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Music at the End of Life: Bringing Comfort and Saying Goodbye Through Song and Story

Amy Clements-Cortés

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Music at the End of Life: Bringing Comfort and Saying Goodbye Through Song and Story

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Authors: Michael Gordon, MD, MSc, FRCPC, FRCP(Edin)^{1,2}; Amy Clements-Cortes, PhD, MusM, MT-BC, MTA, FAMI^{3,4}

Affiliations: ¹Medical Program Director, Palliative Care, Baycrest Geriatric Healthcare System, Toronto, Ontario, Canada; ²Professor of Medicine, University of Toronto, Toronto, Ontario, Canada ³Senior Music Therapist/Practice Advisor, Baycrest Geriatric Healthcare System, Toronto, Ontario, Canada; ⁴Assistant Professor, University of Toronto, Toronto, Ontario, Canada

Abstract: Music has been an important part of the human existence across all continents and cultures since the beginning of recorded time. It is used, for example, in the celebration of happy events, for religious rituals, and to acknowledge the death of loved ones, often as part of spiritual and symbolic rituals. Although the formal and structured use of music as a component of care for individuals in end-of-life palliative care and hospice systems is relatively new in the world of contemporary medicine, its use is growing rapidly and is appreciated by both those providing the music and those receiving the benefits of the music, including patients and their families. This article provides a brief review of some of the current uses of music therapy, including its use in end-of-life care, and illuminates the benefits and potential uses of music through a case example.

Key words: Hospice care, end-of-life care, palliative care, quality of life, alternative and complementary medicine, Alzheimer's disease and dementia, music therapy.

Music is not tangible. You can't eat it, drink it, or mate with it. It doesn't protect against the rain, wind, or cold. It doesn't vanquish predators or mend broken bones. And yet humans have always prized music—or well beyond prized, loved it.

—Robert J. Zatorre, PhD, and Valorie N. Salimpoor, PhD

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.”¹ Music has long been recognized to have a major beneficial impact on individuals in need of comfort, and music as a treatment modality in palliative care and hospice programs is not new, but it is starting to gain more traction. For those at the end of life, music can provide comfort and alleviate the distressing symptoms that arise during the latter stages of a terminal illness. During this time, it is crucial that each patient’s experiences are as physically and emotionally suited to him or her as possible, and music can often help to achieve this goal due to its personal impact.

Our organization, the Baycrest Geriatric Healthcare System, has a robust music therapy program to assist and provide succor and inspiration to those who come to us for the final stage of their lives, which can last anywhere from mere days to weeks or even months. Beyond managing our patients’ clinical symptoms, we try to find ways to affirm their life and its meaning, and sometimes that happens through music. In this article, we present a case example that details how one of our former patients benefitted from music therapy. Following the case example, we outline some of the benefits that music therapy can provide to patients at the end of life and take a brief look at how neuroscience is enhancing our understanding of music therapy and its benefits. Finally, we review how institutions with limited resources can provide music experiences to their patients and discuss factors that they need to carefully consider as they do so.

Case Example

Chaim, a 91-year-old man, was admitted to Baycrest’s palliative care unit with an estimated prognosis of 3 to 6 months to live due to lung cancer and other illnesses. He had worked as a lawyer until the age of 85 and kept himself actively engaged in professional activities after retirement by reading about and discussing politics and current events with others.

Chaim grew up in Montreal with his parents and brother, and he attended college in Toronto, where he opened a private legal practice after completing his degree. Chaim married and had three children with his first wife, Rebecca. After Rebecca passed away, he met and married his second wife, Sarah, who accompanied him during his final weeks of life. Music had played a significant role in Chaim’s life since his childhood. Although he took piano lessons for only 1 year because he disliked practicing, his brother continued to take lessons and performed for the family on Sunday evenings, which brought Chaim considerable enjoyment and provided him with many fond memories. Chaim continued to be engaged with music, using it to study and relax as a young adult, and he introduced music lessons to his children at an early age.

Five years prior to his admission to Baycrest’s palliative care unit, Chaim received a lung cancer diagnosis and underwent radiation and chemotherapy treatments, which resulted in a period of remission. When Chaim’s cancer returned 3 years after the initial diagnosis, he underwent another course of chemotherapy and radiation, but the treatments were not successful. Chaim also developed other health problems during this time, including pneumonia, arteriosclerosis, and a myocardial infarction, all of which resulted in recurrent acute hospital admissions. When it became too difficult for Sarah to care for him at home, Chaim and his family pursued end-of-life care at Baycrest.

On admission to the palliative care unit, Chaim spoke with the social worker about his love of music and drama, and also about an urgent need he had to complete his memoirs, a project he had been working on for the previous 2 years. The social worker referred him to our music therapy program because she thought he would enjoy participating in a music-centered intervention and that it would enhance his quality of life.

Reflections on Music Therapy With Chaim: As Narrated by Coauthor Amy Clements-Cortes

Keeping the ultimate goal of writing his memoirs in mind, Chaim decided that I could help him use his life stories to create a play. When I proposed the idea of adding music to the play, Chaim agreed that it would enhance the stories. He decided to turn his memoirs into an opera, which he named *Heroes* as a way to honor Rebecca and Sarah—the two most important relationships of his life.

To fulfill his goal, we began our music therapy process together by writing the dialogue, or what is known as the *libretto* in opera. By engaging in this practice, the important stories and relationships that were central to Chaim's life surfaced. He also thoughtfully reflected on the most appropriate songs to accompany the stories in his play, and he had a prominent role in writing the music with me. The idea was that writing the libretto, analyzing the lyrics, and selecting and writing the songs to accompany his stories would enable him to express any issues that he had with the individuals in the stories, which in turn would allow him to complete his relationships with them.

The concept of *relationship completion* refers to five sentiments that must be expressed in the lifetime of a relationship: "I love you," "Thank you," "Forgive me," "I forgive you," and "Goodbye."² According to Dileo and Parker,³ "Songs can convey these messages more powerfully and completely than words alone." Further, Dileo and Magill⁴ assert that various clinical methods can be used to facilitate the expression of these sentiments, including song choice, song improvisation, song discussion, song dedication, song narrative, creation of song legacies, and songwriting. During our sessions, we discussed the meanings expressed in the songs we shared, the relationships described in the songs, the emotions that arose from those ruminations, the work needed for relationship completion, and the feelings associated with relationship completion.

For example, writing the song for Rebecca, titled *Come Now Friends*, expressed the love he felt for her and captured the feelings he experienced before her death when he struggled with how he would live without her. This expression of love for Rebecca helped Chaim to honor her and say a final goodbye to her, which in turn enabled him to close that chapter of his life and complete his relationship with her.

His opera also included two songs dedicated to Sarah. The song titled *The Love I Feel for You Sarah* focused on the love he felt for his second wife on their first anniversary. What follows are the lyrics to the song:

Tell me Sarah, say it's love,

Why dost thou do me favour?

I am unworthy of thy grace.

The gracious smile upon thy face,

My very soul doth savour.

I watch thee bathed in morning sun;
I seek the night's sweet holding.
Yes, thou has saved this solemn soul,
And caused me to perform a role,
That keeps our world unfolding.

So, at this first anniversary
I celebrate my love for thee,
I say to thee on bended knee,
It is a lasting certainty.
I will love you always!

Listen to the song here>>

The second song he wrote for Sarah was titled *Gratitude*, and it enabled Chaim to express his appreciation to her for many things, including being his wife, being his friend, and giving him a reason to engage in life again after Rebecca's death. Writing this song also facilitated Chaim's awareness of the importance of discussing his impending death with Sarah and articulating his wishes for her once he died. By expressing "I love you" and "thank you" to Sarah in both of the songs he wrote for her, he was working toward completing his relationship with her. The final thing for Chaim to do before his death was to say "goodbye" to her. To give him this opportunity, we invited Sarah to join our sessions, which enabled Chaim to verbally express his love to her, both through the songs and in the discussions that ensued. By Chaim reading the story of their anniversary and me singing *The Love I Feel for You Sarah*, he was able to speak to Sarah about his impending death and his desire for her to continue to engage in life after his death.

Another significant person who weighed heavily on Chaim's grieving process was Joseph, his grandson who had recently passed away after a short illness. He wrote a song for him, and reading the story of Joseph's death from the opera and singing *The Rose*, a song performed at Joseph's funeral, facilitated a discussion of grieving and the importance of seeking grief support. These were important things for Chaim to discuss with Sarah to help him reduce his anxiety over his own death and Sarah's grieving process. It assisted Chaim in communicating to Sarah his desire for her to obtain support and help when he passed away, as well as his wishes for her to find new things to put her energy towards.

Chaim was able to finish writing the opera before he died, and I, per his wishes, completed the project by recording the songs for his family after his death. Listening to this legacy gift played an important role in their grieving process.

While Chaim's case is quite unique in that writing an opera is an ambitious goal that relatively few individuals at the end of life would be able to achieve due to the energy required to complete such a task, there are many examples of powerful and transformational music therapy work in palliative care. For example, many patients are able to compose original—even if relatively simple—music, and this can often be completed within one to three sessions, depending on the length of the song and the patient's energy levels. Although persons with advanced dementia might have serious limitations, those with mild cognitive impairment can participate successfully in songwriting projects with great personal satisfaction when structure is provided by a music therapist. The sessions can even involve the participation of a family member or a significant other. As demonstrated by Chaim's case, the involvement of a family member in the music therapy sessions can add another therapeutic dimension, helping that individual cope with his or her grief and find closure.

Discussion

Music has been universally enjoyed and treasured by people throughout human history, in all cultures and in all parts of the world. While the formal practice of music therapy in palliative care originated nearly 40 years ago, Forinash⁵ described a rich history on the use of music in the context of death and dying that predates its formal use in palliative care. According to West,⁶ music has been associated with medicine since the Paleolithic era, and Riedweg⁷ stated that Pythagoreanism, a religious movement founded by the ancient Greek philosopher Pythagoras, is associated with connecting music and healing. In addition, the sixth-century philosopher and theologian Boethius maintained that harmony provided a balancing effect for different parts of the body and the soul.⁸

Over the past few decades, there have been many initiatives in North America to formalize and improve the philosophy of end-of-life palliative and hospice care, whether that care is provided in dedicated units, long-term care facilities, or even general hospitals, where many patients spend the early days of this last phase of their lives. Music therapy has been one such initiative. In fact, one of the pioneers in palliative care in North America, Balfour Mount, described how music therapy has made a significant contribution to a wide variety of palliative care problems.⁹ The use of music across care settings has been well received by patients and their families, including at our institution. It is often able to provide comfort when words are inadequate or inappropriate, and it may even provide a means of positive interaction and facilitate the expression of feelings. In fact, a wide variety of social, emotional, physical, and spiritual benefits have been reported in the literature.

Benefits of Music Therapy in End-of-Life Care

There has been growing literature on the importance and benefits of music in end-of-life care. Music therapy can offer support to the patient and help palliate symptoms that are common at the end of life (eg, pain, fatigue, sleep disturbances, nausea, existential and spiritual concerns, anxiety, fear).¹⁰ It can help individuals achieve an awareness of their own limitations and losses¹¹ and can assist with one's life review and relationship completion. It has also been found to be a valuable intervention to achieve common palliative care goals.^{12,13} Hilliard^{14,15} reported that music therapy is a creative and innovative way to meet the multidimensional needs of terminally ill patients and their loved ones, and can address their spiritual and existential concerns. Music therapy has been used successfully in the treatment of a variety of physical, emotional, and spiritual issues within palliative care, including decreasing social isolation and loneliness and lessening emotional distress (eg, depression, anxiety, anger, fear).^{12,16-18} Music therapy is also used in palliative care to improve pain management and relaxation, which are important goals for

many palliative care patients.¹⁹⁻²² Some other general goals of music therapy include improving quality of life; enhancing learning; enabling self-expression, communication, and self-development; and facilitating self-awareness.¹⁴ In their 2006 study, Gallagher and colleagues²² found that music therapy had a significant effect on several symptoms in patients with chronic and/or terminal illness, including shortness of breath, body movement, facial expression, and verbalizations.

Similar to music therapy, *music thanatology* is another specialty that has been used during the dying process. Developed in the 1970s by Therese Schroeder-Sheker, music thanatology provides live harp and vocal music at the bedside of the dying patient.²³ Music thanatologists are formally trained to adjust their harp and vocal music to respond to specific organic changes that are occurring in their listeners, such as changes in breathing rates or circulation. The goal is to support the patient in his or her own process by offering music in a prescriptive manner to create an environment that can enable the patient to experience what he or she needs to experience in the most supportive way possible. Prescriptive music is not specifically outcome-based, meaning that the music thanatologist does not try to control what the patient is experiencing but instead works to support the patient in whatever he or she is experiencing. For example, creating a supportive musical field may be helpful to a patient who is anxious by making it easier for him or her to calm down or to become more at peace.

The Neuroscience of Music

The growing literature on music and end-of-life palliative and hospice care is supported by recent scientific studies that more formally document and demonstrate the neurobiological basis for the enjoyment and satisfaction that comes from hearing music, which, according to the end-of-life literature, presumably can occur even during the terminal phase of one's existence. The recent review by Zatorre and Salimpoor²⁴ provided scientific-based explanations for what most music lovers understand as the special sensual qualities of music. In the following passage from a recent article that appeared in *The New York Times*, Zatorre and Salimpoor²⁵ explain the already-established neuroscience that elucidates the way in which music works in humans, which is based on their aforementioned review:

More than a decade ago, our research team used brain imaging to show that music that people described as highly emotional engaged the reward system deep in their brains—activating subcortical nuclei known to be important in reward, motivation and emotion. Subsequently we found that listening to what might be called “peak emotional moments” in music—that moment when you feel a “chill” of pleasure to a musical passage—causes the release of the neurotransmitter dopamine, an essential signaling molecule in the brain.

After a detailed explanation of the processes by which music affects the brain, the authors conclude, “In the cross talk between our cortical systems, which analyze patterns and yield expectations, and our ancient reward and motivational systems, may lie the answer to the question: does a particular piece of music move us? When that answer is yes, there is little—in those moments of listening, at least—that we value more.”²⁵

These experiences, for which there is now a good scientific basis, can occur even during the waning months, weeks, days, and hours of life. This fact allows us to use music to provide whatever semblance of joy can exist in what remains of the life of those we love and care for.

Music Therapy Considerations for Allied Healthcare Professionals

Once an individual is deemed a suitable candidate for music therapy, a music therapist conducts a formal assessment that takes into consideration patient preferences and abilities and establishes a baseline with goals and objectives. The types of interventions vary widely and may include, for example, songwriting, singing, moving to music, lyric discussion, and/or listening to music. Because music therapy offers a variety of active and passive activities, musical ability is not required for a patient to participate in or benefit from this intervention.

To ensure optimal support, the music therapist needs to take the patients' musical preferences into careful consideration. After all, patients in hospice programs can vary in age and have different tastes; thus, it is impossible to select music that would appeal to this entire population. In addition, Hogan²⁶ maintains that there are multiple benefits of using familiar and preferred familiar music with terminally ill patients, including providing them with a sense of achievement, enabling greater control over their environment, providing them with a physically and mentally stimulating experience, heightening their awareness, and encouraging exploration of their emotional needs. Familiar and preferred music can also enhance purpose and self-worth by stimulating creative participation, and creating recordings of familiar music may provide comfort to the patient in times of fear and loneliness while leaving behind a legacy gift for family members in the bereavement process, as demonstrated in the case example.²⁶ Mitchell and MacDonald²⁷ found that preferred music was distracting, had a positive affective impact on the experience of pain, and increased tolerance time of painful stimuli and perceived control over pain in both male and female patients.

Although not every long-term care facility, palliative care program, or hospice unit may have the benefit of—or in some cases, the luxury of—professional music therapy staff to assist in providing musical interventions, there are many resources that can help healthcare professionals and social service providers in these settings bring music to those who might benefit from it. Attempts can be made, for example, through a volunteer department to explore who, among the volunteers, might have a significant musical background and interest in learning about and providing music to patients and their families. Although these musical interventions may not be as sophisticated as professional music therapy programs, they still have the potential to achieve the goal of providing meaningful musical support during the end-of-life experience.

When implementing such resources, healthcare professionals need to keep in mind that music has a very personal and intimate meaning for each individual, a fact that demands a great deal of respect. Therefore, it is important to stress the need for a careful assessment of each individual patient before introducing musical interventions. An example of an appropriate approach might be for a healthcare provider to suggest that a patient use music if he or she is having difficulty falling asleep and recommend one of several CDs that have been created for this purpose. Another example is playing background music during a painful procedure or routine care.

Conclusion

Most people understand the positive impact of music in their lives, but they may not realize that music can have a therapeutic effect for a wide array of clinical conditions, with these effects going well beyond the “enjoyment” factor that music brings in all its various formats and methods of presentation. For individuals in the later stages of life, especially when in need of palliative, long-term, or hospice care, music may offer another important modality of clinical intervention that may provide comfort and emotional satisfaction to those susceptible to its effects. Practitioners working in these care settings

generally become adept at manipulating medications to achieve the therapeutic goals of comfort while maintaining the patient's ability to participate as much as possible in human activities, especially visits with loved ones. For those in whom music is helpful in this endeavor, it is important to note that, as far as is currently known, music has no lingering adverse effects. It can be discontinued quickly if necessary; it can engage other members of the family in a conjoint effort; and, as in the case of Chaim, it can tap into the core humanity of the person who is either the recipient of the music or the participant in the musical project that they have chosen.

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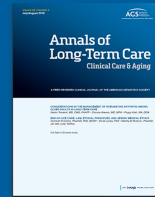
Address correspondence to: Michael Gordon, MD, MSc, Baycrest Geriatric Healthcare System, 3560 Bathurst Street, Room 1C24, Toronto, ON, M6A 2E1, Canada; m.gordon@baycrest.org (mailto:m.gordon@baycrest.org)

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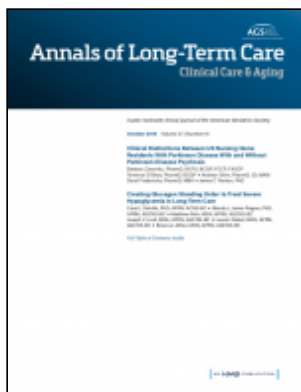
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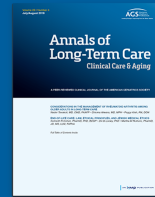
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