Dance/Movement Therapy at End of Life:
A Clinical Method to Enhance Quality of Life for
Pediatric Palliative Care Patients and Their Families

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Abstract

Dance/Movement Therapy at End of Life: A Method to Enhance Quality of Life for Pediatric Palliative Care Patients and their Families
Ambre Nina Bethoux

The purpose of this study is to develop and implement a dance/movement therapy clinical method to address challenges for palliative care and end of life situations in children with varying terminal illnesses, relating to cognitive, emotional, and social aspects of quality of life, through integration of the patient’s caregivers. Relevant literature, research, and past dance/movement therapy sessions with identified patients will be reviewed to help guide and create this method. The literature review includes articles and research about end of life and pediatric palliative care, quality of life, pediatric patients’ and families’ identified needs, family-centered care, and the impact of creative arts therapies on quality of life, end of life, and family-centered care. The developed clinical method is strength based, relies on micro-assessments that aim at identified mental and social quality of life goals, provides the patient with a multichannel sensory input through utilization of visual, audio, and tactile components, and helps foster the relationship between caregiver and patient. The method provides and integrates different interventions, the Kestenberg Movement Profile rhythms, micro goals, and phrasings that can be used within the sessions. Sessions where the method was implemented are discussed as well as reflections on how the method can be further developed, multicultural considerations, and future research implications. This method shows how dance/movement therapy can have a positive impact on the quality of life of pediatric palliative and end of life patients and their families, as well as how it can help foster and expand relationships between caregiver and patient.
CHAPTER I: INTRODUCTION

While there are common themes that have been identified around hospitalization for children with terminal diagnoses, it is important to not generalize the experience for all patients. How a child experiences hospitalization and copes with the diagnosis, course of illness and treatments varies individually. How one four-year-old copes with his or her diagnosis of cancer may be different than another four-year-old with the same cancer. Therefore, it is important for therapists to observe the patient during sessions with a blank slate and meet the client’s therapeutic needs in that moment. The design for this project was to implement a dance/movement therapy (DMT) method that integrated caregivers and addressed challenges for palliative care and end of life children with varying terminal illnesses related to cognitive, emotional, and social aspects of quality of life. The developed method focused on different identified quality of life goals and on fostering the relationship between caregiver and patient. The method was implemented at a children’s hospital within individual sessions with nonverbal patients at different developmental ages and with different palliative diagnoses.

Pediatric palliative care, as defined by the World Health Organization, aims at increasing the quality of life for both the patient and the family, integrates family in the therapies and treatments, focuses on the body, mind and spirit of the patient (World Health Organization, 2017), and integrates symptom reduction and pain management. End of life care, included in palliative care, provides care for individuals in the end stages of their life-limiting illness and encompasses the individuals’ medical, physical, psychological, spiritual, and social needs (National Quality Forum, 2012). In 2008, the state of Pennsylvania identified several problems within pediatric palliative care units. These included poor attention to siblings of ill children, lack of knowledge and offering of palliative care to families, poor quality in the established palliative care units, limited education provided to healthcare professionals, poor communication among palliative care team members (as well as between parents and health care providers), poor access to services for families, and a lack of support and information provided to families who need to make difficult decisions regarding their child’s medical outcome (Pediatric Palliative and Hospice Care Task Force, 2008).

It is important to take into consideration the developmental stage of the child to better facilitate communication of the child’s understanding of their medical situation during palliative and end of life care. Dance/movement therapy can help children understand their current medical situation, express their fears and worries about their hospitalization by addressing the emotional and physical issues (Goodill & Morningstar, 1993), and match the child’s needs in the moment through appropriate developmental interventions, such as symbolic play.
and imagery (Hain, Lonnie, Hellsten, Cohen, Orloff, & Gray, 2011). In the developed method, discussions surrounding difficulties with or fears about a palliative diagnosis or hospitalization could not be facilitated as the patients were nonverbal. However, how the patient was coping with these could begin to be understood from their affect, facial expressions, interactions, and movement observations during DMT sessions.

Eight aspects of quality of life have been identified as being important to palliative care patients: cognitive, emotional, healthcare, personal autonomy, physical, preparatory, social, and spiritual (McCaffrey et al., 2016). For pediatric patients with advanced diseases, physical, psychological, social, and life style value domains were identified as being the most important (Evan, Calonico, Tan, & Zeltzer, 2012). Dance/movement therapy can provide psychosocial support for children in medical settings (Chambers, 2013), can help children identify changes in their bodies, and facilitate building a healthy body image in relation to their illness (Goodill & Morningstar, 1993). Dance/movement therapy integrates the mind, body, and spirit, suggesting a holistic approach, to encourage these explorations and can help the individual prepare for death on “physical, psychological, and spiritual levels” (Dillenbeck & Hammond-Meiers, 2009, p. 109). Dance/movement therapy supports movement exploration not only through visible movements but also through stillness and internal exploration of the self, allowing for a deeper understanding of the self to surface. Through these observations, movement expressions or emotions that developed during sessions where the method was implemented, were guided and supported based on the age and developmental stage of the patient (Dillenbeck & Hammond-Meiers, 2009).

Family-centered care was found to have a positive impact on the quality of life and life satisfaction of patient’s caregiver and lower levels of anxiety, caregiver burden, and depression and distress symptoms were reported (Crespo, Santos, Tavares, & Salvador, 2016). Caregivers have voiced their desires to be kept informed of their child’s prognosis, to receive medical information that is both general and specific to their child’s illness, and to develop a therapeutic alliance with their child’s health care team that allows them to make decisions and provides support and respect (Holm, Joan, Patterson, and Gurney, 2003). In accordance with these findings, the developed method for this project integrated the caregivers of the patients when possible to create a more family-centered care method and to support positive patient and caregiver relationships and interactions.

When treating a patient, it is important to take into consideration the families’ culture, values, and beliefs. Although little research has been done on cultural influences on family management in the United States, specifically with children, health care providers need to understand that an individual’s cultural practice will shape
their definition of death, how they express grief, and how the individual or the family wants the illness to be treated (Koenig & Gates-Williams, 1995). Through understanding and acceptance of these practices and assessing the patient as a unique individual within the context of their family, healthcare providers can help create a more positive and effective end of life care for the individual (Koenig & Gates-Williams, 1995).

Thibodeaux and Deatrick (2007) discuss how sociocultural context influences how family defines and manages the illness of their sick child but that there is a lack of research to further explain this. Specific sociocultural factors affecting these families are still not known despite the American Cancer Society recommending that interventions should meet the needs of the patients by also taking into consideration the family, culture, and socioeconomic factors, suggesting a “blended family management and culture care framework” (Thibodeaux & Deatrick, 2007, p. 228). Therefore, it was important for all of the above factors to be considered when the method was developed for this project and how it may work differently with certain patients.

When this method was developed and implemented, past observations from sessions with pediatric palliative care patients were considered and integrated into the interventions created. Initially, this method was meant to further discussion about the patient’s illness and create positive interactions between caregivers and patients through both movement and dialogue but due to the demographics of the internship setting, the method was created for pediatric palliative care patients who were nonverbal, with some being developmentally delayed. Through these changes, it was found that this method could elicit important interactions between caregivers and patients that may have been forgotten or that were difficult for the caregiver to approach. Additionally, this method created a voice and a conversation for the patient through movement and interaction, eliciting a powerful exchange between patient and caregiver or therapist. Case vignettes are provided in Chapter 3 to demonstrate the evolving interactions and quality of life components for the patients and caregivers that participated in the DMT sessions.
CHAPTER II: LITERATURE REVIEW

2.1 End of Life Care and Pediatric Palliative Care

2.1.1 End of life care. End of life care provides care for individuals in the end stages of their life-limiting illness and encompasses the patient’s medical, physical, psychological, spiritual, and social needs (National Quality Forum, 2012; Pediatric Palliative and Hospice Care Task Force, 2008). In end of life care, the goal is no longer to prolong life but instead to enhance the quality of life (QOL) of the patient and provide a smooth transition into death for the family and patient. This is done through the use of holistic and family-centered care (National Quality Forum, 2012; Hilden, Himelstein, Freyer, Friebert, & Kane, 2001; Pediatric Palliative and Hospice Care Task Force, 2008). End of life care, often referred to as Hospice care, utilizes both palliative and supportive care to aid in accomplishing this goal (Pediatric Palliative and Hospice Care Task Force, 2008).

Basu (2013) discussed four epoch groups in end of life care: preparation-family, active-family, recovery-family, and recovery-caretaker. Basu noted that confusion, lack of control, and unpreparedness are reported by families when their child reaches end of life, highlighting the importance of preparing families and the dying patient through honest and open communication which will be discussed in more detail further in this literature review. These families have identified the importance of QOL, degree of pain, and likelihood of improvement as important factors (Basu, 2013; Hilden et al., 2001). This includes the importance for families to have positive environmental memories to help cope with bereavement. For families to make positive and comfortable decisions about end of life care for their child, several factors such as the families’ understanding of the diagnosis and prognosis, the effects the disease will have on their child, physical and emotional problems that may impact the course of illness, and resources available to the families need to be provided (Hilden et al., 2001).

While there are some barriers to end of life care such as infrequency of caring for end of life children, prognostic uncertainty, cultural specific differences, and lack of formalized education and training for staff (Basu, 2013; Hilden et al., 2001), the Quality of Death framework provides a structure for staff to understand the personalized needs of the patient and their family. This framework includes five questions to be asked to both the patient and family, involves partnering with hospital services that specialize with the dying process, and describing and designing the procedure of death (Basu, 2013).
2.1.2 Pediatric palliative care. Pediatric palliative care, as defined by the World Health Organization (2017), aims to increase the QOL for both the patient and the family, integrates the family in the therapies and treatments, focuses on the body, mind and spirit of the patient, and integrates symptom reduction and pain management. While palliative care is typically provided to patients whose illness(es) do(es) not respond to curative treatment, it is also available to those with chronic, life-limiting conditions who may still be undergoing curative treatments (World Health Organization, 2017; Crozier & Hancock, 2012). Studies have found that initiation of palliative care and preparation discussions of end of life early on in treatment improves symptom management, QOL, and has a positive impact on grieving as families are provided with time to process, decide, and accept their child’s end of life care (Klick & Hauer, 2010).

Similar to end of life care, palliative care should include honest and open dialogue between the families, patients, and the child’s medical staff (Klick & Hauer, 2010). Klick and Hauer (2010) discussed the importance of effective communication for families of dying children, inclusion of families in setting goals for the treatment course of their child which can later be revisited when the child’s illness begins to worsen, and inclusion of the child in understanding their illness and treatment through developmentally appropriate discussions. In palliative care, families are asked in an open-question format what their goals, hopes, and objectives are to determine where they currently stand on the prognosis of their child’s illness. A goal or treatment plan that may be discussed with the families is how to proceed with treatment as the illness progresses. This may include setting a goal for the patient to be comfortable throughout the process, not suffer, and focus on QOL (Klick & Hauer, 2010). By setting these goals early in treatment, it can help the family make decisions in the future.

2.1.3 Differences between end of life care and palliative care. One of the main differences between end of life and palliative care is that end of life care is introduced when the patient’s illness has a prognosis of six months whereas palliative care is typically introduced earlier in the disease process (Pediatric Palliative and Hospice Care Task Force, 2008) and is provided to the patient throughout the disease trajectory (Crozier, & Hancock, 2012). Palliative care co-exists with curative treatments whereas end of life care signifies that curative treatments are no longer effective or there is no curative treatment for the life-limiting illness as it approaches the six-month prognosis (Crozier, & Hancock, 2012). In addition, end of life care programs place an emphasis on dying at home whereas palliative care is provided to patients in a medical setting (Crozier, & Hancock, 2012).
2.1.4 **Holistic approach.** The holistic model of care is centered on the whole person and acknowledges that changes to an individual’s mind, body, or spirit affect the overall health and QOL of the patient and their family (Ahmed, Ahmedzai, Collins, & Noble, 2014). This highlights the interrelatedness of body, mind, and spirit when experiencing an illness and the need for a multi-disciplinary team in palliative and end of life care (Brennan, 2013). Holistic care acknowledges the “interdependence among one’s biological, social, psychological, and spiritual aspects” (Zamanzadeh, Jasemi, Valizadeh, Keogh, & Taleghani, 2015, p. 2) and focuses on the patient as a whole person instead of as a set of problems that need to be fixed (Hain, Lonnie, Hellsten, Cohen, Orloff, & Gray, 2011). The patient’s thoughts, emotions, cultures, opinions, and attitudes are taken into consideration during the treatment process, allowing the patient to partake in the decision making of their care (Zamanzadeh et al., 2015).

In their article, Ahmed et al. (2014) highlighted the importance of using a more systematic holistic assessment with patients in palliative care to better capture the total symptom experience of the patient instead of relying on routine medical assessments that utilize open-ended questions. In a study conducted by White, McMullan, & Doyle (2009), it was found that on average, eight further symptoms were detected per patient when a systematic assessment was made compared to self-report. By providing the patient with an active role in their treatment and encouraging self-care, holistic care can lead to therapeutic consultation, increased hope, dignity, and self-discipline, social growth, sense of autonomy, vigor, and vitality (Zamanzadeh et al., 2015). Holistic care provides the space for self-awareness and self-confidence, allows the treatment team to gain a better understanding of the patient’s true needs and of the effects the illness has on the patient’s entire life, and improves harmony between mind, body, emotions, and spirit (Zamanzadeh et al., 2015).

2.2 **Quality of Life**

2.2.1 **Defining and measuring quality of life.** Pediatric QOL is a “multidimensional construct that is a state of complete physical, mental, and social well-being for a child” (Evan, Calonico, Tan, & Zeltzer, 2012, p. 1). It must be acknowledged that these areas of QOL are influenced by the person’s beliefs, expectations, and perceptions of death meaning that individuals with the same health status may have different perspectives of QOL (Evan et al., 2012). Due to QOL being multidimensional and subjective, assessment tools, even multidimensional instruments, cannot accurately identify a patient’s QOL as they may mask “important differences between patients, and between different models of care” (Salisbury, Bosanquet, Wilkinson, Franks, Kite, Lorentzon, & Naysmith, 1999, p. 6).
There is currently no instrument that can assess all aspects of QOL from the perspective of a patient with a life-limiting condition (McCaffrey, Bradley, Ratcliffe, and Currow, 2016). If evaluation tools used in research do not include aspects of QOL valued by patients, “palliative care and other health professionals may fail to address complex issues such as preparation for death” (McCaffrey et al., 2016, p. 319) and may instead mainly focus on management of physical symptoms.

2.2.2 Patient’s perspective, understanding, and needs for better quality of life. In their systemic review and synthesis of qualitative research, McCaffrey et al. (2016) identified eight important aspects of QOL from adult palliative care patients’ perspectives: cognitive, emotional, health care, personal autonomy, physical, preparatory, social, and spiritual. Their analysis showed intrinsic characteristics such as individual values, personal qualities, characteristics, and attitudes could influence the importance of certain QOL aspects for individuals. In their qualitative study to identify and describe quality of end of life care from the patient’s perspective, Singer, Martin, and Kelner (1999) found that adult patients identified five domains of quality of end of life care: adequate pain and symptom management, avoidance of inappropriate prolongation of dying, achieving a sense of control, relieving burden, and strengthening of relationships with loved ones.

For pediatric patients, it can be difficult to assess a child’s perception of their QOL as cognitive and verbal skills vary and parents are often the decision makers (Evan et al., 2012). However, it is still important to obtain self-reported assessments of QOL from these children. In their qualitative study aimed at understanding QOL of pediatric patients with advanced disease, Evan et al. (2012) found that physical, psychological, social, and lifestyle values were the main domains identified by participants. They discussed that the children cited physical limitations, such as being unable to participate in sports, being self-sufficient, and walking, as one of the most bothersome parts of being ill as it served as a source of stress and frustration and impacted social functioning.

Social interactions and relationships with others were noted as being very important to the participants regarding their overall QOL. Some of the benefits of social interactions described by the participants were the feeling of hope for the future, having someone to talk to, and providing a positive outlook on life (Evan et al., 2012). In the lifestyle value domain, the participants stated rules to live by and values that improved their QOL. This study demonstrated the need for a multidimensional framework when defining QOL and that by using open-ended questions about distress level and the patient’s meaning of QOL, healthcare providers can assess the overall QOL of pediatric patients more effectively.
2.3 Pediatric Patients

2.3.1 Understanding of death; developmental and age-related differences. When caring for a child with an advanced disease, it is important to be aware of how the child’s developmental stage affects his or her understanding of death (Hurwitz, Duncan, & Wolfe, 2004). By communicating with a child at the appropriate developmental level, this approach can improve the child’s understanding of their disease, reduce stress and anxiety, and increase comfort and the child’s involvement in their care and decision making (Klick & Hauer, 2010).

In their literature review about children’s and adolescents’ understanding of their own terminal illness and death, Bates and Kearney (2015) discussed how a child’s understanding of death can fall under four concepts: universality, irreversibility, nonfunctionality, and causality. They noted that children aged four or younger cannot differentiate between death and separation from their caregiver and correlate death with non-natural causes. Those five to seven years old have a partial understanding of these concepts with the exception of causality and correlate death with natural causes (Bates & Kearney, 2015) and those aged six to eight years old often believe that the death may have been caused by their own bad behaviors or wishes (Hurwitz et al., 2004). Children aged ten to twelve begin to have a more adult understanding about death and correlate it with spiritual causes (Bates & Kearney, 2015).

Researchers have identified the importance of five major aspects of understanding death which are mastered in sequential order between the ages of five and ten years old: inevitability, irreversibility, cessation or nonfunctionality, and causation (Slaughter & Griffiths, 2007). Young children, before preschool age, think of death as behavioral and conceptualize death as an “altered state of living” (Slaughter & Griffiths, 2007, p. 526) such as living in heaven or in an underground tomb.

This signifies that the child believes the dead are still alive elsewhere (Slaughter & Griffiths, 2007). They do not understand causes of death and typically correlate dying with internal and external agents such as fatal illness or guns (Slaughter & Griffiths, 2007). Once children reach pre-school and early school age, they begin to conceptualize death in biological terms which has been linked to a decrease in fear of death (Slaughter & Griffiths, 2007). A child’s earliest accurate understanding of death, occurring by the age of five or six years old, involves the realization that those who die cannot come back to life (Slaughter & Griffiths, 2007).

The ability of a child to deepen their understanding about death and dying is influenced by the child’s dying process and how their caregiver(s) manage(s) that process (Bates & Kearney, 2015). A child’s language to “discuss or think about death may be limited to cultural references or other second-hand information taken out of
context” (Bates & Kearney, 2015, p. 42). Therefore, it is imperative that discussions of death be developmentally appropriate and that children are provided the space to express their beliefs about death and dying.

2.3.2 Early discussions of end-of-life prognosis with patients. In palliative care, communication aims to decrease conflict, confusion, and to enhance decision-making through eliciting a sense of teamwork and facilitating collaboration (Klick & Hauer, 2010). Bates and Kearney (2015) found that most end of life discussions for those who are terminally ill did not begin until one month or less before the patient passed away. By neglecting to have these discussions, the patients were unable to appropriately share their fears, seek comfort, or cope with their prognosis. It is important to discuss with patients their diagnosis and prognosis early in a developmentally appropriate manner, as not doing so leads to increased distress, anxiety, mistrust, and isolation (Bates & Kearney, 2015; Hurwitz et al., 2004), and less opportunity for “authentic shared experience, grieving, comforting, and acceptance” (Bates & Kearney, 2015, p. 42).

Before discussing end of life prognosis with the patient, end of life discussions should first be addressed with the family to ensure that no boundaries are being overstepped. The family’s influences such as culture, religion, and/or spiritual beliefs should be considered and respected when these discussions arise. Discussions with children about their prognosis should assess what the child may already know or believe through open-ended questions, being present, and listening. Specific end of life discussions with children should be continuous and should be delivered in developmentally appropriate ways (McSherry, Kehoe, Carroll, Kang, & Rourke, 2007). For example, in young children, these discussions may take place through play, movement, or drawing rather than verbally as it is a more developmentally appropriate way for them to express themselves. Children often know when they are dying even if they are not directly told. By providing an open discussion about their prognosis, it provides the ability for the child to voice their preference about treatment and care decisions (Klick & Hauer, 2010).

2.3.3 Behavioral/psychosocial/emotional issues. The effects of hospitalization on children vary and are dependent on a range of factors such as individual differences, age, temperament of the child, the nature and prognosis of the illness, the characteristics and organization of the hospital, and the response of siblings, family members, friends, and other individuals who are in contact with the child (Lizasoain & Polaino, 1995). Psychologically, hospitalized children stated experiencing depression, anxiety, and being uncomfortable as a negative effect of their illness (Evan et al., 2012). Despite this, psychological symptoms were found to be addressed and treated less than physical symptoms (Evan et al., 2012). However, some participants stated some positive
psychological effects of their illness such as being more appreciative for things in life and giving importance to new things (Evan et al., 2012).

A child’s emotional response to their experience of the illness is affected by their developmental level (McSherry et al., 2007). Anxiety is frequently reported over the unknown and sadness over losses with loss of control over their body and what is happening, loss of personal identity, and loss of interpersonal relationships listed as the most distressing (McSherry et al., 2007). In younger children, moments of sadness may arise over missed opportunities and/or hospitalization while in older children and adolescents, the sadness is more continuous (McSherry et al., 2007). Some behavioral changes in children who experience hospitalization include regression, aggressiveness, uncooperative behavior, refusal to cooperate with medical treatment, changes in sleeping and eating habits, and rejection responses (Lizasoain & Polaino, 1995). The length of hospitalization also has an effect on behavioral changes with hospital stays longer than one week associated with significant increase in behavioral changes (Lizasoain & Polaino, 1995).

Children hospitalized for the first time experience more severe emotional reactions than those who have been previously hospitalized (Lizasoain & Polaino, 1995). However, those who have had past negative hospital experiences have higher levels of anxiety than those with no prior hospitalization (Lizasoain & Polaino, 1995). Additionally, “the absence of orientation and support for the hospitalized child, offered by teachers, psychologists, parents and hospital staff, poses an added risk for the onset and course of psychopathological manifestations” (Lizasoain & Polaino, 1995, p. 18). In addition, past research has found that ill children had higher psychological adjustment problems than their healthy peers (Cohen & Walco, 1999).

2.4 Family-Centered Care

2.4.1 Benefits/core principles. The American Academy of Pediatrics (AAP) (2012) identifies the following principles for patient and family-centered care:

- Listening and respecting the child and family and honoring and incorporating multicultural background and socioeconomic status into the healthcare plan.

- Allowing for flexibility in organization policies, procedures, and provider practices in order for services to be tailored to the child and family’s needs, beliefs, and cultural values, in order to enable choice about approaches to care.
● “Sharing complete, honest, and unbiased information with patients and their families on an ongoing basis and in ways they find useful and affirming” (p. 395) to allow for effective participation in care and decision making with health information provided in the range of cultural and language diversity.

● Providing formal and informal support during each phase of the child’s life as followed by ethical and legal guidelines.

● Including the patient and family at all levels of health care which includes allowing the patient and family to serve as members of child or family advisory councils, committees, and task forces.

● “Recognizing and building on the strength of individual children and families and empowering them to discover their own strengths, build confidence, and participate in making choices and decisions about their health care” (p. 395).

Additionally, the AAP lists some of the benefits of patient and family-centered care for healthcare providers, such as building a stronger alliance with family, improved clinical decision making, an opportunity for the health care team to learn from the families how care systems work rather than how they are intended to work, and a better understanding of the family’s strengths and caregiving capacities. Efficient and compassionate communication between the family and patient has been found to promote quality end of life care (Hurwitz et al., 2004). In a telephone survey conducted by Mack, Hilden, Watterson, Grier, Weeks, and Wolfe (2005), overall care was rated higher by parents of children who died of cancer when physicians clearly informed the family about what to expect during end of life for their child, utilized sensitive and caring communication, helped in preparation for the child’s death, and had direct communication with the child when appropriate.

For caregivers of children with disabilities or chronic illnesses, reduction in stress and improved emotional well-being have been reported when they were provided with a family-centered care approach. As reported by Manne, Bakeman, Jacobsen, Gorfinkle, Bernstein, & Redd (1992) and Jacobsen, Manne, Gorfinkle, Schorr, Rapkin, & Redd (1990), parental distraction and procedural explanation by parents led to increased child coping behaviors and lower amounts of distress. Additionally, studies have found that when parents were included as coaches in interventions for cancer related procedures, the child’s pain, anxiety, and distress were reduced (Holm, Patterson, & Gurney, 2003). In their qualitative study aimed at addressing the literature gap on parental perspective and broader involvement in their child’s medical cancer care, Holm et al. (2003) found advocacy as the overarching theme of their results. Advocacy was defined as “parents speaking and acting on behalf of their child, as an intercessor and
champion, to ensure that their child’s needs are met” (Holm et al., 2003, p. 304) and was most apparent during the diagnosis and treatment phase.

Some difficulties encountered by families advocating for their children were identified as the disconnect between the parent’s knowledge of their child and limited knowledge of the medical terms and procedures, uncertainty about pressing the medical team when they had questions or concerns out of fear of being disrespectful and being intimidated by the environment or physicians. However, as found by Holm et al. (2003), in the diagnosis and treatment phases of their child’s diagnosis, parents sought medical explanation for their child’s symptoms, persisted in pursuing an accurate and complete diagnosis despite negative test results, and informed themselves about their child’s medical status and needs. Involvement in decisions about their child’s medical treatment (e.g. necessity in bringing child for additional medical care when there are changes in symptoms or health status, which medical facility to use for treatment), and actively and intentionally supporting and fostering the relationships with their child’s medical staff were also important for parents.

Caregivers have voiced their desires to be kept informed of their child’s prognosis and medical information that is both general and specific to their child’s illness and to develop a therapeutic alliance with their child’s health care team that allows them to make decisions, provide support and gives the parents a sense of respect (Holm et al., 2003). The results of these studies indicate the importance of family-centered care in medical settings to improve both the patient’s and caregivers’ QOL.

Family centered care practices have been associated with lower levels of family burden through more efficient care coordination, fewer hours towards caregiving, reduced financial costs, and fewer needs to stop working for parents with children requiring special health care needs (Crespo et al., 2016). Time constraints felt by the caregivers and poor time management can also be eased by family centered care through the promotion of flexible schedules to fit the family’s needs and helping the parents feel empowered and supported in their caregiving role (Crespo et al., 2016). Family centered care is also important in helping parents of terminally ill children adapt to their new caregiving role and burdens that may arise (Crespo et al., 2016). Through building care based on the family’s needs and preferences, providing adequate and timely information, and promoting collaboration between health professionals and the family, less burden associated with the caregiver role may be experienced by the parents, which may positively impact their QOL (Crespo et al., 2016).
2.4.2 What families value in care. Some studies identified QOL, chances of getting better, pain or discomfort, unlikely survival of hospitalization, and what the child wanted as the top five factors important to parental end of life decision making (Meyer, Burns, Griffith, & Truog, 2002). Feeling a lack of control over the situation during the final days of their child’s life, realizing they would have made different decisions related to their child’s care, and feeling as if they were ill informed about who they could speak to during their child’s care were also experiences reported by parents (Meyers et al., 2002).

As found in Meyer, Ritholz, Burns, and Truog’s (2006) qualitative study aimed at identifying and describing parent’s perspective of the priorities and recommendations of end of life care, six priorities were found: ready access to staff, communication and care coordination, emotional expression and support by staff, preservation of the integrity of parent child relationship, and faith. Parents described the need for honest and complete information regarding their child’s diagnosis and prognosis as well as having access to healthcare members to gain information and to “foster reassurance, trust, and emotional peace of mind” (Meyer et al., 2006, p. 651) as highly important. Not being able to contact or have access to physicians and particular staff members or interacting with healthcare members who were in a hurry and/or reluctant to meet led to additional stress for the parents (Meyer et al., 2006).

Parents also noted the number of different healthcare professionals and lack of coordination of communication and care between each other as lowering their confidence and trust in their child’s care and placing additional time and emotional burden on them (Meyer et al., 2006). Mack et al.’s (2005) qualitative study pursued similar aims but focused more specifically with parents of children with cancer and reported similar results. Parents in this study appreciated when physicians delivered bad news in a sensitive and caring manner, and clear information regarding expectations surrounding end of life were delivered leaving them feeling prepared for the circumstances around their child’s death (Mack et al., 2005).

Parents in Meyer et al.’s (2005) study appreciated and encouraged healthcare member’s genuine expressions of kindness and compassion that were perceived as authentic, and reflecting care that was beyond their role, especially when attempting to humanize the environment and situation. Parents also shared wanting to be recognized for their parental duties in their child’s life and medical care. They valued not being judged, being respected, included in decision making, and being listened to. They also identified the need for privacy to feel close to their child, and not being rushed or intruded on during those moments (Meyer et al., 2006).
Parents’ needs and value in the care of their child should be identified and considered by the healthcare team. Parents can provide individualized knowledge and insight of their child’s needs to the healthcare team. However, parents’ still need support throughout this process to ensure that they are fully aware of their child’s illness and prognosis, in order to prepare them for what will happen at end of life for their child. Parents need to feel a sense of security and respect from the healthcare providers to lower their emotional strains allowing them to be more attentive to their child in a positive manner.

2.4.3 Psychosocial health of parents. Due to the inter-dependence of family members, when one family member is affected by an illness, it will also affect the rest of the family (Brown, & Warr, 2007). Additionally, how parents are told about their child’s diagnosis will affect how the parents and family will adjust to the situation, in turn affecting the well-being of the ill child (Brown, & Warr, 2007). Post diagnosis of their terminally ill child, parents often feel confused and have high anxiety due to the uncertainty of their future and the new central focus on their child’s illness (Brown, & Warr, 2007). Many parents report feeling isolated as they try to cope with their child’s diagnosis through constant adjustment to their child’s new demands as the illness progresses. Brown (as cited in Brown, & Warr, 2007, p. 129), identified the following emotions that parents of terminally ill children experience: disillusionment, aloneness, inequality, insignificance, and past orientation including a range of sadness, anger, shock, and disbelief.

Social support and family relationships are important for parents with a terminally ill child, but parental worry and distress often results in irritability and tension which reduce available support from family and friends (Brown and Warr, 2007). Additional research has shown some differences in the way mothers and fathers experience distress when they are caring for a terminally ill child. Mothers of ill children will experience increased distress and will often take on the responsibility for the majority of domestic tasks (Brown and Warr, 2007).

There is conflicting research on whether mothers experience more distress than fathers. Research by Affleck, Tennen, and Rowe (as cited in Brown & Warr, 2007, p. 131) found that while mothers reported higher distress levels, fathers “were reluctant to express their distress outwardly and focused their attention on helping their spouse cope” (p. 131). Murphy (as cited in Brown, & Warr, 2007, p. 131) found that fathers viewed the emotional support they needed to provide as a large strain and were fearful of becoming attached and interacting with their child due the child’s terminal diagnosis.
In their research study, Crespo, Santos, Tavares, and Salvador (2016) aimed to identify the “direct and indirect associations, through caregiving burden, between parents’ FCC [family-centered care] and quality of life and life satisfaction” (p. 31). They explained that parents of children with cancer are at risk for developing high levels of distress, problems with psychological adjustment, and report having a lower QOL when compared to population norms and parents with healthy children. Furthermore, they stated that family-centered care has been linked in other studies with lower caregiver burden, reduced financial costs, a decreased need to relinquish employment, and lower levels of anxiety, depression, and distress symptoms. Additionally, in their multi-institutional cross-sectional study that looked at factors related to parental perception of the family-centered approach of pediatric oncology services, Dix, Klassen, Papsdorf, Klaassen, Pritchard, and Sung (2009) found that lower parental psychosocial health scores were tied to lower family centered care ratings.

For their study, Crespo et al. (2016) recruited 204 primary informal caregivers of a child with at least a three-month diagnosis of cancer who was receiving treatment for a newly diagnosed or relapsed cancer or had finished antineoplastic treatments within the past five years. Their findings further confirmed the negative psychosocial health aspects of parents with terminally ill children. The study also revealed that older parents and parents of older children had higher levels of family centered care, lower caregiver burden, and elevated life satisfaction, with longer time since diagnosis being associated with lower levels of caregiver burden and higher QOL.

2.4.4 Experience of living with and/or caring for an ill child. In addition to the significant psychosocial challenges faced by caregivers of terminally ill children, additional burdens have been identified which are linked to low QOL and life satisfaction. In their cross-sectional prospective qualitative study, Collins, Hennessy-Anderson, Hosking, Hynson, Remedios, and Thomas (2016) aimed to discover the lived experiences of primary caregivers in Australia who were currently providing care for a terminally ill child. Their findings identified four key themes: trapped inside the house, the protector, living with the shadow, and travelling a different pathway. Parents identified their seclusion from the community due to feeling contained to the house as a result of the equipment and care supports needed for the child (Collins et al., 2016). They listed the difficulty of participating in everyday activities outside of the house, traveling, and having their child be excluded from social occasions, such as birthday parties and sporting events, due to the fragile and unpredictable physical condition of their child. Due to
these restrictions, parents felt they were a burden to others as their own stress and need for support increased (Collins et al., 2016).

Parents also shared how their caring demands “restricted them from carrying out formal vocational aspirations” (Collins et al., 2016, p. 954). Some parents were forced to quit their jobs to care for their child while others changed to more voluntary and casual work roles that offered flexible hours, as committing to regular work hours was not possible due to the parents’ need to be available to attend to their child’s needs at all times (Collins et al., 2016). The loss of work has also led to financial strains due to demanding costs of caring for a terminally ill child (Hurwitz et al., 2004). Despite feeling a sense of loss when needing to give up their work and expressing desires to return to the workplace, many parents felt unsupported to do so by the working community (Collins et al., 2016). The loss and exclusion from the workplace was viewed as lost opportunities to engage in adult conversations, participate in the work community, and maintain a sense of self (Collins et al., 2016).

In addition to the emotional health, the high demands of caring for their child also impacted the physical health of parents (Collins et al., 2016) which could be associated with sadness, guilt, anger, exhaustion, and insomnia (Hurwitz et al., 2004). However, parents felt they were unable to take care of their own health needs or attend their own healthcare appointments as their caring responsibilities were constant and the child’s wellbeing a priority (Collins et al., 2016). The role of protector was identified as the parent holding all the knowledge about their child’s specific and unique care needs and ownership of those responsibilities (Collins et al., 2016). This lead to feeling that others were unable to understand the needs or ways of communicating with their child as they felt that they were the only ones who knew how to respond immediately in an emergency which would often happen without warning (Collins et al., 2016).

Parents took full ownership of the care tasks to lessen the impact on the physical and emotional health of their child and other family members (Collins et al., 2016). However, this led to parents feeling as if they were unable to take a break from caring for their child without compromising the standard of care (Collins et al., 2016). The parents shared how the possibility of their child receiving suboptimal care in order for them to take a break was unacceptable and led to significant emotional burden (Collins et al., 2016) with parents of multiple children also struggling with the competing demands of their healthy children (Hurwitz et al., 2004).

Fear of the future was also highly prevalent among these parents. Uncertainty for the future led parents to focus on survival statistics, timeframes provided by medical professionals, and focusing on the present (Collins et
Despite times of stable condition for their child, parents continued to fear for the future as they understood that the child’s care needs and potential for another crisis were still approaching. Parents reported feelings of helplessness and abandonment as they knew that death was inevitable for their child leading to anticipatory grief (Collins et al., 2016). Parents also identified grieving for the life that could have been for themselves and their child as well as grief for personal losses (Collins et al., 2016).

Through all of this emotional and physical burden and limited resources available to fully support the families and caregivers (Hurwitz et al., 2004), parents were able to describe how their caregiving role changed their perspective on life. It allowed them to see what was most important and instilled an inner resilience from surviving the ongoing hardships and adversity of their caregiving role (Collins et al., 2016). Their earlier losses of self and relationships were consoled through the new capacity to see what is meaningful in life, and their new caregiver role identified as the beginning of a new life path that often included the support of a new community going through similar challenges (Collins et al., 2016).

2.4.5 Siblings of terminally ill children. Siblings of children who are terminally ill have poor psychosocial outcomes including emotional problems, behavioral problems, academic difficulties, adjustment issues, peer-related difficulties, and low self-esteem (Brown & Warr, 2007; Fullerton, Totsika, Hain, & Hastings, 2016; Lane & Mason, 2013). Social development may be impacted as parents may find it difficult to provide normal social opportunities for their well child (Lane & Mason, 2013). Common emotions experienced by siblings of terminally ill children include guilt, worry, resentment, sense of loss, embarrassment, and responsibility which could create difficulties in relationships with their parents and ill sibling (Lane & Mason, 2013). Parents may not be aware of the sibling’s emotions and may be unable to aid in helping them cope as they are facing their own emotional and practical burden (Lane & Mason, 2013) leading to parents underestimating the sibling’s experience of the terminally ill child (Fullerton et al., 2016; Lane & Mason, 2013).

Children are dependent on the family for support, including their siblings. Some medically well siblings may use acting out behaviors at school and home to display their irritability and anger towards how their medically fragile sibling’s illness is disrupting their lives (Brown & Warr, 2007). Often, well siblings feel that the medically fragile child is the parents’ favorite child, that they fall short of their parents’ expectations, and that they are no longer an important part of the family (Brown & Warr, 2007). This can lead to some siblings trying to prove they are worthy of love and affection by trying to be good at all times, neglecting their own needs, and experiencing lowered
self-esteem in an attempt to win their parents’ approval (Brown & Warr, 2007). Additionally, physical health problems such as aches and pains and poor sleep have been experienced by well siblings (Brown & Warr, 2007).

While some may experience school-related difficulties due to their stress, others, especially older siblings, may excel at school due to imposing elevated expectations on themselves to not further their parents’ distress and disappointment (Brown & Warr, 2007). Older siblings may also develop a sense of responsibility for their parents and younger well siblings in an attempt to alleviate their parents’ pain and sadness (Brown & Warr, 2007). For younger children, isolation from peer groups have been identified, as younger children may find it difficult to express their emotions and for their friends to understand them (Brown & Warr, 2007). Loneliness may also occur, especially for siblings who had shared experiences with their ill sibling pre-diagnosis as they are now unable to share in those experiences anymore (Brown & Warr, 2007). However, that relationship often becomes intensified as the medically fragile sibling has become the well sibling’s closest friend.

Many of these siblings experience a change of role and status in their family as some of the well siblings may become caretakers of the terminally ill child or may feel unsupported, neglected, and confused about who they are and/or who they are supposed to be due to the lack of parental attention (Brown & Warr, 2007). How a child will cope with the death of their medically fragile sibling is based on their age, gender, personality, coping strategies, role in their family, past encounters with loss, change, and death, their relationship with the medically fragile sibling, inclusion in family discussions surrounding the medically fragile sibling, and duration and type of illness the ill sibling has (Brown & Warr, 2007). How children manage their emotions may be influenced by how the parents interact with them.

Children develop patterns of adjustment and coping strategies that will be used throughout their lives. The grieving process is shaped by the child's individuality, family situation, and home environment. However, some research has indicated that siblings of terminally ill children may develop higher empathy, compassion, patience, and sensitivity (Fullerton et al., 2016; Lane & Mason, 2013). In a study conducted by Fullerton et al. (2016) that explored psychological adjustment and relationships of siblings of children with life-limiting conditions, prosocial skills were found to be significantly lower than the general population which could be linked to the limited opportunities for social interactions and high levels of social strain.

However, they found that well siblings whose parents worked outside of the home had higher prosocial skills which could be linked to their need to take on a larger role in caring for their sibling. This could include direct
caregiving or aiding other carers of the ill child. Additionally, lower socioeconomic status was associated with higher conflict among sibling relationships and lower QOL as opposed to higher socioeconomic status (Fullerton et al., 2016). Those whose ill siblings were offered hospice-based services had increased physical QOL, with time since diagnosis being associated with less total impact, status/power relationship imbalances, and increased sibling relationship but not with sibling behavioral problems (Fullerton et al., 2016).

It is important for family centered care practices to include siblings in discussions and educate parents about the potential needs of their well child and how to provide them with the support they need. By providing children with information about their terminally ill sibling, it allows the well sibling to identify misconceptions, provides reassurance, and helps answer questions he or she may have (Bellin & Kovacs, 2006). Cognitive, behavioral, and psycho-educational group interventions have been found to increase self-esteem, improve family relationships, reduce anxiety, improve adjustment, resilience, and coping skills, and increase knowledge of illness for the well siblings (Bellin & Kovacs, 2006). How a sibling experiences grief is unique and not all may experience complicated grief. Some may grow up to be caring and sensitive due to their experiences. By keeping the well siblings involved in discussions about the ill sibling, it allows them more opportunities for coping, increased opportunities for expressing emotions and concerns, allows them to feel involved in the family rather than pushed off to the side, and could allow parents to understand and acknowledge the well sibling’s participation in the family (Bellin & Kovacs, 2006).

2.4.6 Cultural influences/practices and spirituality. When treating a patient, it is important to take into consideration the families’ culture, values, and beliefs. Although limited research has been done on cultural influences on family management with ill children, health care providers need to understand that an individual’s cultural practice will shape their definition of death, how they express grief, and how the individual or the family wants the illness to be treated (Koenig & Gates-Williams, 1995). Through understanding and acceptance of these practices and assessing the patient as a unique individual within the context of their family, healthcare providers can help create a more positive and effective end of life care (Koenig & Gates-Williams, 1995).

Thibodeaux and Deatrick (2007) discussed how sociocultural context influences how a family defines and manages the illness of their sick child but that there is a lack of research to further explain this. Specific sociocultural factors affecting these families are still not known despite the American Cancer Society recommending that interventions should meet the needs of the patients by also taking into consideration the family, culture, and
socioeconomic factors, suggesting a “blended family management and culture care framework” (Thibodeaux & Deatrick, 2007, p. 228).

It is equally important to not assume a patient’s cultural practices based on the general knowledge that may be known about that culture. Assuming an individual belongs to a certain culture based on little information provided such as name, ethnicity, or race, or oversimplifying cultural or religious practices (Wiener, McConnell, Latella, Ludi, 2013) should be avoided as the individual may have some different values or ways of approaching their culture. “Cultural practices and spiritual beliefs are the foundations on which many lives are based” (Wiener et al., 2013, p. 48) which requires medical providers to be culturally sensitive and competent and to consider their own constructs of bias and belief (Wiener et al., 2013).

It is also important for healthcare providers to be mindful and respectful when communicating through gesture and touch as they have different meanings in each culture (Wiener et al., 2013). The healthcare provider could unknowingly disrespect the family or ill child leading to mistrust of the health-care team. When communicating about death or prognosis of the ill child, it is essential for the healthcare providers to learn and respect the family’s and child’s wishes, which are often rooted in ethnic culture, so as to avoid communication pitfalls (Wiener et al., 2013). Additionally, experience and meaning of pain as well as pharmacologic treatment of pain varies through cultures making pain assessment and treatment difficult for the healthcare providers (Wiener et al., 2013). This heightens the necessity to understand the patient’s cultural beliefs and values surrounding medical care and illness.

Every culture has a different view on medical treatment, who is the primary decision maker, the meaning of illness, pain, and death, and communication with the child about their diagnosis and prognosis (Wiener et al., 2013). Parents of children who are receiving palliative care have noted that faith is central to providing them with guidance, making sense of their situation, granting permission about end of life decisions, and better coping (Wiener et al., 2013). Most families have religious customs that they would want respected around end of life care for their child such as having a priest at the child’s bedside to complete death rituals (Wiener et al., 2013). Therefore, it is essential for healthcare providers to ask family members about their preferences and rituals to better understand the family’s needs and desires which will also help to reduce stereotyping (Wiener et al., 2013).
2.5 Creative Arts Therapy

2.5.1 Quality of life and end of life.

2.5.1.1 Dance/movement therapy. One key aspect of DMT is that the therapeutic intervention does take into consideration and observe/meet the patient and family culture where they are. This approach can be a wonderful tool for building trust and understanding individual differences. As defined by the American Dance/Movement Therapy Association (2016), DMT is “the psychotherapeutic use of movement to promote emotional, social, cognitive, and physical integration of the individual, for the purpose of improving health and well-being”. Rooted in the idea of the mind body connection, DMT highlights the “reciprocal relationship between body movement and inner psychological processes” (Cohen, 2000, p. 2). While there is limited research or literature on DMT with end of life children, available literature highlights how DMT can help individuals through several aspects of QOL and facilitate the dying process.

Dance/movement therapy often focuses on increasing QOL through incorporating goals for enhancing emotional well-being, meaningfulness, optimism, increasing sense of control, self-perception, and social functioning (Goodill, 2005). In DMT, body movement is used for therapeutic change through the use of body movement interactions, building awareness of self and others, increasing communication of feelings, and engaging in empathic relationships (Cohen, 2000). This can be accomplished through several different interventions using components such as props, gestures, postures, images, breathing movements, and/or self-touch which can help children explore emotions related to their diagnosis and treatment (Cohen, 2000).

Dance/movement therapy enables the exploration of repressed emotions by developing a relationship with the individual’s feelings using techniques such as active imagination and fantasy (Dillenbeck & Hammond-Meirs, 2009). Interactions are structured by the patient’s spontaneous movement patterns as sessions focus on feelings, sensations, and interactions emerging from the movement process (Cohen, 2000). Sessions are often led by the individuals needs in the moment and their expressive initiations rather than being led by the therapist, and typically unfold in an interactive and improvisational manner (Goodill, 2005).

When working with pediatric patients, Goodill (2005) described the aims for DMT as: decreasing anxiety related to hospitalization and procedures, helping in adjusting to temporary or permanent changes in the body and functional abilities, affirming positive aspects of body image, providing an active experience with the body, providing an environment where feelings about the illness and hospitalization can be appropriately expressed, and
addressing the total child instead of focusing on the disease. For terminally ill children, DMT can help promote mind-body integration in facing end of life issues (Cohen, 2000).

In their pilot study aimed at exploring the experiences and needs of dying individuals, how dance/movement therapists can aid in the dying process, and tools dance/movement therapists can utilize with dying individuals, Dillenbeck and Hammond-Meiers (2009) asked open-ended questions during an interview to five hospice workers aged 26-65 years old with at least two years of direct contact with terminally ill individuals. Their findings showed that as someone nears death, their physical body deteriorates, pain increases, and the individual may feel contempt towards their body. They noted the importance for dance/movement therapists to be attentive and build from small movements the individual produces at this stage, as movement is very limited. They also discussed how individuals at this stage of life identify trust as being important in their relationships and that they benefit from touch. Through DMT, they discussed the therapeutic relationship and the use of touch to help the individual re-connect, allow exploration of their emotions, thoughts, and sensations, and bring awareness to areas of their body that are not painful.

Through using both verbal and nonverbal communication in the therapeutic relationship, DMT can allow those with decreased verbal capacity to continue being seen and understood (Dillenbeck & Hammond-Meirs, 2009). Movement, and more specifically empathic movement, can be a safe way to express one’s experience, emotional reactions, and can facilitate interactions in a contained space with the dance/movement therapist. It can be used as a form of interaction when the individual has limited verbal communication abilities or when the individual cannot verbally express their end of life journey. Dance/movement therapy offers several techniques to unite the conscious and unconscious as the individual’s self and self-identity begin to adjust to “life in death” (Dillenbeck & Hammond-Meirs, 2009, p. 111). Movement can facilitate bringing to awareness memories, images, sensations, and emotions buried in the unconscious either through the therapist attuning and reflecting back the movements of the moving individual or through the mover’s own personal moving experience (Dillenbeck & Hammond-Meirs, 2009).

2.5.1.2 Music therapy. Music Therapy (MT), as defined by the American Music Therapy Association (2017), is “an established health profession in which music is used within a therapeutic relationship to address physical, emotional, cognitive, and social needs of individual.” Music therapy offers an alternative way for the child to express their emotions through music as opposed to just speaking, can help in relaxation and pain control, emphasizes the healthy body parts of the ill child, and provides the space to make choices and regain some control
over their environment (Dun, 1999). Bradt (2014) discussed three core concepts in MT: health, creation versus loss, and QOL. In the concept of health, MT can provide mastery over parts of the child’s life that they still have control over.

In the concept of creation versus loss, MT can offer a bridge between health and sickness for the child. Through music, the child can express his or her life values and personality, taking on a different identity than the child that is dying, and can identify healthy aspects of themselves. Additionally, MT can help the child validate life while still acknowledging the dying process (Bradt, 2014). In relation to QOL, MT incorporates several of the characteristics of QOL within its therapeutic goals for end of life children. Some of these goals may include comfort care, pain and symptom management, improving self-esteem, emotional expression, providing choice and control, identifying and teaching coping strategies, fostering social connections and family support, providing stimulation, and normalizing the environment (Clark, Siden, and Straatman, 2014).

In their review examining five years of program redevelopment at Canuck Place Children’s Hospice, Clark et al. (2014) identified the above goals as benefits of MT for end of life children, but also included distractions from medical procedures and legacy work to the list. Several techniques such as receptivity, creativity and re-creativity, and approaches such as listening to “live, therapist-composed, improvised or pre-recorded music, performing music on an instrument, improvising music spontaneously using voice or instruments, composing music, and music combined with other modalities” (p. 26) are used in MT with end of life children. Using receptive MT techniques such as listening to music is common with these patients as it can help in managing physical symptoms, and listening to music chosen by the child provides the space for expression of feelings though singing rather than speaking (Clark et al., 2014).

In her article and case studies, Daveson (2000) highlighted how MT can help children and adolescents in in-patient palliative care as well as their families. She stated that MT can help patients and families address issues of loss, death, grief, pain, and separation. Daveson explained how certain techniques, such as song writing, can help a patient process their illness and hospitalization, facilitate reflection and self-expression, and identify and express emotions in a nonthreatening manner.

Similar to all creative arts therapies, MT focuses on the abilities of the patients rather than the disabilities. Although, as concluded by Bradt & Dile (2010) in their Cochrane review aimed at examining effects of MT with “standard care versus standard care alone or standard care combined with other therapies on psychological,
physiological, and social responses in end-of-life care” (p. 1), there is not enough evidence to conclude the benefits of MT on QOL of end of life patients, even though MT focuses on several aspects of QOL within identified interventions and goals.

2.5.1.3 Art therapy. Art therapy (AT), as defined by the American Art Therapy Association (2017), is “an integrative mental health and human services profession that enriches the lives of individuals, families, and communities through active art-making, creative process, applied psychological theory, and human experience within a psychotherapeutic relationship” and is used to “improve cognitive and sensory-motor functions, foster self-esteem and self-awareness, cultivate emotional resilience, promote insight, enhance social skills, reduce and resolve conflicts and distress, and advance societal and ecological change”.

In AT, the child is in charge of the work through deciding which materials should be used, the intent and imagery of the art, when the piece is finished, and whether the art will be saved or thrown away (Council, 2012). In a medical setting, creative work can help children regain a sense of hope and rebuild their self-esteem, autonomy, sense of well-being, and competence through a safe and contained space that is provided to help facilitate expression of emotions (Council, 2012). Additionally, patients can use their artistic expression in AT to relay their needs, wishes, perceptions, fears, and hopes to their healthcare team and family (Council, 2012; Madden, Mowry, Gao, Foreman, 2010).

When assessing a patient, the art therapist will focus on the child’s adjustment to the illness, their coping capabilities and skills, their cognition, understanding of their body, and for end of life patients, the child’s understanding of death (Council, 2012). Through focusing on the strengths of the patient, AT can help “bridge from the sad and lonely places of illness to the joy of human connection and understanding” (Council, 2012, p. 227).

In her integrative literature review aimed at examining the effect of AT in pediatric cancer patients, Aguilar (2017) found three key themes across seven articles reviewed: emotional expression and communication, coping skills and distraction, reduced symptoms, and improved well-being. After AT interventions, the patients were able to express their emotions, had improved communication skills and coping skills, and improvement in their symptoms and behavior towards their illness (Aguilar, 2017).

Art therapy can also help with symptom relief and coping with procedures. Through providing proactive tools to cope with pain, patients are able to learn more about themselves and the procedures they will undergo (Council, 2012). For example, a drawing of the pain scale by the child can help them express their pain in a way
that makes sense to them, and a drawing of what they believe will happen during procedures can help identify any misconceptions and provide the patient with some comfort. Through visual representations of their experience, pediatric patients can help relieve frustration felt when their symptoms persist despite pharmacological intervention (Councill, 2012).

2.5.1.4 Drama therapy. Drama therapy, as defined by the North American Drama Therapy Association (2017), is active and experiential, providing “the context for participants to tell their stories, set goals and solve problems, express feelings, or achieve catharsis” as well as the exploration of inner experiences and enhancement of interpersonal skills. There is very limited research and literature in the field of drama therapy related to both adult and pediatric medical population.

Jung’s theory of the unconscious influences drama therapy due to the fact that it creates an environment that is empowering and validating where individuals can physically embody their unconscious that is causing their suffering. In drama therapy, as is found in other creative arts therapies, the unconscious and conscious are viewed as working together to “heal and bring peace to the chaotic mind” (Rosell, 2011, p. 19).

Creativity is a large process in drama therapy and incorporates the collaboration of psychological functions such as imagination, fantasy, and symbolization. Described by Gordon (as cited in Rosell, 2011), fantasies embody impulses, fears, and wishes found in the unconscious with image and imagination animating them. Through this, symbolization in which the individual can “recognize something new within himself, resulting in a greater awareness and understanding of the self” (Rosell, 2011, p. 24) is achieved.

In drama therapy, a client will go through the five identified phases of Renee Emunah’s Integrative Five Phase Model: interactive dramatic play, developed theatrical scenes, role play dealing with personal situations, psychodramatic enactments exploring core themes, and dramatic rituals related to closure, with each phase building on one another. The goal of these phases is to build the individual’s “spontaneity, creativity, and imagination” (Rosell, 2011, p. 25) to gradually delve deeper into the personal experience and therapeutic process.

Drama therapy, being rooted in play, can be beneficial for pediatric patients. In her book that details sessions with terminally ill children through the use of the story drama method to interpret the connection between the patient’s fiction and reality, Bouzoukis (2001) described how in her work with terminally ill patients, she incorporated the three stages of the play therapy process as defined by Ann Cattanach: establishing a relationship between the therapist and child, exploration of toys, objects, and dramatic play, and development of self-esteem and
positive identity. Slade (as cited in Bouzoukis, 2001) acknowledged the significance of dramatic play for developing a sense of self and defined two forms of play: personal and projected.

Storytelling, a drama therapy technique commonly used with children, can involve the use of puppets, masks, make-up, dolls, and costume accessories (Bouzoukis, 2001). Through storytelling, the listener can take the story and explore their own roleplaying through using the above props to promote exploration of expressions. How a child takes on the role of a character in the story is left to their discretion and is not prompted by the drama therapist, allowing the child’s needs to surface through their role.

The stories used with Bouzoukis’ patients explored stress related issues such as separation anxiety, fear of loss of control, and fear of bodily harm or death that were worked through in the story by the child. The children were essentially acting out their own stress-related issues through a fictitious role. The stress-related issues in the stories were not always noticed by the children and were not mentioned by the drama therapist to prevent bias.

During reflection of their role play, direct interpretations by Bouzoukis were avoided to maintain the child’s sense of security in their newly discovered self-expression. Additionally, Bouzoukis did not interpret the relation between the child’s fictitious role and everyday life unless it was discovered and discussed by the child to elicit more genuine and natural expressions. Some of the patients showed changes in behavior and psychological symptoms such as reduced stress (as measured with The Stress Measure which is based on the Symptoms of Stress by Michael Antoni), increased containment of the body (less fidgeting and inattention), increased interactions and self-expression, and improvement in health immediately after the sessions (Bouzoukis, 2001).

Despite the gap in research and literature with end of life pediatric patients and drama therapy, Bouzoukis case study research illustrates the positive effects drama therapy can have on terminally and chronically ill children. Similar to DMT, drama therapy can provide the space for symbolic play to be formed by the terminally ill child, providing a safe space and tools for them to creatively express their underlying fears and concerns, and explore the concept of death and dying.

2.5.2 Creative arts therapy and family centered care.

2.5.2.1 Dance/movement therapy. Limited research in DMT and family centered care or family therapy was found or accessible. Therefore, this section will focus primarily on components of DMT family therapy and how they can relate to the pediatric medical population. In DMT, techniques such as the use of space, movement phasing, nonverbal interchange, mutuality, accommodation, and physical support can be integrated into family
therapy sessions to help in understanding family interactions (Harvey, 1990). Nonverbal communication among family members is important to bring to awareness during sessions (Harvey, 1990). In medical settings with children, many unnamed and unacknowledged emotions are felt but not verbally conveyed. However, these emotions and thoughts are still portrayed nonverbally. The use of movement, as well as incorporating other media such as art and drama, can help define and resolve conscious conflicts and connect the mind with the physical self (Levy, 1988).

Through movement, the family member’s definition and respect of boundaries can be identified, as well as the ability for the family member to engage in mutual activities, the amount of “sensitivity and reciprocity present within an interaction, and the amount of synchronization and mutual nonverbal rhythms” (Harvey, 1990, p. 242). In symbolic play that may arise in sessions, the family member’s ability to generate roles, stories, and plots involved in certain scenarios such as basic family conflict and conflict resolution can be observed (Harvey, 1990). Family centered care in DMT can help parents regain a playful relationship with their ill child, regain control over their parental role and relationship with the child, and recreate or adapt their family dynamic/relationship.

2.5.2.2 Music therapy. In MT sessions with family members, legacy work can be incorporated through having the patient and family create music together, engage in a musical life review, or write songs as a lasting memory (Duda, 2013). Patients and their families are able to communicate their feelings surrounding the child’s illness in these interventions through their choice of lyrics, instruments, rhythm, volume, harmonic structure, and tempo (Duda, 2013). For terminally ill patients who want to leave a gift for their family after they die, music therapists can help facilitate songwriting that may include themes surrounding what parts of their life the patient wants their family to remember after passing away (Duda, 2013). The musical memories and creations that were developed during MT sessions between the child and family may also be left as a legacy (Lindenfelser, Hense, & McFerran, 2012).

In pediatric palliative care, MT utilizes family centered theoretical frameworks and is strength-oriented. In her article detailing case examples of MT with pediatric palliative care patients, Hillard (2003) described how the music therapist provided “opportunities for the family to feel as though they were making a difference in the QOL for their daughter” (p. 130). Music therapy provides comfort to parents and families through addressing and meeting the psychosocial needs of children who are terminally ill (Hillard, 2003).
In their study aimed at understanding bereaved parents’ experiences of MT with their terminally ill child, Lindenfelser et al. (2008) discovered five global themes voiced by the parents: “altering the child’s and family’s perception of their situation in the midst of adversity, music therapy as a significant component of remembrance, music therapy as a multi-faceted experience for the child and family, music therapy enhanced communication and expression, and parent’s shared perceptions of and recommendations for improving music therapy” (p. 337-338). For these parents, MT provided a calm, peaceful, nonmedical, playful, and happy experience that enabled them to take their attention away from their child’s reality in that moment (Lindenfelser et al., 2008). The parents expressed gratitude towards the music therapist for being flexible and meeting the child’s and family’s needs as it made it easy for the child and parent to relate and connect with the music therapist and view him or her as a trustworthy individual. Most of the parents stated that MT had contributed to keeping the memory of their child alive as it gave them something to hold on to after the child had died (Lindenfelser et al., 2008).

**2.5.2.3 Art therapy.** While no literature on family centered care with AT was found, available research and literature touched upon the benefits AT has on the parent through the child’s experience in AT sessions, as well as the benefits of family therapy using AT. Through facilitating expression of emotions during AT sessions, enhanced communication between pediatric patients, their families, and healthcare providers can be accomplished (Aguilar, 2017). In one study (as cited in Aguilar, 2017), an adolescent diagnosed with a brain tumor found that sharing with her family metaphorical symbols focused on coping skills she drew during AT sessions helped her cope with missing them while she was hospitalized. This can also help rebuild connections between the patient and the family members.

Through the art-making process, family members are able to articulate emotions and thoughts in a visual manner, allowing for individual self-expression to be made permanent through the art (Kerr & Hoshino, 2008). This could be used in family centered sessions with pediatric patients as both the parents and patients often have difficulty expressing their emotions and thoughts about the current situation. This can begin to open up the dialogue of each person’s experience and how it affects them and their child.

Through family-oriented therapy, the therapist can begin to understand the family structure, communication patterns, and boundaries (Kerr & Hoshino, 2008). In a medical setting, this can help the therapist identify and process changes in these areas with the family and ill child since the child’s diagnosis and discussion of prognosis. Additionally, the art-making process can facilitate “needed energy for the families” (Kerr & Hoshino, 2008, p. XV)
that appear trapped in certain emotions or lack thereof. The art-making can create a sense of accomplishment and can be liberating (Kerr & Hoshino, 2008) as the family and patient begin to acknowledge changes and areas of feeling stuck.

2.5.2.4 Drama therapy. No literature on family centered drama therapy with pediatric patients was found. Therefore, this section will discuss general family drama therapy. Family interactions between spouses, children, and parents can be observed in drama therapy through dramatization. This can be done using interventions such as the family puppet interview where fictional role playing will occur and the family dynamic will be visible to the therapist (Landy, 1994). This can then be identified by the family and can begin to modify their everyday interactions (Landy, 1994).

At times, role playing of family members can be done in regular group therapy where participants role-play their own family members. Through this role playing, the client or patient is able to view the issues in the family from a safe distance as those family members are not present in the group (Landy, 1994). These findings can then be incorporated into family group sessions if that is a possibility. Role-reversing, typically enjoyed by adolescents, and image making are other techniques that can be used in family drama therapy (Landy, 1994). Often times when using image making, patients create images of their family, their childhood, or their life using toy animals or puppets (Landy, 1994).

Similar to systemic family therapy, drama therapy focuses on stories and narratives told and heard by the family members, and metaphorical language. During these sessions, the drama therapist is a witness and reflector rather than an interpreter of what is occurring (Strevett-Smith, 2010). Through playful narrative methods, the family is able to develop stories into less problematic situations, achieved through aesthetic distance and emotional containment by the therapist (Strevett-Smith, 2010).

These family drama therapy-oriented techniques and interventions can be used with end of life individuals and their families. Through the array of different emotions family members and the ill child encounter, the formulation of stories and role playing different characters, or even family members, can allow the patient to feel in control of those characters and how they will affect him or her in that moment. These techniques can also allow the parents and other family members to explore different ways of interaction with their child, can bring awareness of how the child is coping, and how the child is perceiving their reactions to their illness through a safe and contained exploration.
2.6 DMT in Pediatric Hospital for Quality of Life and End of Life

2.6.1 Clinical methods.

2.6.1.1 Goals and assessments. In addition to the goals listed in a previous section, Goodill and Morningstar (1993) list six themes that may emerge during DMT sessions with end of life children: not having control over the situation, the fear of death, loss, and harm, autonomy and dependence, invasion of boundaries, anger, and the need for nurturance which evolves into a theme of growth and hope. As Mendelsohn (1999) further elaborated in her article about the use of DMT with hospitalized children, DMT focuses on the nonverbal cues from the children’s body language to begin to understand the child’s internal and sometimes unconscious emotions, in order to help them cope with their illness and hospitalization in a healthy and positive manner. Dance/movement therapists accomplish this through interpretation of body patterns, such as posture, movement choice or lack of movement, breathing patterns, and their expressions (Mendelsohn, 1999).

Mendelsohn goes on to state that the dance/movement therapist examines the child’s movements at three different levels to complete assessments and interventions; Body/functional, interpersonal, and symbolic. Body/functional level refers to the child’s present physical abilities as body image is greatly impacted by illness, pain, injury, and procedures. The child may misjudge his or her physical abilities and movement potential due to a disruption in body image (Mendelsohn, 1999). The use of play with a prop can help the healthy and damaged portions of the child’s body functioning surface (Mendelsohn, 1999). However, the exposure of body ability is more greatly emphasized than the limitations, which allows the child to discover their movement potential and help them to realize that they may not be as limited as they believed (Mendelsohn, 1999).

Interpersonal level relates to the dialogue created between the therapist and child when movement is introduced as communication (Mendelsohn, 1999). Similar to Goodill and Morningstar (1993), empathic reflection is used. Mendelsohn (1999) describes the goal of the therapist as needing to provide a sense of trust and safety so that the therapeutic space can be used in any way the child or therapist may like. Symbolic level refers to the creative play the child uses to express his or her fears, wishes, or unconscious thoughts (Mendelsohn, 1999). As reality and fantasy begin to overlap, the child’s and therapist’s unconscious begin to join together allowing for a deeper dialogue between the child and therapist (Mendelsohn, 1999). At this time, the child may take the lead in a session which can open a window into the soul of the child allowing the child’s nightmares and fears to manifest themselves (Mendelsohn, 1999).
It is important to understand the change in tension-flow the child will experience. “Tension flow is the initiator of all efforts that follow and can determine at a certain level the affect or emotion underlying a body’s posture, gesture, or movement” (Plevin & Parteli, 2014, p. 232). The child and the family must adapt to the flow of the hospital, and to the often long waiting periods during treatment which interrupt their natural daily rhythms, especially as their movement and space become restricted (Plevin & Parteli, 2014). Often times, this results in neutral flow in the child, leaving the child as appearing and feeling unanimated (Plevin & Parteli, 2014).

This concept is highlighted in the use of Kestenberg Movement Profile (KMP) as an assessment tool. The KMP utilizes tension-flow attributes and tension-flow rhythms to assess children’s movements (Tortora, 2016) and incorporates the Laban Movement Analysis (LMA) qualities. There are five elements of the LMA system that are used to analyze nonverbal qualities of the patient’s movements: Effort, Shape, Body, Space, and Phrasing. The Effort quality provides information about how an action is performed; Body provides information about what body parts are being used in the movement action; Shape and Space describes the “forms the mover’s body makes in space” (Tortora, 2016, p. 166) and how the mover relates with him or herself, others, and the environment; Phrasing conveys how the movements are “clustered together over a period of time creating a flow, pulse, rhythm and melody, as the actions start, continue, pause, and stop” (Tortora, 2016, p. 166).

In their article, Plevin and Parteli (2014) explored the use of movement analysis, specifically LMA, fundamental body connections, and KMP as a clinical approach to DMT on an onco-hematology unit of a pediatric hospital. They described the importance of noticing and incorporating the Efforts of Time, Space, Weight, and Flow as well as the dimensions, planes, and spatial pulls in interventions to attend to and understand the child’s needs at that time. They discussed that these elements also indicate to the dance/movement therapist how she or he may need to adjust their personal “body-environment” (p. 235) to create and foster the therapeutic relationship.

Plevin and Parteli (2014) identified several questions that dance/movement therapists ask themselves when with a patient. On a functional level, they must assess what is physically possible for the child. On a developmental level, they must identify what kinds of sensory or cognitive interventions may be age appropriate. On a psychological level, they must understand what message the child is conveying through movement about him or herself and the stage of the illness, know where the child is in their treatment, why the child is in the hospital (symptoms, surgical procedures…), and what emotional consequences are visible and invisible. Additionally, the
dance/movement therapist must pay attention to how the child is reacting to their presence in the room (Plevin & Parteli, 2014).

2.6.2 Oncology. Creative expression has been linked to increased QOL and ability to cope with hospitalization in both adult and pediatric cancer patients (Madden et al., 2010). Dance/movement therapy is an emerging field that can provide psychosocial support in clinical settings for children and adolescents with cancer and facilitate the integration of coping mechanisms within an interdisciplinary team (Chambers, 2013; Cohen & Walco, 1999).

In her Master’s thesis about DMT with pediatric cancer patients, Chambers (2013) explained how her research and interventions had an impact on the development of social skills and peer relations with children who were isolated from their peers due to their cancer diagnosis. Chambers stated that children diagnosed with cancer often have restricted space, physical activity, and interpersonal contact because of their immune deficiencies and risk of injury. She expressed that in children, social relationship and support are major concepts when it comes to assessing QOL and coping behaviors. She indicated that treatments for pediatric cancers are focusing more on these concepts and using interventions that treat both physical and psychological concerns.

Chambers’ interventions focused on addressing the following key social skills: assertiveness, communication, cooperation, empathy, problem solving, and social initiation. She noted that the interventions were adapted to the developmental level of the child and that she utilized specific movement qualities from the KMP to support her goals. Her observations and final data collection showed that the children who were engaged in the DMT sessions showed a greater development in their identified social skill needs than in the psychosocial treatment goals. In a more in-depth analysis, she identified that some children were able to self-advocate and communicate their needs, had increased movement impulses and organization, and had greater impulse control. Chambers noted that the body-based therapeutic relationship and creativity of DMT “makes this approach uniquely suited to address the psychosocial coping needs of children experiencing body-based stressors” (Chambers, 2013, p. 62) and that DMT provides a safe space for the patients to express and address concerns.

Through case examples, Plevin and Parteli (2014) proposed that movement interventions help the child shift focus away from their illness, creating an elevated sense of well-being, as the interventions hold, organize, or contain “in an appropriate way a child’s fear, confusion and sadness” (p. 244) through acknowledgment and presence of the emotions. These interventions can also help the child comprehend and accept their new reality of
having and enduring a diagnosis of cancer. Dance/movement therapy can help children with cancer understand on a body level their emotions and attitudes and how they are related to coping, helps the child integrate “information about the self and relationship with others” (Cohen, 2000, p. 2), and enables developmentally appropriate creativity and exploration (Cohen, 2000).

### 2.6.3 Expression of self/illness

During significant life events or stressful situations, “the self attempts to accommodate the new experiences in an effort to integrate changes” (Dillenbeck & Hammond-Meirs, 2009, p. 111). Goodill and Morningstar (1993) noted that DMT helps the hospitalized child to introduce changes in their body functioning and appearance (allowing them to realize their potentials), build a healthy body image in accordance with their illness, injury, and treatment, and allow the child to express their feelings about their illness and being hospitalized, all by using the physical self to address the emotional and physical issues related to the reason for hospitalization.

Mendelsohn (1999) shared that children who are medically ill will express their knowledge of their situation if they feel they are in safe and trustworthy environment. Children are able to sense if the individuals around them want to understand them, so it is important for the therapist to provide this environment for the child, giving them the opportunity to express themselves with symbolic language. Once the child is able to communicate their emotions, they no longer feel alone in having to carry their burden and the therapist can begin to aid the parents to deal with the pain of their child’s illness in a more effective way (Mendelsohn, 1999).

In hospitalized children, negative body image is common, especially in adolescents, which could create a feeling of an even greater loss, passivity, and withdrawal, and will affect the individual’s portrayal of themselves (Cohen & Walco, 1999). The use of DMT interventions that focus on emotional self-expression can help the patient regain a positive sense of self. Through movement and verbalization, a more dynamic body image can be explored, and the individual experiences the negative feelings associated with body image concerns on a body level rather than passively acknowledging them (Cohen & Walco, 1999).

However, when using interventions geared towards body image and sense of self, the patient’s developmental level needs to be taken into consideration to determine if it is appropriate and how to facilitate the session. Through attuning to the individual’s body, mind, and spirit (physical, mental, and emotional aspects), the dance/movement therapist can help the individual build self-awareness, a sense of wellbeing, and acceptance of the body especially at the end of life (Dillenbeck & Hammond-Meirs, 2009).
2.6.3.1 Symbolic play. Play is a way for a child to make sense of the world, and having opportunities for play helps a child work through stressful situations through gaining mastery and expression of fears and anxieties (Hain et al., 2011). Mendelsohn (1999) brought the reader’s attention to Winnicott’s concept of play and potential space, which explains playing as a way of communicating and states that children are only able to be creative and use their entire personality when playing. Play is the most “developmentally appropriate and powerful medium of young children to build adult-child relationships, develop cause-effect thinking critical to impulse control, process stressful experiences, and learn social skills” (Schaefer & Drewes, 2010, p. 15). It can provide the child with a sense of power and control when solving problems and mastering new experiences, and enables the child to communicate with others nonverbally and symbolically (Schaefer & Drewes, 2010). Symbolic play allows the child to “communicate their emotional pain” (Mendelsohn, 1999, p. 69) while still “preserving their necessary defenses” (Mendelsohn, 1999, p. 69). The dance/movement therapist establishes the environment of trust and safety with nonverbal communication, allowing the child to express feelings they are unable to access by highlighting the healthy parts of the child through the process of playing (Mendelsohn, 1999).

In the three sessions described by Goodill and Morningstar (1993), the dance/movement therapist incorporated several therapeutic interventions to help develop the rhythmic, qualitative, interactive, and expressive portions of the child’s nonverbal activity. In one of those sessions with a 4-year-old girl hospitalized for an infected finger and exposure to chickenpox, the patient’s need for physical intimacy was illustrated from the very beginning when the patient hugged the therapist with a clinging quality, despite the therapist being a stranger. It was observed that the patient maintained a physical closeness to the therapist during the session. At one point, the patient initiated childhood games with the therapist which then led to a hiding game where the patient verbalized wanting to hide from the doctors and nurses because she was frightened of them and she wanted to scare them away because they had “stuck” her. This then developed into symbolic expression where the patient pretended to be Freddy Krueger.

From this session, it was noted that the patient identified with the aggressor which symbolizes a defense mechanism to “master the fear of harm” (Goodill & Morningstar, 1993), utilized the Freddy Krueger image to showcase her personal concerns with her hands, and the changes in her movement play showed how a child’s fear can turn to anger. It also illustrated the mixed and confusing emotions these children feel during a hospitalization. Play creates freedom from restrictions and provides adaptive flexibility (Nachmanovitch, 1990). During play, all that exists is the child’s experience in the world they have created. Through symbolic play, DMT can provide
hospitalized children with opportunities to realize their potentials and can help them express their feelings towards their reason for hospitalization in a manner that most children rely on to express themselves.
CHAPTER III: PRODUCT/REVIEW

3.1 Developed Method Description

The following clinical method was developed after several pediatric palliative care and end of life children participated in individual dance/movement therapy sessions with the dance/movement therapy intern at a children’s hospital. Due to the patient demographic at the clinical site, the method is aimed towards palliative and end of life children functioning at 10 years of age or younger, who are delayed and nonverbal. Caregivers, or the most prominent adult in the patient’s life, are incorporated into the method which is centered around different aspects of rhythm, rhythmic vibrations, and vocal sounds.

The developed method is based on the following identified mental and social QOL goals: expression of self, positive interactions and emotions between patient and primary caregiver, quality of playfulness, decreasing distress/stress reduction, honoring multicultural family customs, making choices, and sense of agency. The method used with these patients is strength based, relies on micro-assessments that aim at the identified QOL components, and will provide the patient with a multichannel sensory input as it will utilize visual, audio, and tactile components.

The method is divided into different categories from which the dance/movement therapist would choose to arrive at a suggested method. The categories are as follows: micro QOL goals, Kestenberg Movement Profile (KMP) rhythms/Tension Flow Attributes (TFA) of the patient, the adult or caregiver’s role, and the methods. These categories overlap and support the overall method. The KMP rhythms are used to help the adult/caregiver attune to the patient’s current developmental stage and natural movements, with therapist support as needed, to help facilitate a more natural progression of the interactions within the sessions. The phrases support the KMP rhythms through once again matching and supporting the patient’s natural development of movement but also to enhance and expand the movements and interactions between patient and caregiver. The interventions utilize the identified KMP rhythms and phrases to further the interactions and tailor the process to the patient’s natural movement and expressive state. The KMP rhythms, phrases, and interventions support the micro goals, as described above, to help increase quality of life and facilitate positive interactions between patient and caregiver.

The therapist will begin by choosing 1-2 micro goals they wish to achieve during the session, followed by choosing the appropriate KMP rhythm/TFA of the patient, and the role of the adult or caregiver in the session. The adult or caregiver’s role will include introducing different phrasing patterns within the method which can be
supported during the session through the quality of voice used to help label what is happening and matching the Efforts of the patient. These phrasing patterns can additionally help provide a mini container for the patients to express themselves. The therapist may choose to involve the adult or caregiver in choosing 1-4 phrasing patterns that can be utilized in the session.

The therapist will model for the parent the patterning and phrasing that will be used with the patient and will then let the caregiver or adult join. The therapist will continue to provide support throughout the session by labeling what is happening between the patient and caregiver and providing suggestions if needed but will ultimately attempt to have a more passive role. If a family caregiver is not available, the therapist or a member of the medical staff who is well acquainted with the patient can take on the role of the adult. Observations of the patient’s movement preferences and Efforts from prior sessions and the current session should be incorporated into the interventions to better attend to the patient’s needs and create a more natural development of movement and interaction between the patient and caregiver/adult.
A. Micro Goal
- Expression of self
- Positive interactions and emotions between patient and primary caregiver
- Quality of playfulness
- Decreasing distress/stress reduction
- Honoring multicultural family customs
- Making choices, sense of agency

B. KMP Rhythm/TFA
- Sucking-Snapping/Biting: TFA Flow adjustment
- Twisting-Strain/Release: TFA Flow intensity
- Running/Drifting-Starting/Stopping: TFA Flow outpouring
- Swaying-Surging/Birthing
- Jumping-Spurting/Ramming

C. Caregiver/Adult Phrasing
- Increasing
- Decreasing
- Increase/Decrease
- Decrease/Increase
- Swing
- Vibratory
- Impactive
- Accented
- Long/Short
- Even
- Impulsive

D. Method
- Tambourine
- Tactile Rhythm
- Feather/Scarf
- Adapted weight sharing
- Vocal Attuning with Matching Movements/Rhythm
3.1.1 Detailed methods.

- Tambourine
  - Using a tambourine, produce rhythmic vibrations on different parts of the child’s body by tapping, shaking, or other methods through matching of the child’s preferred Efforts and the selected phrasing(s). The child should be allowed to choose where they want the tambourine to be on their body. For example, those who are in the oral developmental stage may choose to feel the vibrations on or in their mouth and their face. If the patient is unable to place the tambourine where he/she decides or cannot cognitively process what is to be done, the caregiver/adult can choose for them. However, careful attention should be made to the patient’s nonverbal response to having the tambourine on that body part and adjustments made based on those responses.
  - At this point, the patient could be encouraged to reproduce the rhythmic vibrations on the caregiver/adult with the tambourine aiding in playful connection. Vocal attuning to the phrases and rhythms is encouraged to further support the interaction. The therapist may choose to include or support the caregiver/adult in including opposite Efforts if desired to provide a variation in rhythmic vibrations to better determine which rhythmic vibrations are preferred by the patient.

- Tactile Rhythm
  - It should always be confirmed with the patient beforehand if it is ok to use touch with them before proceeding with this method. Similar to the tambourine, the therapist and caregiver/adult will reproduce and incorporate rhythms through touch onto the patient’s body using tapping, shaking, squeezing, or any other method that seems appropriate. If applicable, the patient could then reproduce those rhythms onto different parts of the caregiver’s/adult’s body and may be further explored onto objects around the space (the bed rail, the bed, pillow…). The caregiver will incorporate the chosen phrasing(s) throughout the intervention and may choose to support the intervention further through incorporating vocal attuning, matching the chosen phrasing(s) and rhythm(s).

- Feather/Scarf
  - This method utilizes a feather, scarf, or other light object that is appropriate to use with the patient and will elicit more indulging Efforts and light movements. The chosen object can be used to
lightly rub on the patient’s limbs, if the patient consents to touch, and if applicable can then be reversed to having the patient do the same to the caregiver/adult. If the patient is unable to reproduce the intervention onto the caregiver/adult due to their illness or cognitive ability, then attention should be placed on how the patient reacts to where the object is being used on their body. The caregiver/adult can still reproduce the effects of the intervention on him/herself and attune to the child’s identified reactions to the body parts. This intervention could also develop into blowing on the object to make it move around the space.

- Adapted weight sharing
  - For this intervention, a stretch band, sheet, or the patient and caregiver’s/adult’s body can be used to simulate adapted weight sharing in a seated position. If a sheet or stretch band is not available or cannot be used with the patient, the patient and caregiver/adult can hold hands and take turns pulling/pushing each other in the Sagittal Plane where incorporation of the full torso and head should be encouraged. The caregiver/adult can use the chosen phrases, changing the speed, Efforts, Space, and rhythm used. The patient and caregiver/adult can go in any direction that is desired while sharing weight through their hands (up and down, side to side, front and back, diagonals), exploring all Planes. If needed, this can be adapted to have the patient and caregiver/adult holding forearms for more stability. To further support the intervention, verbal sounds that match the phrasing and rhythm may be incorporated by the caregiver/adult. This can be incorporated the same way if a stretch band or sheet is used.

- Vocal Attuning with Matching Movements/Rhythm
  - This intervention relies on attuning to verbal sounds produced by the patient which can be done through having the caregiver/adult verbally attune to the sounds and incorporating movements to match the intensity and intonation of the patient’s sounds. A call and response game can also be incorporated where the caregiver/adult slightly alters the sounds produced by the patient to then have the patient reproduce. The caregiver/adult can also encourage the patient to mirror the movements they are matching with the sounds. This can be further supported through having the caregiver/adult physically guide the child through the movement.
The caregiver/adult can incorporate the chosen phrases in their verbal and movement attuning and different rhythms can be used within the phrases to further the interactional play. For example, a verbal sound of “aaaaahhh” with a heightened inclination at the end can be exaggerated by the caregiver/adult with an increasing phrase and guiding the patient’s hands and arms up over their head. A rhythm that could later be incorporated into that example would be a shaking rhythm which may call for more accented or vibratory phrasing. This can then be changed by the caregiver/adult by using decreasing phrasing to change the intonation of the “aaaaahhh” sound.
3.2 Case Vignettes

The following case vignettes describe three different patients and their respective caregivers with whom the above developed clinical method was implemented. In order to maintain the patients’ privacy, pseudonyms were used, and their medical diagnoses were not explained in depth. Additionally, information about the parents was also kept to a brief and neutral explanation to protect their privacy. Within each vignette, the goals, KMP rhythms, adult phrasing, and methods will be indicated, with an explanation of how they were used within the sessions, and a discussion of the importance of the chosen components and more detailed observations about the adult and child interaction.

3.2.1 Vignette 1.

Liam: Six-year-old, delayed, nonverbal, and physically limited patient on palliative care at time of sessions. Liam was end of life during hospitalization in October but medically progressed enough to continue on palliative care. I met with the caregiver on a few occasions but at the time this method was implemented, the caregiver was unable to make it to the hospital. Therefore, I took the place of the “adult” during both sessions. The following sessions were our fourth and fifth time together but only our second and third time together since this particular hospitalization stay during which the method was implemented.

Goals: Expression of Self, Quality of Playfulness

KMP Rhythms: Sucking, Snapping/Biting

Adult Phrasing: Vibratory, Increase/Decrease, Decrease/Increase, Accented

Methods: Tambourine, Vocal Attuning with Matching Movements and Rhythm, Adapted Weight Sharing

Session 1

Through past movement observations, Liam showed a preference for Strong and Direct movements, with a phrasing preference of impactive and increasing. It should be noted that Liam has difficulty moving his left arm and while he is able to move his legs, he does not always choose to do so. Additionally, Liam cannot walk and is typically sitting in bed, supported by it, with the exception of a few times where he is in his wheelchair.
The session began with our typical greeting ritual: I extend my hand out in front of him to which Liam responds by impactfully hitting my hand a few times, almost like a high five. I reciprocate this movement to him as my way of acknowledging his greeting. After a small tactile body warm-up, I introduced the tambourine to Liam and began implementing the method. His first instinct was to place it in his mouth to begin exploring it. As he was doing this, I began to mirror his Effort preference of Strong and Direct onto the tambourine through tapping, creating vibratory and accented phrasing that translated into his mouth. As this continued, Liam began placing it on different parts of his face, waiting for me to create the rhythmic vibrations, and responded by smiling and making vocal sounds. I attuned to those vocal sounds and began matching them to the rhythmic tapping I was producing on the tambourine, using the selected adult phrasings as a guide.

When Liam appeared finished with the tambourine on his face, as evidenced by him taking the tambourine off of his face, we moved on to exploring shaking the tambourine. With some help and support from me, Liam began shaking the tambourine with his right hand. I then translated that shaking into different parts of his body through touch, while vocally attuning to the shaking rhythm and intensity. I encouraged the exploration of the different chosen adult phrasing through, for example, shaking the tambourine together and raising our hands above our heads as the phrasing increased and vice versa. I vocally attuned to the rhythms and movements we produced which were mirrored back at times by Liam. Throughout the session and utilization of this method, Liam was laughing, smiling, and producing positive vocal sounds. While not an identified goal for this session, he showed a decrease in muscle and facial tension and spontaneously moved his legs and left arm during the interaction.

Session 2

During this session, Liam was in his wheelchair. Once again, we greeted each other with our typical hand ritual. After a small tactile body warm-up, I implemented the method once again but added adapted weight sharing due to a back and forth movement produced by Liam during the session. Before re-introducing the tambourine, Liam began to move his upper body back and forth, tilting his head up and down in the process. At this point, I extended my hands to nonverbally welcome Liam to hold my hands. Once Liam did so, we engaged in a push and pull movement that I grew into a bigger movement as we progressed. Liam initiated producing a quicker motion and creating a more accented or impactive phrasing when safely hitting our back into our own chairs. I then progressed this to include exploring the upper and lower space, utilizing the increasing and decreasing phrasing selected,
matching it with vocal sounds which were attempted to be mirrored by Liam. Throughout this process, Liam was smiling and laughing and creating his own vocal sounds to go with our movements.

When the tambourine was re-introduced, Liam immediately placed it on his face, waiting for me to tap it to produce the rhythmic vibratory sensations he was seeking. As I continued to explore the tapping with the previously described phrasings, Efforts, and vocal sounds in session 1, Liam began to produce his desired rhythms on the tambourine by himself while it was on his face as well as placing the tambourine on my face and hitting the tambourine for me to feel the rhythmic vibrations. We alternated who had the tambourine on their face as he continued to choose rhythmic tapping which mainly consisted of Strong and Direct but alternated between Quickness and Sustainment and at times Lightness with my support.

We finished the session by re-exploring the increasing and decreasing phrasing in the vertical dimension with the shaking of the tambourine, similar to what was described in session 1. After a small tactile body cool down, the session ended. Throughout this session, Liam was once again smiling and laughing and was actively engaging and making decisions in how he wanted to interact with the tambourine and the adapted weight sharing intervention. While the initial goals did not include sense of agency and making decisions, it developed during the session as Liam felt comfortable with the tambourine and through interactions with me.

3.2.1.1 Session summary. As discussed above, Liam’s mother, his primary caregiver, was not present for these sessions as she has to care for other children with special needs at home. Due to this, I had to take on the role of the adult for Liam and hope to share the information that I have obtained through the use of this method with his mother. I had been seeing Liam for the past 7 months every time he was hospitalized. This led us to develop a strong therapeutic relationship over time and enabled us to explore several different themes throughout our sessions such as expressing emotions.

For the described sessions, I chose the goals of expression of self and quality of playfulness as I wanted to continue exploring previously identified themes in our other sessions. Liam is confined to his bed for the majority of the day and is often alone. The chosen goals were aimed to provide Liam with a safe space to express himself and play within a structured session but by making choices of his own, something that often lacks for hospitalized children. The chosen rhythms/adult phrasings were aimed at increasing his use of space and exaggerating his preferred rhythms along with ones that he has not explored yet.
Liam’s interactions and use of the methods in the above sessions highlight his ease of interacting with others and his desire to connect with others. While I introduced and directed the session, Liam was also constantly provided the opportunity for choice which helped develop a sense of autonomy. Liam’s Effort preferences of Direct, Strong, and Quick mirror his experiences while hospitalized. Through this method, he was able to direct that energy and strength in a more meaningful and safe way and was able to connect with me through our developed rhythms and vocal attuning.

3.2.2 Vignette 2.

**Abhik Soumy**: 18-year-old delayed, nonverbal individual with severe mobility limitations who does not speak or understand English. Abhik Soumy was thought to be near the end of life when he was admitted to the hospital but was placed on palliative care as his parents wanted everything done to save him. He progressed medically but continues to be followed by palliative care. Abhik Soumy’s father, who has limited understanding of English and only knows a few English phrases, was present in the room during these sessions. I took the role of the adult during session 1 due to reluctance of the father to join in session but he joined session 2 where we shared the adult role. The following sessions were Abhik Soumy’s and my second and third time together during which the method was implemented.

**Goals**: Positive Interactions and Emotions between Patient and Primary Caregiver, Expression of Self  
**KMP Rhythm**: Unable to determine due to limited mobility  
**Caregiver/Adult Phrasing**: Increasing, Decreasing, Accented  
**Method**: Tactile Rhythm, Vocal Attuning with Matching Movement and Rhythm

**Session 1**

Abhik Soumy was lying in bed when I entered the room with his head turned to the right supported by a pile of small towels facing away from the door with his body slightly slumped over to the right. I observed permanent joint “locking” in his elbows, wrists, ankles (more severe on right side) due to a medical condition which limits his movements. Abhik Soumy’s right arm, held off to his side, was bent with his hand flexed at the wrist and tensed/hyperextended fingers with a grip bar in his hand placed by OT. His left arm was also bent but less restricted
with his fingers relaxed and laying partially on his stomach.

After greeting Abhik Soumy both verbally and nonverbally while at eye level, which was reciprocated by Abhik Soumy through eye contact, I initiated soothing touch on his hand to gage if he would welcome touch. As he did not negatively respond, I continued the soothing touch on his arms, hands, fingers, legs, and feet with my hands which I matched with verbal sounds. I progressed to rhythmic tapping with light pressure with a sensory spiked ball, still accompanied by verbal sounds, beginning with the chosen phrasing of increasing, followed by decreasing and accented while using stronger pressure.

Abhik Soumy was responsive to touch and maintained focus on me and our interactions throughout the session through eye contact. He was laughing and smiling throughout our time together. Abhik Soumy extended and curled his toes around my fingers and slightly moved his legs side to side when I was using the tactile touch intervention on his feet and toes. He responded positively to soft touch on left hand/palm and right fingers (brushing my hand under his fingers) through smiling and slight movement in fingers.

During the interaction, self-initiated movement from Abhik Soumy developed. He extended his right arm down through the Vertical dimension and brought his left arm up towards his face through elbow initiation accompanied by faint smiling. These movements were mirrored at first by me and then exaggerated the second time over Abhik Soumy which prompted him to produce a big smile and move his head to the center. I chose to also match his movements and my exaggerated ones vocally to enhance the experience.

The session ended with soothing tactile touch to slow down his body. Although not described as an intended goal, Abhik Soumy was visibly more relaxed at the end of our session. As I was leaving, Abhik Soumy maintained visual contact with me and moved his head to the left as far as he could to watch me leave the room. Abhik Soumy’s father was present during this session and came to the bedside to explore the sensory spiked ball on his own face and hands but did not participate in the session.

**Session 2**

This session began like our previous session with me greeting Abhik Soumy verbally and nonverbally at eye level at which time Abhik Soumy smiled and reciprocated eye contact. Once again, I began with rhythmic soothing tactile touch, beginning at his hands and following through to the rest of his body, and matched it with vocal sounds. I then re-introduced the stronger, rhythmic tapping with the spiked sensory ball and vocal attuning throughout his body. At this point, the father once again approached the bedside. I nonverbally, due to language
barriers and unavailability of a language line, invited the father to use the spiked sensory ball on his son as I was previously doing.

The father took this opportunity to mirror the gentle but accented rhythmic tapping I had been using on Abhik Soumy with the ball, moving it down his son’s left arm and across his chest to the other arm. I continued to support this interaction through vocally matching the rhythm the father was using but in a quieter voice so as to not disturb what was happening at that moment between father and son. This interaction lasted about three minutes before the father handed the ball back to me while smiling and returned to another area in the room. Abhik Soumy was smiling and looked at his father throughout the interaction. I chose to end the intervention at this point to not interfere with the private interaction that had just occurred and ended the session with a tactile body cool down to slow the body. Once again, as I was leaving, Abhik Soumy maintained visual contact with me and attempted to move his head to the left to watch me leave the room.

3.2.2.1 Session summary. Abhik Soumy and his father were not familiar with the American culture or the English language as they have only been in the United States for a few months. Due to this, I had to educate myself on their culture, specifically regarding touch, to make sure that I did not overstep any boundaries with both the father and his son. Although I was unable to communicate with the father due to the language barrier and unfortunate unavailability of a translator, I was able to rely on nonverbals and few select English phrases to communicate. Abhik Soumy was described to me by the palliative care doctor as a boy who was rigid, did not move, and looked scared. Through this method, Abhik Soumy was able to exercise choice, have positive interactions with his father, and was able to freely express himself as seen through his emotional reactions of laughing and smiling.

The above sessions highlight the importance and power of nonverbals and how a safe environment for the father and Abhik Soumy could still be created. Through this method, Abhik Soumy and his father were able to connect nonverbally and on a body level through the use of the ball prop. The father was able to explore the sensations his son was feeling when I used the ball with Abhik Soumy by incorporating it onto his own face. After this exploration, the father felt comfortable enough to use the ball with Abhik Soumy and may have felt he understood why his son was enjoying the use of this prop on his body.

Through this, a new positive interaction that involved eye contact and smiling between himself and his son was created. As the therapist, I nonverbally supported the father through this interaction through small movements, encouraging him to continue exploring this meaningful moment, but also supported and enhanced the interaction
through quiet vocal matching of the rhythms. Through all this, I was able to provide and maintain a safe environment for both the father and his son. Throughout these sessions, the father was very receptive and attentive to how Abhik Soumy was reacting when I was implementing the method, often coming to the bedside to observe and understand in his own way what was happening.

Additionally, the method provided a new way for the father to interact with his son and invited curiosity and attention to what was making his son laugh and smile. The increasing, decreasing, and accented phrases were chosen because as the therapist, I wanted to exaggerate the movements and interactions as I had discovered that Abhik Soumy responded with laughter and movements of his own when that was incorporated in previous sessions. These phrases allowed Abhik Soumy to experience the method in a more inclusive and dynamic manner, something that he is not able to explore on his own. These phrases also provided a framework for the father to join nonverbally at his discretion.

3.2.3 Vignette 3.

**Zola:** 11-month-old neurotypical patient on palliative care at time of sessions who is unable to speak or make sounds due to intubation. Patient has full movement range capacity but has equipment that restricts her movements and limits the ability for people to pick her up. The patient’s inability to freely move or be picked up has led to some missed developmental milestones which could be future concern for developmental delay. Mom was present during both sessions and took the role of primary caregiver. The following sessions were our third and fourth time together during which the method was implemented.

**Goals:** Quality of Playfulness, Positive Interactions and Emotions between Patient and Primary Caregiver

**KMP Rhythms:** Twisting, Starting/Stopping

**Caregiver/Adult Phrasing:** Impactive, Increasing, Decreasing

**Method:** Tactile Rhythm, Vocal attuning with Matching Movements and Rhythm
Session 1

Through past movement observation, Zola showed a preference for Quick, Direct, Strong, and impactive movements with her legs and arms. She has the capacity to mirror movements and shows a preference for moving through the vertical dimension with her arms and through the vertical and horizontal dimension with her legs.

When I entered the room for our session, Zola was lying in bed on her back, facing the door. She appeared calm and followed me with her eyes as I settled in the room. We began our session with our typical greeting of extending my hand for her to take and allowing her to guide me in the space around her body, at which point she began to smile. After a small tactile body warm-up, I introduced the method. I chose to expand her impactive phrasing and introduce increasing and decreasing phrasing with her movements. She began to move her arms up and down in the vertical dimension while outstretched in a Quick and Direct way which I mirrored verbally and movement wise. I vocally mirrored the impactive ends of her hands hitting the bed to create a definite stop and impact with an object. At this point, Zola’s mother came into the room and immediately came to bedside to see what we were doing and participate. I explained to the mother what was happening and encouraged her to join us in our intervention.

With my support, the mother introduced rhythm into Zola’s body beginning with her arms using tapping and squeezing. I encouraged the mom to use increasing and decreasing phrasing with changes in tactile pressure and using vocal sounds. This was then transcribed into moving Zola’s arms with her tightly gripping mom’s fingers, with the same increasing and decreasing phrasing with vocal sounds. This was then incorporated into Zola’s legs, using the bottom of her feet to guide as Zola pushed her feet into mom’s hands. Throughout this process, I continued to support through participating with the vocal sounds and encouraging exploration of movement and play with other body parts.

Throughout this process, both Zola and her mom were smiling as they engaged in play together. Zola was observed with lower muscle tension in her body after this session and was actively interacting with both her mom and I. Her mom had previously shared her frustration with being unable to pick up and hold Zola and that there was only so much she could do with her lying in bed. Her mother expressed gratitude for this interaction, stating that she “didn’t realize how much Zola can do” and that it felt like Zola was dancing in her own way. The mom expressed wanting Zola to continue having dance/movement therapy during her hospitalization.
Session 2

For this session, Zola was in a therapy chair that was placed in her crib. We greeted each other again as we did in the described session above and after a small tactile body warm-up, I once again implemented the method. During this session, mom and I shared the adult role as I supported her through the process. At this point, Zola was already moving her legs up and down in the vertical dimension and extending them out with Quickness and Directness in the vertical and horizontal dimension. At this point, I mirrored the impactive phrasing she was producing with the end of her movement through hitting the middle of the chair that was sticking out between her legs and matching a vocal “boom” to it to which Zola responded with smiling and laughing.

I encouraged mom to join me in this and we did this a few times together. Zola then mirrored mom and I’s movements through hitting the middle of the chair with her foot, which was again mirrored vocally by me and mom with the “boom” sound. Mom and I explored using big open and close movements with our arms during this interaction and increasing or decreasing the impact. At one point, mom helped guide Zola’s foot to help mimic the lighter impact on the chair as Zola had difficulty doing this herself.

After this was accomplished a few times, I encouraged mom to have us explore this movement and vocal sound with Zola’s arm movements. Mom and I hit the side of the chair as Zola moved her arms up and down through the vertical dimension ending with an impactive end on her legs. Once again, I encouraged mom to explore the lighter impactive end by guiding Zola’s arms. By the end of this session, both mom and Zola were smiling and engaging in play with minimal support from me. The increasing and decreasing phrases used with the impactive ending were also mirrored with vocal sounds by mom and I through increasing or decreasing the volume of our sounds. Mom thanked me for this interaction with her daughter and they were still playing with parts of this method as I left the room.

3.2.3.1 Session summary.

Being a young mother, Zola’s mom shared with me her frustration of not being able to pick up or fully play with her daughter, especially since she is unable to come visit as often as she would like. This interaction with mom prompted the decision to include positive interactions and emotions between patient and primary caregiver as a goal for our sessions where the method was implemented. Mom was receptive to the dance/movement therapy sessions, asking how often Zola would receive these services and standing at beside to encourage Zola throughout the session.
It should be noted that Zola had some restrictions to her movements due to intubation. As the therapist in these sessions, I aimed to maintain a safe environment and supported Zola’s mom throughout her interactions with Zola as the method was implemented. Mom’s openness and receptiveness to the method and dance/movement therapy allowed for an abundance of playfulness between mom and daughter. The phrasings of impactive, increasing, and decreasing were chosen due to the movement observations I had made in previous sessions with Zola. I had observed that Zola liked to have a response to her movements which is why vocal attuning and mirroring of movements were incorporated into the above session.

The interactions between mom and Zola helped mom understand the different ways that she could interact with Zola. They engaged in play and exhibited positive emotions throughout the implementation of the method. As the therapist, I supported mom and helped guide her to discover other ways she could connect with Zola and attended to their attunement and mother/daughter needs. Zola can sometimes fluctuate in her emotions, feeling happy at one moment and sad the next. Several staff members have described to me how she is depressed and yearns for the ability to interact and move like a normal infant. The positive emotions that this method elicited in Zola and her mother and the exploration of different interactions begins to show how DMT coupled with family centered care could improve QOL for pediatric palliative care patients and their families.
CHAPTER IV: REFLECTION

4.1 Development as a Therapist

As a growing therapist, the development of this method helped me continue to appreciate the small details in interactions and relationships. My work with this method has shown me the importance of involving family in therapies to help them view their child through a different lens while in the hospital instead of continually viewing them through the medical lens. When I originally chose to develop a clinical method for the pediatric palliative care population, I had not begun my internship at the children’s hospital and began to imagine what my method could include based on the medical literature on pediatric palliative care and the limited literature on DMT and hospitalized children. My intentions were to develop a method that would integrate verbal processing within the session to enhance and support the experiences of the patient and family members.

However, upon beginning my internship, I realized that the palliative care patients at the hospital had no use of verbal language, were not meeting typical developmental milestones, and had moderate to severe movement limitations. This greatly altered my vision of my intended method and made me feel a little lost. It wasn’t until I began working with these patients, that I realized how much they had to teach me and how much I could eventually offer them. It was through interactions and sessions with these patients that I developed this method. My patients, in a sense, showed me what they were lacking and what they were craving, even if they did not always cognitively understand themselves what that was. I learned that although I could not incorporate verbal processing with the patients, the interactions within the methods with me and their parent was enough in the moment to meet some of their needs and improve their QOL in that moment.

Throughout my time in graduate school and at my internship, I have learned the uniqueness of every individual. My supervisors have guided me in my growth as a therapist and have explored with me different tools and ideas that I can carry with me throughout my career. I have grown in discovering what it means to be a therapist and what that means to my patients. My patients have taught me that sometimes all they need is someone to hold their hand or to be there with them as they experience a rush of emotions. This has allowed me to take a step back and reflect on how the small aspects of DMT can have the largest impacts on our clients.

4.2 Successes and Limitations

Positive response from both patients and parents, cultural inclusion, engagement and adaptations that originated from the patients show the positive effects this method can have on pediatric palliative care patients and
their families. Through the use of this method, parents who participated either verbally or nonverbally acknowledged how they were able to make a connection with their child through a different medium. For parents who were unable to convey verbally how they felt during and/or after the method was implemented, I relied on qualitative changes in nonverbal behavior such as body attitude and posture, facial expressions, nonverbal communication such as eye contact, and increased interactions with the child. Allowing the child to guide the session and helping the parent attune or, as the therapist taking on the role of the adult, personally attuning to the child’s movements or vocal cues helped created a unique and personal connection.

By tailoring to the child’s KMP rhythms, the method did not force new movements or rhythms to occur but instead helped expand the interaction and increased engagement naturally through attuning to the child’s movements and rhythmic phrases both vocally and nonverbally. This method can help parents recognize and build on the strengths of their child and of themselves empowering them to uncover new strengths and can provide them with a space to make choices and decisions, following core principles of family centered care (American Academy of Pediatrics, 2012). This method provides the parents and the child the ability to take control and participate in a nonmedical medium.

Some difficulties I faced when implementing this method was the lack of parental or family presence. Due to several outside factors, some families were unable to be with the hospitalized child, making it difficult for me to implement the method in the way it was intended. Additionally, the lack of privacy and interruptions that may occur within the hospital rooms made it difficult at times to hold focus. I also had to be aware of not disturbing other patients and their families, as some patients resided in the bay area where patients do not have their own rooms and are separated by curtains.

Limitations were also placed on the types of props that could be used within this hospital setting. Fabric props could not be used unless they were to remain with the patient which limited the use of certain interventions or how they could be implemented. For example, a stretch cloth could not be used during the push and pull method or could not be used as a separate intervention within the overall method to help foster relationship, comfort, and attunement between the child and parent.

Finally, within each session, I had to make sure to assess the patient’s movements as either implicit or explicit. Due to the amount of medication each patient received, it was important for me to assess and understand if the movement I witnessed was authentic and intentional or if it was unintentional and a side effect of a medication. I
was able to distinguish this through researching the medications and understanding the effects they may have on the patient, partaking in discussions with health professionals taking care of the patient and parents if possible, and referring to past sessions and notes. Additionally, I paid attention to the patient’s reaction when I attuned to their movements in order to understand and extend the meaning behind their movements.

4.3 Multicultural Consideration

When developing and implementing this method, I wanted to make sure that it could be adapted to be culturally sensitive. However, in order for this to be successful, it is the therapist’s job to research the culture, ethnicity, and religion of the patient and his or her family and if possible, speak with them about the intentions of the method and determine together what is and may not be appropriate. It should never be assumed that a family belongs to a certain culture or that their values and ways of practicing their culture is the same way as others within that culture (Weiner, McConnel, Latella, & Ludi, 2013).

Additionally, while this method is being implemented, the therapist should check-in with the patient and the family to be certain that no boundaries, such as family values and practices, are being crossed and that the therapist is maintaining respect for their cultural practices. The use of touch and certain gestures can communicate or imply certain meanings in different cultures, so it is imperative that the therapist be mindful and respectful when interacting with the patient and family (Wiener et al., 2013). As stated by the American Academy of Pediatrics (2102), one of the core principles and benefits of family-centered care is to listen and respect the child and family as well as honor and incorporate their multicultural background and socioeconomic status within the devised plan.

I had the opportunity to work with and implement my method with a father and son from a different culture, ethnicity, and religion. While I did my best to research their cultural practices, I did not have the opportunity to speak with the father about it, or to ask him what his culture meant to him and what it meant to his son. Instead I had to rely heavily on the nonverbal cues while the father was participating in the session but also when he was not a part of the session but actively witnessing what his son and I were doing together. As discussed by Thibodeaux and Deatrick (2007), a family’s sociocultural context influences how the family will define and manage the illness of the ill child, and using a blended family management and cultural care framework will help create a more inclusive and positive experience for the family.
4.4 Future Considerations for Implementation of the Method

In the future, I hope that this method can be expanded and grow into an even more powerful tool to use with pediatric palliative care patients and their families. This method could grow to include other individuals in the “adult” role. For example, staff members or other professionals who are a daily part of the patients’ and families’ lives in the hospital could be included as part of the method, to help grow relationships and to help the staff member or other professionals view the patient through a different lens.

The inclusion of siblings in sessions with the parents and/or without could help foster and potentially repair family dynamics as well as regrow appropriate relationships with each other. At times, siblings feel that they are no longer a part of the family due to most of the parent’s attention and energy focused on the medically fragile sibling. As discussed previously, siblings of medically fragile children often do not feel that they are able to achieve their parent’s expectations and feel that they are no longer an important part of the family (Brown & Warr, 2007).

Siblings often have difficulty expressing their emotions surrounding the change in their family dynamic and the diagnosis of the medically fragile child, leading to poor psychosocial outcome. It can also lead to older siblings sometimes taking on the role of caregiver for other younger siblings in the family (Brown & Warr, 2007; Fullerton et al., 2016; Lane & Mason, 2013). Through the development of this method, the inclusion of siblings can help recreate a playful relationship between them and the medically fragile sibling, and provide a safe space for the medically well child to experience being a child again.

Additional future considerations of this method would be to expand and adapt it to use with verbal patients. As discussed above, when this method was a growing thought in my mind and before I began my work at my internship, I was planning to include developmentally appropriate verbal processing about the child’s illness, maybe death if it were to arise in conversation, and processing of how the child feels their relationship with their family may or may not have changed.

4.5 Future Research Potential

For future research, this method could be used to measure how a patient and their family feel before the method is implemented and how they feel afterwards. Ideally, quality of life would be measured but as discussed in the literature review, there is currently no instrument that can assess all aspects of QOL from a life limiting patient’s perspective due to the different perspectives of QOL each individual has and their perception of death and dying
(Evan et al., 2012; McCaffrey et al., 2016). Therefore, qualitative research could be used to determine and discover common themes among families and pediatric palliative patients before and after the implementation of the method.

The quality of the relationship between the parents and patient, the relationship between the patient and well sibling(s), and/or the relationship between the parents, patient, and well sibling(s) could all be measured to determine any changes in the quality of relationship, growth in relationship, and any other changes within the interactions. Additionally, how each person felt individually within the session, and how their perspective on the prognosis and diagnosis of the medically fragile child may or may not have changed, could also be measured. There are endless possibilities of how this method could be adapted or used within research to begin the discussion of how DMT can help pediatric palliative care patients and their families.
REFERENCES


https://www.qualityforum.org/Publications/2012/04/Palliative_Care_and_End-of-Life_Care%E2%80%94A_Consensus_Report.aspx


**APPENDICES**  
Appendix A: Laban Analysis (LMA) Efforts

<table>
<thead>
<tr>
<th>LMA Effort</th>
<th>Element (Indulging)</th>
<th>Element (Condensing)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>FLOW</strong>: relates to continuity, ongoiness, progression, emotions, and involvement.</td>
<td><em>Free Flow</em>: Outpouring, letting the inside out and the outside in, uncontrollable, can’t be stopped, open hearted, fluid, etc.</td>
<td><em>Bound Flow</em>: Contained, controlled, keeping the inside in and the outside out, can be stopped at any moment, rigid, boundaries, clarity, etc.</td>
</tr>
<tr>
<td><strong>WEIGHT</strong>: about sensing, intention, feeling my own weight, “me” oriented (me, myself, my physicality), presence, relationship to earth/gravity.</td>
<td><em>Light (Active Weight)</em>: Delicate, fragile, overcoming one’s weight, buoyant, lifted up, etc.</td>
<td><em>Strong (Active Weight)</em>: Power, “standing one’s ground”. immovable, etc.</td>
</tr>
<tr>
<td><strong>TIME</strong>: about intuition, decision making, related to the moment, now vs. not now, knowing the right moment to act, reinvesting in the moment.</td>
<td><em>Sustained</em>: Lingering, drawing out the moment, luxuriate, languidly, adagio, prolonging, leisurely, “not yet, not now”, etc.</td>
<td><em>Sudden or Quick</em>: Urgent, instantaneous, staccato, quick, hurried, condenses the moment, spark-like, now, now, NOW!</td>
</tr>
<tr>
<td><strong>SPACE</strong>: about thinking, attention, intellect and ideas, perception—using my senses, environment/other related, external.</td>
<td><em>Indirect</em>: Multi-focused, overlapping, roundabout, scanning, taking it all in, expansive, seeing all the possibilities, etc.</td>
<td><em>Direct</em>: Channeled, honing-in, riveted, linear, laser-like, single-focused, pin pointed, —this is it, “this is the way.”</td>
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*(Konie, 2011)*
Appendix B: KMP Rhythms

<table>
<thead>
<tr>
<th>KMP Rhythm</th>
<th>Developmental Phase</th>
<th>Description</th>
<th>Visual Representation</th>
</tr>
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<tbody>
<tr>
<td>Sucking</td>
<td>Oral (Indulging)</td>
<td>Smooth alteration between of Free Flow and Bound Flow. It is never abrupt but is instead a steady, smooth, and repetitive rhythm. It helps to develop a clearly defined and adaptive rhythm and promotes attunement between mother and child.</td>
<td><img src="image" alt="Sucking" /></td>
</tr>
</tbody>
</table>
| Snapping/Biting   | Oral (Fighting)     | **Snapping:** A tapping-like rhythm that alternates between Free and Bound Flow but has sharp transitions as it reverses directions.  
**Biting:** A tapping-like rhythm that alternates between Free and Bound Flow but has a short holding portion instead of sharp transitions  
Body Boundaries become defined and stability and differentiation from the primary caregiver begin.  
Begin to experience self as a separate, distinct being with boundaries. This rhythm promotes individuation and separation. | ![Snapping, Biting](image) |
| Twisting          | Anal (Indulging)    | This rhythm encourages the child to move from the pelvis and promotes playfulness. The child enjoys the sense of touch and feeling the weight and texture of objects. There is little stability in this rhythm as the body begins to transition to vertical alignment. | ![Twisting](image)    |
| Strain/Release    | Anal (Fighting)     | The child masters physical process of straining and releasing and psychological process of holding, pushing, and letting go. Child is able to give something away without wanting it back. This rhythm contributes to the development of needing to engage in clearly defined and structured behaviors and the development of being assertive.  
Straining: helps child gain stability and develop a feeling of self-assurance, desire for greater autonomy, and a willingness to confront others as they are stable in the vertical plane. | ![Strain / Release](image) |
<p>| Running/Drifting  | Urethral (Indulging) | This rhythm shows gradual increases or decreases of muscle tension of low level of intensity. The child becomes more pliable and agreeable and begins to orient in the Sagittal plane as they bulge forward, drifting fluidly throw space. A child’s body attitude is fluid but has little control to make definitive starts or stops. | <img src="image" alt="Running, Drifting" /> |
| Starting/Stopping | Urethral (Fighting) | The child gains more control over stopping and starting with the rhythm characterized by sharp transitions. The child begins to learn how to run in a coordinated manner, are impatient, and have short attention spans. In this rhythm, the body is mobile and elastic and is sagittally oriented. | <img src="image" alt="Starting, Stopping" /> |</p>
<table>
<thead>
<tr>
<th>Movement Type</th>
<th>Genital</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Swaying</td>
<td>Inner Genital (Indulging)</td>
<td>This rhythm consists of wave-like contractions of gradually increasing and decreasing intensity. This rhythm is useful for integration of various impulses and of needs associated with the past, present, and future. Creativity begins to surge during this phase with some moments of regression. The child’s body attitude takes on the form and movements of gendered children rather than toddlers.</td>
</tr>
<tr>
<td>Surging/Birthing</td>
<td>Inner Genital (Fighting)</td>
<td>Rhythm gradually builds to high levels of intensity. The child begins to push away valued toys and parents and the world of fantasy becomes more distinct from reality where the mother is blamed for the loss of fantasy. The child’s body attitude in this phase is usually rounded in the belly region as the body is in preparation for spiraling turns and is full of dynamic intensity.</td>
</tr>
<tr>
<td>Jumping</td>
<td>Outer Genital (Indulging)</td>
<td>This rhythm is abrupt with smooth transitions and are usually of high intensity. The child moves in a single body movement. In this phase, the child does not make strong distinctions and differentiations with abruptness usually depicted in the quick shifting mood swings. The child’s body attitude in this phase is a long, thin, springy, single body unit.</td>
</tr>
<tr>
<td>Spurting/Ramming</td>
<td>Outer Genital (Fighting)</td>
<td>This rhythm has sharp transitions and high intensity as movements and process of thinking become more sharply differentiated. The child becomes more purposeful, aggressive, penetrating, and focused. This rhythm is characterized as the most aggressive and potentially violent rhythm. Gender identity begins to be more clearly differentiated in this phase. The child’s body attitude is still long and thing but is differentiated, sharp, and is vertically and sagittally oriented.</td>
</tr>
</tbody>
</table>

(Amighi, Loman, Lewis, & Sossin, 1999; Longstaff, 2007, Typical examples of tension flow rhythms from Kestenberg Movement Profile (KMP), http://www.laban-analyses.org/laban_analysis_reviews/laban_analysis_notation/effort_dynamics_eukinetics/Kestenberg_rhythms.htm)