Evidence-Based Integration of Music in Donor Family Care

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Background

While music therapy has been well-established in end-of-life care settings, recommendations for music in the donor family care setting has been limited. Research on music therapy best practices has advanced in recent years with improved evidence for optimal music selections as well as benefits of active versus passive involvement. A systematic meta-analysis of qualitative studies showed moderate to strong evidence for improved health-related outcomes associated with music provided to adult informal carers of adults with life-threatening illness pre-bereavement (1). Consequently families encountering acute and traumatic loss of a loved one life in the donor family care setting may greatly benefit from appropriate integration of music whether it is instrumental music at honor walks, donor remembrance gatherings or at the bedside.

In many palliative care settings, acoustic music played at the bedside has had beneficial impact (Figure 1). For example, licensed music therapists provide instrumental music to patients in home hospice visits. Hospitals, likewise have palliative care teams with music therapy often integrated within the interdisciplinary team providing care at the patient bedside.

Organ procurement organizations who provide support to families facing a particularly traumatic and unforeseen loss, may benefit from considering the integration of music. The following explores evidence base to define where 1) There are specific aspects of musical selections ideal for supporting families facing acute, traumatic grief, 2) There are care settings unique to organ procurement organizations where instrumental music be ideal for supporting donor families facing imminent loss, and 3) There are opportunities where music provided can create an active versus passive experience.

Music in the treatment of anxiety and post-traumatic stress has been previously studied for appropriate choice of genres and musical selections (3). Musical selections with repeating melodies that are widely familiar and those which resolve harmony and dissonance may be more comforting. A predictable rhythm and restful tempo are also important to consider. In the acute pain setting, one study identified that music entrainment, or a tempo-matching of the resting heart rate was ideal (4). In donor family care, unlike most other areas of end-of-life care, limited encounters prevent the ability over the long term to assess and reassess family preferences for music integration into care.

Methods

An evaluative analysis of challenges applying music in the setting of end-of-life circumstances unique to donor families was conducted with reference to evidence-based music therapy practice. Because of the acute and dramatic nature of terminal illness in the organ donor population, donor families are particularly susceptible to the effects of acute traumatic stress.

This contrasts with music played in other palliative care environments such as home hospice where grief and preparation of the end of life can occur over months or longer.

In unique donor family care situations, music may play an important role when acute traumatic stress is a barrier. Clinical research has established that music may have a beneficial effect on physiological recovery from the acute stress response both at the autonomic nervous system and the hypothalamic-pituitary-adrenocortical axis (2).

In other areas of the end-of-life healthcare care continuum, the integration of music therapy or bedside music in end-of-life care setting has advanced. Many inpatient palliative care programs and home hospice teams integrate music therapy for patients and their families in an end-of-life setting. While music in the healthcare setting has great potential for supporting families of organ donors, these families face unique aspects of grief that are important to consider. In one respect, the loss these families face is much more imminent. Their terminally ill loved ones are already expired by neurological criteria or is expected to expire by circulatory criteria relatively soon after discontinuation of a life support device.

In contrast with families facing end of life in other settings, donor families are often anticipating the celebration of a lifesaving anatomical gift that may affect several lives and families as a result of selfless compassion unique to organ donation. These concepts can be translated into practical considerations for donor family care teams supporting families who experience acute grief in often complex circumstances. The following scenarios as well as suggested music selections may be of interest to organ procurement organization donor family care teams, especially where there is a team member able to play instrumental music.

Results

Opportunities for Integrating Music in Donor Family Care

The author presents two scenarios where music in the donor end of life care setting has been integral to donor family care. Both scenarios are representative of real cases where instrumental music with a slow, rhythmic and calming nature was played intentionally at a time of acute family stress.

Scenario 1 An Invitation to Communication: A donor mother was in grief to the extent she was refusing any meetings, direct communication, or in-room presence of the donor care team. Instrumental music provided by a donor family care team member was provided in the room adjacent to the donor family with choice of music guided by donor family members. Music was chosen in accordance with the mother's culture with selections embodying the selflessness and compassion of the deceased donor.

The hospital care team, family and donor care team were in quiet presence of a mother deeply and vocally grieving while music was provided. Music, here was an important sharing of mutual respect from the donor care team without the use of words or phrases. In the moments following open communication and collaboration with this family was made possible. The donor brother who shared of the family's Christian background, chose selections of Ave Maria and Jesu Joy of

Man's Desiring. With permission from the intensive care unit nursing team, instrumental music was played in an empty room juxtaposed to the donor and donor family.

Scenario 2 Fostering Hope, Honor and Gratitude: A donor family, grieving their loved one shared their sense of chaos in what they felt was an unfair and premature loss of life. This family was initially opposed to donor recovery procedures or any disposition of remains one week following declaration of brain death. For this family who was of Buddhist faith, selections of *Amazing Grace* and *Canon in D* were played bedside as well as during an honor walk to the operating room in accompaniment of family and donor.

Music played a defining role in helping this family begin to appreciate the selflessness of their loved one's gift and hope for the potential lifesaving outcomes that followed. The family shared written words (Figure 3) to describe their experience, indicating the importance that music played: "It's hard for us to explain into words, but it deeply touched us and brought a sense of calm and gentleness in an incredibly painful moment."

There are important aspects of these cases worth noting. In both donor families the matriarchs were of limited English proficiency and had limited prior experience with the acute critical care setting. In both cases, families expressed the sentiment that they were expecting further hospital-based efforts prior to planning for disposition or donor recovery procedures. Music in both scenarios was carefully selected in accordance with family preferences and in achieving a range of emotions.

Music Selection

The musical qualities of melody, harmony, rhythm and tempo have the ability to contribute to positive physiologic and emotional responses. A randomized controlled clinical trial of palliative care participants of one music therapy intervention found significantly improved spiritual well-being, acceptance and sense of meaning (5). Qualitative research suggests that musical elements of predictable rhythm, moderate tempo and recognizable melody are associated with physiologic relaxation (3). Such selections may be more appropriate in the acute palliative care environment where death has recently occurred.

Both pairs of musical selections in the above scenarios have been historically shared in settings of mourning, redemption and hope. A family's cultural background may inform the choice of music selection. In the above examples, one pair of selections (Amazing Grace and Cannon in D) is more secular whereas the other pair (Jesu Joy of Man's Desiring and Ave Maria) are historically accompanied by religious lyrics. All four music selections provide a readily identified rhythm (Figure 2) ideal for music entrainment to the resting heart rate (60-80 beats per minute). As perhaps the greatest affirmation for the importance of music playing a positive role for families, multiple donor families have reached out to the OneLegacy Family Support Team following the day of recovery, specifically requesting the music be played at funerals following the readings of donor outcome letters.

Conclusion

The life-threatening nature of illness preceding donation after death is much greater than that occurring in the hospital-based palliative care and home hospice settings. While music has been part of interdisciplinary end of life care in many settings, it is important to note unique challenges and opportunities in the donor family care setting. While there is relatively limited time with donor families at the end of life, it is still possible to engage certain families with music guided by their preferences and cultural background.

As has been learned in research on music therapy, music carrying a range of emotions especially if families remain hopeful of lifesaving outcomes, may be more appropriate than music typically shared in a period of mourning. It is hoped that the above concepts as well as suggested music may be of interest to organ procurement organization donor family care teams, especially where instrumental music is possible.

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Figure 1: Music therapy for palliative care patients with weeks to months of prognosis. How does this differ from music for patients and families facing acute loss within hours to days of death?



Figure 2: A visual portrayal of musical entrainment of the resting heart rate at 60-80 beats per minute and music at a moderate tempo.

Donor Family Feedback About Music
"I would like to express my sincere gratitude for the beautiful violin music you played at my brother's honor walk and later at his funeral, the final day when we said goodbye to him."

"I just want to say that the music was truly special. It's hard for me to explain into words, but it deeply touched us and brought a sense of calm and gentleness in an incredibly painful moment."

"I recorded the video of you playing violin during the honor walk as our loved one was taken to the operating room. The music brought comfort and peace to our family during one of the most difficult moments of our lives. The comfort it was to our family is something we will always carry with us."

"Thank you again for walking alongside our family during such a heartbreaking time."

Figure 3: Excerpts from donor family feedback regarding experience of music at hospital bedside and funeral.

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INTRODUCTION

While music therapy has been well-established in end-of-life care settings, recommendations for music in the donor family care setting has been limited. Research on music therapy best practices has advanced in recent years with improved evidence for optimal music selections. A systematic meta-analysis of qualitative studies showed moderate to strong evidence for improved health-related outcomes for adult informal carers of adults with life-threatening illness pre-bereavement (1).

Consequently, families encountering traumatic loss of a loved one life in the donor family care setting may greatly benefit from appropriate integration of music whether it is instrumental music at honor walks, donor remembrance gatherings or at the bedside. In many palliative care settings, acoustic music played at the bedside has had beneficial impact (Figure 1). For example, licensed music therapists provide instrumental music to patients in home hospice visits. Hospitals, likewise, have palliative care teams with music therapy often integrated within the interdisciplinary team providing care at the patient bedside.

Organ procurement organizations who provide support to families facing a particularly traumatic and unforeseen loss, may benefit from considering the integration of music. The following explores evidence base to define where: 1) There are specific aspects of musical selections ideal for supporting families facing traumatic grief, 2) Whether there are care settings unique to organ procurement organizations supporting donor families facing imminent loss, and 3) Whether there are opportunities where music provided can create an active versus passive experience.

Music in the treatment of anxiety and post-traumatic stress has been previously studied for appropriate choice of genres and musical selections (3). In donor family care limited encounters prevent the ability engage with music over multiple encounters. With this in mind, musical selections with simple, repeating melodies and those which resolve dissonance into harmony may be more ideal. A predictable rhythm and restful tempo are also important elements to consider. In the acute pain setting, a clinical study identified that music entrainment, or a tempo-matching of the resting heart rate was ideal (4).

METHODS

An evaluative analysis of music in the setting unique to donor families was conducted with reference to evidence-based practice. Because of the acute and dramatic nature of terminal illness in the organ donor population, donor families are particularly susceptible to the effects of acute traumatic stress. This contrasts with other palliative care environments such as home hospice where grief and preparation of the end of life can occur over months.

There are certain donor family care environments where music may play an important role where acute traumatic stress is a barrier. Clinical research has established that music may have a beneficial effect on physiological recovery from the acute stress response both at the hypothalamic-pituitary-adrenocortical axis (2). The aim of this research was to incorporate evidence-based selection of music appropriate for acute grief and an exploration of opportunities where instrumental music may be appropriate in donor family care.

In other areas of the end-of-life healthcare continuum, the integration of music therapy or bedside music in has become integrated as a core service. Many inpatient palliative care programs and home hospice teams integrate music therapy for patients and their families in an end-of-life setting. While music in the healthcare setting has great potential for supporting families of organ donors, these families face unique aspects of grief that are important to consider. In one respect, the loss these families face is much more imminent. Their terminally ill loved ones have already expired by neurological criteria or are expected to imminently expire by circulatory criteria after discontinuation of a life support.

In contrast with families facing end of life in other settings, donor families are often anticipating the celebration of a lifesaving anatomical gift that may affect several lives and families because of selfless compassion unique to organ donation. These concepts can be translated into practical considerations for donor family care teams supporting families who experience acute grief in often complex circumstances. The following scenarios provide suggestions of music selections and settings that may be of interest to organ procurement organization donor family care teams, especially where there is a team member capable of instrumental music.



Figure 1: Music therapy for palliative care patients with weeks to months of prognosis. How does this differ from music for patients and families facing acute loss within hours to days of death?



Figure 2: A visual portrayal of musical entrainment of the resting heart rate at 60-80 beats per minute and music at a moderate tempo.

Figure 3: Excerpts from donor families regarding instrumental music at bedside and funeral.

"I would like to express my sincere gratitude for the beautiful violin music you played at my brother's honor walk and later at his funeral, the final day when we said goodbye to him."

"I just want to say that the music was truly special. It's hard for me to explain into words, but it deeply touched us and brought a sense of calm and gentleness in an incredibly painful moment."

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FINDINGS

The author presents two scenarios where music in the donor end of life care setting has been integral to donor family care. Both scenarios are representative of real cases where instrumental music with a slow, rhythmic and calming nature was played intentionally at a time of acute family stress.

Scenario 1 An Invitation to Communication: A donor mother was in grief to the extent she was refusing any meetings, direct communication, or in-room presence of the donor care team. Instrumental music provided by a family care team member was provided in the room adjacent to the donor family with choice of music guided by donor family members. Music was chosen in accordance with the mother's culture with selections embodying the selflessness and compassion of the deceased donor.

The hospital care team, family and donor care team were in quiet presence of a mother deeply and vocally grieving while music was provided. Music, here was an important sharing of mutual respect from the donor care team without the use of words or phrases. In the moments following, open communication and collaboration with this family was made possible. The donor brother who shared of the family's Christian background, took part in choosing the selections of *Ave Maria* and *Jesu Joy of Man's Desiring*. With permission from the intensive care unit nursing team, instrumental music was played in an empty room juxtaposed to the donor and family.

Scenario 2 Fostering Hope, Honor and Gratitude: A donor family shared their sense of chaos in what they felt was an unfair and premature loss of life. This family was initially opposed to donor recovery procedures or any disposition of remains. For this family who was of Buddhist faith, selections of *Amazing Grace* and *Canon in D* were played bedside as well as during an honor walk to the operating room in accompaniment of family and donor.

Music played a defining role in helping this family appreciate the selflessness of their loved one's gift and hope for lifesaving outcomes that followed. The family shared written words (Figure 3) to describe their experience, indicating the importance that music played: "It's hard for us to explain into words, but it deeply touched us and brought a sense of calm and gentleness in an incredibly painful moment."

CONCLUSION

There are important aspects of these cases worth noting. In both donor families the matriarchs were of limited English proficiency and had limited prior experience with the acute critical care setting. Both, families expressed the sentiment that they were expecting more would be offered from hospital-based efforts. Music in both scenarios was carefully selected in accordance with family preferences and in achieving a range of emotions.

The musical qualities of melody, harmony, rhythm and tempo have the ability to contribute to positive physiologic and emotional responses. A randomized controlled clinical trial of palliative care participants of one music therapy intervention found significantly improved spiritual well-being, acceptance and sense of meaning (5). Qualitative research suggests that musical elements of predictable rhythm, moderate tempo and recognizable melody are associated with physiologic relaxation (3). Such selections may be more appropriate in the palliative care environment where death has recently occurred.

Both pairs of musical selections in the above scenarios have been historically shared in settings of mourning, redemption and hope. A family's cultural background may inform the choice of music selection. In the above examples, one pair of selections (*Amazing Grace* and *Cannon in D*) is more secular whereas the other pair (*Jesu Joy of Man's Desiring* and *Ave Maria*) is historically accompanied by religious lyrics. All four music selections provide a readily identified melody and moderate tempo approximate to the resting heart rate (60-80 beats per minute). A significant affirmation for the positive impact of instrumental music was feedback from donor families requesting reading of a donor outcome letter at their loved one's funeral with the same music played at bedside on the day of recovery.

In conclusion, music therapy research has provided certain insights pertinent to the choice of music selections for families facing acute and traumatic grief. Music, the only language that requires no translation, has great opportunity to palliate in the right setting. The scenarios presented and suggested music selections intend to help other donor family care teams consider the incorporation of instrumental music into donor family care.