressing the ability of music therapy helping a child reach an important milestone, one parent stated,

You co-treated with speech therapy for a while there and tired to get her to talk. And her first word was singing a song. I mean, no matter how many times we tried to get her to speak, it wasn’t until music therapy that she spoke her first word.

In regards to providing both the family and the child with quality of life and an avenue for coping, one participant stated,

Music therapy has really helped us understand our own emotions and cope. This is not going away at all during her life and we need to be able to make sense of how we’re feeling and music is the perfect avenue for that. It’s great and it helps

on so many levels. It helps her make sense of what is going on but it helps her cope, too. It has been a huge blessing.

Table 2.1 in Appendix C provides a list of quotes that represent this global theme and corresponding meaning units.

**Theme 3: Music therapy has a primary impact on parents of children receiving palliative care.** The global meaning units from which this theme was derived were that music therapy (a) informs and provides insight to parents regarding their child's care and well-being; (b) helps the child and family to understand their experience, and; (c) provides families with a feeling of control.

Music therapy was described as having the ability to inform parents of their child's care, understand their experience, and provide a sense of control. One parent commented,

Music therapy helped me in that time to think about what I have in my hand – a little angel that was sent to me. And I probably wasn't thinking about that. I was just trying to find the reason or why this situation was happening. But when our music therapist was playing, I just thought, 'it might be only two, three, or four years, but my son has come into my life and taught me a lot'. So when I listen to what the music therapist is singing, I apply it to my life. So I'm thinking about how beautiful life is and sometimes we just aren't enjoying what we have in our life.

Another participant stated, "music therapy makes a big difference. The music therapists are one of the things that help me understand a lot about life". Another parent commented,



I felt like even though I wasn't the music therapist and I wasn't the one providing the music, I was making sure that this was something that I could make sure was done to take care of my son. I couldn't do a lot for him and the nurses and doctors have to do everything, so I felt kind of helpless. But I can make sure that we stay on top of having music therapy come. I can make sure that continues to happen because I know he benefits from it. So that made me feel better.

Table 1.2 in Appendix C provides a list of quotes that represent this global theme and corresponding meaning units.

**Theme 4: Music therapy has a secondary impact on parents of children receiving palliative care.** The global meaning units from which this theme was derived were that (a) if music therapy helps the child, it in turn, helps the parent; (b) music therapy provides an opportunity for parents to watch their child enjoy something; (c) music therapy provides an opportunity for parents to see their child thrive, and; (d) parents saw music therapy as an opportunity for their child to be treated like a “typical child.”

Parents often described secondary impacts of music therapy with comments such as, “music therapy has made a difference in my life because it's made a difference in her life more”. Another parent's comment touched on the legacy aspect of music therapy work, as she commented,

It makes me happy because I know he is happy. And he loves music. And I can see him trying to move his eyes and he's telling me, ‘I love music, mom’. And I just think, later on, I know how I can remember him.

Participants described music therapy's ability to bring out their child's potential with comments such as, "when she was waking up, I felt like I was getting a piece of my daughter back every day. And music therapy, I think, sped that along. I got more of her back with music therapy". Another parent commented,

For me, [music therapy] is a chance to see, to have somewhat of a normal thing you would do if your child didn't have the illness and the things that she deals with. You get these moments where it's like, 'this is what it could be like or would be like in a way'.

Music therapy was also described as one of the only, if not the only service in the hospital where the child was treated like a "typical child". One parent commented, "it lifts your heart up a little bit to see your son. Like he's just getting to be a kid right now and somebody isn't just seeing him as a patient".

Table 2.3 in Appendix C provides a list of quotes that represent this global theme and corresponding meaning units.

**Theme 5: Music therapy has a continued permanence and meaning outside of music therapy sessions.** The global meaning units from which this theme was derived were that (a) children and families look forward to receiving music therapy services; (b) music therapy is viewed by families as a valued experience worthy of remembrance; (c) families recognize the therapeutic relationship as sustaining and important; (d) music therapy's importance is greater with children suffering from chronic conditions, and; (e) music therapy recordings are used outside of the hospital setting.

Participants described music therapy as having a continued permanence and meaning, even outside of the hospital setting. Parents also reflected upon the need for the therapeutic relationship between music therapist and child. One parent stated,

Besides that connection, your child is able to develop another relationship. And it's not a relationship that involves pain. If you think about it, when you're in the hospital, so much of what they are doing scares or hurts. So to have somebody coming in that's not doing those things, that is helping them to get better, is so nice. It is so nice to have somebody that helps that doesn't have to hurt them while they're helping him. I love that. I love that about music therapy.

Another participant commented,

I was surprised by the relationships that she builds with you guys. That she remembers you and you remember her so well. She'll hear you coming down the hall and she'll know and it's really nice to see the relationship built.

Participants also commented on the importance of music therapy specifically for children receiving palliative care, rather than all children in the hospital. One parent commented,

I don't think there is enough music therapists to take care of the need for an entire hospital of sick kids. And so if you're thinking, 'okay we have this amazing tool, this amazing mental health medicine, this relief, this companion, this comfort that we can bring to families' – what families need it the most? It's the families that have no end in sight to their child's suffering.

Another participant stated,

I think about it this way – if my son was in the hospital with the flu or something really sick, music therapy might be something we would do and it would be like,

‘oh that was cool, that was fun’. But for my daughter, I almost want to say it’s an integral part of her life.

Table 2.4 in Appendix C provides a list of quotes that represent this global theme and corresponding meaning units.

### **Global Essence**

Music therapy offered both an emotional and physical reprieve for parents of children receiving pediatric palliative care. Music therapists were able to build a relationship of trust with each patient, therefore allowing both the child, and the parent, to feel comfortable having a reprieve. Parents described music therapy as being one of the only times, if not the only time, where their child felt safe enough to be able to let their mother leave their room. In addition, music therapy was often a time where parents felt like they could mentally and emotionally escape the hardships of their medical journey. Participants often described this as an “escape” from difficult feelings, hard conversations, and general anxiety.

Parents described music therapy as offering flexibility to the family. This was in the form of following the child’s cues and interests in therapy, while also meeting the child at whatever physical, mental, emotional, and medical level they were at. Music therapy offered new opportunities and experiences to families, from providing an avenue for new social connections, to helping parents have the ability to interact with their medically fragile child. More so, many parents described how music therapy filled a need that they were experiencing. From not feeling heard or validated, to not having the ability to engage their child in developmental play, music therapy provided families with what they needed in that moment.

Music therapy also served to alter the child and family's perception of their experience in the hospital. Music therapy offered a re-direction to patients when they were in procedures or experiencing pain. Music therapy was often one of the only sources of enjoyment for both child and parent, and it offered an outlet for emotional expression and creativity. Parents described music as having helped them to cope with their emotions and their experiences in the hospital.

Music therapy had a primary impact on parents. A primary impact, as defined by the researcher, indicates experiences in which the parents were influenced by music therapy services, unrelated to their child. One primary impact that was described by parents included how music therapy provided insight that was otherwise unknown, or misunderstood. Parents described music therapy as helping them to understand and find "peace" in the experiences they were having and that music therapy offered a feeling of control that was rare to have in the hospital.

In addition to having a primary impact, music therapy had secondary impacts on parents. A secondary impact, as defined by the researcher, indicates a time in which music therapy impacted the parent because of the impact music therapy had on their child. Simply, if music therapy was helping the child, music therapy was helping the parent. Music therapy was described as being enjoyed by the child, thus relieving anxiety on the parent. When their children were otherwise incapacitated or misunderstood, music therapy was a time where parents saw their children thrive, communicate and communicate. Furthermore, music therapy was often the only time where parents felt like their children were being treated as well as a typically developing child would be treated.

Music therapy has continued permanence, importance, and meaning outside of the hospital. Parents described music therapy as something that the family looks forward to and misses when they are not in the hospital. Parents described their memories of music therapy with fondness, and discussed the importance of recording music therapy sessions. Parents recognized the value of the therapist-patient relationship and how that bond has continued to foster throughout various inpatient stays at the hospital. In addition, parents described music therapy as having greater importance to both them, and their child, because their child suffers from a critical illness.

## Discussion

The purpose of this study was to examine parents' experiences when observing or participating in music therapy sessions with their child. The research questions addressed in this study included:

1. What are parental experiences of music therapy with children on pediatric palliative care services?
2. How are parents impacted by music therapy when observing or participating in music therapy sessions with their child in palliative care services?

Limited research exists regarding pediatric palliative care. More so, most palliative care research is focused on hospice, bereaved individuals, or individuals at end of life. This study served to add pertinent research regarding this at-risk population to help music therapists and other medical professionals gain an understanding of how music therapy can greatly impact this population.

This researcher found that parents of children receiving both palliative care and music therapy viewed music therapy as a positive, important resource to their child and family. One hundred percent of participants stated that music therapy was aligned with the treatment goals of the palliative care team. In addition, 100% of participants stated that music therapy made a difference in their child's life and in their life as a parent.

These significant findings demonstrate the ability of music therapy to provide an increased level of care to patients and their families. HCAHPS, the Hospital Consumer Assessment of Healthcare Providers and Systems, is the national standardized assessment of patient perspectives of hospital care (Hospital Consumer Assessment of Healthcare Providers and Systems, 2018). A survey consisting of 32 questions, covering nine topics,

the HCAHPS tool generates important information that is available to other hospitals and the general public. Hospitals are under great pressure to improve patient satisfaction scores and findings from this study indicate that music therapy could improve those scores if they were measured.

Music therapy was described as having a secondary positive impact on the parent. Participants described feeling joy, relief, and comfort when seeing their child interact in music therapy. Participants also described music therapy as giving them an opportunity to see their child thrive, succeed, and act like a typical, non-hospitalized child.

These results are consistent with one finding from Thompson's (2017) study regarding family quality of life with children on the autism spectrum. Thompson found that mothers felt "relief" when seeing their child thrive in music therapy sessions. Although Thompson's (2017) study did not classify this result as having a "secondary impact", findings from the study indicated that music therapy influenced parents because parents saw an influence of music therapy on their child. In other words, as one participant stated in the current research, "music therapy has made a difference in my life because it's made a difference in [my child's] life more."

Participants repeatedly discussed the impact of their child's medical condition as causing stress, worry, anxiety, and sadness. Oftentimes, participants described these emotions as being caused by the unknown trajectory of their child's illness and the inability to bring their child comfort or relief in the hospital. Therefore, the secondary impact of music therapy on the parent of these children has great significance.



During a child's hospitalization, often a hospitalization in which the child was fighting for their life, participants described music therapy as a means for providing hope during an extremely difficult time. One parent stated, "I feel like all the music therapy interventions were helpful to me because they let me see how it took my daughter to another place." Another parent stated,

It's just comforting knowing you have those moments where your child is happy.

It's hard to describe in any other way. Just being happy in the hospital. Those two don't go together normally. And so it's just a good thing to help me feel at ease as well.

Additionally, a parent stated, "at that stage in life, I didn't know if I was doing anything right. But to see a step going forward [in music therapy], even that tiny step of being able to shake a rattle, gave me hope." These participant sentiments demonstrate the ability of music therapy to provide peace and hope for parents of hospitalized, pediatric palliative care children. These moments are extremely important for both music therapists, and other medical staff to be aware of, as the stress of hospitalization on caregivers can lead to many negative effects, such as an inability to cope, psychological issues, and prolonged grief (Knapp et al., 2010; Lane & Mason, 2014; van der Geest et al., 2014; Kreicbergs et al., 2004; Verberne et al., 2017). Therefore, these findings indicate that music therapy's positive effect on parents could help mitigate the negative impact of hospitalization.

In addition to positive secondary impacts of music therapy, participants described positive primary impacts of music therapy. Parents stated that music therapy helped

inform the parent about their child, helped them to understand their own hospital experience, and offered a sense of control in an otherwise uncontrollable environment.

Music therapy was described as an opportunity for parents to see their children excel, to thrive, and to enjoy themselves in a difficult environment. More so, participants described music therapy as having a continued meaning and permanence in their lives and their child's lives. The notion of legacy, a concept that was not brought up by the researcher in the interview questions, was often discussed throughout these reflections. One parent stated,

This might sound morbid to you, but when I think about, 'what if my child were to pass away, what would I do?' I would totally want music therapy to play at my child's funeral because you guys have been an important part of his life. So to put things into context, you only put the most important people on the funeral program.

Another participant commented,

We know we always want music therapy because we know what it does. And it's something we always carry through. We always have that in our lives because we know what helps and what works for him. We always know that it will be part of our lives. And I've always imagined it being a big part up until the very end.

This finding of music therapy's ability to provide parents with cherished memories, memorabilia, and experiences echoes the findings in Lindenfelser et al.'s (2008) study. In this study, researchers discovered that music therapy provided parents with "treasured memories" of their child that had passed. Still, it should be noted that parents of the current study recognized the "legacy" ability of music therapy pre-bereavement. This

recognition is valuable, as music therapists may choose to create interventions based on the ability to give parents' tangible "legacy" items in preparation for the child's passing.

Parents also described their music therapist as someone who could truly see their child for who they were, regardless of their cognitive, physical, or medical condition. Participant sentiments often reflected upon music therapy's ability to provide the core moral principle of autonomy, "the principle that addresses the concept of independence...allowing an individual the freedom of choice and action" (Forester-Miller & David, 1996, p. 2) One parent stated,

I think when anyone takes the time to really get to know your kid when no one else has, and comes in when he's struggling like that, it's amazing...we don't expect someone to pay attention to him or look for his cues. Someone who is trying to get to know what he likes and dislikes.

Another participant commented,

I got to see him be the little social butterfly that he is. And seeing that people understand him and that they talk to him, instead of saying, 'well mom, does he do this? Does he do that?' And you would give him choices so that it made him feel important.

These participant comments demonstrate the ability of music therapy to provide children with autonomy in the hospital – regardless of their age, medical condition, or abilities. By providing autonomy through music therapy, both the child and their caregivers are benefitting.

Music therapy was also described as having helped to inform parents of their medical decisions and how their child was progressing in the hospital. One parent stated,

it's a constant stress trying to figure out, trying to keep them happy. It's always kind of a guessing game but when music therapy is there, it's not a guessing game. She is just happy and we know it. And so we have that piece of time where we know that this is something she looks forward to and is happy about.

This ability of music therapy to help inform parents of their decision-making within the hospital setting is crucial. Previous research shows that a hospital admission of a child with a life-limiting illness often causes an overwhelming amount of stress and anxiety in parents. These negative impacts can be observed in decision-making, comprehension, and overall care (Foster et al., 2016; Horne-Thompson & Grocke, 2008). Music therapy can help to not only alleviate stress and anxiety in parents, but to help in their comprehension of care, and confidence in decision-making.

### **Interdisciplinary Team**

The researcher believes that the dedicated commitment of involving music therapy as part of palliative care's interdisciplinary team is a form of best practice in this setting (Clark et al., 2014; Hilliard, 2003a). One of the reasons music therapy may have helped inform parents of their decision-making in the hospital could be due to the music therapy team's role in the hospital.

At the researcher's hospital, music therapy is staffed with four full-time therapists and two part-time therapists who all serve as part of the interdisciplinary team with palliative care. The Rainbow Kids Palliative Care Program (RKPC) is staffed with a pediatrician, nurse practitioner, nurse manager, social worker, and chaplain. Committed to interdisciplinary practice, RKPC staff work together on cases and music therapy is consulted when appropriate. Once music therapy is involved, weekly interdisciplinary

meetings are held for all staff to discuss the patients, their needs, and how to best support the family.

As patient needs are often complex, a combination of many medical practices and specialized health professionals are valued (Hyson & Sawyer, 2001). Through this high level of involvement, music therapy staff can help give parents a voice at the team level, rather than acting as an outside consultant with limited knowledge of the patient's whole health.

Although previously published literature has touched upon the impact of music therapy with parents of children receiving music therapy, there has been no published literature specifically researching music therapy's impact on parents of living children receiving pediatric palliative care. Some of the themes found in this study are consistent with other music therapy literature examining the effect of music therapy with bereaved parents, including themes of altering the child and family's perception of their situation, providing a means of coping, and offering an opportunity for expression, creativity, and enjoyment (Lindenfelser et al., 2008). Still, no published literature has purported that music therapy has both a primary and secondary impact on parental caregivers of pediatric palliative care patients.

Parents described music therapy as a positive, memorable experience that has had lasting effects outside of the hospital sessions. All participants described a desire for receiving more music therapy during their hospital stay and to have access to music therapy in outpatient medical settings and the community. In addition, parents expressed a sense of gratitude and thankfulness for the music therapy services they received. In addition to stating that music therapy was a "blessing", numerous participants indicated

that they agreed to participate in this study because of how grateful they were to have received music therapy.

### **Limitations**

This phenomenological study sought to investigate the impact of music therapy on parents of children receiving palliative care. In this study, the researcher often played a dual role as being both the researcher and the music therapist of the participant's child. This could have impacted the reliability of the information collected through the open-ended interviews. It is possible that parents wanted to state only positive memories of music therapy to offer non-offensive, socially acceptable, commentary. If an outside researcher had conducted the interviews, parents may have felt more open to discussing any negative memories or impacts of music therapy they may have experienced. However, because the researcher was also the music therapist for many of the participants, this could have helped parents feel more open and trusting in sharing their true opinions of music therapy. As 100% of parents mentioned the importance of the therapeutic relationship during their interview, the researcher believes that this dual role was primarily beneficial, as parents may have felt more expressive and open because of their established rapport with the clinician.

The recruitment procedure of using purposive sampling may have impacted the validity of the results, as the researcher specifically chose potential participants to contact. However, due to the various restrictions of possible participants, it may have been more harmful to advertise the study. For example, if the researcher had posted this study in the pediatric palliative care parental group, parents that did not meet the study qualifications may have asked to be in the study. As the researcher was not an outside

investigator and was often the music therapist for these parents, this could have hurt the therapeutic relationship and efficacy of therapy in the future. In addition, purposive sampling is often the recruitment method used in phenomenological studies (Wheeler & Murphy, 2016). In this case, it was important to the researcher that a range of ages and diagnoses were included, as to help demonstrate that the commonalities among participants were not due to their child having the same illness.

While the researcher did not intend for only mothers to be included in this study, the majority of eligible participants, via the inclusion criteria, were mothers. In the researcher's experience in the hospital setting, mothers were often the main caregivers of the hospitalized children. Frequently, fathers were unavailable during music therapy sessions due to other obligations such as work and caring for other siblings. More so, if both a mother and father of one patient met inclusion criteria, the participant was chosen based on who had been present for more music therapy sessions.

Additional participant limitations of the study include the exclusion of participant information such as age, race, and socioeconomic status. This information was not requested from the participants and therefore this demographic data are not in the study. In a future study, it is encouraged for additional participant information to be gathered and for fathers to be included in the research, as they will offer a different perspective of their experiences with music therapy and would add to the results of the study.

## **Conclusion**

The parents who participated in this study shared invaluable information and insight into their experiences of music therapy with their child receiving pediatric palliative care. Results of the study demonstrate that music therapy has a powerful,

positive impact on children receiving palliative care, as well as on the parents who are supporting their child through this process.

Previously published literature studying palliative care has often focused on the adult population or bereaved caregivers. Therefore, there is a huge need for continued research specifically with the pediatric population, especially with children who are still living and receiving palliative care services. Unlike hospice, palliative care can be implemented throughout one's lifespan. With medically complex patients, palliative care is implemented throughout the trajectory of an illness – from times at end-of-life to times of stability, to everything in-between. So, with such diverse courses of illness and corresponding needs, why do most palliative care studies only focus on patients at end-of-life or on bereaved families? Results from this research clearly indicate a need for a broader range of topics to be researched with the palliative care population.

The findings of this study indicate positive primary and secondary impacts of music therapy on pediatric palliative care caregivers. These results can help inform best practices for music therapists and for other medical professionals in the pediatric hospital setting. More so, these results indicate the need for, and positive impact of, music therapy as part of the interdisciplinary medical team.

With this information, music therapists have the ability to tailor music therapy interventions and goals to be family-centered, with a focus on parental involvement in sessions. The ability of music therapists to assess and treat the child in the moment, regardless of what hardship is occurring medically, has been shown to be of extreme importance to caregivers. Whether the music therapist is focusing on physical, social, emotional, or cognitive goals, results of the study demonstrate that what is most



important to caregivers is treating their child with autonomy, assessing the primary need of the patient in the moment, tailoring each session to the unique needs of the patient. Through these actions, it is assumed that a strong therapeutic relationship will be formed, thus serving to strengthen the therapy process and allowing for trust of the patient and caregiver to develop.

Music therapy should be viewed as an essential resource to patients and families receiving palliative care. Music therapy uses a flexible, adaptable approach to serve the needs of patients and families throughout their continually changing, life-limiting illness. In addition, music therapy proves to enhance the concept of a family-centered, interdisciplinary team approach to care. Through family-centered care, music therapy can enhance the life of a patient and family during a hospitalization and has been shown to have a lasting impact outside of the medical setting.

### **Implications for Future Research**

More research is needed regarding the pediatric palliative care population. Future research could include working with pediatric palliative care patients who are old enough, and cognitively aware enough, to engage in an interview about their own music therapy experience. Future research could also look into the impact of music therapy on the siblings of pediatric palliative care patients from both individual sessions to family-centered sessions. More so, a study regarding music therapy's impact on patient satisfaction scores could have a significant impact on future music therapy employment. Lastly, there is a greater need for research that involves families of patients who are still alive. As most of the research is on bereaved individuals, there is a lack of understanding into the hourly, daily, and weekly needs of families who have medically complex

children. Professionals need to know how to help these families now, not just in a time of bereavement.

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## APPENDIX A

## INTERVIEW QUESTIONS

**Background: Let's start with some background information on you and your child**

1. Can you tell me about your child's illness?
2. Where is your child in the process of his/her journey right now?
3. What are some of the challenges you face?

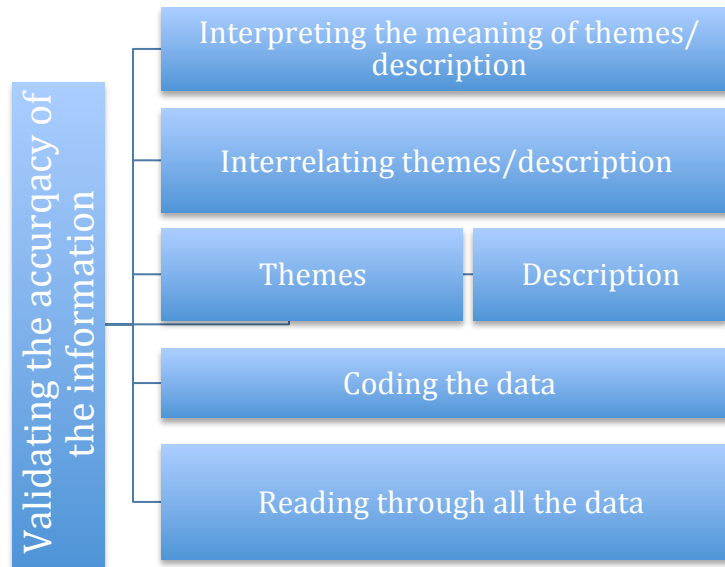
**Experiential: Music Therapy History**

4. What comes to mind for you when you think about the music therapy services your child received in the hospital?
5. Are there any music therapy sessions that specifically stand out for you? Can you tell me about those session(s)?
  - a. How did those sessions impact you?
6. Was there ever something in a session that you wanted to record?
  - a. Why was recording that important to you?
  - b. If you recorded it, have you gone back to look at those videos?
  - c. Have you shared them with anyone else? What was their response?
  - d. How has that impacted your life?
7. Are there any specific music therapy interventions that were helpful to you personally? (For example: songwriting, listening to music, making music together, etc.)
  - a. In what way were they helpful to you?
  - b. Why does that session/intervention stick out for you?



8. Knowing your child has a serious condition, how has this impacted the way you view music therapy services? (Does knowing that your child has a complex, chronic condition impact the way you view music therapy services?)
9. In general, how do you think music therapy fits in with palliative care?
10. Have you seen an impact of music therapy on your child? How does that experience impact you?
  - a. Physically
  - b. Emotionally
  - c. Spiritually
11. Was there anything unexpected about your own personal experience with music therapy?
12. Is there anything you wished you could change about the music therapy services your child received?
13. Is there anything within music therapy that you think could be helpful in the future for you?
14. Do you feel like music therapy has made a difference in your child's life?
  - a. Tell me about that
15. Do you feel like music therapy has made a difference in your life?
  - a. Tell me about that
16. Is there anything else you want to say/anything else that you would like me to know?

## APPENDIX B

CRESWELL'S TABLE FOR DATA ANALYSIS IN QUALITATIVE RESEARCH  
(Creswell, p.197)

## APPENDIX C

Table 2.0

*Data Categorized as: "Music therapy as a Reprieve"*

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Interview Quotes

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"Music has helped this little man and that's his escape"

"Music therapy is very helpful. It gives the kids an escape, it gives them something to look forward to"

"These kids don't have any other options and music helps give them reprieve. It gives them a way to express themselves. To feel something different than maybe just the care they're receiving or the situation that they're in. It can take them to a different place and while the music is going, they know they're safe"

"When music therapy came in, it was a break for me. I didn't have to entertain my child. I knew that he was happy. I knew that it was what he needed. And sometimes I could even leave the room because he got to the point where he trusted music therapy and I could go down the hall. I literally never left because he just got a lot of anxiety if I would leave his room. So it was really good for music therapy to come and to have that emotional break for me. Because emotionally, it was so nice for me to just let you guys take over for a few minutes"

"Music therapy was a breakaway. It was fun, it was happy, it was relaxing. Sometimes it was like a party. And like, 'let's just be forget about all of this sad, scary, stressful crap and let's just be happy and have fun'"

"Sometimes you just don't want to talk about your feelings. And sometimes you want to be distracted by your feelings. And I felt like that's what music did. Let's just stop talking about why we're here and just feel good. And it was so, so cool"

"Music therapy makes these kids happy, and their families, too. It's something different; not the same thing every day or our routine with them. Something different that makes them happy and relaxed and to forget where we are with everything"

"As a parent, there was no stress or worrying about having to perform. Because when physical or speech there comes in, there's a certain amount of anxiety that a parent feels because you're hoping that your child can perform and advance. But with music therapy, there are not those tasks that the child has to do. And so as a parent, I'm less anxious'

"It's really nice to be able to just enjoy and not feel like I have to always sing, too. It's nice to just sit back and enjoy the moment and admire it. Because with almost every

other thing we do with her, either mom or dad has to help initiate it or help to be part of the play”

“I feel like music therapy was for the parents every bit as much as for the kids. It was an emotional and even a physical break for the parents. Caregiver burnout, I feel like, is such a real thing and to be able to go down the hall and go to the bathroom or to be able to just sit in the room and not feel like you have to entertain your child because music therapy is there and they’re happy and getting what they need in that moment – that is huge for parents. It’s huge”

“To have someone else that can come in and do what I can’t do, it just takes a lot of stress off of me and helps with the whole process of just dealing with what you have with your child being sick. It’s almost a chance where I can take a deep breath and I’m not the one, for a moment, that has to worry. I have that time where it’s not on me for a little while. And it’s still in the back of my mind, I’m obviously thinking about it, but it’s a stress relief. It’s kind of, it’s just a big deep breath moment is the best way to describe it”

“The great thing about music therapy is wherever you’re at, you come to us. There were times in the hospital where my child was able to tinker around on the piano and other times where she was throwing up during music therapy. You’ve seen it all!”

“What I loved about music therapy was that each session was so tailored to what he needed”

“I was surprised by the un-traditional ways that music can be therapy. And in my son’s case, more often than not, it was the active expressions of using musical instruments for therapy. In whatever ways he needed”

“Music therapy gives the kids a chance to experience something different. It gives them a chance to try something new. Music opens new doors that maybe wouldn’t be opened up otherwise”

“We couldn’t hold him. I couldn’t play with his arms or legs. All I could do was read or talk to him. I couldn’t provide music therapy to him. I could not provide that kind of care as his mom. And neither could the doctors, nurses, or other therapists. It was something that only the music therapists could provide for my child. And he needed that. Hands down, he needed that.”

“Music therapy has brought a lot into our lives. I know when the hospital didn’t have it, it was like, ‘okay, we are searching for something’”

“Before we realized that music therapy was something we could access or something she would enjoy, it was hard. It was hard to find what could help her to calm down and not be so anxious about everything going on”

“We’re super grateful. Music therapy is something we can’t do, you know? It’s different and it’s soothing in it’s own way. And it’s therapeutic in it’s own way. And it’s something that parents cant offer, you know?”

“It’s very hard for families at the hospital and giving this therapy helps us to feel better when we are there in our hard time”

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Table 2.1

*Data Categorized as: "Music therapy alters the child and family's perception of their situation and experience"*

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Interview Quotes

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"Music therapy helps my son away from his pain, to forget the IV's that he's getting, the shunts in his head, and being stuck in a bed. I think it takes him to a place other than right there in the hospital room. It makes him think that he's important and the music takes things away."

"We see her not having to focus so much on her body. To just have a moment where you see her heart rate lower or if it does raise, it's because she's laughing and having fun. And to see that change in her for that time that she has music therapy in her room is huge. That's huge in the healing process because you have something to look forward to, you have something to keep the mind, as well as your body, busy"

"Music therapy has come in and played for him and soothed him. And he was able to go to sleep and it distracted him from whatever was going on and helped him calm down so he could rest"

"Music therapy distracts him from those tough moments and gets his brain switched over to something else. Whenever anyone from music therapy would come in, it was always like, 'pew - maybe he'll finally have some peace and settle down'"

"When he is in pain or in a hard time, if I play the music therapy recordings close to him, it helps him relax. And sometimes he has tears in his eyes. Sometimes he holds my hand like he's saying, 'we're not lonely'"

"When I think of music therapy, I think of happy memories of hard times. I think of music therapy like a ray of sunshine. It was a ray of sunshine when there are storm clouds. Like little rays of sunshine poking through"

"As soon as music therapy comes in, she lightens up. And it is something we look forward to when we're there"

"It's kind of hard to put into words but just how she lights up during [music therapy] and how she looks forward to it"

"It made him so excited and happy to have the attention just geared toward him. And it was something that he could enjoy because there's not a lot of other things he could enjoy. This was something that could entertain him and have fun with and he didn't have a lot of other things. So that was the highlight of his day - having music therapy come in"

“It’s imaginative play for her as well. It’s a chance for her to, like we did as kids, like wanting to be part of a band, pretending to be part of a band – she gets that opportunity”

“I loved when she started creating her own music. I think that was kind of a turning point for her too, where she wasn’t just singing lyrics to songs that brought her comfort, but she was trying to express what she was feeling inside, too. And that has proven to be a great, great coping mechanism for her”

“It was an outlet for him. It was an outlet for my child and something different. And it was a way for him to use his creativity”

“When I go to the hospital, I always worry about what they are saying to me or where I am with my son. So it’s hard. Music therapy helps me sometimes by taking all of my emotions and sadness. Sometimes I just cry and cry and after that, I just have to keep going. It helps me to let out all of my emotions”

“You co-treated with speech therapy for awhile there and tired to get her to talk. And her first word was singing a song. I mean, no matter how many times we tried to get her to speak, it wasn’t until music therapy that she spoke her first word”

“There were many times where my son would reach a new milestone, a new goal on his heart rate or respiration rate because the music therapist was there playing for him. He would hit his ne lows and then we would start to see them stay that way a little bits longer and then, maybe during our next admission, the music therapist would come and we would see a new low that we had never seen before”

“For my son to be able to shake that rattle and shake it with the music therapist, that was cool. For him to be able to do that, because before then, he couldn’t pick up or handle or manipulate a toy”

“Another moment was when we came upstairs and played the piano for the first time and she was remembering some of the pieces that she had practiced so many times before this happened. And with her right side paralysis, it broke our hearts to see [her struggling] but at the same time, that started a spark of, ‘okay I need to get this hand working, this hand has a purpose, a very functional purpose’ and that was probably the first I think that she made that connection to, ‘I need this to work to heal but to do things I enjoy, too’”

“Music therapy was a big part of his life as a toddler. That was equally as important as any of the milestones that he would have had, had he not had these heart issues in the hospital. And music therapy emotionally helped him meet those milestones in the hospital”

“What comes to mind when thinking about music therapy is probably the coping. An avenue to help not only the patient, but the families to cope and wrap their brings

around something that they can. Because when you're in the moment, it's really hard to make sense of what's going on. You just can't. It's really hard. But music therapy, it kind of takes you out of that element for the half and hour that you're there. And helps you to find enjoyment"

"Music therapy helps those kiddos and families to have just one more tool in their toolbox and to cope and to put their feelings into words"

"Music gives the kids an escape or something to climb into that helps them cope with whatever they need to or how they're feeling"

"My son's outcome could have been so different because of so many different variables that music therapy had a direct influence on. So we're just grateful. That's one of those quality of life things, you know?"

"Music therapy has really helped us understand our own emotions and cope. This is not going away at all during her life and we need to be able to make sense of how we're feeling and music is the perfect avenue for that. It's great and it helps on so many levels. It helps her make sense of what is going on but it helps her cope, too. It has been a huge blessing"

"If my son was unhappy or depressed or wasn't loving his experience, or if it wasn't a quality of life, we may have made different decisions. So music therapy was one of those things that helped him reach those milestones"

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Table 2.2

*Data Categorized as: "Music therapy has a primary impact on parents of children receiving palliative care"*

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Interview Quotes

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"I think it brings comfort. It brings comfort to see that we know something that interests her, we know something that can help her, and something that she enjoys"  
 "Most kids would want to play or want toys but with these kids, sometimes you don't know what calms them, you don't know what can help them. And so knowing what helps her, what can relax her, what can be supportive to her medical needs as well"

"It's a constant stress trying to figure out, trying to keep them happy. It's always kind of a guessing game but when music therapy is there, it's not a guessing game. She is just happy and we know it. And so we have that piece of time where we know that this is something she looks forward to and is happy about"

"I got in fight with the intensive care unit doctors and music therapy would come in and the doctor would say, 'we're not sure if he's listening'. Well, you could see a difference in my son's saturations, his monitor- - the little man was there. And it helped him to calm"

"I remember being in the pediatric intensive care unit. I remember which room it is and everything, and we were so worried about his pain. I remember the music therapist playing for him and I was so worried about his heart rate and his respiration rate and I'm just like, 'crap', because we're trying to make sure we did the right thing by getting him a tracheostomy. And I went for the tracheostomy but I was so, so worried because I kept thinking, 'why has this not gone down? Did I make a mistake? Did I fail him by making this decision?' And the music therapist was playing for him and he was asleep, just lying there. But his heart rate and respiration rate kept dropping, lower and lower. And I was like, 'oh my gosh, okay good. Okay it's just because he's trying to recover and it's not because this new system is going to fail him'"

"We know we always want music therapy. Because we know what it does. It's something we always carry through. We always have it in our lives because we know what helps and what works for him"

"At that stage of life, I didn't know if I was doing anything right. But to see a step going forward [in music therapy], even that tiny step of being able to shake a rattle, gave me hope"

"I felt supported through the process because sometimes I didn't know what to do. Because emotionally you're just drained. And when other people know your child and know what they need, too, you just feel that support as a parent"

“Music therapy has made a difference in my life because it helps me be able to sit back and reflect”

“Music therapy forces you to put words to what you’re feeling if that makes sense. And when you hear songs or try to create music, it kind of takes it out and let’s you see what you’re experiencing. It takes the infection out and makes you look at it. It takes out all the stuff you don’t know how to deal with”

“Music therapy helped me in that time to think about what I have in my hand – a little angel that was sent to me. And I probably wasn’t thinking about that. I was just trying to find the reason or why this situation was happening. But when our music therapist was playing, I just thought, ‘it might be only two, three, or four years, but my son has come into my life and taught me a lot’. So when I listen to what the music therapist is singing, I apply it to my life. So I’m thinking about how beautiful life is and sometimes we just aren’t enjoying what we have in our life”

“I was having a lot of questions with no answers. And when the music therapist came to the room and started singing, I just thought, ‘I have to enjoy day by day with my little boy”

“I was surprised by with how much I’ve learned to be able to express myself better. That I don’t care what other people think. That I can sing off key because I haven’t sang for so long but at least I’ll sing while music therapy people are there”

“Music therapy makes a big difference. The music therapists are one of the things that help me understand a lot about life”

“Music therapy makes our life a little bit easier with where we are at. I think that my son and I, we have found in music, the peace that we need in that moment It helps me to understand, maybe not all, but part, of where our situation is and teaches me to enjoy every moment with my son.

“Even if my son was asleep and completely zonked out or on heavy pain medicine and wasn’t even aware of what was going on, for me to sit there and listen to the music therapist be relaxing, playing relaxing, sot lullaby music to my son – I wanted to close my eyes and just go to sleep as well”

“Music therapy gives me peace and hope, sometimes. It helps me to think that life is just once and we have to enjoy it all the time”

“Initially I felt guilty for listening to music because she was deaf and couldn’t hear it. And I thought, ‘shame on me. Shame on me for enjoying something she can’t enjoy’. But now I’m starting to sing again in the car, with the radio on, and music is starting to make more of a difference to me, too. It’s become more of a coping mechanism. And I don’t think that I would have arrived at that point. I may have eventually but music therapy helped me reach that point a lot sooner”

“I felt like even though I wasn’t the music therapist and I wasn’t the one providing the music, I was making sure that this was something that I could make sure was done to take care of my son. I couldn’t do a lot for him and the nurses and doctors have to do everything, so I felt kind of helpless. But I can make sure that we stay on top of having music therapy come. I can make sure that continues to happen because I know he benefits from it; so that made me feel better”

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Table 2.3

*Data Categorized as: "Music therapy has a secondary impact on parents of children receiving palliative care"*

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Interview Quotes

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"I feel like so many of my emotions are tied into her emotions. When she is having a good day, I'm having a good day. When she is happy, I am happy. And when I see her frustrated, my heart aches for her. So when I'm watching her and watching music, or listening to music as I watch her go through these experiences, it has been comforting. It really has been a good experience. And to see how much it means to her, too, has been great"

"When you have that time where music therapy comes in and I see my daughter light up and see the reaction as soon as she sees you guys...as soon as all that happens, seeing her relax and seeing her happy, to me, it immediately kind of relaxes me. It let's me see that my child is happy and that she has these moments during the day where she is happy and she is good. It does a lot for her and in turn, that does a lot for me. It helps me to relax; it helps me not to worry. That's my time where I'm not worried about her because I can see that she is in a good place so it kind of resets everything for us for a bit"

"It makes me happy because I know he is happy. And he loves music. And I can see him trying to move his eyes and he's telling me, 'I love music, mom'. And I just think, later on, I know how I can remember him."

"Hearing about music therapy coming in and having a positive effect on him is such a great relief. I instantly go home and I'm able to say, 'well thank goodness he was having such a tough time but we're so grateful because luckily music therapy came in and was able to calm him down'. It's a calm relief feeling. You're just extremely grateful for those moments"

"It's just comforting knowing you have those moments where your child is happy. It's hard to describe in any other way. Just being happy in the hospital. Those two don't go together normally. And so it's just a good thing to help me feel at ease as well"

"It makes me feel good that something can take him somewhere; that it's hitting a place in him that he's comfortable enough to express himself without caring or worrying about what other people see or hear"

"What surprised me is just how my child had personally responded to music therapy. And what it did for him. And I think my reaction to that"

"I'm happy if my flock is happy. So if my husband is doing great and my kids are going great, then I'm great. I'm fine. So if my son is doing good, then I'm good. And

so, that's how music therapy affected me. If my son was doing good, I was good. And that's all I needed. I needed him to not be stressed and not frustrated that he was stuck in a hospital. And during music therapy, he was good. So I was good."

"I feel like all the music therapy interventions were helpful to me because they let me see how it took my daughter to another place"

"Music therapy has made a difference in my life because it's made a difference in her life more"

"It made me feel good because I knew he was still in there fighting. I knew that he was going to be okay because he was enjoying something that meant something to him"

"Music therapy is something we look forward to when we're there. And it's also a big stress relief for me too, because I know that she's going to have that time where she's going to be happy and enjoys it"

"It's amazing because I get to see this little guy that's just like, 'hey, that's me! That's what I like!' So to see him laugh and giggle and see those things and know that he understands what was going on and that I recorded them – I'm glad I did because those are things that you can't bring back"

"It's wonderful because I get to see a little man that...my child doesn't communicate like other people do. But you bring him alive"

"For me, it's a chance to see, to have somewhat of a normal thing you would do if your child didn't have the illness and the things that she deals with. You get these moments where it's like, 'this is what it could be like or would be like in a way'"

"When she was waking up, I felt like I was getting a piece of my daughter back every day. And music therapy, I think, sped that along. I got more of her back with music therapy"

"He would socialize, even just through facial expressions with the music therapist. And that was really cool. Because even occupational therapists and physical therapists coming into the room to work with couldn't get him to socialize or get him to react. But he did with music therapy"

"I got to see him be the little social butterfly that he is. And seeing that people understand him and that they talk to him, instead of saying, 'well mom, does he do this? Does he do that?' And you would give him choices so that it made him feel important"

"I just want to make sure that she knows she's cared for. And that she's heard. That's the big thing – to make sure she's heard. And so when music therapy comes in, it's a

chance for her to be heard. It's not as difficult for her to express what she wants, what songs she wants, what musical instruments she wants. It's just a chance for her to have a voice"

"It lifts your heart up a little bit to see your son. Like he's just getting to be a kid right now and somebody isn't just seeing him as a patient"

"I think when anyone takes the time to really get to know your kid when no else has, and comes in when he is struggling like that, it's amazing. I mean, first of all, talk about emotional. That catches parents by surprise because we definitely don't expect something like that. We don't expect someone to pay attention to him or look for his cues. Someone who is trying to get to know what he likes and dislikes"

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Table 2.4

*Data Categorized as: "Music therapy has a continued permanence and meaning outside of music therapy sessions."*

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Interview Quotes

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"When you guys came, it was the highlight of his day. That was the time when he didn't want anybody bugging him and that was his music time"

"That was the highlight of his day - having music therapy come in"

"Recording was important to me because I wanted to have those memories because I didn't know how long I would have him"

"When I look at the recordings, I get to watch the little man and see how special he was and still is. I see the change from what has happened until now. And I see that little boy who was so happy of life, and that still is, who struggle snow. And it's hard to see that he has lost so much. But how much he still has left to give"

"Music therapy is one of the things that my son talks about. He talks about it all the time"

"It's definitely one of our top things we have for memorabilia for my daughter. Those moments because we get to see her so animated. She's much more animated than she is at any other point in her life when you're enjoying music with her"

"It's important for me to record sessions because of the memories. My hard times at the hospital. And because I know he loves to hear music, listen o music. And sometimes when I'm at home, I play the music to him or I show him and I talk to him"

"He still talks about his experiences in the hospital. And I know if he were ever to be inpatient again, that he would want music therapy in his life always"

"To see him laugh and giggle and see those things and know that he understands what was going on and that I recorded them. I was glad I did because those are things that you can't bring back"

"This might sound morbid to you, but when I think about, 'what if my child were to pass away, what would I do?' I would totally want music therapy to play at my child's funeral because you guys have been an important part of his life. So to put things into context, you only put the most important people on the funeral program"

"It meant a lot to him to have his music. And someone who cared actually about him and was there for him. Not to poke him, not to prod at him"

“I was surprised by the relationships that she builds with you guys. That she remembers you and you remember her so well. She’ll hear you coming down the hall and she’ll know and it’s really nice to see the relationship built”

“I was surprised by the connection that the music therapist would make with my child. Like I knew that, the music therapist didn’t have to say it, I knew that he cared about my son’s wellbeing. And I knew that he cared about the progress that my son would make”

“The relationship that you guys get with those patients is so important. They need you. They need you so much. It’s so important”

“My son has a special connection with his music therapist. He a very special connection with her and we love her a lot”

“To have that little bit of time that’s not a bother, that isn’t someone bugging you, that isn’t someone that’s going to cause pain – that is some nice, relaxing time – you can see it as she get’s older. She knows when you guys are coming and she knows that this is precious time”

“Besides that connection, your child is able to develop another relationship. And it’s not a relationship that involves pain. If you think about it, when you’re in the hospital, so much of what they are doing scares or hurts. So to have somebody coming in that’s not doing those things, that is helping them to get better, is so nice. It is so nice to have somebody that helps that doesn’t have to hurt them while they’re helping him. I love that. I love that about music therapy”

“I think about it this way – if my son was in the hospital with the flu or something really sick, music therapy might be something we would do and it would be like, ‘oh that was cool, that was fun’. But for my daughter, I almost want to say it’s an integral part of her life. She’s at the hospital so much that when you go to the hospital, music therapy is something to look forward to. And it gives her a chance to be more like another child, you know?”

“I think music therapy is essential because this isn’t going away. I really do. I mean, it’s not going away. It’s always going to be with her. And we need as many things as we can. She needs those, she needs to find enjoyment in everything that she can, she needs to explore the world and she many not be able to enjoy certain things because of her limitations, but music is something that she definitely can enjoy. And can benefit from, too. Because it is not going away, we can use music therapy to our advantage”

“If I knew that this was something that my son is going to outgrow, if I saw it like that, I would see music therapy as fun and entertaining or that it’s something that is helpful while we’re at the hospital. But knowing that that is not the case, it’s special”



“I don’t think there is enough music therapists to take care of the need for an entire hospital of sick kids. And so if you’re thinking, ‘okay we have this amazing tool, this amazing mental health medicine, this relief, this companion, this comfort that we can bring to families’ – what families need it the most? It’s the families that have no end in sight to their child’s suffering”

“He loves to see the those music therapy recordings. He loves rocking to them, he giggles at them. So yeah, those videos meant something to him because he gets to see himself and exactly what he was going. So for him, it’s awesome”

“We watch the recordings all the time. Sometimes it’s just the entertainment, other times it’s the calming. It just kind of relaxes her.”

“It was a few weeks ago and I said, ‘every time you feel that pain, because it is not going to go away, why don’t you sing your song in your head?’ and that’s been a great tool she’s had in her toolbox to take her mind off of what she can’t control”

“We know we always want music therapy because we know what it does. And it’s something we always carry through. We always have that in our lives because we know what helps and what works for him. We always know that it will be part of our lives. And I’ve always imagined it being a big part up until the very end”

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