Music therapy with imminently dying hospice patients and their families: Facilitating release near the time of death

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Abstract

Hospice care seeks to address the diverse needs of terminally ill patients in a number of physical, psychosocial, and spiritual areas. Family members of the patient often are included in the care and services provided by the hospice team, and hospice clinicians face a special challenge when working with families of patients who are imminently dying. When loved ones are anticipating the patient's impending death, they may find it difficult to express feelings, thoughts, and last wishes. Music therapy is a service modality that can help to facilitate such communication between the family and the patient who is actively dying, while also providing a comforting presence. Music therapy as a way to ease communication and sharing between dying patients and their loved ones is discussed in this article. The ways in which music therapy can facilitate a means of release for both patients and family members in an acute care unit of a large US hospice organization are specifically described. Case descriptions illustrate how music therapy functioned to allow five patients and their families to both come together and let go near the time of death. Elements to consider when providing such services to imminently dying patients and their families are discussed.

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Background

Music therapy is a complementary treatment modality which increasingly is being recognized as an important adjunct service within hospice and palliative care organizations.[1-8] A number of patient and family needs can be addressed simultaneously through music therapy as a creative holistic service within hospice care.[9] When these needs are addressed, the patient and family can express and share feelings, as well as continue to communicate and interact in a meaningful manner, even as the patient declines and ultimately dies.[10-13]

A critical and often difficult period for families and loved ones is the time immediately before the patient's death. Although patients receiving hospice care have a life expectancy of six months or less, should a disease process follow its anticipated course, determining exactly when a patient will die is impossible for doctors and other hospice care team members.[14] However, terms such as "imminent death," "approaching death," "impending death," and "actively dying" are used to describe patients whose vital signs are rapidly declining towards expiration.[15-20] Some signs and symptoms of approaching death include a cooling of the extremities, coloring or mottling of the skin, slow and/or irregular breathing, an increase in sleeping, a buildup of fluids and secretions in the lungs and throat, apparent confusion, and restlessness and agitation.[5] Various rating scales may be used to describe the patient's status as he or she declines toward death. The Karnofsky Performance Scale, which is used at the Hospice of Palm Beach County in West Palm Beach, Florida, rates a patient whose fatal processes are rapidly progressing as being moribund, with a score of 10 out of a possible 100. A score of zero indicates that the patient has died.[21]

When imminent or impending death is noted in a patient's care plan, family members are often informed

that they may wish to plan their last visits with the patient as soon as possible. During this last period of the patient's life, family members often are faced with the challenge of expressing their feelings without the patient being able to overtly communicate in response to them. Family members may feel frustrated when the patient cannot look at or speak with them, or even hold or squeeze their hands. The patient's appearance may also be disturbing to the family, as it may have drastically changed or deteriorated since a previous visit. For example, apnea, sounds of congested breathing, or observed restlessness and agitation may be troubling to visitors. For loved ones, even being able to determine the exact time at which the patient dies can be difficult. As Kastenbaum noted, the perceptible moment at which life ends is not always clear to the observer, as vital signs may slowly diminish and fade almost imperceptibly at the actual moment of death.[22] Visitors may not realize that the patient has expired until a physician or nurse has checked vital signs and pronounced the patient to have died.

Music as therapy

Active expression of feelings of grief and anguish by loved ones during this time is considered to be both normal and healthy, and the entire hospice interdisciplinary care team helps to facilitate this process.[23] The team can include a wide variety of professionals, including the physician, nurse, nursing aide, social worker, pastoral counselor, dietician, physical therapist, music therapist, a volunteer, and additional clinicians such as an art therapist, massage therapist, acupuncturist, movement therapist, Reiki practitioner, and others. When family members and other loved ones visit shortly before an anticipated death, the hospice music therapist has a unique opportunity to engage them and create a meaningful experience for them with the patient.

As each patient's and family's situation and needs are unique, music therapists provide individualized interventions based on these needs at the time of the session. The music used during a session with patient and loved ones can include original, folk, contemporary or popular, jazz, classical, spiritual, and many other styles. The music can function in a number of ways during the therapeutic process. The first consideration is maintaining the physical comfort of the patient. Music therapy with imminently dying patients may include techniques to facilitate pain control, help provide physical and emotional comfort, assist in relaxation, and reduce anxiety. Music therapy may also involve passive or active participation by the family. As one example, the selecting, singing, or listening to familiar or favorite songs of the patient and family may stimulate discussion relating to life memories, reminiscence, and life review. Family members may request a specific song, listen to or sing with the therapist, and then reflect on the significance of that song to them and the patient. The music may elicit an emotional response that can then allow for the sharing of feelings and emotions. These feelings can then be validated, normalized, and explored by the therapist. Teahan[24] used the acronym VINE to describe the work of the hospice team in facilitating the Validation, Identification, Normalization, and Expression of feelings of anticipatory mourning on the part of the patient's loved ones, a process that contributes to a healthy grieving process. For families with a strong religious base, hymns or other sacred songs may result in sharing feelings of spiritual strength with the patient and one another. Each session is unique, and the music therapist must be flexible about the needs of the family and patient at the time of the session.

Following are five single-session case descriptions, vignettes that are designed to illustrate how music therapy enabled a joining of the patient with family members shortly before the patient's death. Music therapy offers release in different ways. The actual clinical death may be a considered a physical release for the patient at the end of her or his life. The death may also provide a release for the family and loved ones, in their knowing that the patient is no longer ill or in discomfort. While this release is a closure of sorts, it is also just one event in the grief journey of a family member or other loved one.

Case examples

The following sessions all took place at the C.W. Gerstenberg Hospice Center at Hospice of Palm Beach County, Florida, an organization that serves approximately 650 patients per day. The Gerstenberg Center houses an acute care unit. Some patients admitted for skilled care physically decline as a result of their disease process, and then further decline toward eventual and imminent death. Family and friends of patients are free to visit 24 hours a day, seven days a week. Each private room has convertible sofas and chairs for sleeping. It is not uncommon for family members to remain continuously at a patient's bedside during the final days and hours, including the time of death. While none of the patients were overtly responsive at the time of these sessions, the patients' caregivers were all present. The caregivers gave their consent for a brief description of the session to be shared in an article to be used for educational purposes, with the understanding that no actual patient or family names or specific identifying information would be used. As such, the names or initials of the following patients have been changed, with the

exception of Ms. T, whose first name was Rose. The sessions are described in the first person from the author's perspective as the clinician.

Case one: Ms. P

Ms. P was a 37-year-old woman with ovarian cancer. Immediately before meeting with Ms. P and her family, I had been visiting with another patient in the common area of an inpatient unit. As I provided live songs as comfort and support for the other patient, Ms. P's aunt and brother walked through and stopped to listen. They entered Ms. P's room, and remained there while I finished my visit in the common area. After concluding the first visit, I entered Ms. P's room to offer music therapy services. Ms. P was reclining in bed with her head leaning to her left on her pillow. Her eyes were partly open, and her breathing sounded shallow and dry. Ms. P seemed to be minimally responsive and not able to communicate with her family members. Impending death was noted on Ms. P's care plan.

I asked Ms. P's aunt and brother if I could share some music with Ms. P and them to provide comfort. Ms. P's brother replied. "She can't hear us, she's almost gone." I told them that Ms. P might be able to hear even though she could not speak. I addressed Ms. P directly, telling her "My name is Robert. I'm a music therapist, and you are with us here at hospice. You are very safe, and your family is here with you. We will keep you comfortable. I am going to sing some songs to help you relax. Just listen to the music. It is a gift from your family to you, and it is a privilege to visit with you."

I then asked Ms. P's aunt and brother what type of music she enjoyed. Both replied "hymns and gospel." Ms. P's aunt asked to hear "Amazing Grace" and "anything else you like." I began with "Amazing Grace," and then continued to play a medley of spiritual songs, including "Michael, Row the Boat Ashore," "He's Got the Whole World in His Hands," "This Little Light of Mine," and "Kumbaya." During the music, Ms. P's aunt sang with me (I had provided copies of the words), and Ms. P's brother sat next to the patient with his hand on her left shoulder. I began the songs at a moderate tempo and then slowed the pace and lowered the volume through the final verse. "Kumbaya" was thus sung in a gentle and tender manner. The final words of the song were "Oh Lord, come by here," the translation of the song title from Angolan to English. Both Ms. P's aunt and brother appeared to appropriately express feelings and emotions during the session, crying lightly at several points.

After concluding the music, I stayed with the patient and family to provide support and to thank them for traveling across the country to visit. I also explored their support system with them and validated their feelings of impending loss. Ms. P's aunt and brother thanked me several times for visiting, saying that the music helped them interact with Ms. P in a meaningful manner. Ms. P died later that night.

In summary, Ms. P's aunt and brother had offered a cue that music was meaningful to them by stopping in the unit to listen as I provided music for another patient. In the room, their interaction with the patient shifted from passive ("She can't hear us") to active. Both family members told me that the music helped them say goodbye to their loved one.

Case two: Ms. G

Ms. G was a 78-year-old woman with a terminal diagnosis of dementia. I had provided some music for her and several of her adult children the previous day, and the family requested that I return again. During the first visit, Ms. G presented as minimally responsive, as she did on this visit.

When I entered the room, Ms. G was lying in bed with her eyes closed. She appeared to be comfortable and relaxed. Six family members, including adult children and some of their spouses, were present. During the previous visit, the family had asked for spiritual songs from the Roman Catholic faith. These had included "On Eagle's Wings" and "Be Not Afraid." During the current visit, a daughter asked me to play and sing "Wind Beneath My Wings." We briefly spoke about the meaning of the song, and she shared that "Beaches" had been a favorite movie of the patient. She also shared that the patient had "always been there" for the family. I validated and reinforced this sentiment for the family, noting that this was a time that the family was able to "be there" for their loved one. We briefly explored the theme of the song and movie (support of a loved one during a long terminal illness), with the support metaphor being "the wind beneath the wings." I also addressed the patient directly, saying, "This is a song of love and support from your family. It is a gift they would like to share with you now."

During the singing, family members focused their eyes and attention on the patient. Two daughters, one on each side of Ms. G's bed, held her hands. Several family members grasped tissues and dabbed their eyes. The patient appeared comfortable throughout but did not appear to respond to the music in an overt manner. After the song ended, a wonderful stillness was present in the room. No one spoke for 30 seconds. This silence was not uncomfortable for me, nor did it appear uncomfortable to the family members. It was nothing that can be measured quantitatively, but the stillness felt like it was comforting for all persons in the room. I waited until a family member spoke before I spoke, to avoid intruding upon the family's moment. A son then expressed sincere

appreciation for the song. I shared that this was a special time, and that having the family together in such a supportive manner made the music much more powerful than if I had been visiting with the patient alone. The work of hospice is best realized when we allow families to come together and share meaningful moments during the end-of-life transition. The family then requested several spiritual songs, including "On Eagle's Wings" and the "Prayer of St. Francis." Again, there was a comfortable feeling in the room both during and after the music. The family thanked me several times for the visit, and Ms. G died within one hour of that visit.

With Ms. G's physical comfort needs met, the family was able to come together to say goodbye to her and share on a psychosocial and spiritual level through the music. The specific choices of songs and hymns appeared to enhance the support that the family provided to the patient and to each other. The music also appeared to connect all in the room—therapist, patient, and family—in a concrete way through the vibrations of the guitar and voice, and the eye contact between us. The music also stimulated the family to touch and hold the patient's hands during the music.

Case three: Ms. T

Ms. T was an 85-year-old woman with a history of breast cancer. I had visited her room once during the previous week. The patient was minimally responsive at that time and had just that day been admitted into the hospice center. The family at that time accepted my support and appeared appreciative of the offer of music, but declined, stating that the patient was still "getting settled." However, the family had requested music therapy today, and I was paged overhead.

Upon arrival, I observed Ms. T reclined in bed with her eyes partly open, appearing to be minimally responsive. Ms. T's nurse described her as "actively dying," and the patient's breathing sounded congested. A number of family members were present in the room, including the patient's husband, children, and adult grandchildren. One of the patient's daughters served as spokesperson for the group, saying, "Ma's close now, and we thought music might be a good thing." I validated that statement, saying, "Yes, she appears peaceful and comfortable. Thanks to all of you for being with her and for asking for me." The daughter related that the patient's favorite song was "The Rose" from the movie of the same name. She said that since her mother's name was Rose, this song had been special to her for many years. I briefly touched on some of the images and symbolism in the song lyrics, focusing on the final two lines of the song: "Just remember in the winter far beneath the bitter snows, lies the seed that with the sun's love in the spring becomes the rose." The family members shared that they related to this image. The patient and her husband had lived in New York City during many cold winters and then had relocated to South Florida in the late 1990s. We also discussed, at the family's initiation, the metaphor of the newly growing rose emerging from the snow, signifying the release of Ms. T's soul to heaven after her impending death.

During the song, family members comforted each other and the patient. Several cried lightly and hugged each other. Following the song, I continued to allow family members to share memories of the patient's life as well as tell stories that involved the patient. Several times these stories involved humorous situations. At one point a grandchild said, "I don't know whether to laugh or cry." I told her gently that both are okay and can happen at almost the same time. The family did not want any other live music, but chose to simply visit with each other and the patient. Ms. T died later that afternoon with the family present.

The use of a meaningful song allowed for the family of Ms. T to communicate on a number of different levels. While listening to a recorded version of the song also may have been comforting for the patient and loved ones, the exploration of the imbedded meaning in the song appeared to be especially meaningful for the family.

Case four: Mr. J

Mr. J was an 83-year-old man with congestive heart failure, renal failure, and Alzheimer's disease. The social worker had said that the patient was actively dying. When I entered the room, Mr. J was lying in bed with his eyes closed, seeming to be comfortable. Mr. J appeared to be struggling with apnea, and I observed pauses of 20 to 30 seconds between noticeable breaths. Seated at his bedside were his wife and his sister-in-law. I introduced myself and provided some supportive and comforting words, telling them what I could offer as a music therapist. Mr. J's wife asked if I knew the hymn "Beulah Land," explaining that the hymn was a significant one for her husband and herself. I asked to be excused for a moment to get the music from my office. Upon re-entering the room, I observed Mr. J's wife standing and holding his hand. Mrs. J appeared to be crying lightly, with her sister physically comforting and supporting her. I stood quietly for a minute, wanting to support the family without intruding on their private and intimate moment. Mrs. J turned to me and asked if I would play "Beulah Land." I began the hymn, with the family supporting each other and listening. As I sang the beginning of the chorus, Mrs. J began to sing with me. She sang along with each verse and continued to hold her husband's hand. After the

hymn, I told Mrs. J that I was honored to be able to play a hymn that was so meaningful for the patient and family. Mrs. J related that hearing the words of the hymn reinforced her belief that her husband was going "to a better place, Beulah Land." We briefly discussed this image and conviction as related to the family's spiritual background. I thanked the family and then left the patient's room. Mr. J died one and a half hours after my visit.

Music therapy appeared to help the patient's wife and sister-in-law actively express their belief that their loved one was leaving his physical body to go to "a better place." The singing and sharing of that hymn at that time appeared to help them with a release of their feeling, and may have helped the patient experience release as he died.

Case five: Mr. Y

Mr. Y was a 77-year-old man with cancer of the pancreas. While checking with a unit nurse regarding new patients, I learned that Mr. Y was minimally responsive and that his wife was keeping a vigil by the bedside. Upon entering the room, I observed Mr. Y lying in bed with his eyes open but with his gaze fixed and his eyes appearing to be cloudy. His wife was sitting by his side, gently massaging his forehead. Upon seeing the guitar around my neck, she exclaimed "Oh how wonderful, music for you" (saying the patient's first name). I introduced myself, and Mr. Y's wife began sharing about her husband and their relationship of over 40 years. When I asked about their family, Mrs. Y described their adult children and grandchildren and where each family lived. Although none lived locally, she told me that many had been to visit the patient at home during the past several months "while he was good."

Mrs. Y then turned to her husband and said, "It's okay to let go, we're going to have some music." Turning my attention again to Mr. Y, I observed that his breathing appeared quite shallow, with a pause of 10-15 seconds between each breath. I asked if there was a special song that I could sing to provide comfort. Mrs. Y said, "I have a spiritual song that I wrote for my husband. Can you follow me?" She then began to sing, and I found chords on the guitar that supported her melody. The words related to her belief that God would take her husband from her when He was ready for him. The words also said, "I will see you again in the arms of the Lord." Mrs. Y sang the words several times, and I observed Mr. Y's breathing appear to quicken. Mrs. Y indicated after the song that she wanted to be alone with her husband. I left the room very quietly, not wanting to break the wonderful stillness and love that I felt in that room. Mr. Y died that night.

Hearing her original spiritual song appeared to have specific meaning and significance for the patient's wife. Getting to sing that special song to her husband one last time seemed to be especially important for her. It may have been a stimulus for Mr. Y to be able to let go as well.

Conclusions

In each of the above sessions, music therapy played an important role by helping family members to be actively involved in the last hours of the lives of their loved ones. The music therapist did not set a specific agenda or plan for each session. Rather, each session unfolded based on the presenting needs of the patient and family at that moment. The time immediately before the death of a person can be especially difficult for the family. Within the context of the interdisciplinary care team, music therapy can help to bring comfort to patient and family alike.

It is important for the music therapist and other care team members to remember that the final days and hours of a patient's life are times for helping loved ones to visit and say goodbye in their own ways and styles. There are times when family members do not want others, including staff members, to intrude on that private time. In other cases, loved ones look to the hospice clinicians for help and support in finding ways to visit and say goodbye. It is during these times that we as members of the hospice team can provide support and facilitate meaningful release for both the patients and those who love them.

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