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Music Therapy and Pediatric Palliative Care:
A Clinical Decision-Making Model to Meet Palliative and Rehabilitative Goals
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Abstract

The purpose of this article is to provide music therapists with a clinical decision-making model for use with pediatric palliative care (PPC) patients. After reviewing current literature and analyzing my own clinical work in community-based PPC, eight (8) decision trees were created to assist clinicians in determining appropriate music therapy methods and interventions to treat the diverse goals seen within this setting. Music therapists working in PPC may address both palliative and rehabilitative goals, as medically complex children often receive both comfort care and functional, rehabilitative therapies simultaneously. Additionally, several clinical variables were identified that may affect a music therapist's decision to choose one intervention over another when there is more than one appropriate option to address a goal. Available music therapy interventions were extracted from a variety of theoretical approaches, and co-treatments with interdisciplinary team members were explored.

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Music Therapy and Pediatric Palliative Care:

A Clinical Decision-Making Model to Meet Palliative and Rehabilitative Goals

The number of medically complex children continues to grow worldwide, as the age of viability for preterm infants increases and new treatments are discovered for life-limiting illnesses (Cohen et al., 2011). In a recent analysis of the Nationwide Inpatient Sample (NIS), the rate of hospitalized children with more than one Complex Chronic Condition (CCC) doubled from 1991 to 2005 (Burns et al., 2010). CCCs can be defined as “a medical condition that lasts for >12 months and involves several different organ systems or one organ system requiring a high level of specialty care and hospitalization” (Cohen et al., 2011, p. 531). CCCs affect many children receiving PPC. Other qualifying diagnoses and conditions include neurologic, respiratory, cardiovascular, renal, gastrointestinal, and metabolic disorders, as well as malignancies and dependence on mechanical ventilation (Feudtner et al., 2014). The unpredictable nature of these illnesses creates a wide range of social, emotional, and physical needs that affect the family unit as a whole.

Music therapy is the evidence-based use of music by a credentialed therapist to address physical, emotional, cognitive, and social needs of a wide variety of clients of all ages (American Music Therapy Association [AMTA], 2019). Within the hospice and palliative care setting, music therapists work as members of the integrative medicine team to relieve the physical symptoms and psychosocial effects of the disease process (Hilliard, 2005). Music therapists working in *pediatric* hospice and palliative care also address developmental skills such as communication, gross and fine motor movement, sensory integration, and cognition (Kennelly, 2000). Music therapists assess the salient needs of pediatric patients by determining which goal

areas are most urgent at any given time, and often treat more than one domain within the same session.

The purpose of this paper is to create a clinical framework from which music therapists can choose appropriate music therapy interventions and goals for PPC patients, based on the client's salient needs, time in therapy, and developmental level. By first determining appropriate goal areas, the clinician is then able to select which music therapy interventions best meet those needs. The establishment of the first American PPC programs in the late 1990s and early 2000s (Feutdner et al., 2013) created unique clinical opportunities for music therapists. These community and facility-based programs allowed music therapists to follow patients for longer periods of time, as a child's involvement with a PPC team typically lasts at least one year (Smith et al., 2015). Previously, music therapists working with this population had most often treated medically fragile children during their inpatient stays at the hospital, where the average length of stay for a child aged 0-17 is 3.9 days (Witt, Weiss, & Elixhauser, 2014). Prior to the development of organized palliative care programs, music therapists did not have many opportunities to assess long-term goals in the medical setting. This project intends to fill a gap in the PPC literature by providing a decision tree model for music therapists containing appropriate interventions to meet the dynamic palliative and rehabilitative needs of these children.

Review of the Literature

Approaches to Music Therapy

Music therapists practice within a wide variety of theoretical orientations that influence how they approach therapy. Several common approaches to music therapy include behavioral, neuropsychological, psychotherapeutic, and ecological (Bruscia, 2014). In the diverse field of PPC, each of these approaches may best serve a patient and his/her family at any given time.

Behavioral. Music therapists who utilize a behavioral orientation use positive music experiences to reinforce desired behavior (Madsen, 1968). Behaviorally-oriented music therapists may also withhold reinforcers such as music, instruments, preferred songs, and verbal affirmations to decrease unwanted behavior. During sessions, music therapists practicing from a behavioral approach provide opportunities for the client to model target behaviors that are common in everyday life, thus building skills that transfer beyond the walls of the music therapy session. Behavioral therapy was first popularized in the 1960s and has since provided the basis for applied behavior analysis (Baer, Wolf, & Risley, 1968) and contingent music models (Standley, 2000). Behavioral music therapy is common in school settings, and may take place in a classroom, small group, or individual setting (Bruscia, 2014). In a PPC setting, music therapists may utilize this approach by providing positive reinforcement when a child “takes a risk” during an improvisation, performance, or songwriting exercise.

Neuropsychological. Music therapists who utilize a neuropsychological approach to therapy primarily address their clients’ physical and cognitive rehabilitation following an illness, accident, or trauma (Thaut & Hoemberg, 2014). Music therapy has been shown to significantly improve gait patterns (Thaut et al., 1996), speech fluency (Tomaino, 2012), and executive functioning skills (Hitchen, Magee, & Soeterik, 2010) in this population. Therapists practicing within a neuropsychological context help clients to “regain previous levels of functioning or adjustment to the extent possible” (Brusica, 2014, p. 162). Recent advances in neuroimaging have supported the use of music with this population by demonstrating music’s ability to form new neural pathways in the brain (Wan & Schlaug, 2010). Within a PPC setting, a music therapist may utilize a neuropsychological approach when co-treating with a child’s physical or occupational therapist to address hemiparesis following a stroke.

Psychotherapeutic. Music therapists with a psychotherapeutic orientation assist their clients in the process of self-actualization. By helping clients access conscious and unconscious material using both receptive and active music interventions, the therapist encourages and facilitates inner change within the client (Scovel & Gardstrom, 2005). Therapeutic goals may include the resolution of inner conflicts, cognitive restructuring, and the development of healthy relationships (Bruscia, 2014). Psychotherapeutic approaches to music therapy draw from the writings of Freud, Adler, Jung, Erikson, and Fromm, among others, and may involve significant dialogue between the client and therapist (Wheeler, 1981). Therapists who practice at this level hold graduate degrees in music therapy or a related field (Wheeler, 1983). Qualified music therapists working in PPC may utilize this approach when facilitating musical improvisation with an adolescent who is experiencing existential anxiety following a recent cancer diagnosis.

Ecological. Music therapists practicing with an ecological approach are interested in supporting communities as a whole, as well as the relationship between their individual clients and their respective communities (Bruscia, 2014). Therapists working with an ecological background often expand the barriers of traditional music therapy by providing large group therapy with communities who have experienced trauma (Sutton, 2002) and facilitating opportunities for their clients to perform in a community setting (Aigen, 2002). Within this orientation, whole communities are sometimes considered a singular client (Aigen, 2002). In a PPC setting, music therapists may utilize this approach while facilitating family music therapy sessions or performance opportunities for their clients.

Music Therapy Methods

Within the practice of music therapy, there are four main methods of music therapy: improvisational, re-creative, compositional, and receptive (Bruscia, 2014). Within each method

fall a variety of techniques, or specific music therapy applications of these methods. While music therapy *approaches* tend to vary widely in their theoretical models (Hillecke, Nickel, & Bolay, 2005), music therapy methods bring cohesion to the field by acting as umbrella categories for a variety of specific interventions, which are utilized by all music therapists regardless of their professional orientations.

Improvisational. Improvisational music therapy methods include both referential and non-referential experiences in which the client improvises freely on an instrument or with his/her voice, often accompanied by the music therapist (Bruscia, 2014). Musical improvisation acts as a communication stream between the therapist and client(s), and is suitable for use with pre-verbal children and adolescents (Graham, 2004) as well as neurotypical adults. Common goal areas for improvisational music therapy include self-expression, socialization, and communication. In a recent study, a group of hospice patients who participated in an improvisational music therapy group twice per week stated that they felt the group had provided them with a safe “haven” or “escape,” as well an opportunity for stress relief and meaningful communication with peers (Pothaulaki, MacDonald, & Flowers, 2012).

Re-creative. Alternatively, re-creative methods incorporate the use of precomposed songs for musical engagement (Bruscia, 2014). The client replicates the presented music on his/her preferred instrument to address sensorimotor, cognitive, and interpersonal skills. A sense of mastery of an instrument may improve the client’s self-esteem and quality of life (Baker, Wigram, Stott, & McFerran, 2008; Hanser & Thompson, 1994). Choosing, learning, arranging, and performing specific songs allows clients to communicate with others while developing a stronger locus of control and sense of self (Standley & Hanser, 1995). In PPC, providing choices

to children who have little control over their environment can be a meaningful way to empower and develop their individual identities (McFerran & Sheridan, 2004).

Compositional. In compositional activities, the client works with the therapist to create original songs and compositions (Bruscia, 2014). These experiences provide opportunities for the client to process and express emotions, while practicing executive functioning skills such as decision-making and planning. In addition, clients may learn to practice songwriting exercises independently between sessions. Providing clients with coping skills that they can access independently promotes the client's success following the completion of the therapeutic relationship (Rolvsjord, 2010). Patients receiving palliative care have written about a variety of themes including meaningful memories and relationships with significant others (O'Callaghan, 1996).

Receptive. Receptive music therapy methods incorporate activities in which the client actively listens to live or recorded music to promote relaxation or emotional/cognitive awareness (Bruscia, 2014). Examples of receptive interventions include guided imagery, entrainment, and song discussion. Both pre-recorded and improvised music convey mood and may greatly affect the client's environment (Grocke & Wigram, 2006). The clinician may consider utilizing the "iso principle," a term first coined by psychiatrist Dr. Ira Altshuler (1948), to use the elements of music to match the client's presented mood state, affect, breathing, or heart rate before gradually changing the music to elicit the client's desired state. Receptive music listening methods have been used in palliative care to ameliorate pain, reduce anxiety, (Horne-Thompson & Grocke, 2008) and engage patients in low awareness states (Magee, 2007).

Hospice and Palliative Care

Palliative care, which comes from the Latin “palliare” (to cloak), is described as an additional layer of support for individuals experiencing severe illness (Center to Advance Palliative Care, 2017). Palliative care is provided by an interdisciplinary team of doctors, nurses, social workers, volunteer coordinators, chaplains, and integrative therapists who treat the patient’s body, mind, and spirit in an inpatient, outpatient, or homecare setting (World Health Organization, 2012). When a patient is referred to palliative care, his/her primary care team remains in place while individuals with specialized training in comfort care and best practices at end-of-life (EOL) provide pain management, case management, social services, bereavement, and spiritual care (Sepulveda, Yoshida, & Ullrich, 2002).

Although the terms “hospice” and “palliative” are sometimes used interchangeably, a person may receive palliative care at any point in the disease process but must have a prognosis of six months or less to qualify for hospice care in the United States (Hospice Care General Provision and Definitions, 2018). However, the goals for both hospice and palliative care remain the same, with a primary focus of improving quality of life for the patient, regardless of their prognosis or stage in the disease process.

Training of professionals. Clinicians with extensive training in this setting are vital to the success of palliative care programs that provide support throughout the course of an illness and allow for a “better death” at EOL (Payne, Langley-Evans, & Hiller, 1996). Researchers at Children's Hospitals and Clinics of Minnesota found that children enrolled in PPC programs at the time of death were more likely to receive integrative medicine, better pain management, and fewer diagnostic/monitoring procedures at end-of-life than those who were not (Osenga et al., 2016). While medical residents are now able to specialize in Hospice and Palliative Medicine

(HPM) through the American Board of Physical Medicine and Rehabilitation (ABPMR), music therapists wishing to specialize in hospice and palliative care can pursue advanced training through interdisciplinary conferences and graduate-level courses.

Music Therapy in Hospice and Palliative Care

The majority of music therapy research in hospice and palliative care has been conducted with adults, due to the greater prevalence of life-limiting illnesses within this population. A series of systematic reviews have demonstrated that music therapy may be effective in increasing physical comfort, mood, and spirituality (Hilliard, 2005), improving quality of life (Bradt & Dileo, 2010) and reducing pain (McConnell, 2016) in adults receiving palliative and/or hospice care. In addition, music has been shown to decrease dyspnea (Burns, Perkins, Tong, Hilliard, & Cripe, 2015; Canga, Azoulay, Raskin, & Loewy, 2015; Ergin, Midilli, & Baysal, 2018), nausea (Madson & Silverman, 2010), and migraines (Oelkers-Ax, 2018) across a variety of settings. These three symptoms are commonly experienced by pediatric patients at EOL. Finally, music therapy has been shown to reduce perceived levels of pain in both adult hospice patients (Gustgell, 2013; Krout, 2001) and children (Nguyen, Nilsson, Hellström, & Bengtsom, 2010). Within PPC, music therapy goals most often include pain management, legacy building, facilitating expressive communication, and providing family support (Lindenfelser, 2013).

Although PPC is a relatively new, small field, music therapists have documented a variety of applicable music therapy interventions that are developmentally appropriate for use with children in the medical setting (Duda, 2013; Hanson-Abromeit, 2008). Many of these interventions are also employed in an adult hospice setting. For example, some music therapy applications appropriate for both settings include songwriting interventions to process illness-related trauma, receptive music listening activities to address pain management and relaxation,

interactive improvisation, and instrument play to increase nonverbal communication and expression of self (Lindenfelser, 2013). Newer interventions developed in the 21st century incorporate the use of heartbeat recording (Schreck, 2018) and music technology to create legacy projects (Magee et al., 2011; Magee & Ramsey, 2014).

Music Therapy to Address Holistic Needs of Pediatric Palliative Care Patients

Although the number of children appropriate for PPC services continues to grow, the population is relatively small compared to that of other related fields including adult hospice and special education. That being said, palliative care has become one of the fastest growing fields of healthcare in the 21st century (Hughes & Smith, 2014). The holistic philosophy of palliative care allows music therapists working with adults and/or children in this setting to address a wide variety of needs. In addition, the collaboration between PPC teams and community resources such as hospitals, school providers, and other social services has led to better coordinated care for families (Pelant, McCaffrey, & Beckel, 2012). Music therapists employed in this setting are able to work with community providers to determine the most salient palliative and rehabilitative needs of each family. However, three overarching goals that are relevant to all PPC families include improving quality of life, addressing relationship completion, and providing concurrent care strategies.

Quality of life. In an international, multi-site, PPC study, a team of researchers found that music therapy sessions benefitted families in two central ways: by improving the child's physical state and providing the whole family with positive experiences, thus improving quality of life (Lindenfelser, Hense, & McFerran, 2011). In addition, music therapy's effect on quality of life has also been well-documented with adults in a variety of other medical settings including inpatient medicine (Walworth, Rumana, Nguyen, & Jarred, 2008), mental health (Grocke, Bloch,

& Castle, 2009), and geriatrics (Ridder, Stige, Qvale, & Gold, 2013). Finally, music therapy has been shown to have a significant positive effect on quality of life of caregivers of hospice patients (Choi, 2010), suggesting that family members should be included in pediatric palliative music therapy sessions when feasible and appropriate.

Relationship completion. Because music is a social activity (Roy & Dowd, 2010), family participation in music therapy often occurs organically. In addition, music therapy has the ability to provide meaningful moments between patients and their loved ones at EOL (Magill, 2009). These patients, many of whom have cognitive deficits, have been shown to exhibit increased verbalizations during and immediately following participation in music therapy (Brotons & Koger, 2000). Practitioners with advanced training are able to incorporate elements of family systems theory within these family music therapy sessions (Nemesh, 2017).

Finally, parents and siblings of children nearing EOL often wish to participate in legacy building projects to honor the memory of their child or sibling (Foster, Dietrich, Friedman, Gordon, & Gilmer, 2012). Intentionally designed music therapy interventions such as song dedications, life review playlists, and musical gifts provide opportunities for clients to leave legacy projects for their loved ones (Clements-Cortes, 2011). Music therapists may encourage legacy building activities by facilitating and recording meaningful moments between clients and their family members at EOL (O'Callaghan, 2013), creating playlists of songs that were meaningful to the client at different times in his/her life (Sato, 2011), and composing original music with their clients (Health & Lings, 2012). Following a model presented by music therapist Brian Schreck, many hospice and palliative care music therapists have recently begun to record their clients' heartbeats using specialized stethoscopes. These samples are then set to an original

song created by the child or to a song that was meaningful to the family (Clements-Cortes, 2017).

Concurrent care. Children with serious illnesses often receive comfort care and curative treatments such as chemotherapy and radiation concurrently. Therefore, the goals of the interdisciplinary team for these children and adolescents may be palliative, rehabilitative, or both (National Hospice and Palliative Care Organization, 2009). For example, in addition to addressing symptom management and other typically palliative goals, music therapists may work with school-based service providers (e.g., tutors, occupational therapists, developmental specialists, physical therapists, speech pathologists, special education teachers) to address developmental skills that may have been affected by the course of the illness.

Concurrent care is defined as any medical treatment that has curative or life-prolonging properties (e.g., hormone therapy, bone marrow transplant, chemotherapy) used in conjunction with palliative or “comfort” care (Miller, LaRagione, Kang, & Feudtner, 2012). Parents and guardians who believe that the implementation of a certain medicine or therapy has a significant chance of prolonging their child’s life elect to incorporate concurrent care in their child’s treatment plan. However, many of these treatments may incur side effects and are not guaranteed to be effective. Therefore, parents must be informed about the realistic expectations of elective and experimental therapies (Wolfe et al., 2000). Whether or not a parent or guardian chooses to “pursue further treatment” by electing potentially life-prolonging therapies via concurrent medical care does not affect the frequency or goals of therapies provided by the child’s palliative care team or school providers. Therefore, music therapists working with children with serious illnesses, whether employed by a palliative care team, hospital, or school system, may address

both palliative and rehabilitative goals as a means of improving the child's overall quality of life (McFerran & Shanahan, 2011).

Development of the Decision Trees

At the time of writing, this writer had been board-certified as a music therapist for 2.5 years, and had been working in a community-based pediatric palliative care (CBPPC) program in New England for two years.

Philosophy

My personal philosophy of music therapy has been greatly formed not only by my education, but also by the community setting in which I work. During my undergraduate education I was exposed to a variety of therapeutic orientations, each of which had individual strengths. While completing my internship in forensic psychiatry, I resonated most strongly with the humanistic approach to music therapy in which clients are provided with radical “unconditional positive regard” and encouraged to remain in the present moment as much as possible (de l’Etoile, 2008). As a new professional working in an urban, medical, homecare setting, I became interested in community music therapy (Aarø & Stige, 2011) and resource-oriented (Rolvfsjord, 2010) music therapy. I viewed both philosophies as critical to this setting, as they both incorporate a strengths-based approach and emphasize utilization of available resources. Finally, I was drawn to the neuropsychological approach to music therapy as a means of helping clients achieve independence via rehabilitation (Thaut & Hoemberg, 2014).

The Decision-Tree Model

A decision-tree model was utilized to provide a framework for making clinical decisions within the pediatric palliative music therapy setting. Treatment goals were placed at the top of the diagram and connected to nodes that branched off into a variety of music therapy methods,

each of which was the source of one or more applicable interventions. These terminal nodes represent not final outcomes, but “convenient stopping points for the scope of the analysis” (Sonnenberg & Beck, 1993, p. 322). Because “palliative” is a broad, encompassing term, families with a wide array of needs often qualify for palliative care. Many factors including the patient’s age, developmental level, and prognosis determine treatment and therapy goals for the interdisciplinary team. Music therapists may consult with one another, as well as other members of the team to determine the patient and family’s salient needs at any given time.

Once goal areas are determined by the treatment team, clinicians may begin to create individualized treatment plans to address those goals. While medical doctors may utilize the hypothetico-deductive method of reasoning outlined in the scientific method as well as the more recent clinical decision-making form of qualitative inquiry (Kovacs & Crosskerry, 1999) to create treatment plans, music therapists may also use a combination of evidence-based practices and intuition to determine the most appropriate music therapy interventions to use during a session. The goal of the current project is not to provide a linear, definitive approach to making clinical decisions in pediatric palliative music therapy, but rather to organize methods and interventions that are utilized in this setting in a visual diagram to aid music therapy practitioners in making individualized, clinical decisions. Decision trees can be used as a clinical tool to “provide a formal process of decision making, in a largely intuitive based area” (Thompson, 2013, p. 61).

Referral. Although the organization and location of PPC services may differ between community-based and inpatient programs (Caroll, Santucci, Kang, & Feudtner, 2007), the referral process for music therapy is similar. Any team member may make a referral to the music therapist if they observe a need for symptom management, physical rehabilitation, or

psychosocial support. In Melbourne, Australia, nurses were found to refer palliative patients to music therapy more often than any other referral source, accounting for 47% of all music therapy referrals (Horne-Thompson, Daveson, & Hogan, 2007). Parents may also self-refer by requesting a music therapy assessment for their child through their hospital, palliative care program, or school system. However, the timing of the referral in relation to the child's disease process may affect which domains the music therapist addresses (Daveson, 2001). PPC specialists often advocate for early referral to palliative care services as a means of better supporting families from the time of diagnosis (Mack & Wolfe, 2006).

Assessment. The amount of information made available during a referral differs across agencies, providers, and even families. For example, a mother may ask that a music therapist provide pain management for her son who has been hospitalized with a sickle cell crisis, while a community-based social worker may write a blanket referral for a family that has requested an initial music therapy assessment but has not identified a particular clinical need. The latter example is common in this setting, due to the accessible, engaging nature of music therapy.

Before the music therapist begins an assessment, she/he will read the patient's chart and consult with the care team to learn about the infant, child, or adolescent's medical and social history. If the electronic medical record (EMR) of the patient is not readily available to the therapist in an inpatient setting, he/she may consult with the referral source to learn valuable information about the client such as any known safety concerns or musical preferences. This information, combined with observations from the initial music therapy assessment, will inform the clinician about whether to address palliative or rehabilitative goals (or both) during the music therapy treatment process. For the purposes of this paper, this writer identified five common *palliative* domains that music therapists commonly address in this setting: pain/symptom

management, legacy building, social/emotional support, caregiver support, and sibling support. Three *rehabilitative* domains were described as follows: expressive communication, fine/gross motor skills, and cognition. It should be noted that this list is not exhaustive, and that goal areas may vary somewhat across inpatient and community settings.

Defining Two Approaches

Working with children with life-limiting illnesses in their homes has allowed me the opportunity to work on a variety of both long and short-term, rehabilitative and palliative goals within this diverse population. In general, a patient's acuity will determine whether the majority of his/her salient needs fall under a rehabilitative, or palliative umbrella. Although the trajectories of pediatric illnesses are often complex and therefore unpredictable (Mack & Wolfe, 2006), patients who exhibit a marked decline in functioning over several months or begin to display physical (EOL) signs such as Cheyne-Stokes breathing or dysphagia of liquids (Hui et al., 2014) fall under the palliative umbrella and receive exclusively comfort care. However, patients who have chronic conditions but exhibit little to no decline often benefit from therapies and services that address rehabilitative goals, which focus on maintaining or increasing a child's independence. When determining clinical goals for a patient during an assessment session, the music therapist may inform the family about his/her role on the team, before asking them to describe which music therapy goals are most important to them in relation to their individual hopes for the child.

Palliative goals. A music therapist working with a child on palliative goals works with the whole family to relieve their emotional and physical suffering (Magill, 2001). The music therapist plays a unique role on the palliative care team by allowing family members to express themselves both verbally and nonverbally through artistic mediums. Caregivers and loved ones

benefit from witnessing joyful moments in the child's life (Lindenfelser, Grocke, & McFerran, 2008), while siblings are able to connect with each other through age-appropriate musical activities. Finally, music therapists can assist the rest of the team in providing a variety of legacy projects for the family to have as needed if the child passes away.

Pain/symptom management. Music has been shown to reduce postoperative (Bradt, 2010) and procedural pain (Walworth, 2005) in children and chronic pain in adults (Guétin et al., 2005). However, music therapists must “tread carefully” when providing music for pain management in order to relax and/or distract the child without overstimulating him/her. For this reason, a music therapist may ask his/herself whether or not the child is awake, alert, and able to communicate effectively with the therapist before choosing an appropriate music intervention. If the answer to any of these questions is no, the music therapist may consider using only receptive music relaxation interventions, so as to not overstimulate the child (Loewy, Stewart, Dassler, Telsey, & Homel, 2013).

However, if a child is awake and able to participate in more interactive methods, the therapist may consider using music and imagery or music entrainment as a means of treating his/her pain. Music-based imagery is defined as “a form of music-assisted relaxation with patient-specific mental imagery” (Tan, Yowler, Super, & Fratianne, 2010) and has been used successfully to decrease patient pain perception in both adults and children (Fratianne et al., 2001; Sahler, Hunter, & Liesveld, 2003). This intervention is believed to decrease patients' perception of pain by flooding the brain with additional sensory stimulation, so that it is not able to attend to pain as closely. This phenomenon is described in Ronald Melzack's neuromatrix theory of pain, which suggests that the brain's ability to perceive pain is controlled by a variety

of cognitive-evaluative, sensory-discriminative, and motivational-affective inputs (Melzack, 2001).

Music entrainment is a second, interactive music intervention that has been utilized successfully to treat pediatric pain (Bradt, 2010). In general, entrainment can be defined as “the process by which independent rhythmical systems interact with each other...through some form of oscillatory activity” (Clayton, 2012). This model of music entrainment was first adapted for pain management by Cheryl Dileo and Joke Bradt, who described the practice of capturing the inherent rhythmic and expressive qualities of pain by translating them onto musical instruments (Dileo & Bradt, 1999). In this exercise the therapist consults with the client to create a soundscape with percussive and/or melodic instruments that mirrors the client’s pain as closely as possible in terms of timbre and rhythm. The client then assists the therapist in creating a “healing” soundscape to transition to after he/she feels that their pain has been successfully externalized. Exercises like these require that the client be able to communicate effectively with the therapist through the use of a common language, assistive technology (AT), or an interpreter. Although it has been suggested that it is possible to modify this intervention for clients who are nonverbal and do not have access to AT (Dimaio, 2010), therapists must use caution in these scenarios. Finally, for patients exhibiting drowsiness or confusion in place of or in addition to pain, stimulative listening may be used to facilitate wake states and promote reality orientation in patients. Figure 1 depicts several interventions available to music therapists addressing pain and symptom management within this setting.

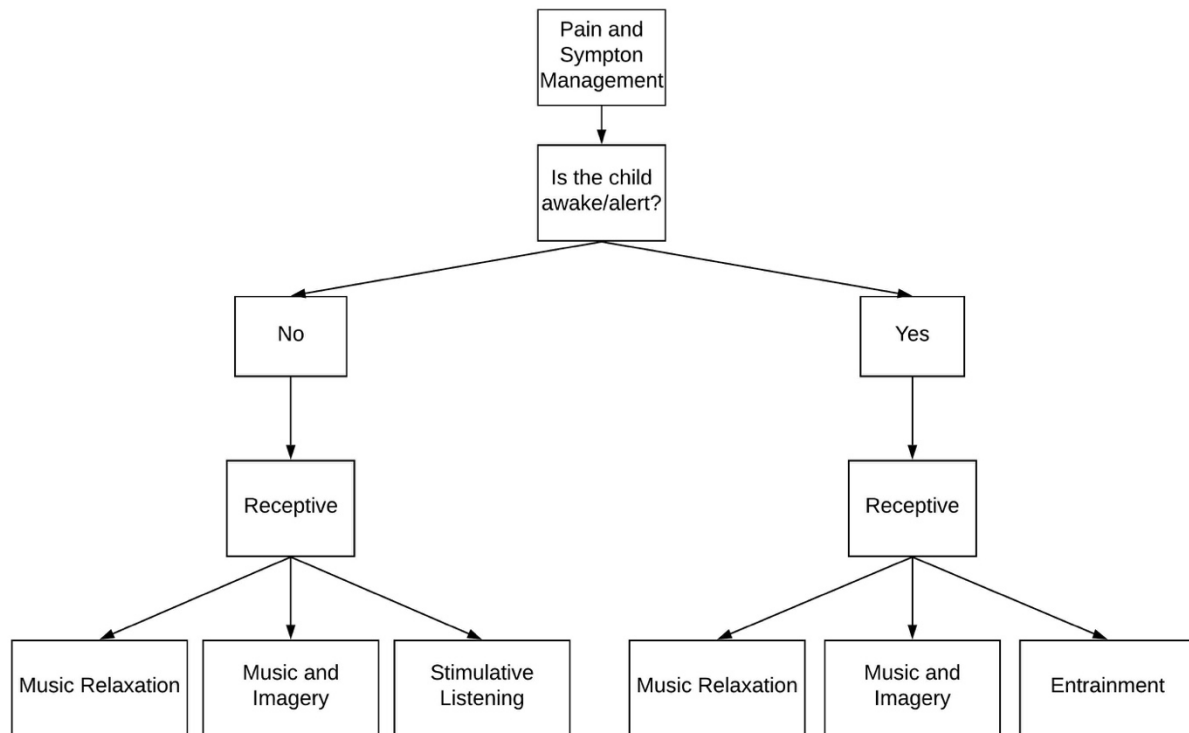


Figure 1. A decision-tree model for addressing pain and symptom management in PPC music therapy

Legacy building. For parents and families of terminally ill children, legacy-making activities such as “memory books, hand molds, songwriting, artwork, photographs, and videos” (Foster et al., 2012, p. 573) serve to comfort families and provide meaningful mementos at EOL. Music therapists may assist with legacy-making activities by composing original songs with the child, facilitating a song dedication from one family member to another, creating a compilation of songs that were meaningful to the child throughout his/her life, or creating an audio or audiovisual recording of the child in music (Clements-Cortes, 2016).

Before beginning legacy work, sufficient rapport should be formed with the child and family (Sisk, Walker, Gardner, Mandrell, & Grissom, 2012). Because death is often an uncomfortable topic to approach, especially within the context of pediatrics, a therapeutic

relationship should be formed with the family before legacy work begins (Braganza, 2014). However, when working with families who are not prepared to discuss legacy options, music therapists may consider reframing the conversation by encouraging families to participate in any of these activities using different language. As a final consideration, if a music therapist arrives in a room to find a child unable to actively engage in a music therapy session, she/he may consider recording the child's heartbeat to use in later sessions after obtaining consent. Figure 2 offers clinical considerations to the music therapist addressing legacy building with PPC families.

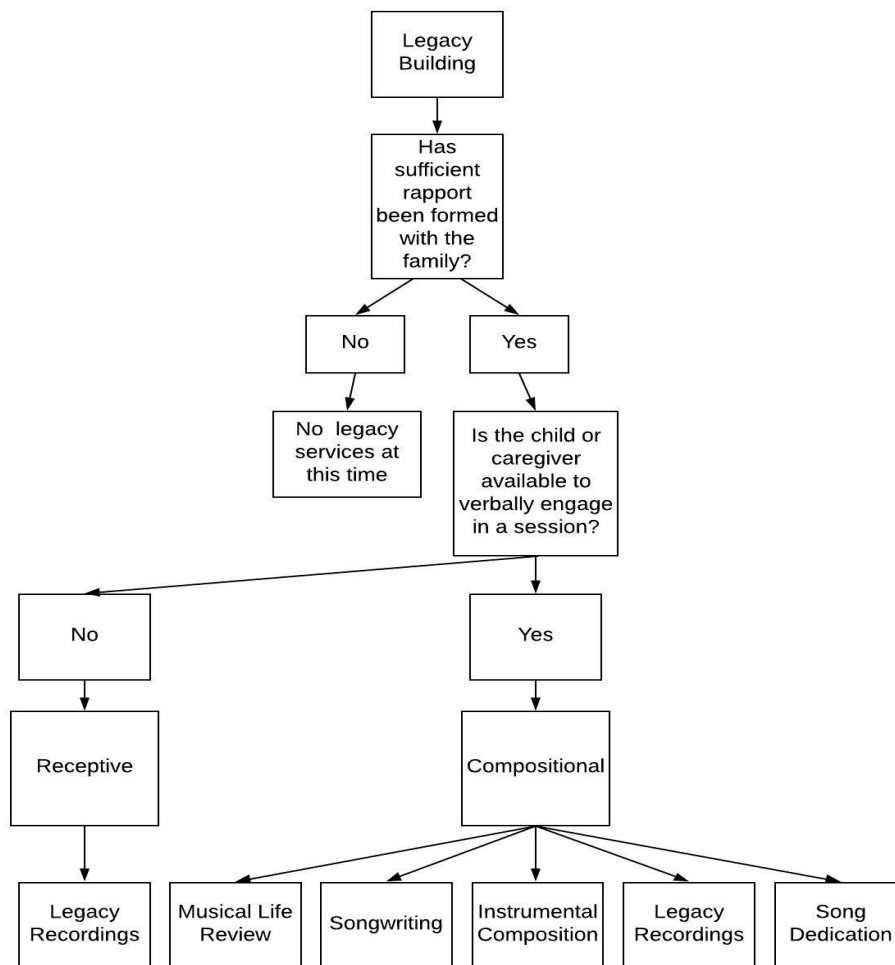


Figure 2. A decision-tree model for addressing legacy building in PPC music therapy

Social-emotional support. When addressing social and emotional health in a medical setting, there are a myriad of intervention options for music therapists. In a pediatric setting that values self-expression and choice-making, it is important that the child have as much control over the session as possible (McFerran & Sheridan, 2004). Therefore, a therapist may narrow the intervention options to those that are feasible and relevant to the therapeutic goal before offering options to the client. As a result, the child will likely invest more energy in and benefit more from an intervention that he/she chooses.

Although music is a motivating medium and can help normalize the hospital environment, children may experience stranger anxiety (Robb, 1999) at the sight of a music therapist or any other member of the care team. Therefore, children and adolescents may prefer to participate in passive music engagement throughout the course of the therapeutic relationship, or until sufficient rapport is formed. Because active music engagement involves risk-taking (Burnard, 2002), passive interventions may be considered “more safe” to an anxious or hesitant client.

A variety of music therapy interventions are available to these clients. A child may choose to regain control by conducting the music therapist, sharing songs, or participating in a variety of self-selected musical games and activities. If the child is interested in creating a musical product but is anxious about performing, he/she may choose to participate in a variety of songwriting exercises. Finally, if the child or adolescent would benefit from discussing lyrics that he/she finds meaningful, lyric analysis may be an appropriate option for them. However, it should be noted that lyric analysis and songwriting activities can often bring up difficult emotions (Hilliard, 2001) and should not be considered “less threatening” exercises.

For children who elect active music engagement, a variety of improvisational and re-creative interventions are available. The therapist may consider offering re-creative interventions if he/she senses that the child would benefit from utilizing preferred, structured music in the session as a means of forming rapport or providing a familiar, grounding environment. However, improvisational methods allow the child a blank slate to project themselves onto, without the expectation of learning the rules of an instrument or replicating the predetermined components of a song. Song improvisations act as a combination of the two methods, by encouraging clients to improvise to pieces of familiar songs. Asking a child to replicate a certain sound, idea, or word on an instrument during a referential improvisation can also provide additional structure to an improvisational exercise. Figure 3 depicts several considerations a music therapist may examine when determining the most appropriate interventions to use with a child to best address his/her emotional needs.

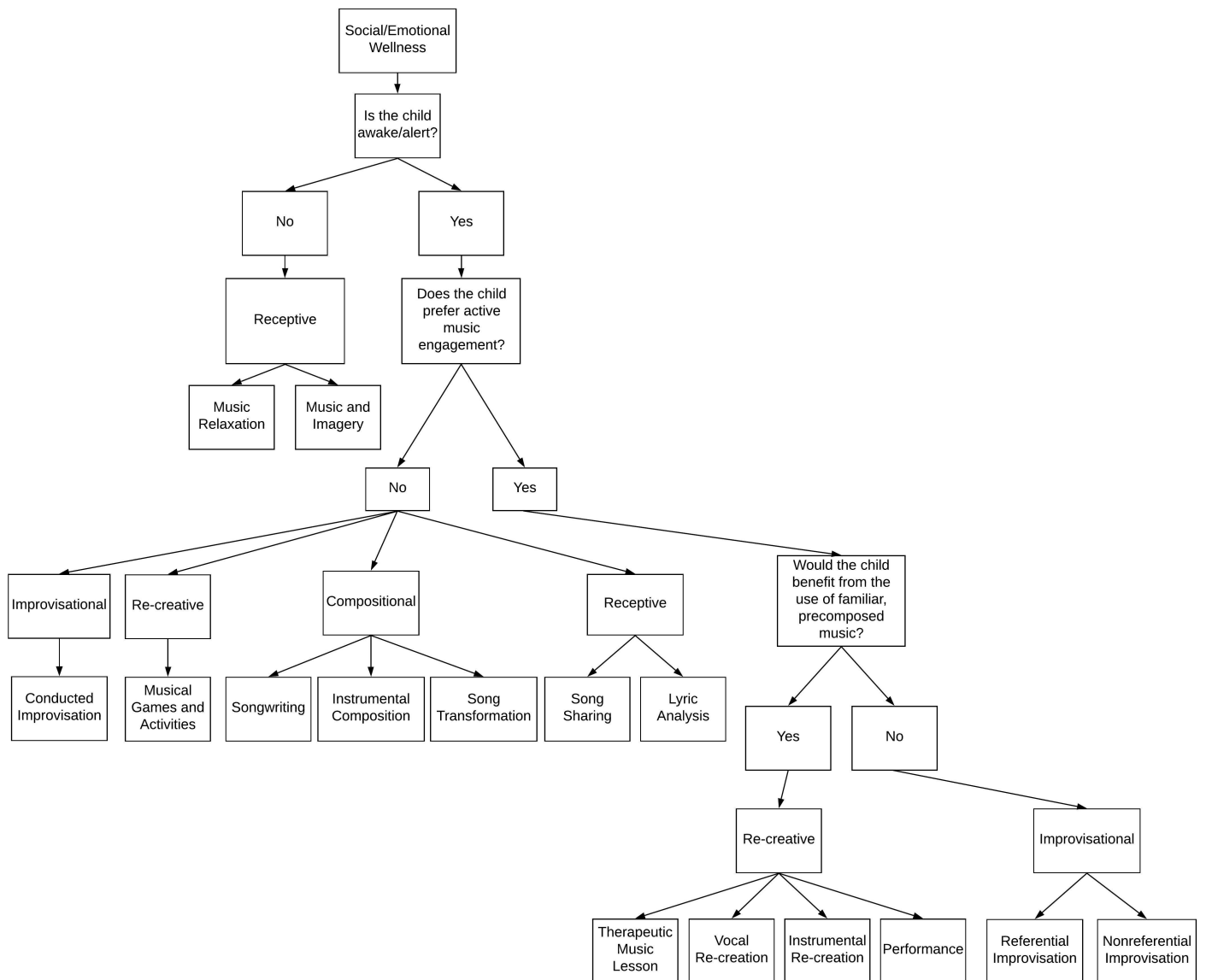


Figure 3. A decision-tree model for addressing social-emotional wellness in PPC music therapy

Caregiver support. Many of the above principles can be applied when working with caregivers in an individual, dyadic, or group setting. Parents, extended family members, and staff members may or may not be hesitant to participate in active music making during a session due to a variety of personal, cultural, and environmental factors such as group size. Therefore, a parent or guardian participating in a music therapy session may choose to participate in either active or passive music interventions to address anticipatory grief, stress, depression, and any

other social-emotional concerns that may be present in the family's life (Halpern, Fiero, & Bell, 2017).

When participating in a music therapy session with the child present, caregivers may participate in interventions that provide meaningful opportunities for family bonding and relationship completion, as depicted in Figure 4. Appropriate interventions may include song reminiscence, song dedication, and songwriting. Song transformation, a process during which the therapist and client changes the lyrics, melody, harmony, or arrangement of a song to create a new version may also be used as a more structured form of songwriting. In addition, group “musicking” can be a meaningful way for parents to create positive memories with their children (Lindenfelser, Grocke, & McFerran, 2008).

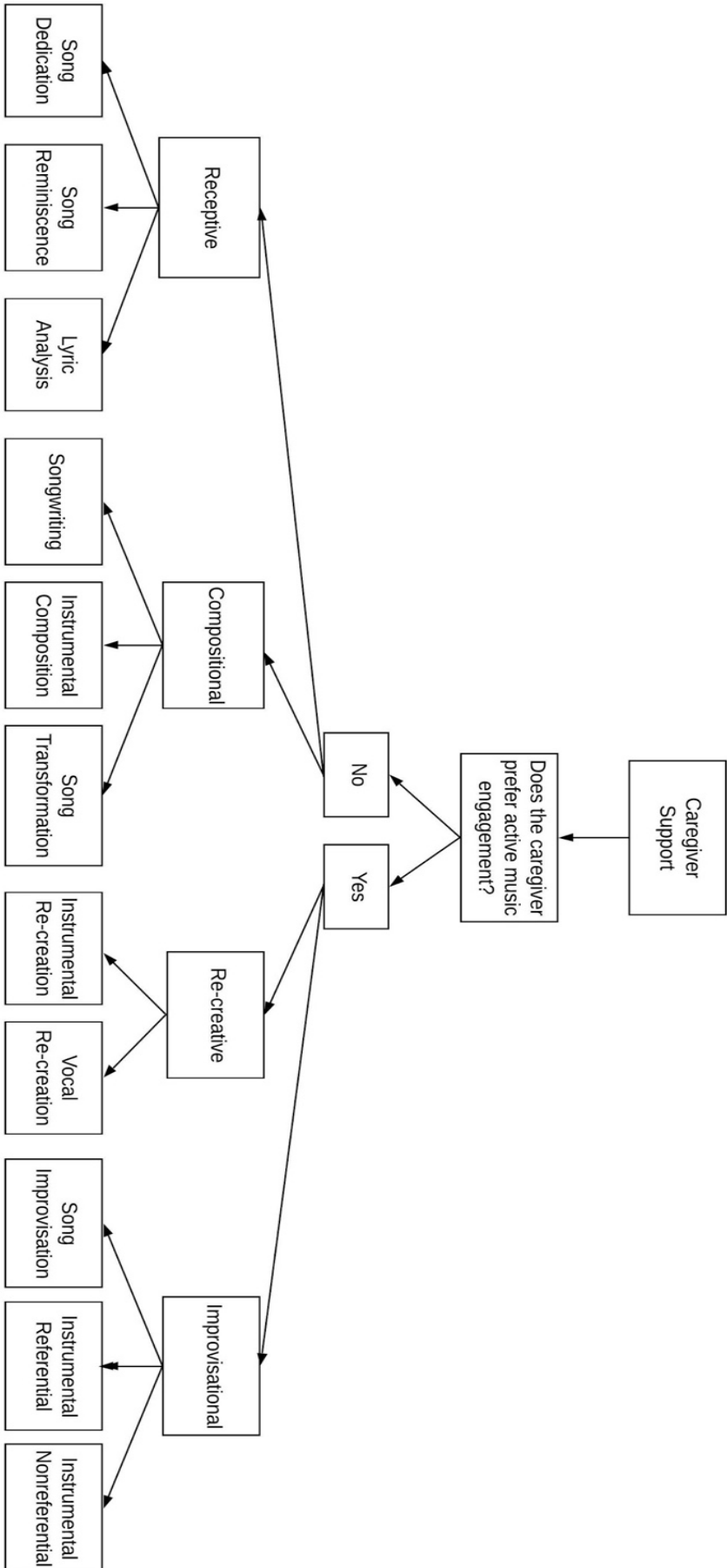


Figure 4. A decision-tree model for addressing caregiver support in PPC music therapy

Sibling support. In some ways, music therapy sessions addressing sibling support may appear similar to sessions addressing caregiver support. In fact, an adult sibling may serve the role of a caregiver at times. However, in many cases the patient's siblings are young children, and therefore some interventions used in caregiver sessions must be modified or explained in a developmentally appropriate manner to be applicable for use with children. To meet this need, musical games and activities have been included in the model to meet the developmental needs of young siblings (Bruscia, 2014).

In addition, school-aged children may present as most interested in therapeutic music lessons due to their prior knowledge of and familiarity with the music education programs in their school systems and communities. However, the therapist may consider using musical games and activities or therapeutic music lessons as a means of providing opportunities for conversation with the sibling about their relationship with their brother or sister who is sick. These supportive music interventions may act as opportunities for rapport building with the music therapist, so that siblings become comfortable in eventually engaging in legacy building exercises or bereavement work with the music therapist. Figure 5 displays the decision tree model designed for use with siblings of children receiving PPC.

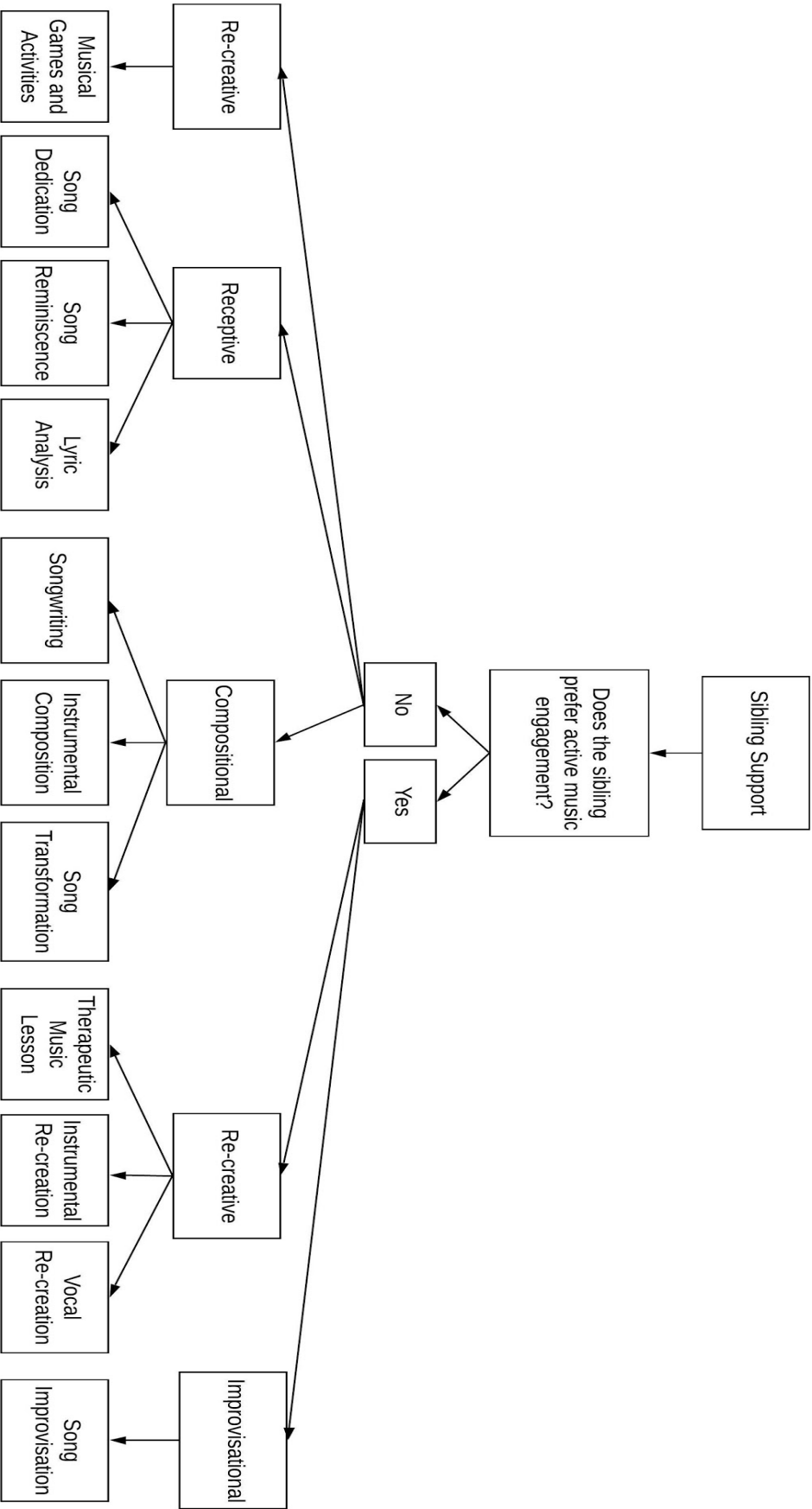


Figure 5. A decision-tree model for addressing sibling support in PPC music therapy

Rehabilitative goals. Music therapists addressing rehabilitative goals primarily, secondarily, or exclusively within this population may focus on motor, speech, or cognitive skills at any given time based on need. Recent advances in neuroimaging have allowed scientists to isolate various elements of music including rhythm, melody, and dynamics to determine their individual effects on the brain (Wan & Schlaug, 2010). These studies have informed the clinical work of music therapists working in neurorehabilitation by providing greater insight into the mechanisms of neuroplasticity and the ways that music can create new neural pathways in the brain (Schlaug, Marchina, & Norton, 2009). In addition, some music therapy techniques have been shown to be more effective than traditional interventions for neurorehabilitation (Thaut & Abiru, 2010) due to music's ability to engage many areas of the brain simultaneously. These findings encourage the implementation of cotreatments between music therapists and speech, physical, and occupational therapists.

Fine and gross motor skills. In recent years, neuroscientists have observed the body's ability to entrain muscle groups to a rhythmic, auditory stimulus (Thaut, McIntosh, & Hoemberg, 2015). Because these rhythmic stimuli are processed in the supplementary motor areas, mid-premotor cortex (PMC), and cerebellum, the body is able to entrain to the steady rhythms found in music (Chen, Penhune, & Zatorre, 2008). When working alongside physical therapists, music therapists are able to enhance gait training exercises by systematically using rhythmic auditory input to prime the brain's motor cortex. Bruscia defines this process as "eurythmic listening."

Music therapists who have completed training in neurologic music therapy (NMT) are able to facilitate an intervention known as rhythmic auditory stimulation (RAS) to assist clients in improving their gait using this entrainment mechanism (Thaut & Hoemberg, 2014). To

facilitate this intervention, the treatment team determines the client's initial stride length and gait velocity (m/s) by performing a 10-meter walk test. The music therapist then provides a metronome click or simple instrumental accompaniment played at the client's baseline walking tempo by converting the patient's gait velocity into gait cadence (steps/minute). The music therapist then increases the tempo of the live music or metronome by small intervals, as the body learns to entrain to a slightly faster beat, allowing for greater speed and stability when walking (Clair & O'Konski, 2006). This intervention has been replicated successfully with a variety of populations including children with cerebral palsy (Kwak, 2007) and adults who have experienced stroke (Cha, Kim, & Chung, 2014) and traumatic brain injury (Hurt, Rice, McIntosh, & Thaut, 1998).

For children who are not candidates for gait training, but have fine and gross motor needs, several music therapy interventions from a variety of approaches are available to the therapist, as displayed in Figure 6. The music therapist may use eurythmic or action listening interventions to target other movements. However, a variety of music performance and improvisation activities, including therapeutic music lessons, are available to the therapist to facilitate the use of affected muscle groups.

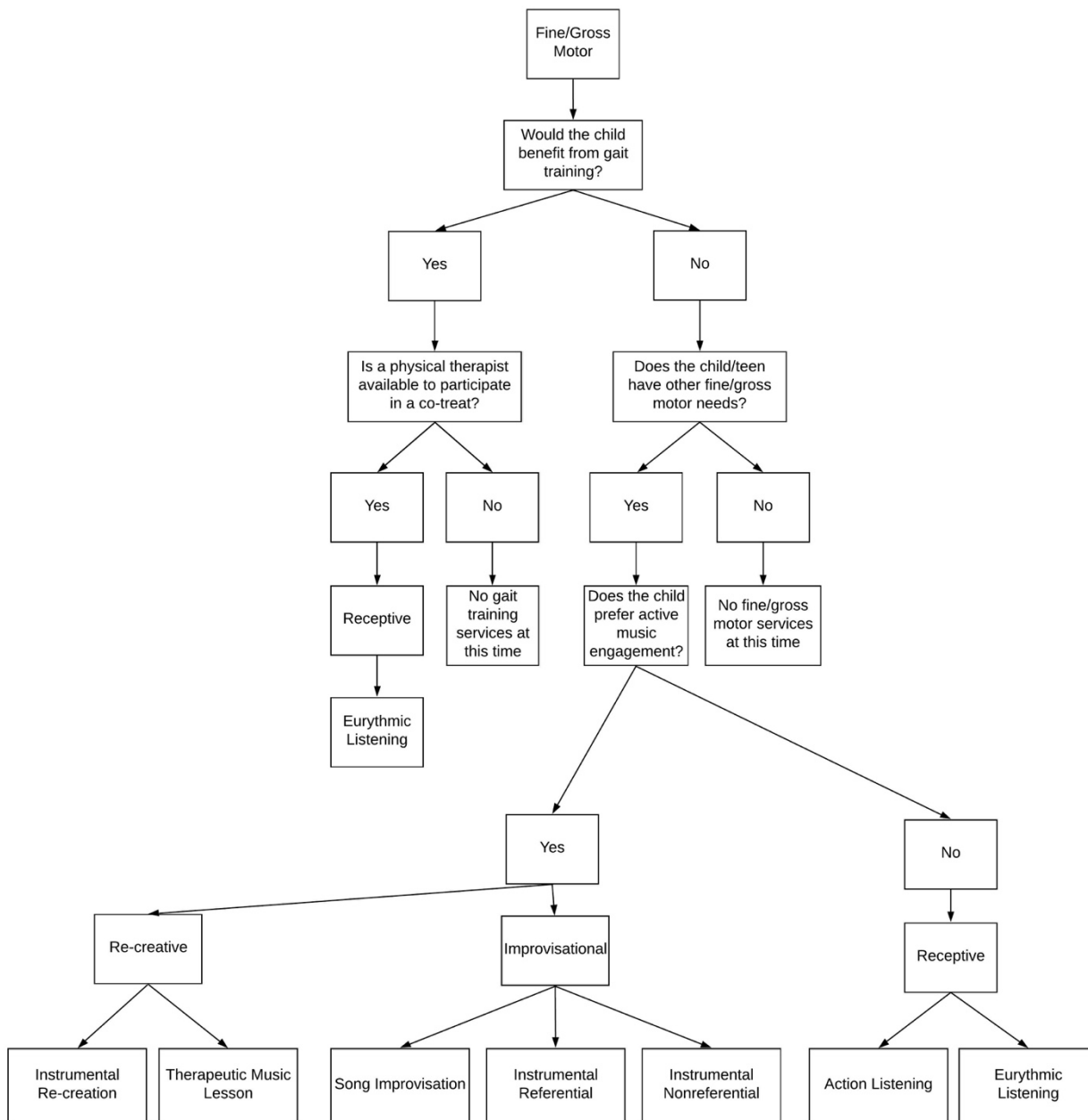


Figure 6. A decision-tree model for addressing fine and gross motor skills in PPC music therapy

Expressive communication skills. Similar neural mechanisms can be applied to the oral-motor skills used in speech production. For children who experience expressive aphasia as a result of a stroke or traumatic brain injury, singing exercises can serve to prompt spontaneous speech using the rhythmic cueing and harmonic and melodic expectations of known songs (Thaut & Hoemberg, 2014). The pairing of a musical stimulus to a spoken phrase recruits additional neural networks to perform expressive language tasks (Schlaug, Marchina, & Norton, 2009). When the client is able to successfully produce a sung phrase such as “I’m hungry” or “hello,” the therapist works with the client to practice speaking these phrases. For children and adolescents who do not produce vocalizations as a result of a brain injury, tracheostomy, or other event or diagnosis, instrumental exercises (whether improvisational or re-creative), allow children to communicate with others through a nonverbal medium. Therapists use mediational listening exercises to pair musical stimuli with visual or auditory information to enhance learning (Bruscia, 2014). A music therapist may use this technique to pair communication cards with musical stimuli for clients who rely partially or wholly on a visual means of communication.

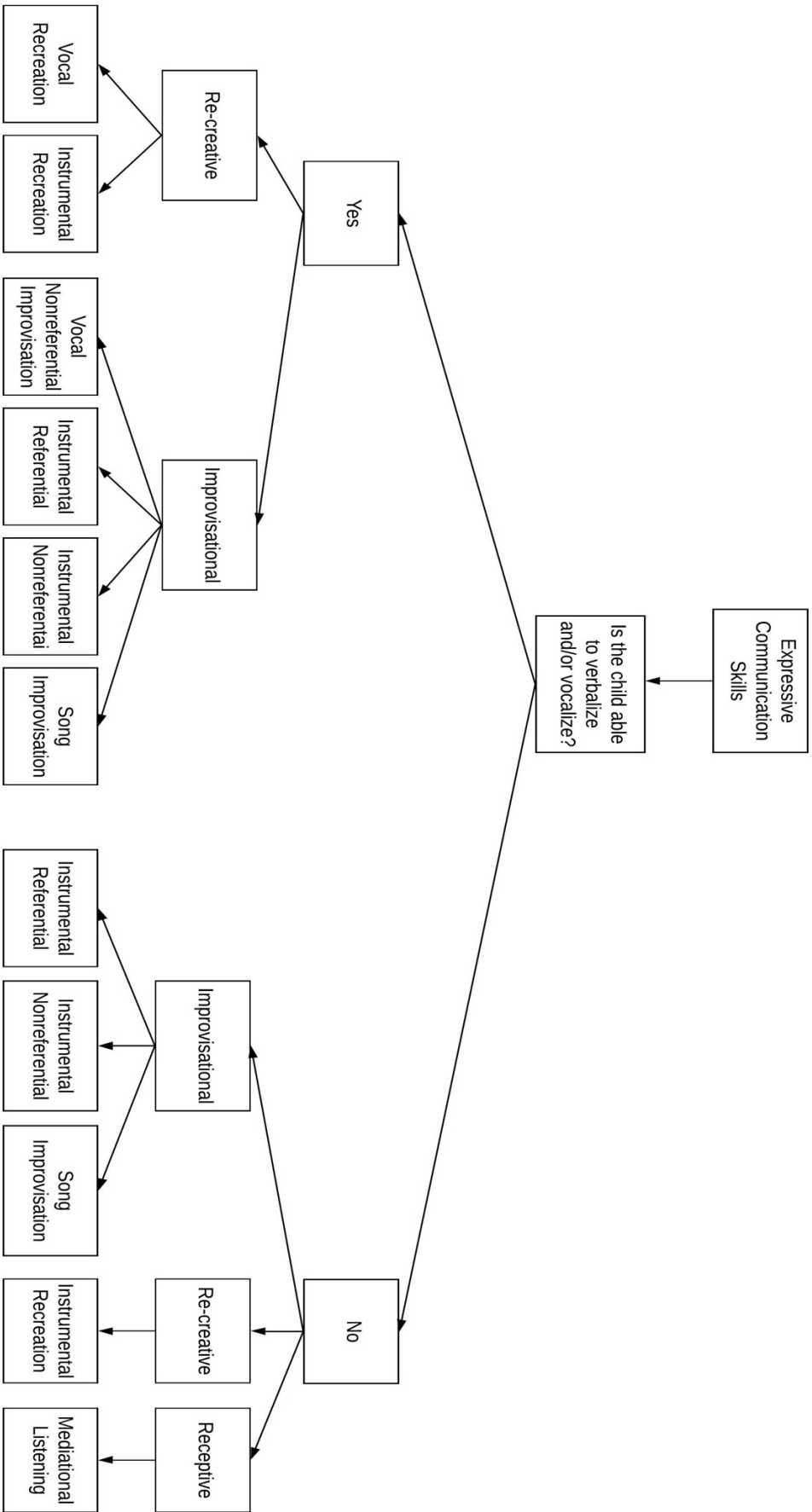


Figure 7. A decision-tree model for addressing expressive communication skills in PPC music therapy

Cognitive skills. Some children receiving PPC require therapies that target executive functioning, learning, and memory skills as a result of seizure activity, developmental delay, or acquired brain injury. For children and adolescents who have experienced memory loss, music's activation of the dopaminergic system may partially provide relief of symptoms (Peck, Girard, Russo, & Fiocco, 2015). Songs that have been "tagged" with strong emotional associations have been shown to be particularly successful in bringing back old memories due to the proximity of the amygdala and hippocampus (Samson, Dellacherie, & Patel, 2009). Song reminiscence is a broad term used for interventions that utilize the use of live or recorded, familiar music to enable memory recall. In addition, Musical Echoic Memory Training (MEMT) and Musical Mnemonics Training (MMT) are two neurologic music therapy (NMT) techniques that address sensory memory and sequencing skills respectively, and are available to certified neurologic music therapists (Gardiner & Thaut, 2014; Thaut, 2014).

Finally, by their very nature nearly all musical activities require the use of executive functioning skills. Whether learning an instrument, improvising in a group, or writing a song, a child learns to apply organizational and problem-solving skills to the activity. Many of the interventions listed in Figure 8 can be applied to social-emotional domains as well, resulting in highly motivating exercises that target more than one domain at a time.

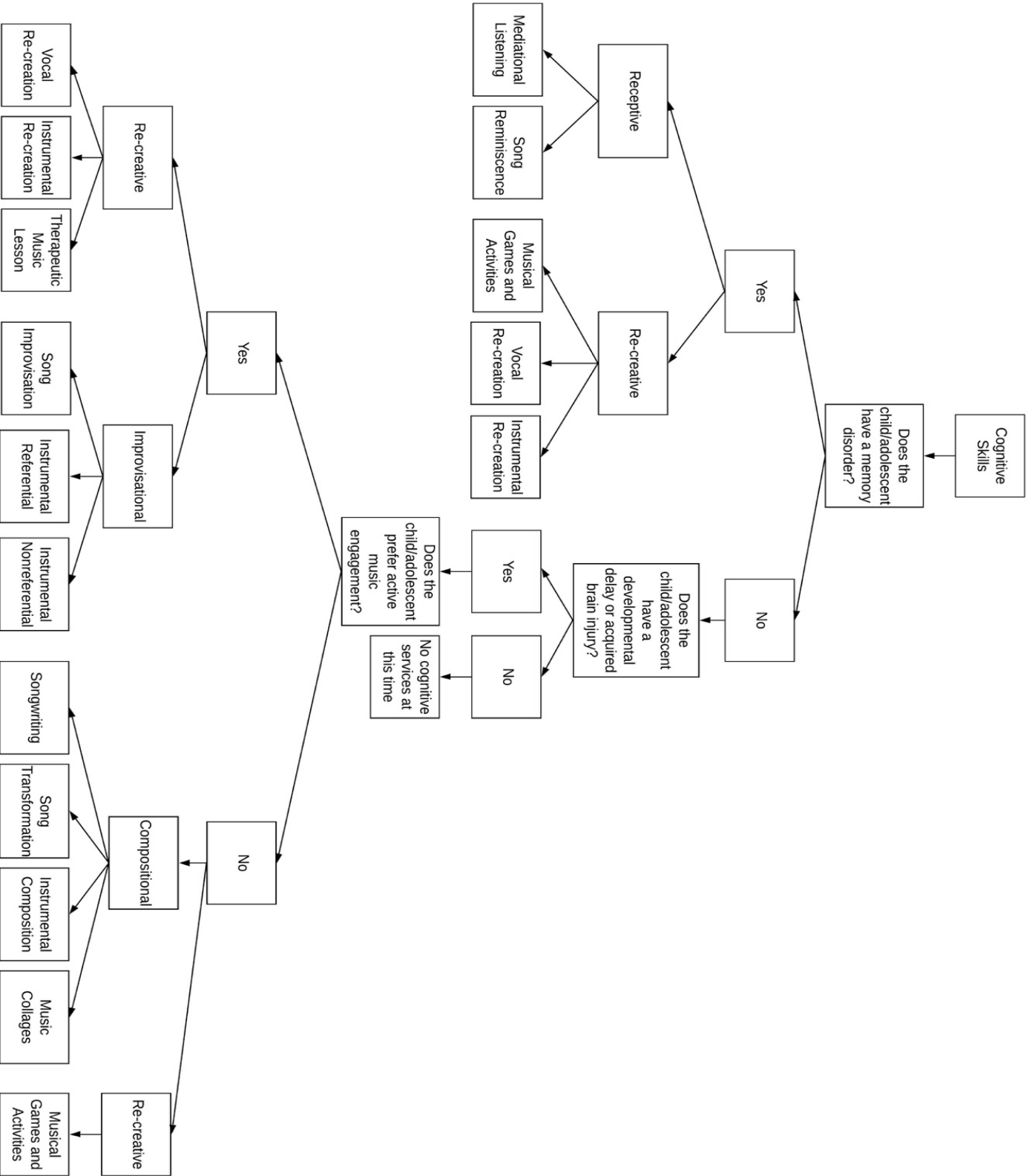


Figure 8. A decision-tree model for addressing cognitive skills in PPC music therapy

Discussion

Considerations

It should be noted that the decision trees created within this project were written in response to my own clinical setting and experiences as a clinician. Although other music therapists were consulted in the creation of this project through formal supervision as well as informal conversation with peers, the design is subjective. Other music therapists with differing theoretical orientations may utilize other applicable interventions not represented in these diagrams. In addition, music therapists working within inpatient PPC programs may approach treatment differently than community-based providers due to practical considerations such as infection control procedures, frequency of visits, and average length of treatment. Finally, the relative acuity of patients may differ between PPC programs; therefore, rehabilitative goals may be more or less relevant across settings.

Future research

As stated above, the field of PPC is relatively small due to the low incidence of serious illnesses in children. The number of research articles available that focus exclusively on pediatric hospice and palliative care are limited due to these variables as well as the larger social taboo of pediatric death. In addition, the majority of PPC programs were founded within the last 10 years. However, the field continues to grow. Music therapists living in the United Kingdom, Canada, United States, and Australia have documented case studies, surveyed parents, and performed quantitative research on the efficacy of specific music therapy interventions within the pediatric medical setting. Additional large scale, multi-site, mixed methods research will serve to protect and/or increase funding sources for PPC programs as well as their integrative therapy departments.

Conclusion

In conclusion, the diverse field of PPC calls for the integration of a variety of music therapy orientations, methods, and interventions. Because it is recommended that PPC be implemented at the time of diagnosis for a child with a serious illness, children can potentially be eligible for these programs for up to 22 years before aging out (Mack & Wolfe, 2006). Therefore, rehabilitative goals may be important to some families early in the disease process due to the meaningful opportunity for children to progress and gain independence. On the other hand, the stigma of the terms “hospice” and “palliative” care continues to create late referrals to these services (Dalal et al., 2011). Music therapists working in settings primarily with children who are nearing EOL play an important role in increasing quality of life, addressing anticipatory grief, and facilitating relationship completion within these families. Further research will continue to measure quantifiable outcomes of the implementation of music therapy interventions within PPC.

Glossary of Terms

Action Listening- “the use of song lyrics or musical cues to elicit specific behavioral responses (e.g. motor movements, daily living activities, verbal responses)” (Bruscia, 2014, p. 108)

Conducted improvisation- a music therapy experience in which the client conducts one or more improvisers using gestures or verbal/instrumental cues

Eurhythmic listening- “the use of music to rhythmically and monitor the client’s motor behaviors, including speech, breathing, fine and gross motor sequences, body exercises, and formalized dance steps...the method is different from *action listening* in that the rhythm of music is used to organize the motor behavior rather than to cue or direct which motor behavior is to be performed” (Bruscia, 2014, p. 107)

Instrumental re-creation- any music therapy intervention in which the client plays an instrument with the intention of recreating precomposed songs or learning the rudiments of an instrument

Legacy recording- any audio or audiovisual recording made during a music therapy session with the intention of preserving the client’s musical offerings; often used as a tool for anticipatory grief

Lyric analysis- a process in which the music therapist facilitates thoughtful reflection on the lyrics of a presented song

Mediational listening- “the use of music as a mediational strategy in learning and recalling information; music is paired to various types of information or to a particular experience in order to make it more concrete, memorable and retrievable” (Bruscia, 2014, p. 108)

Musical echoic memory training (MEM)- a neurologic music therapy technique that “uses the immediate recall of musical sounds presented by singing, instrumental playing, or recorded music to retrain echoic memory” (Thaut, 2014, p. 311)

Musical games and activities- “the client participates in musical games (e.g., name that tune, musical charades, musical chairs, etc.) or ... any activity that is structured by music” (Bruscia, 2014, p. 105); used in pediatric medical settings to meet the developmental needs of children and adolescents

Musical life review- a music therapy intervention in which the client selects meaningful songs to represent various stages in his/her life

Musical mnemonics training (MMT)- a neurologic music therapy technique in which music is used as a “mnemonic device to sequence and organize information and add meaning, pleasure, emotion, and motivation in order to enhance the person’s ability to learn and recall the information involved” (Thaut, 2005, p. 196)

Music and imagery- the combined use of environmental music and guided imagery to promote relaxation

Music collage- “the client selects and sequences sounds, songs, music, and fragments, thereof in order to produce a recording that explores autobiographical or therapeutic issues” (Brusica, 2014, p. 106)

Musicking- “to take part, in any capacity, in a musical performance, whether by performing, by listening, by rehearsing or practicing, by providing material for performance (what is called composing), or by dancing” (Small, 1998)

Music relaxation- any intervention in which receptive, environmental music is provided to induce a state of relaxation

Neurologic music therapy (NMT)- a set of 20 standardized clinical interventions developed by Michael Thaut to address cognitive, speech-language, and sensorimotor rehabilitation

Nonreferential improvisation- a form of “free” improvisation in which the client improvises “without reference to anything other than the sounds or music” (Bruscia, 2014, p. 104)

Referential improvisation- the use of improvised music to portray a nonmusical sound or theme

Song dedication- an intervention in which a client or loved one dedicates a song to the other using re-creative, compositional, improvisational, or receptive methods

Song improvisation- the use of a precomposed song as the structure for an instrumental, vocal, mixed media, or body improvisation

Song reminiscence- the use of familiar songs to facilitate memory recall

Song sharing- the use of client-selected songs to facilitate self-expression and communication with the therapist or other group members

Song transformation- an intervention in which the client manipulates the tempo, harmony, instrumentation, or lyrical content of a precomposed song

Stimulative listening- “the use of music listening to stimulate the senses, to bring alertness, to establish reality orientation or contact with the environment, to increase energy level, to elicit sensorimotor activity, to increase sensory perceptions, or to elevate mood” (Bruscia, 2014, p. 107)

Therapeutic music lesson- a music lesson provided with the intention of addressing cognitive, social-emotional, or fine/gross motor skills

Vocal re-creation- singing precomposed music

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