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Supportive Cancer Care at the End of Life: Mapping the Cultural Landscape in Palliative Care and Music Therapy

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Abstract

In recent decades, the fields of palliative care and music therapy have undergone rapid formal and global development, to be practiced in many countries and cultures. Simultaneous with the global development of palliative care and music therapy has been the world-wide movement of migrants and refugees[1] which has "resulted in many . . . societies . . . becoming increasingly ethnically and culturally diverse." This has led to a growing awareness of the richly diverse cultural experiences and traditions that both clinicians and clients bring to end-of-life care and music therapy. This paper maps the discussion of cultural issues in palliative care and music therapy. The literature will be examined, key issues identified, and the impact of these on the provision of culturally appropriate palliative care and music therapy services explored, and a framework offered for considering the cultural landscape of palliative music therapy practice.

Keywords

culture, music therapy, palliative care

Introduction

It is the end of the week: time to review the music therapy patient case-load with the team. There are 4 new referrals, one for an elderly man of Polish descent, one for an English emigrant, and 2 for young children: one an infant whose family has come to Australia from the Philippines, the other a young boy of Lebanese background. There are also 3 new bereavement referrals, one for an Australian widow and his young daughter, one for a Tongan family, and one for a young Maltese Australian woman. Among those already receiving regular music therapy visits are 4 families of Jordanian, Italian, Vietnamese, and Australian background, respectively. Apart from the ethnic diversity of the clients and their differing geographic origins, there are also other differences that are apparent both across and within different groups: in language, religious beliefs and practices, patterns of relationship within families and between genders, healing and therapeutic practices, and the role of music in these and in daily life.

Mercy Palliative Care is based in the Western Region of Melbourne, an area which is home to a richly diverse community encompassing a broad range of ethnicities, languages, and cultures. This diversity is reflected in the 2006 National Census which shows that one quarter of all Australians were born overseas with a further one fifth having at least one parent born overseas. Further, people arriving in Australia come from more than 200 different countries and an additional 2.4% of the population identify themselves as indigenous Australian.[2] Importantly, when looking at "culture," the Census distinguishes between country of origin and ethnicity: for example, Chinese-born Malaysians, or English-born people of Indian ethnicity who have then migrated to Australia.[2]

How Does the Cultural Diversity of Australia Impact Music Therapy Services in Supportive Cancer Care and Palliative Care?

The cultural diversity of the Australian community at large has, in recent years, impacted the development of health care services and policy, including supportive cancer care services and palliative care. There is a growing awareness of the need for clinicians and health care services to be cognizant of the cultural beliefs and practices of patients and families, and how these may impact service provision, and how, in turn, services may need to be adapted to best meet the needs of a culturally diverse community.[3] Understanding the ways in which people

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enact care of the sick and dying, knowing what is important to them in doing this, and being open to negotiating the potentially changing role of the professional health care team within different cultural contexts are essential skills for the clinician.

Over the past 15 years, the author has worked with clients of diverse cultural backgrounds, each of whom come with their own beliefs, traditions, and practices. On entering a client's home, there is an awareness of the rituals, the patterns of behavior, the traditions and beliefs of the patient/family, and how these may shape what happens in music therapy. For example, when working with a Lebanese family whose youngest child was dying, the time of day at which music therapy visits were held needed to take into consideration the 5 daily prayer times in the family's practice of Islam. Further, instead of working with the mother and child, or with the infant and his siblings, as would most commonly occur in family-based music therapy, the author instead worked with all the female members and children of the large extended family and local Lebanese Community. This included siblings, grandmothers, aunties, cousins, and close friends with there being up to 20 family and community members present during any one music therapy session. Many of the women, particularly the older members of the family, did not actively participate in the music therapy session but wanted simply to be there, to be part of the process and witness to it. This was important—even essential—to the family, for whom daily life is grounded in community rather than individualism. Improvized songs incorporated all the various family members throughout the sessions, acknowledging their presence and role in the therapeutic space. The presence of extended family provided invaluable support to the mother as her son became increasingly unwell and she prepared for his death. The male members of the family did not participate in the music therapy sessions; however, when it was time to talk about a follow-up visit and how the family were coping with the little boy's illness, the women would fetch one of the senior male members of the family group (usually the husband, father, or brother of the infant's mother) and all communications between the women and the author were conducted through him, particularly during earlier visits with the family, while trust was being established.

How Are Cultural Issues Being Discussed in Palliative Care?

Traditionally, cancer care and palliative care services have been grounded predominantly in Western philosophy and theory. However, as communities have become increasingly diverse in their make-up, there has been a growing awareness of the richly diverse cultural experiences and traditions that both clinicians and clients bring to cancer care and end-of-life care.[4] This is reflected in the growing body of literature that has appeared in recent years.

But what is meant by "culture" in the context of palliative care? When the author first started working in palliative care, it was in an inpatient unit with a largely homogenous Western population. Her understanding and conceptualization of "culture" at that time focused primarily on the differences between herself and the patients/families, usually because they each came from different ethnic backgrounds. However, in her current practice, the author conducts home visits with patients/families of many different ethnic backgrounds, encountering both similarities and differences between patients/families, at many levels, and highlighting that the concept of culture is somewhat more complex and subtle than whether the patient/family and the therapist share the same ethnic and geographical origins.

When working with patients/families of diverse cultural backgrounds, it can be helpful to regard each and every patient/family-clinician encounter as being a cross-cultural encounter: the patient/family and therapist may or may not share the same ethnocultural background and/or geographic origins; they may share some similar beliefs and practices; but they may also differ quite markedly in other beliefs and practices. Similarities and differences may occur both across and within groups, so that for example, 2 people may share the same language and religious beliefs but be born in different countries and into very different cultural contexts. Similarly, 2 people may be born in the same city and country, but practice different religions, speak different languages, and have different understandings of the role of family and community in daily life. The experience for each patient/family is unique, shaped by the context in which they are embedded, and hence it is not possible to make generalizations about the cultural beliefs and practices of an individual or group based solely on where they come from.

When working with people of culturally diverse backgrounds in palliative care, it is important to consider not only the cultural background of the patient/family but also the cultural background of the health care professional, the culture and philosophical underpinnings of the health care service, and the congruence of these with the patient/family's cultural background. While some practices and traditions may be familiar and acceptable to the patient/family, others may seem foreign, even intimidating or unacceptable, and not fit easily into the patient/family's world view or cultural understandings. Hence, when considering what culture means in the context of palliative care, it can be helpful to think of it as consisting of the following 3 elements and the intersection between them, as shown in Figure 1:

a) **the culture of the patient and family**, including demographics such as age, gender, ethnicity, country of birth, language, family and community relationships, religious practices,
b) **the culture of the clinician** and the congruence of his or her beliefs and values with those of the patient and/or family,
c) **the culture of palliative and hospice care**, and the congruence of this with the beliefs and values of the patient and family, and
d) **the intersection between each of these.**

Chan et al, in extending the definition of culture beyond ethnicity, suggest that culture includes "what is meaningful

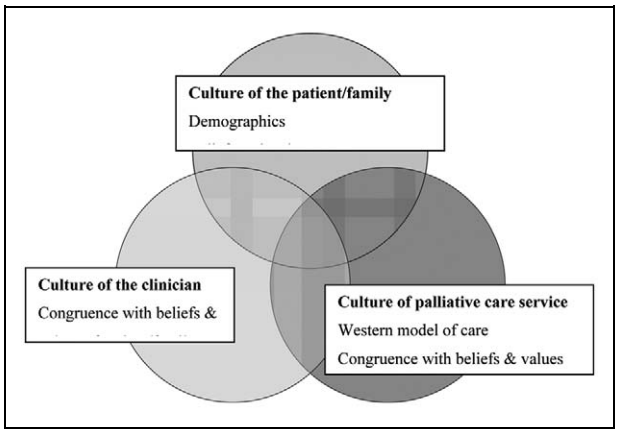

Figure 1. Meaning of culture in palliative care.

and important for patients at the end of life, and their families."[5p117] Further, understanding how patients and families view illness, death, and bereavement in the context of their culture[5] can assist clinicians in ensuring the provision of culturally sensitive care.

The discussion of cultural issues in palliative care is quite diverse. A significant body of literature acknowledges the diversity of cultural beliefs, traditions, and practices that may be present both within and across different groups,[6,7] while there is a growing body of literature exploring the provision of culturally appropriate care within individual ethnocultural groups.[8-10]

In exploring some of the considerations in providing culturally responsive palliative care to a diverse community, there are consistently 3 key areas in which patients and families may diverge in their beliefs and practices.

1. The understanding and experience of illness:

People understand and conceptualize illness in varying ways.[7,11] For some groups, such as Indigenous Australians, a diagnosis of cancer is inherently connected to the spiritual world and may be seen as a curse or punishment for a past misdeed (the author has observed this phenomenon with patients/families of diverse ethno-cultural backgrounds, including Australian, Chilean, Ethiopian, Irish, Italian, Greek, and Vietnamese).[12]

The mother of a young Vietnamese girl who had developed an aggressive brain tumor was visibly distressed during music therapy. When asked what was upsetting her, she said that she believed her daughter was sick as punishment for her being a "bad wife and mother." Her sense of shame and helplessness was very strong, and was impacting her ability to effectively care for her child. She had not told anyone in the local Vietnamese community of her daughter's illness as she said her community believed that the illness of a child was the fault of the mother for a past misdeed. She asked the palliative care staff to come in unmarked cars and remove their ID badges so that her neighbors would not know who the people were who were visiting her home, or why. While music therapy did not change the mother's beliefs, the music therapist was able to reframe her experiences, highlighting and reinforcing all the positive and supportive things that the mother was doing for her daughter both during her illness, and also throughout her daughter's life. Engaging the mother in music activities with her daughter also strengthened her confidence and reinforced her belief in her ability to nurture, support and care for her daughter, which in turn encouraged her to spend more time in play and fun with her daughter.

2. Communication and Language:

For some families, it is preferable neither to tell the patient his/her diagnosis, nor to have discussions about death and dying with either the patient or family as it is believed this is not supportive care, and removes hope.[11,13,14] Where it may not be appropriate to use words such as "death" and "dying" and phrases such as "terminal care" and "end-of-life-care," sensitive topics may be broached using alternate words and phrases. Asking general questions such as "What is important for you in your life and at this time?" and more specific questions such as "Have you thought about where you would like to be (home or hospital) if your situation changes in the future?" or "Can you tell me who you would like to look after you if you became unwell?" can enable discussion at a more general level while also providing the clinician with information about patient/family preferences. Questions such as "Can you tell me how you are feeling today—are you tired, are you eating and sleeping well, does anything hurt?" and focusing on what can be done to alleviate issues that arise can allow exploration of patient symptoms and changes that the patient/family are experiencing without alluding to diagnosis or prognosis. Importantly, following the lead of the patient/family when engaging them in sensitive discussions will help to ensure that inappropriate topics are avoided.

Language barriers and differences in cognizant conceptual frameworks can also significantly impair meaningful discussion between clinicians, patients, and families.[15] Within some languages, there is not a word to describe cancer[16] and concepts such as "palliative care," "pain," and "relaxation" can be difficult to translate from one context and language to another.

With many non-English speaking patients and families, the author uses alternate words to describe concepts such as "music relaxation": for example, music for rest or sleep, music for healing, music that is soft, peaceful, quiet. Similarly, patients may find their own words to describe a concept: for example, a Chilean lady who was very anxious used the following words to describe music relaxation: "music is the lullaby for my heart to rest."

3. The involvement of family, community, and hospice in care of the sick and dying

The way in which patients and families share decision making and undertake care of the sick and dying can vary greatly. Within some cultures, the involvement of family,

church, and community in the care of the dying is preferable to receiving professional care from hospice or hospital staff.[10,11] In other situations, families may rely primarily on the support of such professional services.

The place of death may also be significant. For many Indigenous Australians, connection to homeland is of the utmost importance,[14] and separation from homeland can cause immense grief and even be seen to precipitate death. Similarly, for some migrant families, connection to homeland can be of great importance, and families will sometimes assist the patient to return to their country of birth to die, or alternatively, enable them to remain at home to die, surrounded by family and community, rather than entering a hospice or hospital to be cared for by strangers. However, although some migrant patients may wish to remain at home, they may be unable to due to lack of family and/or community supports.[11]

The wife of a Philippino couple with whom the author worked had an aggressive cancer and was admitted to hospital intermittently for treatment, and when her husband became unwell and was unable to care for her at home. However, she was reported to become depressed during her hospital stays and wanted only to return home to her husband. Due to the distance of the hospital from her home, it was difficult for her husband, friends, and local church community to visit her when she was in hospital, and she said she felt very lonely and sad being apart from them. Likewise, her husband expressed his immense sadness at being separated from his wife during her hospital stays. In contrast to this, when the wife was able to stay at home, she and her husband were closely supported by the local Philippino community and members of their church, and they often spoke of how they felt well-supported, happy, and at peace.

Importantly, when considering cultural issues in palliative care, most authors acknowledge 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.

Culture and Music Therapy

Just as cultural awareness in palliative care has developed globally in recent decades, so too has the awareness of cultural issues in music therapy practice, although the literature to date is still quite limited.

Amidst discussion of the need for clinicians to practice in a culturally sensitive way[17,18] is a growing body of literature looking at the richly diverse cultural experiences and traditions that both clinicians and clients bring to the music therapy process.[4,19-21] Discussions also span the experiences of music therapists working within cross-cultural contexts[22-24]; with single cultural groups, for example, Jewish-Israelis[25,26] and Argentine Australians[27]; and with refugees.[28,29]

Within the field of palliative music therapy, the discussion of culture and cultural issues is quite scant. Dileo and Magill,[30] Dileo and Starr,[20] and Forrest[4] explore aspects of their clinical work and present case material of their work with clients from diverse cultural backgrounds. The authors examine a range of issues including:

- Cultural identity, intergenerational differences in experience within families, and the use of culturally specific songs in palliative care,[4]
- discussion of the use of culturally specific musical styles and song forms that can be used to facilitate songwriting with clients of different cultural backgrounds,[30] and
- cultural meaning and values and how these can shape patient, family, and clinician experiences of palliative music therapy.[20]

Dileo and Loewy[31] also discuss the importance of developing specific skills in order to improve their ability to work multiculturally within palliative care. These include knowledge of one's own "values, beliefs, prejudices and biases . . . sensitivity to cultural variation in common end of life issues" and an "indepth understanding of the pervasive influence of the therapist's and client's cultures on all aspects of therapy."[31p267] Musically, it is important for clinicians to have knowledge of the client's preferred music and also an understanding of the cultural context in which the music is embedded.[22]

Gretel migrated from Russia to Australia following World War Two. In her early music therapy sessions, her preferred music was Western classical, dance, and theatre music. Knowing of her Russian background, the author asked her if she would like to hear some Russian classical or traditional music. However, Gretel said that she had not listened to this music since fleeing from Russia in wartime and subsequently learning of the deaths of her first husband, infant child, parents, and brothers. For Gretel, Western music represented her "new" life in Australia, whilst Russian classical and traditional music was representative both of the atrocities suffered by her family, and her separation from her homeland and cultural heritage, and imbued with unresolved grief and pain. In the context of music therapy, awareness of Gretel's story as part of the broader cultural context of traditional Russian music in her life was essential in ensuring the provision of a safe and supportive therapeutic space in which Gretel could explore her feelings of loss and grief.

So what does all this mean for clinicians providing music therapy services for cancer patients and families of diverse cultural backgrounds? How can clinicians become more culturally aware and responsive within their day-to-day clinical work?

Table 1 illustrates the framework that has developed out of the author's experiences and reflections of providing palliative music therapy for patients and families who come from diverse cultural backgrounds. It considers the cultural landscape of (1) the patient and family, (2) the music therapist, and (3) palliative care music therapy; and how these can inform and guide the therapist's approach. While this table offers an approach for working in a culturally sensitive way with clients, clinicians should also be thoughtful of situations where their presence may not be helpful or supportive of the clients' cultural beliefs and practices—for example, when a male client

Table 1. Framework for Considering the Cultural Landscape of Palliative Music Therapy Practice

The cultural landscape of the patient/family	Demographics—ethnicity, age, gender, country of birth, language, religion, beliefs, and values Presence of or separation from family and community supports; family relationships and roles; social and community roles Migration—From where? To Where? Intercity, Interstate, international, circumstances of migration What is important to the patient/family? How does the patient/family use music: in day-to-day life, in healing, and therapeutic contexts? Patient/family expression and enactment of care of the dying, grieving, and bereavement according to their worldview and cultural understandings
The cultural landscape of the music therapist	Demographics: ethnicity, age, gender, Country of birth, language, religion, beliefs, and values Professional education and training Working within a health care system built on Western values and models of care
The cultural landscape of home-based palliative care music therapy	Medical/nursing needs of the patient; potential interventions; patient/family understanding and acceptance of these People involved in care of the patient, their roles and expectations, and the patient/family's expectations of them Patient/family understanding of and engagement with music therapy—is it considered integral, central, peripheral, unimportant in overall care? Boundaries and capacity of the music therapist—how do these "fit" with the expectations of the patient/family? Time available to work with patient/family—hours, days, weeks, months Going into the family home—personal family culture meeting the culture of the health care service and the clinician Congruence of the music therapist's clinical practices with the cultural practices of the patient/family
Therapist approach	Being mindful of preconceptions and expectations, biases, and beliefs Being open to differences between expectations and reality Ongoing process of checking in with the patient/family: "Is this ok?" "What would you do usually?" Being receptive and responsive to what patient/family client is expressing/requesting; and not expressing/requesting Adjusting presence to meet the individual needs of the client—for example, removing shoes at the door, covering arms/legs/head as required, adjusting music interventions dependent on appropriate patterns of relationship and interaction Learning how families use music in their day-to-day lives Remembering that, in our sameness and our difference, at the heart of every encounter between therapist and client lies the truth of our common humanity

requests a male clinician—or when clients may not accept the clinician for a particular reason, for example, his/her religious beliefs. Clinicians should also be mindful of potential differences in beliefs and practices within a family: this can be particularly apparent at an intergenerational level.

In Closing

Awareness of culture and cultural issues in palliative care and palliative music therapy practice continues to grow. The term ''culture'' is, without question, a challenging and somewhat elusive term to understand and to define, given that it can represent different things to different people.[32] Culture may refer to groups of people, places, events, the arts. However, culture—and more specifically, cultural acts, traditions, artifacts, beliefs and values—is also what informs each person's understanding of the world and his or her place in it. Culture is the contextual lens that frames experience and gives meaning to life. Clinicians have a responsibility to try and work in a culturally responsive way with their clients, and to do this, they must first be responsive to themselves and their own cultural beliefs and biases.[32] When they understand what it is that gives meaning to their lives—whether this be the religious beliefs they hold, the music they use for different celebrations or remembrances, or the way in which they relate to members of their family and community—they can be more open to what is important and meaningful for the client. Awareness of both the similarities and differences between clinicians and clients can help clinicians to engage and respond in a more culturally responsive manner: with openness, empathy, and respect. Ultimately, looking through the lens of culture and cultural expression allows one to see the weave and pattern of humanity, in all its subtlety, complexity, and intricacy, and in its multiple layers of truth.

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Bio

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