A Music Therapy Program Proposal for Pediatric Palliative Care in Hospice

by

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A Music Therapy Program Proposal for Pediatric Palliative Care in Hospice

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Statement of Need

The purpose of this proposal is to provide a framework for Hudson Valley Hospice to add music therapy as a treatment option for the children and adolescents they serve. Pediatric palliative care is a rapidly expanding field in American healthcare (Hildenbrand et al., 2021). The majority of pediatric palliative care programs in the United States do not meet practice standards set forth by The American Academy of Pediatrics. This means current pediatric palliative care programs are not providing patients and families with 24-hour availability and staffing that includes physicians, nurses, social workers, and chaplains (Rogers et al., 2021). Additionally, the lack of clinical units, funding, and the field's ever-changing nature have a negative impact on pediatric palliative patients’ and their families’ care needs.

Maureen McCarthy, head of the Palliative Care Program at Hudson Valley Hospice reports that there are only a handful of pediatric patients who receive palliative care or hospice services in their service area. At the time of this writing there are only three pediatric patients receiving hospice services from Hudson Valley Hospice. She believes that there are lots of treatment options for children and most of them focus on curative care. However, many of the children are supported by hospices that are closer to the pediatric hospital who oversees their care. Ms. McCarthy went on further to suggest that adding a pediatric palliative/hospice care program would distinguish Hudson Valley Hospice from other providers. Further, a pediatric palliative care program would allow for specialized, patient-centered care (M. McCarthy, personal communication, February 21, 2022).

Creative art therapies, including music therapy, are often included in pediatric palliative care. Canuck Place Children's Hospice in British Columbia, Canada, is North America's first freestanding pediatric hospice that provides both palliative care and music therapy (Clark et al., 2014). Partners in Care: Together for Kids (PIC: TFK) in Florida is the first publicly funded
program to provide music therapy services to children and their families with life-threatening illnesses (Knapp et al., 2009). Minnesota's Children's Hospital and Clinics also have a pediatric palliative care program that includes music therapy (Lindenfelser et al., 2011). Additional programs outside of the United States are mentioned in the literature, such as community-based pediatric palliative care programs in Melbourne, Australia (Lindenfelser et al., 2011).

Research suggests that music therapy is effective for children and adolescents with life-limiting or life-threatening illnesses helping to manage pain, decrease anxiety, and improve quality of life. In an exploratory mixed-methods research study, parents of a child receiving music therapy reported that music therapy relieved distress and improved overall comfort (Lindenfelser et al., 2011). Music therapy also supports family communication by allowing members of the family to express themselves to one another as well as to people outside the family (Lindenfelser et al., 2011). Additionally, music therapy was reported to have provided families with a positive and meaningful experience with their child. Families also described feeling comforted and supported as a result of music therapy experiences (You & Ross, 2018). Finally, the child’s and family’s perceptions of life-limiting illness was changed after participating in music therapy. Music therapy provided a positive refocus of attention from the diagnosis, allowing the child to continue to succeed, thrive, and achieve musically. The effects of music therapy resulted in an improved quality of life for both the patient and their family (Lindenfelser et al., 2008).

Music in general is an integral part of a child's and adolescent’s life because it encourages them to express themselves and engage (Clark et al., 2014). Music as a therapy focuses on expression and engagement, as well as pain management, socialization, improving motor functioning, procedural support, quality of life, empowerment, coping, and relationship formation to achieve a sense of holistic well-being. When used alone or in combination with
other treatment modalities, music therapy is effective in improving the level of care for a wide spectrum of patients and families (Clark et al., 2014). This proposed music therapy pediatric palliative care program will address the following goals to provide the best possible care for patients and their families:

1. improve quality of life
2. manage or improve physical and psychosocial symptoms
3. promote intrapersonal goals
   i. channel self-expression
   ii. identify, express, and work through difficult feelings
   iii. engage in communication
   iv. develop spontaneity, creativity, and playfulness
   v. experience choice making and control
4. provide meaningful experiences for the patient and family
   i. promote reminiscence
   ii. engage in communication
   iii. channel expression
5. provide caregiver/family support
   i. develop coping strategies

**Literature Review**

**Hospice Care in the United States**

Hospice care is a service for people of all ages who are terminally ill and have a life expectancy of six or fewer months to live (Department of Health, 2019). The National Hospice and Palliative Care Organization (NHPCO) reported that in 2018, 1.55 million patients receiving
Medicare were enrolled in hospice for at least one day or more (NHPCO, 2020a). Approximately 16.3% of those patients were below the age of 65 years old. The most common diagnoses for individuals admitted to hospice care include cancer, circulatory/heart disease, dementia, respiratory disease, stroke, and chronic kidney disease (NHPCO, 2020a). Hospice is devoted to providing support and care for both the patient and family, in settings such as home care, hospitals, and assisted living facilities. Their philosophy notes that hospice care “accepts death as the final stage of life: it affirms life and neither hastens nor postpones death” (American Cancer Society, 2014, p. 1). Hospice does not provide curative treatment, but rather support from a team of interdisciplinary members, trained to provide supportive, medical, and other care-related needs (Hutcheson, 2011).

The interdisciplinary team in hospice care includes registered nurses, doctors, creative arts therapists, social workers, counselors, chaplains, home health aides, and volunteers. Each makes a unique contribution to the care of the patient and their families. They aid in pain and symptom management, spiritual care, respite care, bereavement care, improving quality of life, promoting relaxation and socialization, and assisting with coping.

Needs of Hospice Patients

Hospice patients are varied and complex. Hospice patients have physical, psychosocial, and quality-of-life needs. Each of these needs serves as the foundation for end-of-life care. If needs in one of these areas are not addressed, other areas may be negatively impacted. For example, if physical needs such as pain management are not met, psychosocial needs such as anxiety may become more severe. Hospice care focuses on meeting ones needs with comfort and care, with no curative intent (Meier, 2011).
Physical Needs of Hospice Patients

The physical symptoms and needs of hospice patients are subjective. The most common physical symptoms include pain, nausea, constipation, perspiration, and headaches (Groen, 2007). Some physical symptoms are side effects of medications. Pain can be induced by pressure ulcers or bedsores. Pressure ulcers are common among hospice patients who are bedbound or do not leave their bed/chair for a number of hours. This happens when the skin starts to break down, and there is limited treatment to relieve the pain and heal the wound. Pain related to illnesses associated with end-of-life care is also a common physical symptom. Patients diagnosed with cancer can experience pain referred to as breakthrough pain (Caraceni et al., 2013). This form of pain is defined as episodes of pain that happen at the same time as other, more regular pain. Caraceni et al. (2013) also reported that patients with breakthrough pain have an average of four episodes a day, lasting between 30-60 minutes. Finally, respiratory distress is another prevalent physical symptom in hospice patients. Dyspnea, also known as labored breathing, was reported in 70% of hospice patients in The National Hospice Study (Moody & McMillan, 2003). This type of pain is commonly seen in patients with end-stage lung disease, lung cancer, or end-stage heart disease (Moody & McMillan, 2003).

Hospice patients often need assistance with activities of daily living (ADL) due to disease progression, lack of mobility, and lack of strength and energy. Family members or other caregivers are relied on for assistance with dressing, eating or drinking, transferring, and hygiene (Rasmussen & Sandman, 1998).

Psychosocial Needs of Hospice Patients

The psychosocial needs of hospice patients include issues with self-esteem, acceptance of illness and death, lack of independence, communication, social functioning and relationships, anxiety, and depression (Hudson et al., 2010). Anxiety and depression surrounding death are two
significant psychosocial needs. Findings from a study of hospice patients during end-of-life by Kozlov and colleagues (2019) support this assertion. The study also recognized that 50% of hospice patients exhibited signs of sadness, 43% displayed signs of worry and 42% displayed signs of nervousness, as perceived by hospice providers (Kozlov et al., 2019). Fear is another psychosocial symptom associated with hospice patients. This feeling of fear is frequently linked to the assumption that hospice care entails "giving up" or "nothing will be done" (Huskamp et al., 2001).

**Quality of Life Needs of Hospice Patients**

Quality of life is believed to be a primary goal and most important outcome of hospice care (Bretscher et al., 1990). Quality of life is a construct “that considers issues of social, physical, functional, spiritual, and emotional well-being” (Garrison et al., 2011, p. 289). These domains of wellness can positively or negatively affect one’s quality of life. Pain, depression, anxiety, and functional status can decrease quality of life. The hospice interdisciplinary teams, particularly the therapy services, aim to maintain or improve a patient's and family's quality of life. A patient whose quality of life has improved will exhibit positive mood and behavior changes, an increase in well-being, a willingness to engage in relationships, and a "changed attitude toward living" (Pizzi, 2014, p. 215).

**Palliative Care in the United States**

Palliative care in the United States is a service for people of all ages with varying diagnoses, regardless of a life expectancy or prognosis. It differs from hospice care in that it works with a patient’s primary treatment team, rather than replaces it. Palliative care addresses the pain, symptoms, and stress of serious illnesses typically in collaboration with curative care services. Palliative care can be provided in any care setting including home care, hospice facilities, group homes, clinics, and hospitals. It is a widely used service, serving over 89,609
seriously ill individuals in 2019, an increase of 3,500 individuals since 2017 (NHPCO, 2020b). The number of children and adolescents in this statistic is unclear, as accurate data on pediatric palliative care is slowly growing (NHPCO, 2015). Nonetheless, the rise in palliative patients reflects the growing importance of palliative care and the need to treat a larger number of individuals.

Palliative care's varied and complex nature necessitates an interdisciplinary team of highly trained, knowledgeable, and adaptable professionals who can meet the needs of the patients they serve. The palliative care interdisciplinary team, similar to that of hospice, consists of registered nurses, doctors, creative arts therapists, social workers, counselors, chaplains, home health aides, and volunteers. These professionals work in collaboration with the “patient’s primary care physician, other specialists, and health care settings they may be receiving services from” (NHPCO, 2020b). For children in palliative care, the interdisciplinary team also suggests a partnership between parents’ employers, teachers, and school staff (Committee on Bioethics and Committee on Hospital Care, 2000). They all work together to improve the lives of patients and their families/caregivers by managing or improving physical, psychosocial, and quality of life needs.

While the World Health Organization (WHO) (2018) reports that chronic and life-limiting illnesses which afflict children are extremely rare, there is a need for palliative care services designed to meet the unique needs of children and adolescents with chronic and life-limiting illnesses. Palliative care for children differs greatly from that of adults. Children are still developing in all domains. Their ability to comprehend, communicate, and acknowledge the concepts of life and death are developing as well. Finally, many children receiving palliative care are nonverbal or noncommunicative due to their medical conditions (Clark et al., 2014). Therefore, it is crucial to recognize these differences to ensure the best level of care for patients.
Needs of Palliative Patients

Palliative care patients' needs are highly individualized and unique. Physical, psychosocial, and quality of life needs are frequently addressed by the interdisciplinary team. Depending on their diagnosis, the needs may vary in priority. Priority level helps determine the proper care required to promote the best possible outcome for the patient and their family. Palliative care seeks to address a patient's symptoms and needs in a way that may be curative (Meier, 2011).

Physical Needs of Palliative Patients

The physical needs of palliative patients are varied but there are some similarities across diagnoses. In patients with end-stage kidney disease, pain was the most prevalent symptom (69%), followed by respiratory secretion (46%), anxiety (41%), confusion (30%), shortness of breath (22%), and nausea (17%) (Axelsson et al., 2018, p. 236). Pain is frequently associated with other symptoms. Patients who are in pain also have low energy levels, poor nutritional intake, and sleep issues (Garrison et al., 2011, pp. 289-290). Fatigue, breathlessness, nausea, and pain were the most prominent symptoms in patients diagnosed with cancer, HIV, heart failure, COPD, and renal disease (Chang et al., 2007). The severity of one's pain may also vary according to one's psychosocial needs. Shatri et al. (2019) discovered a link between patients suffering from depression and anxiety and those suffering from pain. Pain will be exacerbated in patients who have been diagnosed with depression or anxiety.

Psychosocial Needs of Palliative Patients

The psychosocial symptoms associated with palliative care patients are not specific to each diagnosis and may compromise their overall wellbeing. Common psychosocial symptoms include depression, anxiety, worry, and hopelessness. Roughly 45% of palliative care patients suffer from depression (Garrisson et al., 2018). Depression is frequently referred to as a common
side effect of having a terminal illness. As a result, it is usually overlooked and left untreated (Onyeka, 2010). Decreased functioning, concerns about dependency, and uncertainty may lead to depression (Onyeka, 2010). Physical symptoms like pain and nausea, medication side effects, and bodily changes could also contribute to the prevalence of depression. Anxiety is also caused by patients' perceptions of being a burden to their family or caregivers. This could lead to feelings of loneliness and isolation, which might also result in suicidal ideations (Cagle et al., 2017).

**Quality of Life Needs of Palliative Patients**

Palliative care strives to maintain or improve the quality of life of patients suffering from serious illnesses by managing physical and psychosocial symptoms. Lo et al. (2002) stated that quality of life is “multidimensional, subjective, and changes with time or disease progression” (p. 389). Individuals who struggle with symptom control tend to have a lower quality of life (Garrison et al., 2011, p. 289). Cancer patients will also have a lower quality of life as a result of their numerous treatments and inability to function physically (Kasven-Gonzalez, 2010). The quality of life of children diagnosed with cancer was negatively impacted by pain, fatigue, and reduced mobility, according to their families. Patients who are able to develop healthy coping mechanisms and/or symptom control may achieve an improved quality of life (Meier & Brawley, 2011). Improved quality of life can lead to meaningful improvements in a patient's well-being, mood, behavior, socialization, and interaction with others.

**Pediatric Palliative Care in the United States**

In the United States, pediatric palliative care is a relatively new and rapidly evolving field (Rogers et al., 2021). It aims to prolong life for children living with life-limiting illnesses. Hildenbrand et al. (2021) describe pediatric palliative care as an approach to medical treatment emphasizing “holistic, interdisciplinary care of children with life-limiting conditions and their
families to relieve suffering, improve quality of life, facilitate informed decision making, and assist in care coordination between clinicians and across sites of care” (p. 2). Pediatric palliative care is often provided to premature infants, and children diagnosed with congenital disorders and syndromes, chromosomal disorders, cancer, cystic fibrosis, cardiac malformations, neurodegenerative diseases, and metabolic diseases (Bergsträsser, 2013). Pediatric palliative care also has an influence on health care utilization with fewer hospitalizations and intensive care stays.

The interdisciplinary team in pediatric palliative care is very similar to the teams of hospice and palliative care. It is comprised of physicians, registered nurses, nurse practitioners, chaplains, social workers, and creative arts therapists. Pediatric psychologists, bereavement counselors, and psychologists, psychiatrists, and child life specialists also work in collaboration with the interdisciplinary team but are not currently classified as part of the interdisciplinary team in pediatric palliative care (Hildenbrand et al., 2021). These groups of professionals work together to alleviate the child’s physical and psychosocial symptoms and quality of life needs.

**Needs of Pediatric Palliative Care Patients**

Pediatric palliative care targets physical and psychosocial symptoms, as well as quality of life needs. The symptoms and needs of each patient are unique, necessitating the pediatric palliative care team to demonstrate knowledge of rare conditions, flexibility in meeting changing and evolving needs, expertise in family grief and bereavement, and an ability to adapt interventions to meet client needs when little research and insight is available (WHO, 2018).

**Physical Needs of Pediatric Palliative Care Patients**

Pediatric palliative care patients may experience a variety of physical symptoms including lack of energy, dyspnea, nausea, drowsiness, dry mouth, swelling of extremities, itching, and pain (Drake et al., 2003). Numbness/tingling in the hands or feet, skin changes,
seizures, weight loss, and hair loss were also reported as the more severe symptoms in dying children (Olagunju et al., 2016). It is often difficult to manage these physical symptoms, and they're frequently left untreated. Approximately 90% of children experience physical suffering, and 70% or more experience pain (Benini et al., 2008). Pain is managed in less than 30% of cases, and dyspnea and respiratory distress are thought to be effectively treated and controlled in about 20% of cases (Benini et al., 2008)

**Psychosocial Needs of Pediatric Palliative Care Patients**

Children with life-limiting or life-threatening illnesses often experience psychosocial symptoms including anxiety, depression, traumatic stress, and oppositional behavior (Hildenbrand, 2021). Children might also suffer from moderate to high levels of fear, nervousness, worry, and distress, resulting from their illness and/or prevalence of physical symptoms (Drake et al., 2003). Psychosocial symptoms, like physical symptoms, are difficult to manage in children receiving pediatric palliative care. To aid in management, the interdisciplinary team will frequently suggest the use of medications (Crozier & Hancock, 2012). However, there is always a risk of medication errors or possibly over-medicating a child, which could result in more harmful or negative psychosocial symptoms (Michelson & Steinhorn, 2007). This suggests the need for an integrative approach to symptom management that does not rely so heavily on medication.

**Quality of Life Needs of Pediatric Palliative Care Patients**

Improving the quality of life in children and their families is the center focus of pediatric palliative care. Quality of life needs may be different for each child but improving symptom management and communication with the pediatric palliative care team could improve not only the child’s quality of life but also positively impact the course of the child’s illness (Crozier & Hancock, 2012). The interdisciplinary team's assistance may also encourage families to prioritize
quality of life over quantity of life lived and left. Supporting children and their families in living their lives to the fullest while dealing with life-threatening or life-limiting illnesses is critical for achieving enhanced quality of life (Crozier & Hancock, 2012).

**Music Therapy**

Music therapy is an evidence-based discipline in which music experiences, including recreation, improvisation, composition and listening, are used in a clinical setting to achieve health-related goals (Bruscia, 2014). Music therapists provide services in healthcare, educational, and community settings. Goals in music therapy may be educational, medical, recreational, rehabilitative, preventative, or psychotherapeutic. They are designed to address the mental, emotional, physical, intellectual, and spiritual needs of the patient (Bruscia, 2014).

**Music Therapy in Hospice Care**

Music therapy is “one of the most widely used discretionary services within hospice care” (Liu et al., 2015, p. 378). Individualized music experiences are used to alleviate symptoms related to end-of-life care and provide support for both the patient and caregiver. Specifically, music therapy can be utilized to decrease anxiety, increase spiritual well-being, alleviate discomfort behaviors, and improve quality of life (Hilliard, 2005). Music therapists treat hospice patients in care settings including hospitals, nursing homes, and residences.

Patients who receive hospice music therapy are primarily older adults, but there are also younger individuals who suffer from diagnoses such as cancer, chronic obstructive pulmonary disease (COPD), and strokes. Music therapy services are chosen to meet the needs of patients of varying ages and diagnoses because their needs and levels of care are highly individualized. Older adults who are bedbound might engage in music therapy experiences that are less active and more receptive in nature. This might include music listening, therapeutic sing-a-longs, and patient-preferred singing (Bradt & Dileo, 2010). Younger patients who have greater motor skill
strength and functioning might engage in music therapy experiences that are more active including improvisation, instrument playing, and music and movement (Bradt & Dileo, 2010). Hospice patients who reside in nursing homes have varying needs, suggesting that a music therapist might utilize both active and receptive musical experiences. Songwriting, therapeutic sing-a-longs, music listening, music-prompted reminiscence, vocal or instrumental improvisation, and song discussions are a few experiences that might be implemented. In situations where family members are present, a music experience that allows them to choose and listen to a patient's favorite song may provoke an emotional response. The therapist can then provide validation, support, and a chance for the family or patient to explore their feelings (Krout, 2003).

The goals of hospice music therapy include, but are not limited to, improving quality of life, providing relaxation, pain management, offering social support and comfort, assisting with coping and anticipatory grief (DiMaio, 2010). The music therapy methods that are commonly used in hospice care include music-assisted relaxation, unguided imaginal listening, directed music imagining, entrainment, vocal re-creation, instrumental re-creation, music-based life review, song discussion, and composition. Vocal improvisation is also used with hospice patients and has been reported to decrease discomfort behaviors of in-patient hospice patients (Hilliard, 2005, p. 175).

There is a growing body of literature which supports the inclusion of music therapy in adult hospice care. As an example, Hilliard (2005) reported “a significant difference in quality of life for participants receiving music therapy. The more music therapy sessions participants received, the higher the quality of life, even as their physical health declined” (p. 176). Hilliard (2005) also noted that hospice nursing home residents who received music therapy experienced a considerable increase in length of life, in comparison to residents who do not receive music
therapy. Horne-Thompson and Grocke (2008) reported that music therapy in adult hospice care can reduce tiredness and drowsiness, in addition to other symptoms. Potvin et al. (2021) described how playing patient-preferred music for a patient undergoing dressing changes helped the patient relax and breathe more evenly during his procedure. Potvin et al. (2021) also highlighted how music therapy offered a patient spiritual support by singing and playing hymns with the patient. The patient specifically expressed “how powerful it was to share the joy of her faith through music” (Potvin et al., 2021, p. 312). Finally, Cadwalader et al. (2016, as cited in Dingley et al., 2021) found that just one music therapy session reduced agitated behaviors in hospice patients.

Music therapy experiences are also used in hospice to help families come to terms with the loss of a loved one. Music therapy may allow a family to share and connect on a psychosocial and spiritual level with their loved one and experience a “meaningful release” (Krout, 2003, p. 133). Krout (2003) describes a family-based music therapy session with a 78-year-old woman with dementia patient who was surrounded by six family members during her final moments. During their music therapy visit, the music therapist sang pre-composed songs, requested by the family. This allowed the family to have a sentimental moment with the patient while also reflecting and reminiscing with one another. The therapist validated and supported the family and continued to play music requested by the family at bedside. As the patient approached the end of her life, the rest of the session became emotionally heightened. The patients' physical needs were met, and through music, the family was able to come together and say goodbye to their loved one, on a psychosocial and spiritual level. The music seemed to bring everyone in the room together, allowing and enhancing the family's ability to support both the patient and each other. The family members held the patient's hand while the music played, and she took her final breath (Krout, 2003).
**Music Therapy in Pediatric Medical Care**

Music therapy is becoming increasingly recognized in pediatric healthcare settings. Music therapists work with children and adolescents diagnosed with acute and chronic/life-limiting illnesses. In an acute setting, music therapists focus on procedural support, pain management, and anxiety reduction (Whitehead-Pieux et al., 2006). Music therapists also modify their experiences to include adaptations to new treatment protocols and shorter length sessions to meet the immediate needs of the patient (Kruse, 2003). In this setting, sometimes children are seen before the procedure to learn coping strategies, during the procedure to decrease distress or act as a diversion, and after the procedure to promote recovery and the return to normal child activities (Yinger, 2016). Regardless of whether a patient is seen in an acute or longer-term setting, different approaches are applied to meet the subjective needs of each patient. Stegemann et al. (2019) explains:

> Functional and behavioristic approaches are applied to use the activating or relaxing effects of music for stimulation or calming, and to enhance learning of specific skills and behaviors. Humanistic approaches (represented by pioneers such as Juliette Alvin, or Paul Nordoff and Clive Robbins) emphasize creativity and expression of the self within improvisational music-making and the development of positive relationships by allowing the child to find his or her own musical way without fixed rules. Analytically-oriented MT (pioneered by Mary Priestley) employs the symbolic content of improvised music in order to connect with emotions, thoughts, images, or bodily sensations that cannot be verbalized (p. 3).

**Music Therapy in Palliative Care**

Music therapy in palliative care aims to “meet the needs of the terminally ill and their families, with a trained music therapist working as a member of a multidisciplinary health care
team.” (Munro & Mount, 1978, p. 1029). The patients benefit from music therapy because it can address all aspects of holistic well-being (Clark et al., 2014). Music therapy can help with pain management and relaxation, strengthening self-identity, emotional expression and grieving, supporting relationships, and spiritual and whole-person care (Clements-Cortés & Klinck, 2016). Sessions can take place in hospices, hospitals, and home settings. Its aim is to address both past and present needs, as well as future needs, in order to facilitate recovery and healing (Clements-Cortés & Klinck, 2016). These goals are achieved through songwriting, music therapy relaxation techniques, therapeutic sing-a-long s, and music listening (Clark et al., 2014).

Music relaxation and music and imagery assisted relaxation methods are commonly used in conjunction with other music therapy methods. When playing or listening to a drone-like instrument, vocal improvisation can be used. A monochord is a drone-like instrument tuned to the same chord, frequently used in therapeutic settings (Warth et al., 2015). Relaxation can be aided by improvised singing or breathing over this instrument. Warth et al. (2015), note that improvised singing and breathing with the monochord can “increase high-frequency (HF) variations in heart rate and a trend toward greater peripheral blood flow, increase parasympathetic modulation, and reduce sympathetic modulation of cardiovascular activity of the autonomic nervous system” (p. 791). The result of these changes can promote pain and symptom management, improved mood, and enhanced quality of life.

Entrainment is commonly used in palliative care. This approach consists of an individual’s system locking or synchronizing with another individuals’ system to promote pain management and other health-related benefits (Thaut et al., 2015). In terms of achieving pain management, entrainment can occur by having the therapist play music that matches the patient’s pain or mood. Once the therapist has matched the patient's mood, the patient's mood can be altered by modifying the music as needed. Music can be used to transport a patient away from their current pain and into a different, pain-free experience (DiMaio, 2010).
**Music Therapy in Family-Centered Care.** Music therapy in family-centered care focuses on the involvement of both the patient and family in sessions. Family-centered care incorporates the “families’ own perspectives, values, and choices into the design, practice, and evaluation of care, recognizing that parents are the most important people in the care of their child” (Lindenfelser et al., 2011, p. 6). Family-centered care is commonly used with adolescents, children, and infants. Parents of premature infants in the neonatal intensive care unit (NICU) or pediatric intensive care unit (PICU) are often involved in family-centered music therapy. Music therapists might suggest primary caretakers use infant-directed singing, a family-centered approach, to promote caretaker-baby bonding and empowerment.

**Music Therapy in Pediatric Palliative Care**

Music therapy in pediatric palliative care “requires a multidisciplinary approach that involves the patient, the patient’s family, and community resources, and that it can be provided in multiple care settings. Music therapy fits naturally within this paradigm, especially for children and youths” (Clark et al., 2014, p. 179) Music therapy experiences in pediatric palliative care are subjective to each patient and their diagnosis. Music therapy is often provided in the home, but also in hospitals. Different settings might require different treatment implementation or goals. For example, a patient who is in the hospital will have countless medical personnel entering and exiting the room and an array of sounds and beeping machines. This could be overstimulating or make a patient anxious, suggesting that the music therapy experiences target relaxation, using music as a diversion, or music to decrease anxiety. Receptive, re-creative, improvisational, and compositional music therapy methods are used in a pediatric palliative care setting to address psychological health, provide opportunities for social interaction, allow for emotional expression, and awareness of self (see Table 1). These methods are used to help the patient achieve psychological, social,
emotional/behavioral, and sense of self goals. Music therapy in pediatric palliative care also aims to provide family support and provide bereavement assistance to caregivers (Lindenfelser, 2005).
**Table 1**

*Music Therapy Methods*

<table>
<thead>
<tr>
<th>Music Therapy Method</th>
<th>Definition</th>
<th>Examples of Experiences</th>
<th>Goals</th>
</tr>
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</table>
| **Receptive Method** | Receptive music experiences are those in which the patient listens to, and then responds to live or pre-recorded music. | - Somatic listening  
- Entrainment  
- Toning  
- Vibroacoustic music  
- Music listening  
- Song reminisces  
- Song communication  
- Song discussion  
- Imaginal listening | - Relaxation  
- Pain management  
- Reduce stress and anxiety  
- Promote reminisce  
- Communication  
- Relationship completion  
- Coping  
- Improve quality of life |
| **Re-creative Method** | Re-creative music experiences are defined as singing, playing, or engaging musically with pre-composed music. This could also include imitating or reproducing music. | - Instrumental recreation  
- Vocal recreation  
- Performance  
- Musical games and activities  
- Conducting  
- Musical productions | - Expression  
- Empowerment  
- Communication  
- Pain management  
- Reduce isolation  
- Improve quality of life  
- Provide choice and control  
- Decrease stress and anxiety |
| **Improvisational Method** | Improvisational music experiences are those in which the patient will make up music through | - Song improvisation  
- Vocal improvisation  
- Instrumental improvisation  
- Body improvisation | - Expression; identify, express, and work through difficult emotions  
- Reduce stress and anxiety  
- Family engagement |
<table>
<thead>
<tr>
<th>Compositional Method</th>
<th>The compositional method is described as a collaborative experience where the therapist works with the patient to write songs or create a musical product.</th>
</tr>
</thead>
</table>
|                      | - Songwriting  
- Music collages  
- Song transformation  
- Instrumental composition |
|                      | - Decision-making skills  
- Explore ways of expressing thoughts and feelings  
- Improve quality of life  
- Promote creativity  
- Communication  
- Exploration of therapeutic themes |


Research on the efficacy and effectiveness of music therapy in pediatric palliative care is extremely limited. In fact, a review of music therapy literature from 2000 to 2022 identified five research studies. The results of these studies suggest that the inclusion of music therapy in pediatric palliative care settings may result in positive experiences for both the child and their families. Lindenfelser et al. (2008) examined the bereaved parents’ experience of music therapy with their terminally ill child. Results from in-depth interviews and phenomenological analysis strategies suggested that music therapy was valued, provided an opportunity for engagement for the entire family, altered the child’s and family’s perception of their situation, enabled communication and expression, and was a significant component of remembrance (Lindenfelser et al., 2008).
Knapp et al. (2009) carried out a survey study with the parents of children who were enrolled in Florida’s Partners in Care: Together for Kids pediatric palliative care program. The survey results indicated that 98% of parents reported they were very satisfied to satisfied with their music therapy services. Additionally, caregivers of patients who received music therapy were more likely to report being satisfied with their overall care (Knapp et al., 2009). Lindenfelser et al. (2011) examined family-centered music therapy with terminally ill children. Results suggest family-centered music therapy was effective for families with terminally ill children. Families' participation and input were valued, and music experiences that emphasized the child's interests and addressed current and relevant needs were used. The study revealed that music therapy fostered positive experiences, improved the child’s physical state, and facilitated family communication (Lindenfelser et al., 2011).

Clark et al. (2017) carried out a mixed-methods exploratory study with children who were receiving respite or symptom management care, diagnosed with life-threatening severe neurological impairments, and have a cognitive functioning level of one year or less. Following the implementation of two sessions of live vocal and guitar music therapy, findings revealed that children had lower pain and distress levels, improved symptom management, and an enhanced quality of life (Clark et al., 2017). Finally, a recent qualitative study conducted by Franco et al. (2021) found that children with cancer who received music therapy were given a space to communicate, share deep and personal feelings associated with their condition, experience pain relief and improved quality of life.

There are, also, several case reports which describe the use of music therapy in pediatric palliative care. As with the above-cited research studies, these case reports highlight the positive contributions of music therapy to pediatric palliative care. Lindenfelser (2005) reported that the use of musical play and improvisation aided a terminally ill 5-year-old in accepting his illness
and impending death. In a study with an 11-year-old diagnosed with cardiovascular arteriosclerosis, music therapy experiences were implemented to not only bring comfort to the patient, but also the family. Musical experiences were effective in giving the patient’s mother “something to do when she felt she couldn’t do anything else for her son” (Hilliard, 2003, p. 130). Sweeney (2012) also described a case study with a terminally ill 5-year-old boy diagnosed with a brain tumor. This patient was suffering from nausea, difficulty balancing, hearing loss, and vision problems, to name a few symptoms. The child used musical experiences to explore therapeutic themes, process emotions, self-express, and accept the reality of his situation. These experiences included structured improvisation, instrumental play, and singing nursery rhymes (Sweeney, 2012). The patient, with the guidance and support of the music therapist, gave a voice to his illness and developed an acceptance of his fate.

Daveson (2001) reports a case with a 2-year-old girl diagnosed with cancer. She was referred to music therapy for self-expression and participated in a series of self-expressive music-assisted play and improvisations. These therapeutic experiences were used to channel her feelings associated with the changes in her physical appearance. Music therapy created a fun way of remembering what it was like to have hair, while also communicating the feelings associated with her diagnosis (Daveson, 2001). Finally, Garwood (2018) described her work with a 2-year-old who was referred to music therapy after receiving a bone marrow transplant. This child was limited in motor functioning and was unable to sit independently, crawl, or roll-over. Receptive and re-creative methods were used with this patient to achieve goals such as relaxation, decreased muscle tension in limbs, and maintained or increased focus and engagement. Throughout their music therapy journey together, the child was able to achieve a sense of relaxation and pain management, experience an improved mood and engagement, and have an
overall increased quality of life. These outcomes were a result of pure enjoyment in music and the meaningful bond formed between him and his therapist (Garwood, 2018).

**Detailed Description of the Program**

**Theoretical/Philosophical Orientation**

The theoretical orientation of this music therapy program will be based on the humanistic approach which views all individuals as unique beings with the capacity to achieve well-being and personal growth (Abrams, 2015). Carl Rogers, one of the founders of the humanistic approach, espoused a person or client-centered approach to psychotherapy as he believed each individual has a natural desire to make the best of their circumstances (Rogers, 1951). Therapists who align themselves with this approach provide unconditional positive regard, as well as congruence, empathy, and respect within a therapeutic relationship. The theoretical orientation of this music therapy program will also be based on person-centered therapy which emphasizes client experiences, and that the individual has “vast resources for self-understanding, for altering self-concept, attitudes and self-directed behavior” (Rogers, 1974, p. 116). The humanistic approach and person-centered therapy align with the core concepts of hospice care, which believe in meeting patients where they are. Music therapists who work from a humanistic, person-centered perspective strive to meet the patient and family where they are and work collaboratively to provide the best care possible in pediatric palliative care (Clark et al., 2014).

Techniques that are grounded in the cognitive-behavioral approach will be incorporated into music therapy sessions as appropriate. The cognitive-behavioral approach integrates cognitive and behavioral approaches to achieve change. It focuses on using cognitive and behavioral interventions to redirect negative thought patterns and replace them with healthier and/or more positive ones (Dobson & Dozois, 2010). In pediatric palliative care, the cognitive-behavioral approach to music therapy can teach children coping strategies and experience
positive behavioral distractions from the stressors of a medical setting (Uman et al., 2008; Yinger, 2016). Cognitive-behavioral approaches to music therapy can also help foster structure, autonomy support, and child engagement with their environment (Robb, 2000).

Music experiences that are informed by the cognitive behavioral approach help individuals understand challenging situations and their problematic reactions. Myers-Coffman et al. (2020) explained how incorporating cognitive behavioral strategies into a songwriting experience for bereaved adolescents helped improve coping, self-esteem, and mood. Songwriting gave adolescents an opportunity to explore their thoughts and feelings associated with bereavement. Cognitive behavioral approaches, particularly, cognitive reframing, assisted them in identifying which thoughts made them feel better and which did not. Psychoeducation educated adolescents on how songwriting can serve as a positive coping mechanism and aid in grief, validating feelings, and expression (Myers-Coffman et al., 2020). Other music therapy experiences, such as music-assisted relaxation, song discussion, and improvisation, when combined with cognitive behavioral techniques, can greatly benefit pediatric palliative care patients and their relationship between thoughts, feelings, and behaviors.

**Family-centered Music Therapy**

Family centered care, as defined by the Association for the Care of Children’s Health, is “care delivery that recognizes and respects the crucial role of the family, supporting families by building on their strengths, encouraging them to make the best choices, and promoting normal patterns of living during their child’s illness and recovery” (Johnson et al., 1992). Family-centered music therapy is a treatment philosophy that will also be implemented in the program. It involves “collaboration between professionals and families to implement the families’ own perspectives, values, and choices into the design, practice, and evaluation of care, recognizing that parents are the most important people in the care of their child” (Lindenfelser et al., 2011, p.
6. All four methods of music therapy will be used, with a focus on family inclusion and responsiveness to their identified needs. The methods that will be used for each session will be determined collaboratively with the family, after assessing the patient’s needs, interests, abilities, mood, and energy levels. Goals that can be addressed through family-centered music therapy are self-expression, choice-making, managing control, and interpersonal connections (Lindenfelser et al., 2011).

**The Program**

Humanistic and person-centered theory will guide the implementation of this program. CBT techniques will be incorporated into music therapy sessions when relevant to meet patient goals. Music therapy methods will be chosen based on client ability, preference, and treatment goals. Music therapy sessions will be provided to children who are referred for this service (see Appendix A for a sample referral form). Treatment goals will be formulated upon completion of a music therapy assessment (see Appendix B for sample assessment form). Treatment goals will be updated and revised as needed in response to the needs of the patient. Frequency and duration of music therapy sessions will be based on each patient’s individual needs. Both patients, families, and other individuals in the patient’s care will be encouraged to participate in the music therapy sessions. The family will gather on Fridays of each week, along with the music therapist to engage in music therapy experiences that are individualized, strength orientated, and family centered (Lindenfelser et al., 2011). Please refer to Table 2 for the proposed program schedule.

**Table 2**

*Proposed Program Weekly Schedule*

<table>
<thead>
<tr>
<th></th>
<th>Monday</th>
<th>Tuesday</th>
<th>Wednesday</th>
<th>Thursday</th>
<th>Friday</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>8:30-9:30</strong></td>
<td>Plan/</td>
<td>Plan/</td>
<td>Plan/</td>
<td>Plan/</td>
<td>Plan/</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Time</th>
<th>Repertoire preparation</th>
<th>Repertoire preparation</th>
<th>Repertoire preparation</th>
<th>Repertoire preparation</th>
<th>Repertoire preparation</th>
</tr>
</thead>
<tbody>
<tr>
<td>9:00-10:00</td>
<td>IDT* Meeting</td>
<td>IDT Meeting</td>
<td>IDT Meeting</td>
<td>IDT Meeting</td>
<td>IDT Meeting</td>
</tr>
<tr>
<td>11:00-12:30</td>
<td>Music therapy - Home visits</td>
<td>Music therapy- In-patient pediatric unit visits</td>
<td>Music therapy- Home visits</td>
<td>Music therapy- In-patient pediatric unit visits</td>
<td>Family-centered music therapy visits</td>
</tr>
<tr>
<td>12:30-1:00</td>
<td>Lunch</td>
<td>Lunch</td>
<td>Lunch</td>
<td>Lunch</td>
<td>Lunch</td>
</tr>
<tr>
<td>1:00-3:30</td>
<td>Music therapy- Home visits</td>
<td>Music therapy- In-patient pediatric unit visits</td>
<td>Music therapy- Home visits</td>
<td>Music therapy- In-patient pediatric unit visits</td>
<td>Family-centered music therapy visits</td>
</tr>
<tr>
<td>3:30-4:30</td>
<td>Documentation / Preparation</td>
<td>Documentation / Preparation</td>
<td>Documentation / Preparation</td>
<td>Documentation / Preparation</td>
<td>Documentation / Preparation</td>
</tr>
</tbody>
</table>

*Note. *IDT - Interdisciplinary Team Meeting

Receptive Music Experiences

Receptive music experiences are those in which the patient listens to, and then responds to live or pre-recorded music (Bruscia, 2014). Within pediatric palliative care, this method is used for assessing levels of pain and anxiety, providing psychosocial support, assisting painful procedures, tension release and relaxation, and improving quality of life (Daveson, 2001). Receptive experiences are used when a patient is unable to actively engage in music-making due to the severity of their diagnosis, are displaying signs of restlessness, anxiety, or fatigue or prefer
listening rather than active music making. Music can be selected by the patient, family, or therapist. The music therapist may accompany the experience with a guitar or piano, adjusting the music as needed to meet patient needs. Slowing down the tempo, finger-picking the guitar, changing keys, or singing at a significantly lower dynamic level are all options available to the music therapist. These musical adaptations allow the music therapist to capture the child's attention without overstimulation or habituation (Clark et al., 2014).

Listening to music can also be a more intimate experience for children, allowing them to reclaim or create their own personal space. This could be beneficial for a patient in a hospital setting (Shoemark et al., 2018). Song discussions, song dedications, and song communication are other receptive method variations that might be used in a session. Song discussion, listening and then sharing reactions to a song, may assist in stimulating therapeutically relevant discussions with the patient. There are several ways patients can select songs to share. Songs can be chosen to facilitate reminiscence, self-expression, and identity coping skills. Additionally, song discussions can be used by the child and family in processing the child’s diagnosis or facilitating emotional expression. Two specific forms of song discussion used in palliative and hospice care include song dedication and song communication. Song dedication (Bruscia, 2014), choosing a song that has a message the patient or family member would like to share, offers another means of emotional expression, communication, and relationship completion (Clements-Cortés, 2016). This method also aids in the processing of grief and the illness of the child, as well as encouraging child expression. Song communication (Bruscia, 2014), the selection of a song by the patient that communicates something about themselves or their illness, is used to help the patients share their life experiences with the therapist, family, or other care team members. The act of choosing a song and listening to it with others can be empowering for a child.
Re-creative Music Experiences

Re-creative music experiences are defined as singing, playing, or engaging musically with pre-composed music. This could also include imitating or reproducing music (Bruscia, 2014). Recreational experiences are used to aid in anxiety and pain management, reduce feelings of isolation, anticipatory fear, and grief, communicate and release feelings, restore a sense of choice and control, promote a sense of familiarity, and improve the overall quality of life (Daveyson, 2001). The use of patient-preferred music and giving the patient the option to select the song in this experience is especially beneficial, as it fosters feelings of empowerment. Selecting patient-preferred music can also be an intimate and personal experience, bringing the child and his or her family closer together or the child and the therapist closer together (Shoemark et al., 2018).

Vocal recreation can help people feel more empowered and express themselves emotionally, as well as provide a grounding experience where the voice and the body can connect. Playing an instrument can promote decision-making and self-expression. Decision-making is important in pediatric palliative care because children often feel powerless in their hospital and life experiences, and music helps them regain control (Shoemark et al., 2018). In addition, children in pediatric palliative care often face behavioral distress, diagnosis-related distress, and distress from their parents' anxieties. Music therapy provides a safe, musical medium for a child to freely express themselves without fear of overburdening others (Shoemark et al., 2018). During an instrumental re-creative experience, the therapist will encourage the child to choose an instrument that they can play as an accompaniment to a pre-recorded or live performance of a song. Instrumental recreation, which can encompass playing a song on a variety of instruments, has its own set of therapeutic advantages. The drum, for example, could be used to help the child feel more grounded and empowered. The guitar could promote
improved posture (Jacobowitz, 1992). Instruments could also be used to represent different family members in order to foster family unity, alleviate feelings of loss and suffering in children who lack parental figures, and encourage communication (Jacobowitz, 1992).

Digital music applications may be beneficial to children with more severe impairments. For example, the visually appealing and stimulating music app "Magic Piano" encourages the patient to follow light beams to guide their fingertips to the correct note. Songs from a variety of genres are included in the app, including pop, country, classical, movies and musicals, and R&B. The child can also try out different instruments like the harpsichord, organ, and synthesizer from the 1980s. They can also control the pieces' notes, rhythm, and tempo. Patients' goals for self-expression, fine motor skill development, choice and control, improved mood, and overall improved quality of life can be addressed by this musical app (Clark et al., 2014).

*Improvisational Music Experiences*

Improvisational music experiences occur when the patient creates music using instruments, voice, body percussion, or a combination (Bruscia, 2014). Patients are allowed to select the type of improvisation as well as identify the theme or if they would just like to create music spontaneously. Patients can create their own rhythms or improvise over pre-composed music (Bruscia, 2014). The patient could also choose to improvise alone, or with others. Musical improvisation in pediatric palliative care, particularly in acute settings, is a beneficial experience for children who are unable to express themselves or communicate due to pain, distress, altered consciousness, impaired cognition, or altered developmental trajectory (Shoemark et al., 2018). As a result, the music therapist may offer a "scaffolding structure of pulse, rhythm, tonality, timbre, to facilitate the patient’s manifestation of self, which is more satisfactory to the patient than speech, gesture, or other forms of expression at that moment (Shoemark et al., 2018, p. 9). Additional goals include self-expression, exploring and understanding psychological meanings,
promoting verbal discussions surrounding death, stimulating family engagement, and improving quality of life (Hilliard, 2003). Improvisation will be facilitated with the goal of meeting the patient where he or she is at that given time.

*Composition Experiences*

The compositional method is described as a collaborative experience where the therapist works with the patient to write songs or create a musical product (Bruscia, 2014). This may include writing lyrics, recording a music video, creating an instrumental piece, or altering pre-composed songs to implement their own lyrics or musical variations. Songwriting, as well as other composition method variations, will be utilized to facilitate communication, express their feelings about their current situation, and gain a stronger sense of identity and confidence (Clark et al., 2014). The songwriting process will be a shared experience in which the therapist and patient work together to write lyrics and music to accompany them. The patient is free to make all musical decisions and will be supported by the therapist. Children often lack independence when faced with life-limiting or life-threatening illnesses, so independence is encouraged during the songwriting process. Once the song is completed, the music therapist can record it onto a CD or an mp4 track for the patient to keep and listen to whenever they want. The patient's music therapist may also encourage them to share their songs with others in order to promote social interaction. Songwriting with the family of the patient will be encouraged as well. Putting lyrics and music together could help families and children express their grief or reinforce their feelings of hope (Hilliard, 2003).

*Financial Justification*

The annual cost for the yearly salary, employee benefits, mileage and toll reimbursements, as well as incidental costs are summarized in Table 3. A one-time purchase of instruments for music therapy experiences is included in the initial cost is found in Table 4.
### Table 3

**Financial Justification (Salary)**

<table>
<thead>
<tr>
<th>Item</th>
<th>Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Salary</td>
<td>$52,000.00</td>
</tr>
<tr>
<td>Estimated Benefits (30%)</td>
<td>$15,600.00</td>
</tr>
<tr>
<td>Instrument Repairs and Software Updates</td>
<td>$1,000.00</td>
</tr>
<tr>
<td>Facility Work Phone ($32.75/month)</td>
<td>$393.00</td>
</tr>
<tr>
<td>Estimated Mileage Reimbursement (approx. 150-200 miles per week; Hudson Valley Hospice reimburses $0.57 per mile)</td>
<td>$5,200.00</td>
</tr>
<tr>
<td>Estimated Toll Reimbursement (full toll reimbursement, $1.45 per toll)</td>
<td>$250.00</td>
</tr>
<tr>
<td><strong>Total Annual Fees</strong></td>
<td><strong>$74,443.00</strong></td>
</tr>
</tbody>
</table>

*Note: *Salary is based on information extracted from “2021 Workforce Analysis” by the American Music Therapy Association, pp. 11-21. Copyright 2022 by the American Music Therapy Association.

### Table 4

**Financial Justification (Materials)**

<table>
<thead>
<tr>
<th>Item</th>
<th>Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Facility Work Computer</td>
<td>$425.00</td>
</tr>
<tr>
<td>Basic Beat BB201 Egg Shaker Set of 5, 4 packs, total of 20 egg shakers</td>
<td>$7.80</td>
</tr>
</tbody>
</table>
### Remo World Music Drumming PP-WMDC-EE Package E

<table>
<thead>
<tr>
<th>Description</th>
<th>Cost</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Instrument</th>
<th>Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Xylophone</td>
<td>$475.00</td>
</tr>
<tr>
<td>Sonor Primary SXP 1-1 Soprano Xylophone</td>
<td></td>
</tr>
<tr>
<td>Yamaha Piaggero NP32WH Ultra-Portable Digital Piano, 76-Key, White</td>
<td>$329.00</td>
</tr>
<tr>
<td>BOOMWHACKERS</td>
<td>$23.03</td>
</tr>
<tr>
<td>Boomwhackers BWDG 8-Note C Major Diatonic Set</td>
<td></td>
</tr>
<tr>
<td>Kidsplay RB109 Diatonic 8-Note Desk Bells Set</td>
<td>$53.81</td>
</tr>
<tr>
<td>Remo ET-0216-10 16&quot; Ocean Drum Fish Graphic</td>
<td>$65.95</td>
</tr>
<tr>
<td>Makala MK-S Soprano Ukulele Classroom Set, Set of 10 Ukuleles</td>
<td>$564.99</td>
</tr>
<tr>
<td><strong>Total Initial Fees</strong></td>
<td><strong>$5,540.53</strong></td>
</tr>
</tbody>
</table>

*Note: Prices taken from West Music Catalog ([https://www.westmusic.com/](https://www.westmusic.com/))*

### Larger Agency/Facility Context

This music therapy program for pediatric palliative care in hospice will aim to meet the needs of pediatric patients and their families at Hudson Valley Hospice. This program will be an addition to the current palliative and hospice care programs in place. The program will focus on
physical and psychosocial goals which will help individuals achieve an enhanced quality of life. This aligns with Hudson Valley Hospice's mission statement and it demonstrates a commitment to providing the best possible care for the patient and their family (Hudson Valley Hospice, 2019). This program, like the current hospice music therapy program, will necessitate collaboration and communication among the interdisciplinary teams and other health-related professionals. It would advocate for music therapy as an evidence-based practice, that has demonstrated positive effects for individuals with life-limiting or life-threatening conditions. Having a program dedicated to pediatric palliative care patients would help Hudson Valley Hospice reinvent itself as a provider of not only end-of-life care but also pediatric palliative and hospice care.

**Outcomes and Assessment**

Children receiving pediatric palliative care will be provided music therapy sessions if they are referred for this service. They could be referred to music therapy by any member of the interdisciplinary team, family, or other professionals involved in child’s care. See Appendix A for a sample referral form. The treatment plan and goals will be formulated upon completion of a music therapy assessment (see Appendix B for sample assessment form). The music therapist will assess the children based on their strengths and abilities, needs, areas for development, and musical interaction with the therapist.

Once music therapy sessions occur routinely, the music therapist will be continuously documenting and recording progress notes for each visit. The therapist will specifically note the music therapy intervention used in each session and the patient and family’s response. This form will be the same as the sample assessment form, with only a few changes noting that it is a routine visit and not an initial visit. Please refer to Appendix B for sample documentation form.
Program Evaluation

The music therapy program will also be evaluated. Once the child is discharged from the program, the families will be sent a survey to evaluate their music therapy experience. See Appendix C for the sample survey. The program will also be evaluated by Hudson Valley Hospice to determine if the new program has been a beneficial addition to the facility. The evaluation will be based on the number of referrals received over the course of four months. This will signify if Hudson Valley Hospice's pediatric palliative care program was a success or failure.

Conclusion

A music therapy program for pediatric palliative care at Hudson Valley Hospice would be a valuable and beneficial addition to the facility. This program will not only provide enhanced care for the children and their families dealing with life-threatening or life-limiting illnesses but also opportunities for creative self-expression. Music therapy will encourage children and their families to engage in a safe, explorative, and expressive journey using musical mediums and a music therapist as the guide. The pediatric palliative program at Hudson Valley Hospice will expand the facility's scope, making it more accessible and diversified to a wider spectrum of individuals.
References


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https://doi.org/10.1007/s00431-012-1710-z


https://doi.org/10.1007/s10741-017-9596-5


Hildenbrand, Amaro, C. M., Gramszlo, C., Alderfer, M. A., Levy, C., Ragsdale, L., Wohlheiter,


Appendix A

Sample Music Therapy Referral Form

Patient’s Name: ___________________________ Date: _______

Age: __________

DOB: __________

Diagnosis: _______

Type of Visit: Home Visit In-patient

Reason for Referral:

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

Level of Music Therapy Referral Need: Urgent High Coping Quality of Life

Family/Friends/Others Involvement:

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

Any Other Information:

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

Patient Referred By: ___________________________
Appendix B

Sample Music Therapy Assessment/Documentation Form

Patient’s Name: ___________________________ Date: ________

Age: _____________

DOB: _____________

Diagnosis: ___________

Type of Visit: Home Visit In-patient

Select One: Routine Visit Initial Visit

Musical Preferences (songs, genres, instruments, etc.):  
_________________________________________________________________
_________________________________________________________________
_________________________________________________________________

Musical Dislikes (songs, genres, instruments, etc.):  
_________________________________________________________________
_________________________________________________________________
_________________________________________________________________

Data:  
__ Anxiety  __ Impaired QoL  __ Lacking Family Interaction
__ Depression  __ Pain  __ Fear Surrounding Illness/Death
__ Caregiver/Family Support  __ Actively Dying  __ Feelings of Isolation
__ Communication Deficit  __ Transitioning  __ Physical Limitations
__ Respiratory Distress  __ Spiritual Support  __ Other:
__ Impaired Coping  __ Emotional Support
Describe pre-session status of patient/family:

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

Music Therapy Methods (Select all that apply):

__Improvisation  __Music Listening
__Instrument Playing  __Therapeutic Sing-Along/Patient-Preferred Singing
__Legacy/Recording  __Song Discussion
__MT Relaxation Techniques  __Song/Activity Choice Making
__Music-Assisted Art or Movement  __Songwriting
__Song Request/Dedication  __Spiritual Support
__Song Communication  __iPad Music Games
__Performance  __Entrainment
__Music Assisted Relaxation/Guided Imagery

Describe how the method was used:

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

Results

Effectiveness of Treatment (describe the physical and emotional effect(s) that treatment had on presenting problems):

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________
Plan

Current Recommendations and Evaluations for MT Services:

________________________________________________________________________________________

________________________________________________________________________________________

________________________________________________________________________________________

Family/Caregiver Feedback (if any)

Effectiveness of Treatment

________________________________________________________________________________________

________________________________________________________________________________________

________________________________________________________________________________________

Assessment/Documentation/Evaluation Completed By: ________________________________

Appendix C

Sample Evaluation Survey

Patient’s Name: ________________________________ Date: ______

Your Name/Relationship to Patient: ________________________________
Music Therapist’s Name:

How long was the patient on the program?

How long did the patient receive music therapy services?

Do you feel your child was cared for?

☐ strongly disagree  ☐ disagree  ☐ neutral  ☐ agree  ☐ strongly agree

Do you feel your child’s needs were met?

☐ strongly disagree  ☐ disagree  ☐ neutral  ☐ agree  ☐ strongly agree

Were music therapy experiences relevant to your child’s needs and abilities?

☐ strongly disagree  ☐ disagree  ☐ neutral  ☐ agree  ☐ strongly agree

If you participated in music therapy experiences with your child, please describe your experience:

________________________________________________________________________

________________________________________________________________________
**How satisfied are you with your child’s overall music therapy experience?** (Please circle the appropriate number that best reflects your answer)

<table>
<thead>
<tr>
<th>Unsatisfied</th>
<th>Extremely Satisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td>(1)</td>
<td>(10)</td>
</tr>
<tr>
<td>(2)</td>
<td>(9)</td>
</tr>
<tr>
<td>(3)</td>
<td>(8)</td>
</tr>
<tr>
<td>(4)</td>
<td>(7)</td>
</tr>
<tr>
<td>(5)</td>
<td>(6)</td>
</tr>
</tbody>
</table>

**Additional comments:**  

________________________________________________________________________

________________________________________________________________________

**Would you recommend these services to others?** (Circle one)

(Yes)  (No)
Appendix D

Music Therapy in Pediatric Palliative Care Infographic

**MUSIC THERAPY IS...**
an evidence-based discipline in which music experiences, including re-creation, improvisation, composition and listening, are used in a clinical setting to achieve health-related goals.

**MUSIC THERAPY IN PEDIATRIC PALLIATIVE CARE...**
is the subjective use of musical experiences, involving the child, their family members, and other community or health professionals to address goals related to the patient and their diagnosis.

**WHO WOULD BENEFIT?**
Music therapy experiences will be family-centered, focusing on the involvement of both the patient and family in sessions.

**GOALS...**
- **Psychosocial**
  - improve communication
  - improve coping
  - gain insight
  - enhance quality of life
  - emotional expression
- **Physiological**
  - pain management
  - decrease anxiety
  - regulate breathing
  - symptom management
- **Cognitive**
  - pre & post operational support
  - a positive diversion from illness

**TO FIND OUT MORE...**
Please feel free to reach me at:
Alexa Marie Fini
alexamariefini820@gmail.com
or visit this website to view the published program proposal.
Appendix E

Resume
Alexa Marie Fini

8 Bella Vista Court, Campbell Hall, NY 10916 | alexamariiefini820@gmail.com | (845)551-7419

EDUCATION

State University of New York at New Paltz

B.S in Music / Concentration: Classical Vocal Performance / GPA: 3.97
May 2020

M.S. in Music Therapy / GPA: 4.0
May 2022

WORK EXPERIENCE

Hudson Valley Hospice

Music Therapy Intern
Aug. 2021-Present

- Planned, implemented, and evaluated music therapy experiences with hospice patients and families.
- Consulted with interdisciplinary team members (IDT) to address patient progress and concerns.
- Led weekly “Songs for Remembrance” at IDT meetings.

Aurora Music Academy

Voice and Piano Teacher
March 2020-Present

- Created and implemented lesson plans to meet the diverse and individual needs of students 3-16 years old.
- Motivated students to practice and love music; challenge students to reach full potential.

SUNY New Paltz

Graduate Assistant
Aug. 2020-Present

- Managed offices of both music therapy professor and classical voice professor.

The Angel Band Project

Fieldwork Student
Aug. 2020-May 2021

- Co-facilitated music therapy interventions for female victims of sexual violence.

Lutheran Care Center

Practicum Student
Jan. 2020-July 2020

- Engaged nursing home residents with group sing-a-longs and bell choir.
LEADERSHIP AND VOLUNTEER EXPERIENCE

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<thead>
<tr>
<th>Organization</th>
<th>Location</th>
<th>Dates</th>
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<tbody>
<tr>
<td>SUNY New Paltz Music &amp; Music Therapy Department Open House</td>
<td>New Paltz, NY</td>
<td>2018-2021</td>
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<td>Department Speaker</td>
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<tr>
<td>Miami Theatre Players</td>
<td>New Paltz, NY</td>
<td>2018-2020</td>
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<td>Club Member; Vocal Director</td>
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<tr>
<td>Greece Summer Music Program at Anatolia College City</td>
<td>Thessaloniki, Greece</td>
<td>2018</td>
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<td>Vocalist</td>
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<td>First Presbyterian Church Bible School Music Program</td>
<td>Goshen, NY</td>
<td>2017</td>
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<tr>
<td>Music/Choral Director</td>
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</tbody>
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AWARDS: Girl Scout Gold, Silver, Bronze: ’16, Theatre Association of NY State Acting: ’19, SUNY Chancellor’s Fellowship: ’20, Outstanding Graduate: ’20, Dean’s List Honors: ‘21

SKILLS: Vocal, Guitar, Piano; Microsoft Office; Canva; Social Media Platforms; Google Docs, Slides and Forms; EMR