

Your song, my song, our song: developing music therapy programs for a culturally diverse community in home-based paediatric palliative care

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Abstract

Working in home-based paediatric palliative care with children and families of diverse cultural background presents an array of considerations for the music therapist. Developing cultural awareness, sensitivity and responsiveness is paramount in the provision of culturally appropriate palliative care music therapy services. This paper presents a preliminary discussion of cultural considerations in providing paediatric palliative care music therapy services in home-based settings for children and families of diverse cultural background.

Keywords: music therapy, palliative care, paediatrics, home-based care, culture

“You sing your song, I sing my song, but together we create our song”

(Forrest, 2006)

The past two decades have seen the rapid development and growth of specialised paediatric palliative care (PPC) services in Australia, to address the unique and complex needs of families caring for a child with a life-threatening illness. In particular, there has been significant expansion of home-based PPC services to a population that is becoming increasingly culturally diverse. Music therapy is regarded as an integral part of PPC, with its capacity to comfort (Fagen, 1982); ameliorate distress and promote adaptive coping and wellbeing (Daveson & Kennelly, 2000); and provide opportunities for fun, and improved quality of life (Hilliard, 2003). It also provides opportunity for choice and control (Amadoru & McFerran, 2007); enables bonding between parent and child (Duda, 2013); and facilitates stimulation and relaxation, enhances communication and fosters positive experiences for children and their families (Lindenfelser, Hense & McFerran, 2012). However, in spite of the

growing use of music therapy in PPC in recent years, there is only limited literature pertaining to music therapy in home-based PPC (Knapp et al., 2009; Lindenfelser, Hense, McFerran, & 2012; Nall & Everitt, 2005); and no literature discussing the influence of culture and cultural traditions and practices associated with the provision of music therapy in PPC. Given the ever-increasing cultural diversity of the communities with whom music therapists work, and also of clinicians themselves, the need for cultural awareness, sensitivity and responsiveness is paramount.

This article offers an introductory discussion about culture and how it can influence music therapy with children and families in home-based PPC music therapy. The discussion includes the ways in which culture is lived and enacted in the context of family and home life, and how it can potentially influence family engagement with services such as PPC and music therapy. The interaction between cultural beliefs, practices and traditions and the provision of home-based music therapy programs will also be examined. The vignettes presented below are based on the author's clinical experiences working with a culturally diverse community, but are constructed for illustration, rather than being actual cases. They are presented as if real cases for ease of reading. They explore the various ways in which families may engage with music and music therapy in home-based PPC.

Paediatric Palliative Care

Paediatric palliative care (PPC) is “comprehensive care for infants and children when they are not going to get better” (Strong, Feudtner, Carter, & Rushton, 2004). Employing a multi-disciplinary approach, PPC addresses the child's physical, psycho-social, emotional and spiritual needs, and includes support for the family (World Health Organisation, 1998). It may begin at any point along the illness trajectory; and be provided in hospital, at home or through a specialist children's hospice. PPC is “child-focused, family-oriented, and relationship-centered” (Himmelstein, 2006; 163); and involves the provision of culturally appropriate care that offers relief from suffering (Himmelstein, Orloff, Evans, & Wheeler, 2004; Strong, et al., 2004), enhances quality of life for the child, and supports the family into bereavement (Hain, Weinstein, Oleske, Orloff & Cohen, 2004; Himmelstein, 2006).

In my work with Mercy Palliative Care, I provide home-based music therapy programs for children living with a life-threatening illness, and their families. The children present with a range of illnesses and conditions; have various needs and symptoms; and represent diverse cultural backgrounds. Referral to and engagement with PPC and music therapy can vary widely. Some children receive PPC from the time of diagnosis; others access PPC only when

symptomatic or unwell; still others engage with PPC solely for end-of-life care. Hence music therapy engagement can vary from single-session intervention to programs that continue regularly or sporadically for months to years, with children presenting at all points along the illness trajectory, and in varying states of health.

The Home Environment

Working in the home with the child and family, I step into the family's private world, and am immediately immersed in the culture and dynamics of the family, and the roles and rituals that form part of day-to-day life for the family. Each family has its own culture, its way of doing and being, relating and communicating; and the family culture can be affected by beliefs, traditions and practices; length of time in Australia; and level of acculturation. I am a guest in the family home; and there can be many things happening in the home that may become part of, or even prevent music therapy from happening, such as family rituals and behaviours; the presence or absence of family members, friends and pets; and other activities that are taking place at the same time as music therapy. The culture of the family also includes their beliefs, family and community supports, and the ways in which they understand and conceptualise health, illness, death and dying. All can significantly impact family choices about care of the child, communication, family coping, and engagement with palliative care and music therapy.

Benefits and Challenges of Home-Based PPC

Caring for a child at home can offer a number of benefits, potentially allowing greater intimacy between the dying child and family (Himmelstein, et al., 2004), while minimising disruption to family life. Families can stay together, to support one another as they prepare for the death of their child. This can be especially important for the dying child and his/her siblings, who can feel isolated and alone when the child is hospitalised. One young adolescent of Northern Asian background described feeling as though she and her family were living in parallel universes when her dying sister was hospitalised. She came from a small nuclear family with few supports, and noted that within her culture, the death of a child is a source of great shame, something that is not talked about and which usually results in families having to leave the community. Her family would not allow her to visit her sister in the hospital as they believed she might also become unwell and die. She reflected on her sense of being utterly alone at this time, filled with panic and fear at being separated from her family. As I had previously worked with her sister at home, the family agreed to me working with the sibling. Song and lyric writing offered her an outlet to express and communicate her confusion, sadness

and sense of abandonment; and also provided a means for her to communicate with her sister, allowing them to share stories, memories and messages of love and support, and ultimately to say goodbye.

In contrast with this, two families that were part of large extended families and cultural communities, one of Middle Eastern background, one of East African background, cared for their dying children at home. In each situation, the siblings, along with extended family and community were closely involved in the care of the child and support of the family. The focus of music therapy visits was on living fully with the child until the time of death. Each family had strong faith beliefs – Muslim and Christian respectively – and noted that they gained strength and support through their faith. Information about the children’s illnesses was communicated to the siblings in context of these beliefs, and each family embraced music therapy not only for the dying child, but for the siblings, extended family and wider community, using it as an opportunity to celebrate the child’s life, support one another and grieve together, choosing songs for play and fun, but also for quiet reflection and remembrance. In bereavement, the families spoke openly about their deceased children, weaving the stories of the children’s lives into the broader family and community story.

While home-based care undoubtedly offers potential benefits for families, it can also pose a variety of challenges: parents may feel isolated and overwhelmed in their role as home-based carers and feel that they have few or no supports (Himmelstein, et al., 2004). Home-based PPC can place enormous strain on family relationships, roles, and day-to-day life (Orloff, Quance, Perszyk, Flowers, & Veale, 2004), with families living in a constantly shifting state of tension between hope and grief (O’Callaghan & Jordan, 2011). Families may also grieve and struggle with differing hopes and expectations and the care demands of their child in the absence of full-time professional support. All of these things can heighten family anxiety and distress, and exacerbate an already difficult and emotionally charged situation. In these situations, music therapy may not only address the needs of the child, but also provide a time of respite for the family from the stresses and demands of caring for a sick child, and allow them to be together in the moment, to play, interact and share moments of fun, joy, reflection and relaxation with their child.

Developing Home-Based Music Therapy Programs for a Culturally Diverse Community in PPC

While there is no literature discussing cultural issues in PPC music therapy, there is limited literature discussing the provision of music therapy for culturally diverse communities

in adult palliative care. Dileo and Loewy (2005) noted that clinicians should be aware of their own and their patients' beliefs and values, "cultural variation in common end of life issues" and "the pervasive influence of the therapist's and client's cultures on all aspects of therapy" (p. 267). Forrest (2000) discussed inter-generational differences in experience and the use of culturally specific music with palliative care patients.

Working with Families of Diverse Cultural Backgrounds

Mercy Palliative Care (Mercy) spans the Western Region of Melbourne, an area which includes urban, regional and semi-rural communities and is home to "a richly diverse community encompassing a broad range of ethnicities, languages and cultures" (Forrest, 2011;9). The population of the Western Region has a significantly higher proportion of migrants (32.6% to 58.9% (ABS, 2013b)) than Australia at large (26%(ABS, 2013a)). While the ethno-cultural background of the population of the Western Region is not the only defining element in the cultural make-up and identity of the community, a family's migration to Australia, whether recent or distant, can provide insight into family context, customs, beliefs, traditions and ways of life. However, it is important not to generalise on the basis of ethno-cultural background alone, but to be mindful that "cultural diversity occurs at both micro and macro levels, and not only between people of different cultures, but also among people who ostensibly share a similar background" (Forrest, 2011, p. 12). Cultural diversity may also be impacted by factors such as circumstances of family migration, length of time in Australia and extent of acculturation.

Family culture and identity are shaped not only by ethno-cultural heritage and country of birth, but also by the customs & beliefs of the family, and the traditions and practices they engage in. Rituals, behaviours, patterns of relationship and authority, and ways of doing and being may relate directly to a person's faith, age, gender, role, and position within the family and the broader cultural community. The musical culture of the family may reflect the values and social practices of a place and and/or community (Stige, 2002), with music providing a sense of belonging and identity (Ruud, 1998). However, the culture and cultural identity of an individual or family is not static, but rather ecological, changing over time and in response to circumstances and environments, as people move locales and communities. My own cultural background can also impact the therapeutic relationship in both significant and subtle ways: my age and gender, where I come from, my family's background and story, my beliefs, and the experiences I gain through working with a multi-cultural community all shape how I work with each individual family, and their acceptance of me in their home.

So what does this mean in relation to developing music therapy programs for children and families at home? In speaking with my colleagues, I realised that many of them conceptualise terms such as *culture* or *cultural background* only in relation to people who are different from themselves, or who have migrated to Australia. However, when I think about culture, I think about it in relation to each person I meet. Understanding “what is meaningful and important” for families (Chan, MacDonald, & Cohen, 2009, p. 117) at different stages of their journey in PPC, and how they wish to care for their child is integral to the provision of culturally responsive music therapy programs. As a clinician, it involves metaphorically stepping into the shoes of the family and looking at the world through their eyes, listening to their story, learning how the family interact and relate, and respecting their traditions and customs. It also involves understanding the role of music in the family’s life, the relationship between music and health or healing practices, and musical manifestations of cultural traditions and identity. I approach each encounter with a child and family as a cross-cultural encounter (Forrest, 2011), in which families engage with and respond to the palliative care service, music therapy and myself in myriad different ways, dependent upon their personal and family history, and their beliefs, practices and traditions and the congruence of these with my own beliefs, practices and traditions (Forrest, 2011).

Cultural Background and Identity

I work with families who have come to Australia from around the world, as well as second, third and fourth generation Australian families of diverse ethno-cultural background, and Indigenous Australian families. A family’s cultural background and identity may be complex and multi-faceted, for example, their country of birth may differ from their ethnicity, and families may incorporate traditions and practices of both cultures and countries into their lives. Within music therapy this can potentially open up a range of musical opportunities. For example, with a family of English-Indian background who listen to both English and Indian classical music, I may incorporate elements of both genres in the music therapy sessions with the child, for example marrying western classical harmonic progressions with the sounds of *tabla* and *sitar* in improvisation with the child and family.

Music, Migration and Music Therapy

Many families I work with have been in contact with or lived in different countries and cultures on their journey to Australia, and the playing of music associated with these places may elicit memories, both positive and negative, for family members. During my first visit with a family of East African background who had fled civil war to come to Australia, I asked

one of the siblings what songs she knew and liked, and she sang me a children's song she had learnt in one of the refugee camps. Her pleasure at sharing this song with me was apparent, but the song caused great distress for her mother, who asked her daughter to stop singing. It later transpired that this song represented for her what her family had lost, including one of her daughters who had died at the camp as an infant.

Understanding the family's cultural history is paramount. I have worked with families who have fled war, persecution and extreme adversity, and have observed how family history can impact the way in which families grieve and cope. Previous losses, deaths and traumatic experiences, perhaps not yet acknowledged or grieved, can be raised and magnified when the family is caring for a dying child in a safe, free and peaceful country such as Australia. This can be crucial when introducing music, with its power to move, and trigger memory, into the care of the child and family, and the choice of music must be carefully considered. Certain music may also signify oppression or control of one ethno-cultural group by another (Stokes, 1994), an important consideration when selecting songs and music for use in music therapy programs. The therapist may need to seek guidance from the family and/or cultural community about what music is appropriate to use in the context of music therapy.

Family Engagement in Music Therapy

Family engagement in music therapy can vary widely. Some families are part of large cultural communities where many members of the community may wish to observe, or participate in, music therapy sessions. In other situations, I work predominantly with mother-child dyads, or less commonly, father-child dyads. In other situations, parents of various ethno-cultural backgrounds decline to participate in or be present for music therapy. For some this may be a withdrawal from an emotionally overwhelming situation, for others, it is an opportunity to take a break from their carer role.

Developing Trust and Rapport

Some of the families I meet have a deep wariness or distrust of the palliative care service. This has been particularly apparent when I am working with refugees or families who have lived in dangerous circumstances or experienced traumatic events prior to or in the course of their migration to Australia. In these situations, rituals such as taking part in family hospitality and introductory meetings with the family are integral, allowing the family to develop trust with the palliative care team, and be reassured of the team's skills and experience. In one instance, the nurse and I were "interviewed" by the male members of a Middle Eastern

family prior to being allowed to meet the mother and child: the family enquired about our personal backgrounds, beliefs and motivations for working in PPC.

Traditions and Rituals

Traditions and rituals can form an important part of music therapy for many of the families with whom I work. Many families undertake rituals at the start or end of each music therapy visit, for example the lighting of candles or saying of prayers to bless the child, family and music therapist; and the singing of sacred or significant songs. For example, when working with a child and grandmother of south-east Asian Catholic background, I was asked at the end of each visit to sing Amazing Grace, a song that was personally significant for the grandmother, and which she described as being a prayer and blessing for her grandchild.

Ameliorating Cultural Isolation

In some situations, families have few or no supports around them, and are grieving not only the illness of their child, but also separation from their homeland, extended family and cultural community. For example, an Anglo-Irish mother who had lived in Australia for many years found that she yearned for the presence of her Irish family when her young child was receiving end-of-life care. In music therapy, we *skyped* her family in Ireland to allow them to share in the music therapy sessions, and sing sacred and traditional music from their rich Celtic and Catholic musical heritage. In contrast with this, a young couple from West Africa who came to Australia as refugees had very few family or cultural supports in Australia, and grieved not only the impending loss of their child, but also the absence of their family, whose location and wellbeing were unknown. For this family, sharing of culturally specific songs and lullabies in music therapy became a way in which the family could reconnect with their cultural heritage and share some of their story and cultural history with their young child.

Influence of Family Music Culture in Music Therapy

Cultural beliefs and practices can impact the role and function of music in family and social life, the family's understanding of the music therapist's role (as healer, teacher, performer), and the interventions and instruments that are employed in music therapy. Each family has its own musical culture, with some families having had extensive exposure to and involvement in music and music-making; and other families having had little or none. Some families bring songs in their own language or from their own culture to music therapy, bridging the musical and cultural divide between the family and therapist, and inviting the music therapist to share in the family's personal culture. Conversely, families may decline to share

their musical culture with the therapist, perhaps because s/he is not a member of their cultural group, or because it is not appropriate for the therapist to sing certain songs or play certain instruments. For example, in some Middle Eastern and African communities, only male members of the community may play musical instruments; and in some cultures, women may be banned from engaging in music-making of any sort, including singing. Some families that have a strong musical culture may play music with and for the child, both within and outside of music therapy. Other families may seek guidance from the music therapist about ways in which they can support the child using music. For example, in working with a Latin American family, in which all family members performed with a Latin dance band, I created modified guitar, drumming and singing activities that worked to the child's strengths and abilities as his illness progressed. This enabled the child to continue to participate in music-making with his family, and for his parents and wider community to engage with their child in the music which was an integral part of their identity and lives.

What is Music?

Sometimes the clinician needs to ascertain what constitutes music for a family, and what is permissible within the cultural and religious beliefs of the family. For example, some Moslem families have advised me that they do not play or listen to music. However, it may be acceptable for me to use rhythmic percussion instruments and voice in music therapy, although it is not appropriate to use melodic and accompanying instruments such as the piano, guitar and harp. The families generally acknowledge that when their children attend school or hospital, they tend not to follow this edict so strictly, largely from feeling the need to "fit in" with the predominant culture of the school or hospital. Families may also decline to record songs or music from the music therapy sessions onto CD, as music listening may be prohibited within the religion and culture of the family. In contrast with this, other families of the Moslem faith are happy for their child to be able to use and play a wide variety of melodic and rhythmic musical instruments during music therapy, and encourage recording of songs and music from the music therapy visits onto CD.

Cultural Variation in the Use of Music

I observe families from many different cultural backgrounds using songs and music to celebrate or commemorate religious, cultural, social, family or other celebrations and festivities. However, the traditions surrounding the singing of these songs can vary widely from one family or group to another: for example, for one family of European Lutheran background, Christmas carols were only sung on Christmas Eve; while for a family of South

East Asian Catholic background, the singing of Christmas carols began on Christmas Day and continued for the 12 days of Christmas, known as the *Season* of Christmas in the Christian calendar; and for many other Australian families of diverse cultural backgrounds, the singing of both traditional carols and popular Christmas songs can occur throughout December in the lead up to Christmas.

In Closing – Your Song, My Song, Our Song

Working in PPC with children and families of diverse cultural background presents the music therapist with a range of clinical considerations. Culturally responsive practice demands that therapists consider the cultural *song* of the family; their own cultural *song*; and how, through both their similarities and differences, they can come together to create a *new song*. Developing awareness of the cultural background of both self and the family and understanding the ways in which beliefs, practices and traditions can potentially impact engagement with palliative care and music therapy can assist the clinician in working in a culturally sensitive and responsive manner, to provide programs that support and enrich the lives of the child and family in PPC.

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References

- ABS. (2013a). *Cultural Diversity in Australia: Reflecting a Nation. Stories from the 2011 Census*. Retrieved 7/1/14, 2014
- ABS. (2013b). National Regional Profile 2007-2011 Retrieved 7/1/14, 2014, from <http://www.ausstats.abs.gov.au/ausstats/nrmpmaps.nsf/NEW+GmapPages/national+regional+profile>
- Amadoru, S., & McFerran, K. (2007). The role of music therapy in children's hospices. *European Journal of Palliative Care, 14*, 124-127.
- Chan, L., MacDonald, M. E., & Cohen, S. R. (2009). Moving culture beyond ethnicity: examining dying in hospital through a cultural lens. *Journal of Palliative Care, 25*(2), 117-124.
- Daveson, B., & Kennelly, J. (2000). Music therapy in palliative care for hospitalized children and adolescents. *Journal of Palliative Care, 16*(1), 35-38.
- Dileo, C., & Loewy, J. V. (2005). Advanced music therapy training in end-of-life care. In C. Dileo & J. V. Loewy (Eds.), *Music Therapy at the End of Life* (pp. 259-272). Cherry Hill: Jeffrey Books.
- Duda, L. J. (2013). Integrating music therapy into pediatric palliative care. *Progress in Palliative Care, 21*(2), 65-77. doi: 10.1179/1743291X13Y.0000000049
- Fagen, T. S. (1982). Music therapy in the treatment of anxiety and fear in terminal pediatric patients. *Music Therapy, 2*(1), 13-23.
- Forrest, L. C. (2000). Addressing issues of ethnicity and identity in palliative care through music therapy practice. *Australian Journal of Music Therapy, 11*, 23-27.
- Forrest, L. C. (2006). *Singing, Playing, Writing and Story-Telling: Creative Music Therapy Experiences in Community Paediatric Palliative Care*. Paper presented at the 16th International Congress on Palliative Care, October, Montreal, Canada.
- Forrest, L. C. (2011). Supportive cancer care at the end of life: Mapping the cultural landscape in palliative care and music therapy. *Music and Medicine, 3*(1), 9-14. doi: 10.1177/1943862110390820
- Hain, R., Weinstein, S., Oleske, J., Orloff, S. F., & Cohen, S. (2004). Holistic management of symptoms. In S. Carter Brian & Marcia Levetown (Eds.), *Palliative Care for Infants, Children, and Adolescents: A Practical Handbook* (pp. 163-195). Baltimore: The Johns Hopkins University Press.

- Hilliard, R. E. (2003). Music therapy in pediatric palliative care: Complementing the interdisciplinary approach. *Journal of Palliative Care, 19*(2), 127-132.
- Himmelstein, B. P. (2006). Palliative care for infants, children, adolescents, and their families. *Journal of Palliative Medicine, 9*(1), 163-181.
- Himmelstein, B. P., Orloff, S. F., Evans, D., & Wheeler, J. (2004). Palliative care in the home, school, and community. In S. Carter Brian & Marcia Levetown (Eds.), *Palliative Care for Infants, Children, and Adolescents: A Practical Handbook* (pp. 292-307). Baltimore: The Johns Hopkins University Press.
- Knapp, C., Madden, V., Wang, H., Curtis, C., Sloyer, P., & Shenkman, E. (2009). Music therapy in an integrated pediatric palliative care program. *American Journal of Hospice and Palliative Medicine, 26*(6), 449-455. doi: 10.1177/1049909109341870
- Lindenfelser, K. J., Hense, C., McFerran, K. (2012). Music therapy in paediatric palliative care: family-centred care to enhance quality of life. *Journal of Hospice and Palliative Care, 29*(3), 219-226. doi: 10.1177/1049909111429327
- Nall, K., & Everitt, E. (2005). From hospice to home: Music therapy outreach. In Mercedes Pavlicevic (Ed.), *Music Therapy in Children's Hospices: Jessie's fund in Action* (pp. 147-158). London: Jessica Kingsley Publishers.
- O'Callaghan, C., & Jordan, B. (2011). Music therapy supports parent-infant attachments touched by life threatening cancer. In J. Edwards (Ed.), *Music Therapy in Parent-Infant Bonding*. Oxford: Oxford University Press.
- Orloff, S. F., Quance, K., Perszyk, S., Flowers, W. J., & Veale, E. (2004). Psychosocial and spiritual needs of the child and family. In Brian S. Carter & Marcia Levetown (Eds.), *Palliative Care for Infants, Children, and Adolescents: A Practical Handbook* (pp. 141-162). Baltimore: The Johns Hopkins University Press.
- Ruud, E. (1998). *Music Therapy: Improvisation, Communication and Culture*. Gilsum NH: Barcelona Publishers.
- Stige, B. (2002). *Culture-Centred Music Therapy*. Gilsum: Barcelona Publishers.
- Stokes, M. (1994). Introduction: Ethnicity, identity and music. In M. Stokes (Ed.), *Ethnicity, Identity and Music: The Musical Construction of Place*. Bridgend: WBC Bookbinders.
- Strong, C., Feudtner, C., Carter, B. S., & Rushton, C. H. (2004). Goals, values, and conflict resolution. In S. Carter Brian & Marcia Levetown (Eds.), *Palliative Care for Infants, Children, and Adolescents: A Practical Handbook* (pp. 23-43). Baltimore: The Johns Hopkins University Press.

World Health Organisation. (1998). WHO Definition of Palliative Care Retrieved from <http://www.who.int/cancer/palliative/definition/en/>