

In Between: Music Therapy with Inpatients Awaiting a Heart Transplant¹

Cheryl Dileo⁺ and Michael Zanders⁺⁺ (USA)

Abstract

Individuals who are in heart failure and who are inpatients waiting for a heart transplant face many challenges. In this article, the authors describe these challenges and how patients are supported through the use of music therapy. Case examples are provided to illustrate the various uses of music therapy.

Keywords: *Music Therapy, Heart Failure, Heart Transplants*

⁺ Dr. Cheryl Dileo, Carnell Professor, 012-00 Temple University, Philadelphia, PA 19122, USA. voice: 215-204-8542, fax: 215-204-4957 email: cdileo@temple.edu, website: www.temple.edu/musictherapy

⁺⁺ Dr. Michael Zanders, Faculty, Temple University, USA.

¹ Originally published in C. Dileo and J. Loewy (Eds.) *Music Therapy at the End of Life*. Cherry Hill, NJ: Jeffrey Books. Published here with permission of the publisher.

Introduction

You're here in my heart, and I know that my heart will go on (Theme from the Titanic)
They call it the "Heart Failure Hotel." It's the 7th Floor of a large university hospital, and a prominent heart transplant center. Various life journeys have brought the hotel's guests here: a congenital heart defect, chronic heart problems, a series of heart attacks, a simple virus, chemotherapy. Whatever the reason, their present situation is the same at this hotel: their hearts are broken, and they wait for a heart transplant. Most need mechanical devices, such as a left or right ventricle assist device to stay alive. Most realize that their stay is indefinite, for they cannot survive at home without the intensive medical care that the hotel provides. Some realize that this hotel may be their last stop in life.

The grim reality is ever-present: there are not enough hearts available for all 20-30 guests. Also, they face a strange paradox: they must be sick enough and their medical status urgent enough to allow their name to be at the top of the transplant waiting list, but they cannot be so sick that their other organs are also failing, rendering a heart transplant an inevitable failure. Moreover, even with a heart transplant, a good number will have complications and die anyway. The rest who survive the transplant will face a lifetime of anti-rejection drugs, constant monitoring for infection and other lifestyle modification.

So they wait, day-to-day, and month-to-month. For some the wait is short, i.e., several months. For others, because of blood type or various medical reasons the wait can last over a year.

These guests are young and old alike, all races, nationalities and creeds. They can't leave the hotel for a visit home, even for a day. It's impossible for them to even leave the floor to go outside the hospital without resuscitation equipment accompanying them. Their world is an artificial, oppressive and constricted one. Their existence can best be described as "in-between" life and death. What sustains them? For each, the details are different, but for most it is the same: love and spirit.

We are their music therapists. We enter the hotel every Wednesday morning at 9:30 very tentatively-never knowing who has received a heart, who may have been moved to intensive care, who may have been taken off the waiting list and sent home, or who may have passed away. We are daunted by these patients' immense issues and needs (Tables 1-4). However, we bring only our instruments and ourselves - the things we have to offer.

Table 1. Patients' Physical Needs

| |
|--|
| To Remain as Healthy as Possible (Diet, Medication, Sodium Intake, Exercise, etc.) |
| To Maintain Energy Levels |
| To Reduce Excessive Automatic Reactivity |
| To Comply with Medical Regime |
| To Endure Constant Medical Testing |
| To Reduce Pain |

Table 2. Patient's Psychological and Coping Issues

| | |
|------------------------------------|------------------------------|
| Depression | Anxiety |
| Guilt | Impatience |
| Anger/Resentment | Uncertainty |
| Medical Crises | Medical Regime |
| Remaining in Touch with One's Self | Loss of Control Over Lives |
| Need to Accept Vulnerability | Fears of Future |
| Hoping for life/Facing Death | False Alarms |
| Loss of Fellow Patients | Loss of Transplant Status |
| Physical, Financial, Social Losses | Artificiality of Environment |

Table 3. Patients' Spiritual Needs

| |
|--|
| To Find Meaning in Their Experiences To Prepare for Life To Prepare for Death To Trust in Something Beyond Themselves To Find Hope To Be At Peace |
|--|

Table 4. Patients' Social Needs

| |
|---|
| To Maintain Contact with Family/Friends To Receive Support from Hospital Staff To Give/Receive Support from Fellow Patients and Create New Relationships To Have Their Stories Heard To Give and Receive Love To Feel Needed |
|---|

Each week, we offer a group music sessions at 11:00. We go to each guest's room to invite him or her personally to join us. It takes courage to enter each room—to see the tubes, medical equipment, blood draws, and even more so, to face our patients' deteriorating conditions, depression and sometimes despair. The sources of distress at this hotel are many. We spend a few minutes with the guests, checking in on how they are that day and what has happened during the past week. Some greet us with enthusiasm...some not. We understand.

Sometimes there have been false alarms. A heart had become available, the patient had been prepped for surgery, but the heart was not considered viable. Spirits are very low when this happens. What happens to one guest affects all.

When another patient receives a heart, there are indeed mixed feeling, i.e., of joy for that person, but questions of "why not me? I've been waiting longer." The darkest moments of all are when a fellow guest receives a heart, but does not survive. Despair sets in, and questions of "Will this happen to me?" or "Why am I waiting here if I will die anyway" become apparent on everyone's face.

We spend a bit more time with the new guests, assessing their interest in and history with music, their medical status, and their resources for social support. We offer a private music therapy session according to their needs and interests or invite them to attend the music group. For some new guests, there is hope and optimism for receiving a new heart and returning home to live a better life. We know, however, that hope and optimism will eventually fade as their days of waiting turn into months. But we are still there with them no matter what.

These are the stories of their journeys. They are stories of extraordinary courage and valor. It is our privilege to share them with you.

The Patients and the Musical Instruments

a. Daniel

Daniel was one of our first patients on the units. He was waiting for both a heart and kidney transplant, was critically ill, and needed dialysis in addition to all the procedures necessary to sustain his heart. He was warm, engaging and enthusiastic about learning to play a few songs on the guitar—one of his life's dreams. We shared some touching moments together as the guitar became for him a metaphor of hope and of moving towards the future beyond the hospital. His critical condition took a second place to his healthy, creative and expressive parts, and his wholeness as a person.

He learned to play two of his favorite songs rapidly using an open-tuned guitar. His eyes were bright and alive as he managed to change chords and sing, and we sang enthusiastically and joyously with him. The music and the presence of the therapists created the space for him to talk about many issues: his life before and his life in the hospital, the love he shared with his family, and how his illness had been devastating for them emotionally and financially. He performed his songs and played the guitar for his loved ones when they visited. He told us that sang together and cried with joy.

With every subsequent visit, we saw that Daniel was becoming weaker, eventually becoming unable to play, but still singing his songs, as we played the guitar for him. We were fearful of losing him, but his hope for a transplant was ongoing. We worried that each visit with him would be our last, and we wanted to share with him what our experience with him had meant to us. One of the authors (MZ) asked if he could sing a song for him, and Mike selected Elton John's song, Daniel.

I can see Daniel waving goodbye. It looks like Daniel, must be the clouds in my eyes. We never saw Daniel again, and that song to us will always be for him.

Our work as music therapists at this hotel is unlike any other we have done. It presents a continual dichotomy: how do we instill and support hope and courage for living while at the same time prepare our patients to die? Taking one direction or the other ignores the realities that surround us. Working with patients who

are “in-between” also affects us profoundly as human beings. We talk between us, struggle with uncertainty, grief and anger, and try to come to terms with our feelings. We vow to continue, realizing that we may never find the answer for our patients or ourselves. We know above all that it’s worth it.

b. Linda and Gertrude

Linda was a heart failure patient in her 20s with a young, autistic son, Tommy at home. She and Gertrude, a middle-aged patient, were friends at the hotel and came to music therapy sessions together. Linda wanted to learn to play the guitar. Gertrude could play some keyboard but wanted to practice so that she could surprise her family with music when she left the hospital. Both wanted to use music and the instruments to help them through their current situation.

Linda learned chords and songs on the guitar quickly and practiced diligently. Playing gave her a respite from the stressors of being hospitalized and from the monotony of the long days. During music sessions, Linda spoke of her great love for Tommy, her guilt for being in the hospital and for not being at home to attend to his needs. As his mother, she of course knew him best and was the one he relied on. She also knew she could not be at home for his upcoming birthday and experienced a great deal of anguish in not being able to organize a party for him. However, she found a solution through the music.

On his birthday, Tommy visited Linda in the hospital. She took her guitar and played and sang *Happy Birthday* to him. The look on his face was unforgettable, as he was amazed with his mom’s guitar playing and singing. She sang and played the birthday song over and over for him, and she showed him how to strum the chords. He managed to sing several words of the song with her. Her musical gift to him was beyond measure, and they shared a moment of love and intimacy.

The musical instruments we use at the heart failure hotel have taken on special significance, i.e., as metaphors of hope for the future and as a means to share love and intimacy with others. However, we were unprepared for another, very unmusical meaning of the instruments. We sometimes left an instrument in a patient’s room so that he or she could play when we were not present. Such was the case for Glen, a patient who had been a professional musician and who had been using the keyboard to stay connected to his former life and identity. For one particular week, we left the keyboard with Glen as usual, and the next day, he received a heart transplant. The nurses moved the instrument to Linda’s room for safekeeping. That day, Linda was called down to surgery to receive a heart. The nurses then moved the piano to Gertrude’s room. The next day, she received a heart transplant. Obviously, this was nothing more than coincidence, but all of the guests at the hotel was asking us ask to have the keyboard in their rooms.

The Patients and the Songs

As mentioned previously, weekly group sessions are held for all ambulatory patients who are interested. Songs have taken on a variety of meanings in this context. We have found that something as simple as being together, selecting favorite

songs and singing in an ensemble has been responsible for many unique, unforgettable and healing moments, filled with laughter and tears; spirit and love.

There aren't many opportunities or places to express deep feelings at the hotel. Guests inevitably want to protect their families from their intense emotions. The guests know that it's difficult enough for their families to see them as patients, to suffer to consequences of their absence at home, and to wait with them. They don't want to add greater emotional burden.

Patients are reluctant also to share deep and intense feelings with medical staff. There are very stringent criteria for remaining on the waiting list for a heart. Emotional stability is one of these criteria, and patients fear being removed from the list, if they are perceived as unstable. As Gertrude remarked, "music therapy is the only place where we can express the range of our feelings with trust and support and without concern."

Until we began working at the hotel, we never realized how prevalent the word, "heart," is in popular songs. Its metaphors for these patients are profound (see Table 5). We were not surprised then when guests selected a theme song for the hotel: *My Heart Will Go On*.

Table 5. Metaphors of the Heart

| |
|---|
| The Heart Represent Core Intra- and Interpersonal Identity Issues |
| The Archetypal Imagery of a Closed Heart is Associated with Heart Disease |
| The Heart is the Most Valued Organ |
| Damage to the Heart has Marked Repercussions Psychologically and Socially |
| The Heart's Story is Also One's Life Story |

a. Gertrude

Heart metaphors in songs, however, initially were sobering to us in this setting. In one session, Gertrude requested the song, *I left my heart in San Francisco*. We were naturally a bit concerned about the potential impact of these lyrics for a pre-transplant heart patient, and were also cognizant of patients' extreme physical and emotional vulnerabilities. However, we took the risk and honored Gertrude's request. After singing the song, she spoke tenderly and sadly of her guilt in wishing for a new heart so desperately, and at the same time realizing that someone special and loved one would have to die for her to receive it.

There were countless other unforgettable moments when songs from the heart were incredibly meaningful, poignant and sustaining.

b. John

John was the "mayor" of the heart failure hotel. He set the hospital's record for a wait for a heart: 19 months. John was a very intelligent man in his 60s who had sung semi-professionally during his college days. That's where he met his wife, Helen, a professional musician. Songs and music had been in integral part of their relationship. They had developed a repertoire of song duets that they sang read-

ily in sessions. Helen often brought her instrument with her to the music therapy group, and this gave her great satisfaction and comfort. Helen was almost always at John’s side. She literally lived at the hospital, “reverse-commuting” as she called it. They were a close couple, but they had a difficult time expressing feelings to each other, except through music. It was there that the frustration and rage over their situation emerged—in bickering song duets. We witnessed, supported and validated these musical expressions. However, it was also in the music that their tenderness for each other could emerge. One session stands out. It was Valentine’s Day, and John asked to sing a solo in the group for Helen. He sang the following words with all of his heart: *My Funny Valentine...you make me smile with my heart... Don’t change a hair for me, not if you are for me. Stay little Valentine stay. Each day is Valentine’s day.*

Helen was overwhelmed with emotion. It was a moment not to be forgotten, and it provided all the love needed for them to go on in their situation. John did get a heart soon thereafter.

c. Clariece

And there was also our patient, Clariece, and her husband, Henry, who celebrated their 40th wedding anniversary in the music therapy group to the tune of their favorite song played and sung by tearful music therapists: *When I fall in love, it will be forever, or I’ll never fall in love.*

Through this music, they were able to call upon memories of their 40 years together, some of the good times, and some of the bad times, and to realize the richness of the life and love they had shared and continued to share.

Besides validating love and inspiring hope, songs selected by the patients tell us a great deal about how they are coping, what they believe, and what is getting them through this horrific experience. We are thus able to understand their resources, or lack thereof, and either validate or assist them in identifying strategies to continue with their wait for a heart transplant.

After songs are sung, patients open up to their feelings, connect with themselves and each other and share their stories of past and present. We have identified three predictable stages of this process (Table 6).

Table 6. Stages of the Music Therapy Process

| |
|-----------------------------|
| Opening the Heart to Music |
| Opening the Heart to Self |
| Opening the Heart to Others |

d. Gertrude

Gertrude’s condition was obviously deteriorating and her hope was noticeably wavering. We asked if there was a song she would like to sing. Without hesitation, she stated. “Yes,” and proceeded to sing these words: *Then sing my soul, my Savior*

God to Thee, How Great Thou Art, How Great Thou Art. She sang the words tearfully and fervently. When she finished she said, "I'm okay now."

e. Angela

Angela, a Latino patient in her 50s was an enthusiastic member of our group. Prior to sessions, she went from room to room to recruit participants. A determined woman with a deep love of music, her song requests in the group made her coping mechanisms transparent. She would often request this song: *...when the dawn breaks tonight will be a memory still, and the new day will begin* and this song: *You can say I'm dreamer, but I'm not the only one. I hope someday you'll join us, and the world will live as one.*

After she sang these songs, she spoke about her resolve and determination to live, and inspired all in the group to continue hoping for a second chance at life.

f. Tonie

Tonie, a woman in her 40s, was intensely spiritual, and with a quick and lively sense of humor. She was loved by patients and staff alike and was a strong presence at the hotel, giving freely of herself to help fellow patients. She often requested spiritual music to reaffirm her beliefs and to support other's beliefs'. In her last session with us, however, she selected the song: *The Gambler. You gotta know when to hold 'em, know when to fold 'em. Know when to walk away. Know when to run.*

This choice was unusual for her, and we laughed with her about it. Shortly thereafter, she was called to receive a heart. During the surgery she suffered a stroke and passed away. Her song was an eerie foreshadowing of her gamble in waiting for a heart, and in some way, she was directly acknowledging the hotel. After her passing, her husband revealed that, in spite of the negative outcome of her situation, she had told him that she had never regretted her decision to undergo a heart transplant, as her experiences with other patients had been transformational for her.

g. Charlotte

Charlotte was another patient who waited an extended time for a heart. During one of her first music therapy groups, she requested this song: *Blue skies, smiling at me, nothing but blue skies do I see.... Gray skies, all of them gone, nothing but blue skies from now on.*

We sang this song with and for her, and suddenly to her own surprise, she was flooded with very specific memories of earlier days when she had accompanied her grandson to school every morning. She and he would sing this song together, as they walked. She recounted to the group the feelings she had in giving her grandson hope and optimism for life through these lyrics. She was able then to connect this same hope and optimism to herself while waiting for a heart.

During one period of time at the hotel, the composition of our weekly group was very different. Every Wednesday, 6-7 men in their 50's and 60's attended. Most

were working-class men and of a generation and culture that did not easily share feelings. In spite of this, they found music to be the way for them to relate to themselves and to each other, and in the words of one patient, “Wednesday don’t come around quickly enough for us.” These men would have no difficulty asking for the precise songs they wanted/needed to hear.

h. Robbie

Robbie, a gentle man in his early 60’s, was joined one day in the group by his daughter, he requested this song: *Oh Danny boy, the pipes, the pipes are calling you... from glen to glen and down the mountainside. The summer’s gone, and all the leaves are falling. It’s you, it’s you must go and I must bide.*

Indelible in our memories is the image of him putting his head on his daughter’s shoulder, both of them weeping silently and deeply in anticipatory grief. He had seemingly chosen this song to prepare his beloved daughter for his not being able to share the future with her. As we sang, all of the other men in the group validated their experience and wept silently with them. No words were exchanged. They shared this painful moment together, and their sense of unity was in, itself, healing for them.

i. David

David, the usually vocal leader of this group of men, was quite despondent at one group session, and spoke very little. One of the authors (MZ) met with him privately following the group to discuss the reason for his apparent isolation and sadness. David cried and said that he couldn’t stand the wait any longer and was planning to go home, to give up hope for a new heart, and to die. The therapist held his hand, and the two shared a very special moment of silent closeness. The following week David was still at the hospital, and the therapist asked him if he had made a decision about his future. David said that music therapy and his wife were the factors that had given him the courage to remain in the hospital and to not return home to die. David did receive a heart soon thereafter. Very sadly, however, several months later, he returned to the hospital with advanced cancer. We provided his last music therapy session beside him before he died.

j. Loretta

Loretta was a young woman who was having difficulties enduring the wait for a heart. She would not comply with the hospital’s prescribed medical regime, and there was concern that she would lose her status on the waiting list. She came to the music group and was rather reticent to select a song. Finally, however, she discovered the song that felt right to her: *I believe in can fly. I believe in can touch the sky. I think about it every night and day. Spread my wing and fly away.*

After she sang it, she talked about how much she missed her baby daughter, and how much she wanted to return home. At the same time, the song allowed her to feel hopeful that she might have a relatively normal life again with her family one day. She came to the group again several months later, right after she had received a heart transplant. She was getting ready to leave the hospital, and she requested

the same song. After singing it, she talked about how she had survived the wait, and that the music had been a help in allowing her to “fly” away from the difficult circumstances. She was now ready to fly into the life she had imagined. Her belief in this, as inspired by this song, was what sustained her.

k. Kyle

Lastly, there was Kyle, a remarkable young and intelligent man in his 30’s. Kyle had a very keen sense of humor, often trying to challenge the therapists’ musical skill with song requests such as *Flight of the Bumblebee*. His spirit and positive attitude inspired all.

We’re not often at the hotel when a heart becomes available, as this often happens in the middle of the night. At the hotel, there is a ritual for patients who have been selected to receive a heart: No matter what the hour, all the patients at the hotel are awakened, and they go as a group to the potential recipient’s room for a group prayer.

On this day, we were informed when we arrived that Kyle would soon be receiving a transplant, and the transplant team was on its way to harvest the donor heart. We knew Kyle would be anxious, so we entered his room and asked if he would like some music. He requested *Amazing Grace*, and the therapists stood at his bedside and prayerfully sang the first 2 verses of this song for him. Kyle’s eyes were fixed on something far away from and beyond us, as if he were in a trance. After the first 2 verses, one of the therapists (CD) felt that the song was incomplete, and intuitively and spontaneously sang another verse: *Through many dangers, toils and snares I have already come. ‘Tis grace hath brought me safe thus far, and grace will lead me home.*

It was profoundly intimate moment, one that we’ll never forget. We left the room, wishing Kyle luck and thanking him for being a member of our group. We told him that, although he would be getting a new heart, his old heart had been wonderfully loving and generous. During Kyle’s surgery, blood clots required the amputation of both his legs. He died shortly thereafter. We hoped that the last song we shared with him accompanied him through this transition.

Conclusion

It’s difficult to summarize all of our experiences at this hotel into one neat intellectual package, as music therapy with these patients “in-between” has often been ineffable. However, we can offer some broad reflections on the power of music therapy in this setting:

Playing an instrument serves as a metaphor for hope, of going on in life.

Music can access what is still healthy, creative and expressive in our patients, no matter how ill they may be.

Being together in a music therapy process elicits strong emotional ties of love and support.

Music choices reflect where patients are, what they believe and how they are coping; they also provide inspiration for alternate means of coping.

Music provokes memories of the past and summons forgotten resources for survival.

Music therapy facilitates the sharing of past and present stories that prevent the patient from falling out of life and in to the illness.

Music therapy enhances the communication of complex feelings when words are not capable to do so.

Music therapy provides the space for the expression of deep and intense emotion in a way that is safe for the patient.

Music therapy validates ineffable experiences.

Music therapy summons and supports spirituality and hope, providing the means for an individual to be sustained.

Music therapy allows transcendence of horrific circumstances.

Music therapy facilitates the creation of beautiful moments that are memorable within a life's story.

We view our work as occurring on a heart to heart basis. The essence of our work is in allowing our hearts and our music to enter the experience of patients, and to resonate with their hearts. We believe that it is only through this type of connection that healing occurs. We do this knowing full well the risks involved: that our own hearts will absorb patients' suffering and pain. But, as mentioned previously, it's well worth this risk.

At the same time, we've had no greater inspiration in our lives than from these unique and loving individuals, whose hearts are bigger than we can adequately describe. They've taught us how to live better and more fully, and how important each moment of life is. They've taught us the necessity of creating beautiful moments in every day with those we love. They've inspired us to be courageous and to take risks. They've nurtured our appreciation for all that we have. They've challenged us to embrace deep spiritual beliefs. And they've given us a new and deeper appreciation of the power of music to transform. We know for certain that our own hearts will never be the same.

References

Dileo, C., and Loewy, J. (Eds.) *Music Therapy at the End of Life*. Cherry Hill: Jeffrey Books, 2005.