



National Hospice and Palliative Care Organization
Palliative Care Resource Series

**SONGS OF THE DYING: THE CASE
FOR MUSIC THERAPY IN PEDIATRIC
PALLIATIVE AND HOSPICE CARE**

Yelena Zatulovsky, LCAT, MA, MT-BC, CCLS, HPMT

D: A PEDIATRIC PATIENT

We entered the home in the late afternoon. Mom had called us earlier in the day and said that something was different and that D was in pain. Unlike previous calls, she didn't elaborate or offer specifics. In many ways, the team felt we had helped to fulfill all the wishes that D had shared with us and her family. We helped her bridge the communication gap so that D's voice wasn't silenced. We helped make memories and facilitated the family's reunion.

D and I had instantaneous rapport over a love of laughter, fried chicken, and silly songs. It had been 5 months since her admission and although she was trying to hold out for Christmas, when the Social Worker and I entered that day, we knew that wasn't likely.

In a home that was often filled with giggles and music, there was an uncomfortable silence, a palpable pain. Many friends and family were gathered, filling every nook in the small room. Mom was lying next to D in bed, trembling. Dad was sitting silent and still under the window. Upon hearing our voices, D opened her eyes and connected with ours. Her fear and sadness penetrated us. Many clinicians would see this as a blurring of boundaries, but how do you not love your pediatric patients. How do you not become attached to a 4-year old for whom life will end within hours or days.

I maneuvered my way to the bed, placed my hand on her foot (her favorite "tickly" spot) and watched her affect ease and her shoulders lower. My other hand found its way into her mother's, and I began to hum. *Baby Mine* came naturally, a lullaby her mother had heard in passing and asked for during one of our sessions –

*...From your head down to your toes
You're not much, goodness knows
But you're so precious to me
Sweet as can be, baby of mine...*

The Nurse arrived and instinctively joined me in humming, a familiar experience with our very tight-knit team. In many ways that humming held the room, it provided a soundtrack to the pain and the beauty. We wrapped our metaphorical arms around D and felt the power of the music.

As a Board-Certified Music Therapist (MT-BC), I was able to entrain to her respirations, matching the rhythm and cadence; and when mom or D presented with anxiety, the iso-principle offered an intervention to modify those breath patterns and restless somatic presentations back into relaxation and comfort. We never ceased the music, chaining from one melodic motif to the next, the music was the container that was grounding in the moment. After nearly two decades as a therapist at the bedside, I recognized our time was limited and so I made the clinical decision to sing...to sing the pieces that framed D's musical biography...a surprisingly large number for a 4-year old.

As our team made eye contact with the various family members, friends, and their community, they joined in fulfilling D's last wish: the wish to be surrounded by her songs when she "became an angel." Recognizing the sacredness of the moment, the music could serve another purpose.

We know that in most scenarios hearing is both our first and last sense, bookending the cycle of life. So we reminded those present that D could still hear us. I asked each individual, “What would you want her to know? To remember of your bond? To hear at this time?” As they offered their blessings and words, I reflected them through her favorite songs, including the ones we had composed together. Through this, they expressed their gratitude, they bid her goodbye, and echoed “I love you.”

UNDERSTANDING MUSIC THERAPY

What is it about music that makes it such a powerful tool? What was it for D and her family that turned a traumatic event into a beautiful memory? It begins with that physiologic truth that we reiterated to the family – hearing is our first and last sense, so intrinsically our experience of sound is universal. Because hearing develops in the womb, the sensation of hearing is also often aligned with a somatic presence – our mother’s heartbeat, our own, the rhythm of our breath, of our walk...even the sounds in nature have a timbre, cadence, and pitch.

Imagine the call of a particular bird, cicadas in the night, or the sound of ocean waves as examples. Music goes beyond the physical, the gate control theory equates music as a stimulus as powerful as pain, and thus when used clinically it can decrease or alleviate that experience. The neurologic implications are extensive as well, so much so that Oliver Sacks devoted his career to its study alongside Dr. Connie Tomaino, a music therapist and his colleague for decades.

DEFINING MUSIC THERAPY

The American Music Therapy Association defines Music Therapy as “the clinical and evidence-based use of music interventions to accomplish individualized goals within a therapeutic relationship by a credentialed professional who has completed an approved music therapy program.

Music Therapy is an established health profession in which music is used within a therapeutic relationship to address physical, emotional, cognitive, and social needs of individuals. After assessing the strengths and needs of each client, the qualified music therapist provides the indicated treatment including creating, singing, moving to, and/or listening to music. Through musical involvement in the therapeutic context, clients' abilities are strengthened and transferred to other areas of their lives.

Music therapy also provides avenues for communication that can be helpful to those who find it difficult to express themselves in words. Research in music therapy supports its effectiveness in many areas such as: overall physical rehabilitation and facilitating movement, increasing people's motivation to become engaged in their treatment, providing emotional support for clients and their families, and providing an outlet for expression of feelings.”

MUSIC THERAPY IN ACTION

When I sit at the bedside with patients and families alike, every decision I make can be supported from a physiologic, cognitive, emotional, spiritual, or psychosocial perspective:

- When Mr. S, an 87-year old Baptist with a diagnosis of Lewy Body Dementia becomes agitated and is only redirected by a discussion of his beliefs about Heaven, I'm more likely to choose *Sweet By and By* for its lyrical and faith affiliation rather than another random Baptist hymn.
- And when P, a 32-year old mother of two is struggling to say "I love you" to her children, resulting from the brain tumor that has caused Wernicke's aphasia, I might choose the *Barney Song* (she has a 3-year old) or Irving Berlin's *Always* (which her grandmother used to sing to her) because the structure and simplicity of the music will motivate bridging the two hemispheres (where speech and music reside) so that creating a purposeful pause in the music will give P voice. In essence, we used a fill-in song which can be manipulated by the Board-Certified Music Therapists' behavioral, neurologic, psychotherapeutic and expressive training.
- Or when K, a 12-year old whose family is not only afraid but also resistant to telling her she is dying (and we know she's aware), I would take an indirect approach and ask her which pieces of music she is most drawn to now, then provide a lyric analysis to the parents to demonstrate that she knows and is too afraid/sad/worried to disclose her knowledge to them. It's Akon and Michael Jackson's *Hold My Hand*, by the way, which was released after his death so there are many layers that can be approached through this piece with great efficacy.
- Or when J, my 60-year old patient is fearful of his death (compounded by guilt) because he watched his mother's suffering in the last months of her life and felt helpless, I'd broach cautiously with *Amor Eterno* (they are from Mexico) to explore and provide an outlet for his grief first (he was diagnosed only months after her death).
- And when A, a 59-year old deaf woman yearns for connection because of the language barrier, starts to decline and can no longer sit in the common areas with other residents or members of the team, I place the guitar upon the various parts of her body she'd like "warmed" or use a balloon against her cheek or heart to exploit the vibrations as a replacement to the hearing she cannot receive.

Just spend five minutes with a music therapist and they'll impart innumerable stories about the privilege in bearing witness at the bedside with patients and families like D's.

Mom was the last to speak but could not express herself verbally, so our team led with *Silent Night*, knowing that we'd have to make Christmas for them in that moment. We left the room in peace, quiet, and calm, when it seemed appropriate to do so. At five in the morning I received the call. It was mom, she repeated almost chant-like –

*Silent Night, Holy Night
All is calm, all is bright.
'Round yon virgin mother and child,
Holy infant so tender and mild;
Sleep in Heavenly peace, sleep in Heavenly peace*

"I couldn't stop singing because it calmed me...and she took her last breath 'in Heavenly peace, in Heavenly peace.'"

** Dedicated to the patients and families I have been honored to serve and journey with. **

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Themes of Songs Listed Above:

- *Baby Mine* – originally from Disney’s *Dumbo* and reflects on the challenges that a unique child may face but the love that is still felt strongly by the mother.
- *Silent Night* – traditional Christmas carol.
- *Sweet By and By* – traditional Christian hymn, often part of the Baptist liturgy. Lyrics focus upon visual imagery related to the idea of Heaven. The text further alludes to the belief of reunion in the “sweet by and by.”
- *The Barney Theme Song (I Love You, You Love Me)* – from the children’s television series and reflects the bond between families and friends.
- *Always* – composed by Irving Berlin in 1925 for his wife. Lyrics address the promise of presence through all of the cycles and experiences in life, good and challenging.
- *Hold My Hand* – Duet between Michael Jackson and Akon released posthumously in 2010. Refrain emphasizes the need for presence and support. One of the verses specifically focuses on the finality of death and transience of life, and notes a feeling of darkness if one feels alone or isolated.
- *Amor Eterno* – written by Juan Gabriel after the death of his mother, the lyrics are both an homage to her and an expression of his grief, including reflection of the suffering throughout her life and in her death.