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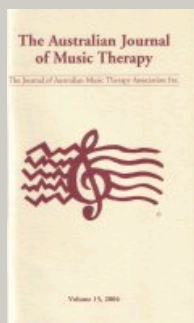
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Expanding from Hospital to Home Based Care: Implications for Music Therapists Working in Palliative Care

By Anne Horne-Thompson [\[Author bio & contact info\]](#)



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The focus of health care within Australia is shifting. Health care programs, traditionally the domain of large hospitals, are increasingly becoming community based. As music therapists, we need to be aware that these changes are occurring and the implications that this has for our work. The purpose of this paper is to present a comparative examination of the role of music therapy with palliative care patients in contrasting settings - home and hospital. The material will be drawn from the author's direct clinical experience as well as music therapy and other health care literature. Awareness of the topics discussed will inform future research in the clinical practice of music therapists working in palliative care, as well as music therapists witnessing this change in other settings.

Traditionally, patients living with a terminal illness in western societies have spent much of their time, and have ultimately died, in hospital. Since the beginning of the hospice movement, care provision for terminally ill patients has been regarded as a philosophy, entailing the provision of holistic care to patients in hospitals and hospices. The term "palliative care" has now been adopted, incorporating hospital, hospice, and home based care (Spencer & Daniels, 1998; Aranda, 1999). Bruera et al. (1999) contended that the shift from deaths primarily occurring in acute care facilities to hospices indicates the establishment of integrated palliative care programs, which increase access for terminally ill patients to palliative care. The purpose of this article is to explore the changes this has had for music therapy and future implications for practicing music therapists.



There are many factors determining the place of palliative care provision. While some people prefer to die in hospital, an increasing number are now choosing to die at home. In Australia, patients' autonomy is encouraged through making choices and taking responsibility for decisions made about their care. In fact, various authors have found that between 50% and 70% of patients with a terminal illness wish to die at home (Dunlop, Davies & Hockley, 1989; Ashby & Wakefield, 1991; Axelsson & Christensen, 1996). In an article, "The Hospitalisation of Death: Should More People Die at Home?", Bowling (1983) stated that home death is more natural and that people dying at home have more chance of influencing their quality of life. Addington-Hall, MacDonald, Anderson and Freeling (1991) found that enabling patients to die at home is preferred by carers and patients. With the majority of people with terminal illnesses preferring to die at home, community based palliative care services are now regarded as an extension of hospital care. This is also believed to be potentially cost effective (Hess, 1999). Often, due to economic necessity, home care is the main form of palliative medicine service across the world (Aranda, 1999).

Other variables which influence place of death include psychosocial, physical, and cultural factors (Van den Eynden et al., 2000). Psychosocial factors influencing whether a person dies at home or in hospital include whether the patient lives alone, whether they have a support network, and what their coping mechanisms are. Among those patients with a willing carer, research findings suggest that family care perceptions may be the primary factor of family care satisfaction (Medigovich, Porock, Kristjanson, & Smith, 1999). In terms of physical factors, complex physical symptoms may not always be adequately managed at home, also affecting the patients' place of death. Patients may be transferred to hospital to cater for complex symptom issues. The prevalence of symptom issues varies among published studies, and these differences are thought to be dependent on the setting (home or hospice), patient selection, study design, different measurement tools, and cancer types (Mercadante, Casuccio & Fulfaro, 2000).

In some cultures, it is more natural to both live and die in the family home. Health care professionals are becoming increasingly aware of the importance of providing comprehensive culturally sensitive care to patients, who often present with varying ethnic differences (McNamara, Martin, Waddell, & Yuen, 1997). This is particularly evident in Australia, which has a high migrant population, as well as an indigenous population. In 2001, 23.1% of Australia's population was foreign born (Australian Bureau of Statistics, 2001). In the author's experience, many European families prefer to care for patients at home, and their extended families provide the care normally offered by health care professionals in hospital settings. Music therapy service provision, traditionally hospital based, needs to accommodate this shift to community based care, and music therapists need to look at the implications that this will have for music therapy services in palliative care.

Hospital and Home-Based Music Therapy Programs: Evolution and Future Challenges

As health professionals working in domiciliary (home based) palliative care services have become aware of the benefits of providing holistic care to their patients, the number of music therapists employed in these settings has increased. Since 1992 in Victoria, home based music therapy programs in palliative care have increased from zero to five (Hogan & Cockayne, 2003).

Literature published on the role of music therapy in palliative care is growing. The vast majority has focused on the benefits of music therapy to patients in hospice or hospital care both in Australia and beyond (Bailey, 1984; Bright, 1989; Hogan, 1998, 1999a; Krout, 2000; Lee, 1995; Martin, 1991; Munro, 1984; O'Callaghan, 1990, 1996a, 1996b; Salmon, 1993). While this literature has informed clinical practice for music therapists working in palliative care, the author found only a limited amount of literature discussing the benefits of music therapy specifically in home based care (Mandel, 1991; Marr, 1996; Munro, 1984).

The author is employed at a palliative care facility, which also provides a domiciliary (home based) palliative care program. The program is multi-disciplinary, with all team members contributing to the care of patients. Patients may be referred to music therapy for a variety of reasons, including both physical and emotional symptom issues. In accordance with Hogan (1999b), ". . . the ultimate aim of music therapy is to assist terminally ill patients in searching for their rite of passage by playing or performing music" (p.69). This includes adapting the elements of the music to address physical, emotional, and spiritual issues. Once immediate issues are resolved, it can reach out to other dimensions of patients' suffering and finally help the patients' transition from this life (Hogan, 1999b).

The author first provided music therapy services in the hospital, followed by the home based program. As work commenced in the home based program, the music therapist found that the differences between hospital and home based care were striking. The methods implemented and developed for inpatient work were not as effective in the community. This was despite the fact that the patients were often the same, as they were admitted from home to hospital and vice versa. The author had been informed by relevant literature discussing inpatient palliative care, including the work of Bailey (1984), Hogan (1998), Munro (1984), and O'Callaghan & Colegrove (1998), but soon developed new techniques and strategies to adequately cater for palliative care patients living at home. The author's experience indicated that the factors influencing the quality of music therapy service provision in the home as opposed to the hospital were: (a) the importance of an effective introduction; (b) the role of music therapy processes and perceptions (c) session length; and, (d) family dynamics. Each of these will now be discussed.

Factors Influencing Palliative Music Therapy in Homes

The Importance of an Effective Introduction

In both the inpatient and domiciliary programs, patients are referred to music therapy by nursing and medical staff, allied health practitioners, volunteers, and families. Self referrals also occur. Hospital staff, however, initiates the majority of referrals, and this is often the first time that patients have ever been exposed to music therapy. The importance of an effective introduction immediately became apparent. The way in which music therapy is introduced can ultimately determine whether or not patients will participate. O'Callaghan and Colegrove (1998) found that patients were more likely to refuse music therapy when their music preferences were not elicited, and when music therapy methods and benefits were explained. The author discovered that hospital based patients are initially more likely to accept music therapy than home based patients. Some reasons why this may occur follow.

Issues of control. West (1994) and Mandel (1991) discussed the importance of offering patients the option to refuse or accept music therapy, in order to experience some control over their environment and identity. Marr (1996) stated that music therapy provides palliative care patients with an opportunity to exercise choice and control at a time when most feel as though they have lost control over their lives. While both hospital and home based patients have the choice to receive or refuse music therapy at any time, patients living at home may often feel they have greater independence and control over their environment. Patients in the home would frequently state that they didn't really "need" music therapy at the moment. Patients in an unfamiliar hospital environment were possibly more vulnerable and, as a result, more likely to comply with suggested health care interventions. When introduced to music therapy, a hospitalised patient recently stated, "Do you think it's a good idea? Okay."

Loneliness. Patients dying at home are usually provided with care 24 hours a day from their carer, most often a partner or spouse. Being surrounded by family and friends reduces isolation. In contrast, inpatients are frequently alone as they are often admitted to hospital because they are unable to care for themselves at home alone, or their partner is too frail to care for them. As a result, these patients are more isolated and, as such, may welcome the increased support of music therapy. This input may decrease their sense of loneliness and increase socialisation.

Observing sessions. When music therapy sessions are observed it provides onlookers with evidence of benefits and outcomes. As many of the rooms in the hospital are shared, inpatients often have the opportunity to see music therapy in action with another patient. This will often encourage them to participate or to request their own music therapy session. This is supported by O'Callaghan and Colegrove (1998), who found that 73% of patients participated in music therapy if they had heard music therapy before meeting with the music therapist. Home based patients do not have this opportunity and, therefore, are not as aware of the benefits to be gained.

Rapport. In the hospital, there are many opportunities to build rapport if patients initially refuse music therapy. Patients may still enjoy engaging verbally, and room mates often participate in music therapy sessions. Patients will often decide to participate after meeting with the music therapist a number of times, once they have gained confidence in the music therapist. Bailey (1984), when discussing music therapy in cancer care, highlighted the importance of establishing rapport: "The music therapist endeavours to develop an environment of satisfaction and trust" (p. 6). She described three stages in the music therapy process, the first one being contact: "The music therapist and patient and/or family establish trust and a working relationship. There is usually a greater focus on other than on self on the part of the patient and/or family" (p. 6). One hospitalised patient refused music therapy to assist in managing his pain, stating that he had never been interested in music. After engaging in general banter with the music therapist over a period of days and gradually becoming more familiar with the music therapist and the concept of music therapy, he asked for a session, stating that "it couldn't do any harm." Alternatively, in the home, there is only one opportunity to establish rapport before a patient decides whether or not to receive music therapy services.

Progression of disease. Home based patients need to have a prognosis of 6 months or less to be admitted to the service. Inpatients have an average prognosis of only 3 months or less and their stay is, on average, approximately 15 days. In the author's experience, home based patients often stated that they were too well to need music therapy. In the hospital, patients were keen for input from music therapy staff, possibly because they thought they were closer to death.

In sessions that occur in the hospital, there appears to be little need to prove the worth of music therapy in the first meeting. Hospitalised patients frequently agree to participate in music therapy with very little verbal introduction. Instruments are nearby, and the music itself allows the music therapist to establish a quick rapport (Weber, 1999). Alternatively, when introducing the concept of music therapy to home based patients via telephone, they would often refuse music therapy participation, despite the fact that the referring staff member (most often their primary nurse) had discussed the benefits with them. The author learnt that it was far more effective to make an appointment with home based patients to introduce music therapy face-to-face, before beginning music therapy sessions (B. E. Hogan, personal communication, May, 1999). This helps to familiarise patients. They can better contextualise the concept and, as a result, are more likely to accept music therapy. Unlike the hospital setting, it is often too threatening to arrive at a first home visit with instruments and sheet music. Equipment is often left in the car while initial contact is made and it is frequently not until the second session that music actually occurs. Once this first contact had been made, patients were much more likely to continue with music therapy.

The Role of Music Therapy — Processes and Perceptions

The perception of the role of the music therapist also varies enormously between home and hospital. The unfamiliar hospital environment can be very threatening for many patients and can lead to anxiety and isolation (O'Brien, 1999; Spintge, 1989). In the author's experience, music therapists are often perceived by patients as one of the less threatening and, therefore, more approachable individuals in the hospital. Music therapy sessions often begin informally, as patients are often delighted to see instruments and music (something familiar to them) in this alien environment. They view music therapists as one of the few health professionals in the hospital who are not going to perform any unpleasant procedures. Additionally, the author found that inpatients have an expectation that they will be visited by many health professionals and are open to this.

Alternatively, in the home, the author found that the music therapist is another one of the many health professionals invading the patients' homes to deal with symptom issues. They are visiting patients in their own environment: in effect, their own territory. Due to the large number of health professionals involved in the patients' care, another visit may be experienced by home based terminally ill patients as invasive and intrusive. Munro (1984) and Marr (1996) discussed the fact that home based patients can often be reluctant to let yet another health professional into their home. As a result, at times a higher expectation is placed on the music therapist working in the home environment.

Once rapport has been established between the hospital patients and the music therapist the role and potency of music therapy is understood more clearly. Once rapport has been established in the home, the relationship becomes less formal, due to the fact that the music therapy session is held in a less official, more relaxed, and familiar environment. As Marr (1996) stated. "The home is the patient's space and the therapist needs to relinquish some sense of control over the session and its content" (p. 124)

Session Length

Once this initial contact has been made, and sufficient rapport established, it is interesting to compare the length of sessions in the home and the hospital. If patients choose to continue with music therapy after the initial contact, session length between home and hospital varies significantly. This is reflected in the service activity statistics that are collected on a daily basis by the music therapist. Direct contact time with patients in the home is more than double the time spent with hospitalised patients.

One possible explanation for this difference is the reduced chance of being interrupted in the home. Patients often scheduled their day around the session and this resulted in fewer interruptions. In hospital, sessions were often cut short by factors such as patients arriving back to their room (the majority of rooms at the hospital are shared) and visitors arriving. In many cases, psychosocial issues can also be explored in more depth in the home, as patients had more privacy and less interruption.

Furthermore, the way in which patients were greeted, whether it was a first or subsequent session, was also of paramount importance in the home. An initial discussion with the patient and/or family about anything from the weather to the patient's situation was always expected in the home (Marr, 1996). This often increased the length of time spent in a session. As Marr (1996) wrote:

This may at first seem to be a precious waste of time (and money), but it is a valuable chance to assess affect, symptoms and general ambience for both

Munro (1984) also mentioned that these greetings become "vital rituals in the therapeutic relationship" (p. 11). Alternatively, in the hospital, patients had an expectation that as a busy health professional you were there to "perform" music therapy and then move on to your next appointment.

Movement of time is also perceived differently in the home as compared to the hospital setting. In a palliative care setting, although quite different to an acute hospital setting, the music therapist has noted an obvious movement of time, with staff, patients, and visitors moving about. In someone's home this does not occur to the same degree and, for patients, the time frame appears to move much more slowly. This difference in length of session between home and hospital may also have further implications in terms of cost effectiveness and would warrant further research.

Family Dynamics

The role of family varies enormously between inpatient and domiciliary programs which, in turn, impacts on the role of music therapy in these settings. One of the main differences is the physical presence of family. In the hospital, some family members play an enormous role in the care and support of the patient. Families are welcome to stay overnight with patients in hospital, by their bedsides, or they are given access to a room providing comfortable accommodation with ensuite facilities. The majority of patients, however, do stay alone, and this can be extremely isolating. Often through necessity, many family members visit after working hours and do not have the opportunity to liaise with many of the health professionals. Elderly patients' partners are often unwell themselves, so visits are limited. As a result, the music therapist will frequently have limited contact with families of hospitalised patients. The music therapist often liaises solely with medical, nursing, and allied health staff about the purpose and outcomes of sessions.

In contrast, patients dying at home have their family members with them. Many spouses and partners of patients take leave or resign from their jobs so that they can provide constant care. Families play a much more active role in the care of the patient. They perform roles such as showering, toileting, dispensing medications, and other care that is normally provided by health professionals. They know what is happening with the patient in much greater detail than anyone else involved in their care. Therefore, this has enormous implications for the music therapist. The families will assess your worth and value in the patients care as much as the patients will. They also have an enormous role in deciding whether or not the music therapist should be involved in the patients' care. In the domiciliary program, the music therapist may liaise just as closely with families about the benefits and aims of sessions as they do with health professionals.

Families are often present during sessions and this makes the role of music therapy particularly potent. It is likely that the music therapy program will be treating family members as much as the patient themselves. Smith (1990) stated:

Support offered to the family in facing the reality before them not only helps them to cope better with the illness, but reduces the likelihood of later complications. We must also realise that the patient's symptoms and the family's reactions are not unrelated, and therefore addressing both aspects is healthier for the patient and the family. (p 127)

Music therapy can help to alleviate the sense of isolation which patients and families often experience (Salmon, 1995). Music therapy can provide a non-threatening and "safe" avenue for patients and their families to express feelings, which they may be unable to do verbally. As well as addressing the needs of the patients, family needs can also be met, and sessions often provide a safe and contained space for this to occur. Consequently, family members will often continue with the music after the session has concluded.

Once initiated, certain activities (singing, making and playing tapes, and searching for songs, etc.) can be continued by persons close to the patient. This may reduce their feelings of helplessness and may turn the focus away from illness to life-confirming activity. (Porchet-Munro, 1993, p. 558)

Conclusion

The purpose of this paper was to compare the role of music therapy within a palliative care

facility, as opposed to the home. Based on the author's clinical experiences, the role that the music therapist plays in the home as opposed to the hospital varies markedly. Although similar aims are addressed, the method and manner in which the deliveries of these occur is quite different. As the shift from facility to community care is expected to continue, music therapists need to embrace these differences and consider new and diverse ways to address the needs of patients and their families.

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