Alternative and complementary therapies

Music therapy in hospice care

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Introduction

Music therapy, a highly effective treatment modality with terminally ill patients and their loved ones, is unfortunately absent from many hospice and palliative care programs.

This article describes the music therapy program at the Jacob Perlow Hospice at Beth Israel Medical Center in New York City. It defines music therapy, procedures for referral and initial assessment, and techniques for implementation. Brief case studies poignantly illustrate how the multi-dimensional nature of music resonates well with the complex needs of the terminally ill. It further demonstrates the integral part that music therapy plays on a hospice interdisciplinary team.

Music communicates, motivates, soothes, calms or enlivens, alleviates pain and anxiety, lifts the spirit. Music is a holistic medium, basic to our existence; our own bodies are made up of rhythmic systems. Music nurtures us with its beauty; it feeds the soul; it "soothes the savage breast" (William Congreve). It is

Rima Joy Starr, MA, CMT, Certified Music Therapist, Jacob Perlow Hospice/Beth Israel Medical Center, New York, New York. called the universal language. "When words fail, music speaks" (Hans Christian Anderson).

Music for healing is nothing new. In biblical history, when the anxiety-ridden monarch, King Saul, was lulled to sleep by the melodious strains of the shepherd boy David's harp, that was music therapy.

Today, music therapy is practiced by a registered music therapist with a college degree in music therapy. The course work includes physiology, sociology, anatomy, acoustics, music methods (learning to play one of each family of orchestral instruments), psychology, and psychotherapeutic techniques including Gestalt, behavior modification, and psychoanalysis. The student must also be in personal psychotherapy.

Music therapy is now used in schools, prisons, hospitals, even in the operating room during some surgical procedures. It is used on the obstetrics unit during childbirth and on the hospice unit during deaths—at the beginning and at the end of life. It is interesting to note that, at Beth Israel Medical Center in New York City, the two units are across the hall from each other.

Music therapy is the skilled use of music by a certified music therapist to

meet the physical, psychological, spiritual, and social needs of patients and their families. An integral component of hospice care since our country's first hospice in the 1970s, music therapy is sorely missing from far too many hospice programs. Still considered a luxury due to lack of insurance reimbursement, it is unfortunate that this highly effective treatment modality is omitted due to lack of funds.

This paper will describe the music therapy program at Jacob Perlow Hospice/Beth Israel Medical Center in New York City—goals, techniques of implementation, and results—documenting the need and offering the framework for more such programs as part of hospice's interdisciplinary team of caregivers.

Program description and goals

Jacob Perlow Hospice/Beth Israel Medical Center has an average census of 90 terminally ill patients with a prognosis of six months or less; ages range from infancy to over 100 years. The focus is on comfort and quality of life for the patients and their families.²

We operate as an interdisciplinary team, including physicians, nurses, social workers, pastoral counselors, a music therapist, volunteers, and other contracted practitioners and therapists. Some patients come to our inpatient unit for particular medical procedures, family respite, or when the preference is not to die at home. Hospice services are usually covered by the patient's insurance plan.

When a patient is referred to hospice, a nurse and social worker visit the patient's home for the assessment and intake procedure, informing them of our various services. The nurse or social worker refers some patients to music therapy based on patient interest or designated referral criteria, such as dementia, depression, acute anxiety, agitation, pain, isolation, and difficulty in communication or self-expression. The music therapist will then telephone the patient's home to schedule their initial session.

During that first session a full assessment is done (patient's music history, preferences, abilities, associations, sense of rhythm and tonality), thereby determining the course of treatment.

The entire hospice team meets bimonthly to update and discuss the care plan for each patient, thus ensuring a unified team approach.

The goals of the program are to:

- facilitate life review;
- provide a bonding experience for patient and family;
- aid in pain control;
- reduce stress and provide relaxation;
- provide a pleasant diversion;
- enhance family coping skills;
- provide a means of communication or self-expression;
- provide mastery activities;

- strengthen spiritual or religious beliefs:
- allow the family to mourn a whole person, restoring their past image of the patient.

Program implementation

Program implementation techniques are illustrated within the following three case studies.

Tzibie

Tzibie was a 76-year-old Jewish woman with a dual diagnosis of ovarian cancer and end-stage Alzheimer's disease. She was incontinent and immobile; with fewer than 10 words left, she was quite limited in her ability to communicate. She often stared straight ahead, babbling in a monosyllabic discourse.

The music therapy sessions were attended by three generations of women: Tzibie, her elementary schoolteacher daughter, and her college student granddaughter. Tzibie had always loved music. She had no formal training in it, but grew up in a musical family, attended many concerts, and loved to sing. Using only one syllable (usually mah), Tzibie could still complete almost every song she heard, from folk songs to complex Gilbert and Sullivan arias. She appeared quite pleased with herself, posturing as if modestly accepting the applause from her audience. Singing became her means of communicating; she expressed a full range of emotions as she related to others through song.

During their first music therapy session, Tzibie's family expressed grief and frustration over feeling ineffectual as caregivers. They greatly loved their family matriarch, whom they had watched deteriorate from Alzheimer's disease over the last 10 years, feeling powerless to offer anything that impacted her in a positive

way. One music therapy intervention was a well-timed directive to Tzibie's daughter: "Think of a song you've sung together during a Sabbath dinner or Jewish holiday. Start us off and we'll all join in." Tzibie joined quickly, recognizing each song immediately, singing and making eye contact with her daughter as she reached out for her hand. Her granddaughter played along on the piano.

The songs elicited life review, evoking vivid memories of the religious rituals that were often a major part of their family events. Rhythm instruments were also used to enhance their musical expression. Tzibie burst into primitive-sounding laughter, as she threw her head back with a joyous expression on her face. She moved her whole body to the beat of the music, dancing in her chair.

Research has shown the music center of the brain to be the most primitive and the last to deteriorate.³ Hence, Tzibie maintained excellent recall of her extraordinary vocal repertoire.

Tzibie's sessions were videotaped and later presented to her family as a legacy. Tzibie died a few weeks later from the cancer. The family had two bereavement sessions, during which time they viewed the tape and processed their many mixed emotions. They expressed their gratitude for having been shown a new way to communicate with Tzibie—a new "tool," something they did for and with Tzibie that was based on her strengths. not on her illness. The last session was a time for support and closure; a time for hugs, tears; and a time to process one more good-bye.

Juan

Juan, a 13-year-old cancer patient, had fallen into a coma. His hospice nurse felt that music therapy might be of some help to the patient and his family.

During his only music therapy session. Juan exhibited no observable

response to a variety of interventions: the singing and playing of familiar songs and hymns close to his face and body, rhythmic, and melodic improvisation; the placing of vibrating instruments of different timbres and tonal registers against his skin. Juan's mother, therefore, became the focus of the session. Her favorite Spanish hymns were played, sung, and discussed, thereby enhancing her religious connection, which she said was her chief coping mechanism. This provided an emotional outlet for her grief, allowing for a catharsis during the session. It also served to support her in her role as caregiver.

As the session ended and goodbyes were being said, the patient was asked if he enjoyed the music. "Yes, very much," he answered. His mother rushed to his side and took his hand. As nurses heard the news of Juan's response, they rushed into his room from other areas of the hospital floor. Their shock and exhilaration seemed almost electrifying.

"Squeeze my hand if you hear me," said Juan's mother, as she kissed him on his cheek. Juan died the next day with his family and loved ones at his bedside.

It is believed that a patient in a coma can still hear; Juan's response further validates the use of music therapy as an appropriate part of his plan of care.

Jenny

Jenny lay in a fetal position on her bed, her face grimacing in pain. A good friend gently massaged her back. The friend's daughter sat next to her, looking frightened.

This was Jenny's second music therapy session, having been referred by her hospice nurse for pain. Jenny was a 40-year-old Freudian psychoanalyst with advanced lung cancer. It appeared that she did not have too much longer to live. As the session began, Jenny was asked what we might do to ease her pain (she had already taken her pain medication). Through her tightly clenched teeth, as if trying to fight the pain, Jenny said, "Let's sing." She hardly seemed able to breathe, much less sing.

"Tell Me Why" was the name of the song Jenny chose; she assigned each of us one solo verse as she sang the harmony; the keyboard was the accompaniment. This evoked Jenny's fond memories of summer camp, which led to processing the song's message. In the first verse, the song asks "why"; in the last verse, it states that there are no answers, only that "God made it so."

The song became the catalyst for Jenny's friend's expression of love. "...Because God made you, that's why I love you."

As the session progressed, Jenny's face relaxed; she lay on her back, her head propped up with pillows. Choosing and orchestrating the songs provided an empowering activity, enhancing her sense of mastery and control. The precise use of tempi and rhythm were the vital interventions used both to mirror and to enhance Jenny's greatly improved state of mind.

"Down by the Riverside" was sung next, with Jenny sitting up in bed, hitting the tambourine. Her friend sang, "I'm gonna lay down twenty-five pounds..." Everyone laughed, including Jenny.

Research has shown that music decreases pain perception by reducing muscular tension, lessening feelings of helplessness, and evoking emotions, which can trigger the release of hormones and endorphins, the body's natural opiates. Also, listening occupies some of the neurologic pathways of brain neurotransmitters, resulting in fewer being available for sending pain messages.⁴

Nine of Jenny's friends encircled her bed during her final hours. She asked them to sing to her. "We all love you, Jenny...Oh Lord, *Kumbaya*." (*Kumbaya* is Swahili for "come by here.")

The Freudian Society of New York City held a memorial service in Jenny's honor. More than 100 psychoanalysts joined in remembering Jenny, as they sang her favorite camp songs.

Clinical implications

Music speaks to us in ways that the heart and soul understand. It works its wonders when all else fails. "It seems to reach a different level—a different depth within the brain and the emotions. Frequently, the nonresponsive respond, the belligerent cooperate, the guarded open up and the hopeless find renewed meaning." 5

"When communication between the Alzheimer's patient and the outside world have been virtually cut off, music therapy can re-open doors to memories, laughter, and feelings of being connected."

Tzibie was isolated, cut off from those she loved, until music therapy offered a new way for her to communicate. The language of music restored their family bond. It reconnected the family to Tzibie's premorbid self, enhancing their memories, so that they could mourn the whole person they once knew. Their coping skills were greatly enhanced as they felt effective in their caregiver roles. Most important was the improvement in the quality of Tzibie's life, her experience of great joy as she creatively participated in musical self-expression, even as she neared death.

"The profound meaning of music and its essential aim is to promote a communion, a union of man with his fellow man and with the Supreme Being." It remains a mystery how and why music pierced through the depths of Juan's coma (only one of many such examples), reaching into the silence to bring him back for one more kiss before his final passage. This, of course, served to reinforce Juan's

mother's main coping mechanism, her religion, giving her the strength to survive the loss of her only son.

"Music transforms me," said Jenny, in the midst of tremendous physical pain. Her pain became more manageable as her attention was diverted by the songs she chose, empowering her with an enhanced sense of mastery, so important in a cancer patient who has lost power to control most things in her environment, including and especially her own body. The associated memories, and the emotions they evoked, led to her body's release of its own natural opiates, further reducing Jenny's pain.

Music enters the medical environment in a nonthreatening way, like a friend, like a soothing balm, like play, like a pleasant surprise, like joy. It breaks through the technical environment and makes it more humane.

Music has the capacity to draw people in a household together, spanning generations, and often helping to heal hurts that have existed between family members for years. The following is from a recent letter from a patient's daughter, right after her mother's death:

Yesterday you came upon a "family" which had never really been a family. Hurts, pain, disappointments, misunderstandings, trauma, years of silence among them had left a fragmented group. Yesterday was the first time I had seen my sister and my

niece in many years. Through your gift, for the first time in my life I felt I had a family: I had a mother and a sister and a niece. Your intuitiveness, compassion and talent were the catalyst and the glue that will go a long way to mend many battered spirits. God bless you in your continued important and good works.

Conclusions

Music is as common and accessible as the air we breathe; all of us need to take advantage of its powers. One need not be a musician or a highly specialized music therapist to use music in a nurturing way. Singing to a patient is an intimate, caring gift, generally well-accepted, with never a comment on the not-so-perfect quality of the singing. We often present lectures, workshops, and training seminars throughout this country and abroad, encouraging health care workers to use music in their daily caregiving.

These poignant, often dramatic and profound, responses of our patients and their loved ones are "matters of the heart." Even the act of writing about them can seem to lessen them; sometimes it seems as if there just are not the right words to capture the uniquely special, nonverbal musical moment of healing. Therefore, too often, we do not like to be involved in the area of research. However, it is only through documenting empirical data, proving the need for this therapeutic modality,

that proper funding will be allocated from insurance companies and others in the health care system.

There is a special healing which occurs in both the caregiver and the patient. "Through musical interaction, two people create forms that are greater than the sum of their parts."

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