Exploring the Value of Opportunities for Choice and Control in Music Therapy within a Paediatric Hospice Setting

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Abstract
This article explores the value of providing opportunities for choice and control in music therapy sessions within a children’s hospice. The field of paediatric palliative care is briefly described and contextualised within better known fields of music therapy practice. Relevant literature is reviewed describing the role of choice and control in adult palliative care, paediatric medical settings, and special education. The unique dimensions of music therapy practice in a paediatric hospice setting are then outlined using a model of the therapeutic interaction, illustrated by three clinical vignettes. The authors conclude by reflecting on issues arising from offering multiple opportunities for choice and control within sessions, including rejection, chaos, and the question of value.

Key Words: children’s hospice; choice and control; empowerment; music therapy; palliative care; paediatrics

Introduction
The field of paediatric palliative care has recently emerged as a distinctive element of traditional palliative care models that requires unique understandings (Hynson & Sawyer, 2001). Unlike adult palliative care, paediatric palliative care may support children and families across many years, through all stages of a serious illness, from birth until death. The range of people embraced by this model includes those with cystic fibrosis, muscular dystrophy, Rett’s syndrome, severe epilepsy, Lennox-Gastaut syndrome, leukodystrophy, spinal muscular atrophy, rare genetic and neurological disorders, as well as cancer and other diseases of sudden onset. A significant feature of these disorders is their chronic nature, meaning that the child’s potential to die is constantly present, either due to...
the effects of the disorder or their decreased immunity to other illnesses. Alternately, the child may live to reach their young adult life with relatively few complications (Horsburgh & Huckle, 2002). Thus, paediatric palliative care is signified by both its breadth and length of availability, and its mission is to provide continuity of care for families as they progress through the various stages of their children’s chronic or terminal illnesses. It acknowledges the uncertainty that exists for families as they attempt to achieve a high quality of life for their children, whilst being constantly aware that their time is limited (Very Special Kids, 2003).

There are a number of features that assist in conceptualising paediatric palliative care within the discipline of music therapy. Although the most obvious is its relationship to the field of adult palliative care, there is also a clear overlap with clients who are typically seen in both special education and paediatric medical settings. The knowledge bases from developmental and medical models therefore also have relevance. A distinctive feature that resonates with each of these models, and perhaps across the breadth of music therapy practice, is the value of offering opportunities for choice and control to clients and families. During the primary author’s clinical placement as a student training with the secondary author, this facet became the focus of clinical work and discussions, resulting in the current article. The aim of this paper is to elucidate these initial conceptualisations and explore the value of opportunities for choice and control in working with young people in a hospice setting. The relevant music therapy literature from the fields of paediatric medical settings, special education, and adult palliative care have been summarised in order to provide a basis for this discussion. This material will be introduced with an explanation of the paediatric palliative care facility where the work took place, and conclude with a brief discussion of issues that have emerged. Three case vignettes are offered in order to illustrate how opportunities for choice and control are actualised within this setting.

The Setting

Very Special Kids (VSK) is a children’s hospice in the inner eastern suburbs of Melbourne. While the VSK organisation was founded by Sr. Margaret Noone in 1985, the free standing hospice opened in 1996. Based upon models of care already provided in the United Kingdom, it was the first facility of its kind in Australia. VSK offers an extensive range of support to families of children with a life-threatening illness, focused around an attractive house where children stay and have access to high quality medical care. The hospice has a multi-sensory room, music room, pool table, TV space, and a spa for use by the children and/or families, as
well as a dining room for the whole family to sit down together. Some families choose to remain fully involved in the child’s care, while others elect to have a well-earned rest. This environment is designed to provide respite for both parents and children who may have few opportunities to spend time away from one another. In addition, there are many complex emotional issues surrounding a child with a chronic illness that make it difficult for all family members to contemplate an unnecessary separation. The role of the children’s hospice is to normalise the need for multiple forms of care and to make this care accessible and attractive at all stages of a child’s life, including the terminal stage.

The organisation aims to improve the quality of life for children in their care through the provision of expert nursing care, coupled with extensive psychological care provided by carers, a music therapist, social workers, and bereavement counsellors. This includes hospice-based programs plus a range of home-based services, including volunteers in both settings. The music therapy program takes place within the hospice, and is informed by existential and humanist theory, with the broad aim of improving the quality of life for the young people during their stay. Music therapy offers opportunities for choice and control, self-expression, and emotional release, encouraging communication that recognises each individual’s uniqueness. The therapeutic interplay that occurs through musical activities is explored to provide experiences that are positive and creative, and that promote a relaxed, fun, and familiar experience in individual, family, and group sessions.

**Literature Review**

The term “empowerment” has been used within recent music therapy literature for this discussion of choice and control. Daveson (2001) described empowerment as “being a means that assists in the restoration of control through the experience of choice” (p. 29). When defined in this way, the term captures the nature of choice and control as it is employed within a palliative framework. Procter (2001) described the aim of empowerment as focusing on people’s ability and potential for wellness, rather than their disability and illness. This understanding of empowerment is also relevant.

Within a paediatric palliative care framework the concept of empowerment is based on the assumption that the experience of chronic illness damages the family’s “perceived” sense of control over the life of their child, resulting in an existential crisis for all concerned. “What is remarkable is not that children arrive at adult views of the cessation of life, but rather how tenaciously throughout life adults hold on to the child’s beliefs and how readily they revert to them” (Rochlin, 1967, p. 63).
The contemplation of death is difficult for most human beings and this task is made more challenging when it is the death of a child (Hynson & Sawyer, 2001). It is this perceived loss of control that is frequently addressed in paediatric palliative care, as well as the actual loss of control, both over the body and the environment, that occurs during the journey through chronic illness.

The literature describing music therapy in paediatric medical settings exemplifies how the music therapist addresses the more practical loss of control through the provision of choice in hospitals. Inpatients experience a loss of personal control in response to surgery and treatments, to which music therapists respond by offering choices regarding participation in music making, instrument choice, and the way instruments are played (Aldridge, 1993; Cowan, 1991; Robb, 1999). This is considered to renew a child’s sense of independence and restore a personal sense of control over a small part of the environment. Therapeutic songwriting is also popular in hospital settings, providing multiple opportunities for choice, including the level of participation, decisions on lyrics, and musical material, as well as the future of the song (Aasgard, 2003; Edwards, 1998; Ledger, 2001). Aasgard, Edwards, and Ledger included mastery as an important aspect of the therapeutic process, with the song representing an opportunity for pride in accomplishment, particularly for adolescents. The influence of the hospital context is clearly present in these descriptions, as the young person grapples with invasive treatments and an unfamiliar and sometimes unpredictable environment. The need for empowerment is immediate and temporary and music therapy is seen to restore rightful control.

In the field of special education, students may be considered as empowered through a therapeutic orientation that addresses development, allowing them to achieve their full potential. Music therapists typically focus on the achievement of developmental milestones across physical, social, cognitive, and emotional domains. The concept of choice and control is often incorporated into the facilitation of emotional expression, with children using their instruments and voices to gain “closer contact with what they are feeling and communicating” (Ford, 1984, p. 12). La Fon (1989), however, noted that typical definitions of music therapy in this context are often limited to the reinforcement of socially acceptable behaviours, an understanding that allows little room for choice and control. Despite this perception, many descriptive articles capture a contrasting approach, particularly with children whose developmental delay is closely associated with emotional distress (e.g., Rickson, 2003). Similarly, Meadows’ (1994) review of the literature for children with severe and multiple disabilities reveals goals such as fulfilling basic needs and developing a sense of self that exist alongside the more educative focus of
goals focused on developing specific skills and dispelling pathological behaviour. He described the therapist’s role as nurturing and accepting the child, conveying a less directive stance than the one more traditionally associated with the field.

Despite the overlap of actual clients with the fields described above, it is the field of adult palliative care that is most clearly aligned with the approach taken in this children’s hospice. The doctrine of quality of life, set forth in the earliest palliative care discussions by Dame Cicely Saunders (1989), dominates the therapeutic encounter. Although countless opportunities are created for the palliative client to make choices and control their experience of music therapy, it is infrequently considered to be an independent goal but, rather, a “way of being” with palliative care patients. West (1994) noted that “the therapist is much less concerned about facilitating change in hospice than in other music therapy settings” (p. 119), implying that the therapist follows rather than leads the client into therapeutic experiences. Similarly, Aldridge (1995) emphasised the focus in adult palliative care as being, rather than having, suggesting that in music therapy “each person is given the opportunity to define themselves as they wish to be” (p. 104). O’Callaghan (1997) articulated the value of choice and control in her description of therapeutic opportunities associated with song writing. In this paper she noted that clients can make creative choices through this medium, both musically and verbally, and that these choices are important as they experience diminishing control over their lives (p. 36). Similarly, Munro (1984) frequently emphasised the importance of client choice, whether this is regarding participation or the methods of working together, as well as within each aspect of the encounter. Bailey (1984) used the term “allowing” in her description of the music therapy framework, which is perhaps the most appropriate term for conceptualising this process within an adult context. In working with chronically ill young people, however, the therapeutic dynamic does encompass the developmental needs of the client. The boundaries of the encounter are frequently established by the therapist, both in facilitating the child’s understanding of the possibilities of personal exploration via creative expression, as well as providing the limit of that expression, with a particular focus on the child’s physical and emotional safety.

The Approach

The therapeutic aim of offering opportunities for choice and control has been suggested as a distinguishing feature of music therapy work in a paediatric hospice setting. The literature from the reviewed fields clearly identifies this as a facet of many music therapy programs. The holistic focus of palliative care however, combined with a flexible and child-
Figure 1. The therapeutic interaction in paediatric palliative care.

friendly environment, clearly endorses quality of life as an important aim. Choice and control are significant features of the paediatric palliative care field, including the way that services are provided, by whom, and the timeframes in which they occur.

Figure 1 illustrates how opportunities for choice and control are incorporated into work at Very Special Kids. The therapist’s role is to provide accessible and appropriate opportunities in which the client may express their choices. These include opportunities for the client to reject
participation, to establish the level of participation, and to influence the style of music or the musical activity. This skill is supported by the therapist’s ability to read the client’s response, which may be verbal, nonverbal or musical. In providing these opportunities, the therapist aims for the client to acquire a sense of control over their experience that will enable opportunities for authentic emotional personal expression to arise. A stronger feeling of confidence may lead to feelings of personal satisfaction and happiness, that may then result in a temporary or sustained enhancing of the client’s quality of life.

Although it is difficult to measure the value of offering opportunities for choice and control, the following vignettes provide examples of how this strategy was implemented by the primary author whilst training at Very Special Kids. After each vignette, perceived outcomes will be explained that illustrate the palliative care framework surrounding this work. Following this, the authors will reflect on the implications for music therapists working in this model based on their experiences in this inpatient setting.

Vignette 1: A Metaphoric Experience of Control Through Story Telling to Improvised Music

Three boys, aged between six and nine with muscular dystrophy (MD), were attending a weekend at the hospice that was arranged specifically for clients with this diagnosis. The weekend involved organised activities including a workshop facilitated by the registered music therapist (RMT) and other activities and games. The workshop began with instrumental improvisation activities that explored feelings, followed by song writing. It became clear that some of the younger boys were not engaged by the song writing process and were given the choice as to whether they wanted to stay with the group or go into the music room with the music therapy student (MTS). After some debate, they chose the latter.

To begin with there was much noise and high energy levels. All three wanted to play the drum kit and were yelling at each other over the top of the noise of the drum kit being played. One of the boys withdrew from the drum kit and sat in the corner saying it was too loud. The MTS asked if he would like to stay and play part of the kit, join the other boys writing the song, or find some quiet space. He chose the latter and left the room with a carer. The kit was split in two so both boys could access it, and they continued to play in an unstructured, loud, and somewhat chaotic manner. The MTS moved closer to the centre of the boys and began to create a story out of the music that she heard,
attempting to make the sounds more meaningful. One of the boys moved himself to the piano and looked to the MTS for a sign to continue. As the MTS intermittently clarified with the boys if what was being said related to the musical sounds they were creating, there was a notable change in their playing. It became more focused, directed, intentional, and musically creative. They paused and interjected verbal ideas into the story at particular moments. They played softly and then brought the volume and intensity up into several climaxes. They interacted together in a positive manner, independently contributing their own individual and unique ideas, as well as listening and following each others musical ideas. The more involved in the story the boys became, the less the MTS provided direction for their expression. The story continued for approximately 40 minutes, coming to a natural end of their own choosing. As the music stopped both boys smiled and looked pleased with themselves, wanting immediately to go and tell the other boys what they had done.

In this illustration, the idea of telling a story to the music clearly came from the MTS, however, as soon as the concept was grasped, the boys chose whether they continued with the story and how they wanted to contribute to the musical activity. They took control of the situation and their immediate environment by choosing whether or not to participate, their level of participation and engagement, whether they interjected verbal and musical ideas, and their level of responsibility in how to respond to each other, e.g., listening, following, directing, and working collaboratively together. The situation went from one of chaos and musical noise to something that was intentional, musically creative, and meaningful.

The story that the boys created could be interpreted as having metaphorical meaning, in that they were being chased and followed by something bad. They knocked it down at times and jumped on top of it, but it always continued to come back. It scared them but they kept fighting for control. Young people with MD become weaker and less mobile due to increasing muscle weakness, often requiring a wheelchair by their teenage years. This disease ultimately damages the involuntary muscles of the heart and diaphragm, often leading to respiratory and heart failure, and death before adulthood. The boys may have been communicating their feelings of potential loss of control over their own bodies and their possible fear for the unknown in a meaningful way. They possibly expressed this both musically and verbally through a creative story to improvised music.

This example also illustrates the importance of the music therapist’s role in establishing a relationship of trust, comfort, and support. The MTS observed, listened, and offered opportunities for control and expression.
throughout the creative dialogue. As a result, the boys experienced primary responsibility for the creative act. They showed an increased level of confidence in the session, observed through their musical and verbal input, and were seen to have achieved a sense of personal satisfaction, shown by their smiles and desire to share their experience with the other boys.

Vignette 2: Controlling Another’s Movement Through Musical Improvisation

An eight-year-old girl with Galactosemia, a genetic disorder that results in speech difficulties, muscle weakness, and intellectual disability, was staying in the hospice for a week. The girl was aware and communicated through clear body gestures such as facial expressions and highly communicative vocal noises. Although she had muscle weakness and walked using a frame, she was capable of strong leadership that clearly expressed her intention.

The girl was familiar with music therapy and approached the MTS upon arrival to secure a session time. After waiting patiently for her individual turn, she hurried with enthusiasm into the music room, leading the MTS along by the hand and laughing with obvious excitement in anticipation of the music to be created. Upon entering the room, the MTS offered her the choice of instruments and she headed directly for the keyboard. She indicated for the MTS to put the keyboard on the floor so she was able to access it easily.

When the keyboard was ready, the MTS asked if there was anything that she could play for her, to which she smiled with a twinkle in her eye and indicated for the MTS to stand up without the instrument. Immediately a game began in which she controlled the MTS’s movements by her musical playing. There were three specific styles that she played on the keyboard (in the high register, lower register, and sweeping her hand down across the keyboard hitting all of the notes from upper register to lower). The MTS responded to these patterns by using three different movements (ballet style floating, heavy stomping, and spinning around and falling to the floor, respectively). The young girl laughed continuously throughout the game and began to vary and extend her musical patterns, although always remaining within the musical pattern that clearly indicated what movement should follow. This continued until the MTS grew exhausted and offered the girl another choice of instrument to play. Initially, the girl frowned, indicating that she was not wanting to end the game, but then moved to the drum kit and indicated for the MTS to play the
piano. She engaged in this improvisation for another fifteen minutes before indicating that she was ready to finish.

Throughout the session the MTS observed, listened, and responded to the girl, offering her musical choices that incorporated what was observed in her behaviour. The girl clearly enjoyed being able to take control of this situation, particularly manipulating the body movements of the MTS through music. Due to the muscle weakness caused by her disease, each of her own movements required full concentration as well as extreme exertion. The opportunity and ability to easily manipulate another's physical movement appeared important to the girl, especially in being able to control the movement of the MTS falling to the floor. She chose this musical pattern most often, laughing spiritedly each time it occurred. Her enjoyment of the game was obvious and clearly seen in her level of concentration on pattern selection, her constant eye contact (intently watching to see if the MTS would respond) and her bright face full of smiles and laughter.

Throughout the drum and piano improvisation she played the drums in a creative and playful manner, appearing to express herself authentically through this new found and powerful voice. This was seen in her steady level of concentration and the enormous amount of energy that she exerted in accessing the drums. During this improvisation the MTS responded by echoing, repeating, extending, and completing musical ideas (Bruscia, 1987), validating the girl's musical expression. The girl responded to this by maintaining strong eye contact, trying new ideas, and smiling and laughing when her ideas were validated.

The opportunities offered to this young girl placed responsibility for the experience in her control. She was able to clearly express responses to choices, despite her inability to speak, and was capable of assuming responsibility without compromising any aspect of her safety. Control over the session and another's body movements incorporated both a perceived sense of control and actual control, although this was limited by safety issues generated for the therapist. This level of empowerment was enjoyable and may have lead to enhanced self confidence and quality of life for the duration of the session.

Vignette 3: Expressing Feelings and Releasing Energy Through Song Writing

Two sisters with cystic fibrosis, aged six and eight, were staying at the hospice for one week during the school holidays. Based on observations from an earlier group music therapy
session, it was apparent that both girls liked to assert their control
over their environment. During the group session the girls played
loudly and disrupted the attention of the other children; talked
over the top of the MTS saying they were bored; and had an
enormous amount of energy. Interestingly, when asked if they
would like to do some more music in the music room, they were
excited, enthusiastic, and rushed into the room, both heading
immediately for the drum kit. Not surprisingly, the session began
with an argument over who would play the prized drum kit. The
eight year old asserted her authority of age and won, while the six
year old searched for another instrument, settling on the piano.
Assessing their energy levels, the MTS offered the girls the
opportunity to have some time on their own to explore the
instruments. They elected to spend time without the direction of
the MTS who then asked how long they thought they would need
to become familiar with the space. They asked for fifteen
minutes.

Upon re-entering the room both of the girls were settled,
co-operatively working with each other, and welcomed the MTS
into the room saying they were ready to do music. They were
offered a choice between singing familiar songs, improvising on
the instruments, or writing a song. In unison, they responded
"Write a song!". The choice of how to write the song - new
composition, word substitution or fill-the-gaps - was offered,
together with a description of each process. They decided upon
word substitution, choosing “Five Little Ducks,” and performed it
to the MTS. After the performance they were offered several
choices of topics and they brainstormed ideas and came up with
the lyrics. They sang it through several times before deciding it
was time to have a break.

Throughout the session, particularly during the song
writing process, the girls remained focused, at times serious, but
also laughing and enjoying themselves. In selecting material for
the lyric substitution, the girls expressed feelings about being
away from their families and the difficulties they experienced
with their illness. They interacted respectfully with each other,
hearing and accepting each other’s ideas with equal input. The
rapport with the therapist developed quickly through the session
and was significantly greater compared to the group MT session,
as seen by how closely they sat to the MTS. The girls’ assertive
attitude had softened, as seen in their body language and verbal
interactions, both with each other and the MTS. At the conclusion
of the session, they stated that they were happy with the song,
asking if they could have the lyrics typed out. After offering them the choice as to what they wanted to do with the song, they decided that they would practice and consider performing it to the other staff. After practicing together with the MTS and alone, they got themselves ready to perform. At the last moment, the older girl decided that she didn’t want to perform and, after asking her permission, the younger girl and the MTS performed it together, resulting in much applause and congratulations to the girls’ achievement in writing the song.

The girls benefited greatly from the choices they were offered through music therapy. They were able to take control over their situation and clearly chose what activities they preferred. To begin the session in the room on their own, and have the freedom to exert and release the physical and emotional energy that they had built up, was clearly what was needed. Following this, they chose to fully engage in the activities and maintained a constant level of participation. They made decisions together as a team and listened carefully to each other’s ideas. They chose the duration of the session, which came to a natural end after they had practiced the final product. They both achieved a sense of personal satisfaction, as seen by the smiles on their faces and the desire to share their song with others.

Although life expectancy in cystic fibrosis has improved markedly over the past decade, and most patients can expect to reach adulthood, the risk of sudden death is always a possibility. Quality of life is a priority for these girls within the hospice setting and this was seen to be addressed through the multiple opportunities for choice-making and the extent of their control over the environment. The respect conveyed by the therapist in allowing them to dictate the boundaries of the relationship indicated her trust in their ability to work independently and to assume primary responsibility. This may have been significant for the two girls whose perceived sense of control over life was likely to be low.

**Final Thoughts**

The concept of choice and control, as described in this paper, is informed by the quality of life doctrine of palliative care, combined with a developmentally appropriate approach. Due to the loss of control experienced in response to chronic illness, it is proposed that the experience of control, both actual and perceived, can contribute to a child’s quality of life and self esteem. Similarly to paediatric medical settings, the actual experience of control over the environment is fostered through opportunities for choice that promote control and mastery. Similarly to adult palliative care, the perceived loss of control experienced due to the nature of their chronic illness is addressed through metaphor.
opportunities to experience control: over music making, another’s actions, and the level of responsibility assumed by the child. The concepts of “allowing” (Bailey, 1984) and “being” (Aldridge, 1995) are suggested as crucial in the resultant therapeutic encounter, but the developmental context of working with young people is also a considered to be a significant influence on how this process emerges.

In concluding, a number of clinical implications for the therapist are also pertinent from these authors’ experiences of working within the paediatric hospice setting. First, the client may not wish to participate, which can result in feelings of rejection or extensive self-questioning on the part of the therapist. Munro (1984) has thoughtfully discussed the challenge of accepting the client’s decision not to participate in music therapy within an adult framework. Although the concept is transparent and respectful, the experience as therapist can lead to self-doubt, particularly when experienced frequently. Belief in the value of music therapy and sensing that a particular client may benefit greatly from a music therapy intervention may prove difficult for a therapist when a client chooses otherwise.

The chaos that can result from offering freedom of choice to young people can also be challenging for the music therapist, who must constantly consider issues of safety and care when working with younger clients. In addition, it reduces control over the rhythm of the session and can lead to times of silence that are not always meaningful, but that do convey the respectful stance of waiting. The balance of spontaneity and structure within sessions requires constant attention and focus that can be exhausting for the facilitator, particularly when a child’s attention span is considered.

Finally, the question of value is frequently prominent in the therapist’s mind. Paediatric palliative care services are often accessed for respite by families, leading to infrequent access by clients across a number of years. The therapeutic encounter occurs sporadically, yet a process does emerge over time. Each session has the quality of a brief intervention, yet the therapist and client may meet many times over the young person’s life. The child’s family may choose to utilise the hospice during the terminal stage of the illness, or the child may die suddenly in hospital without a clear end-stage. Thus, questions are evoked for the therapist regarding whether the music therapy work has benefit, and if so, how?

As illustrated, opportunities for choice and control are a significant aspect of the music therapy service provided to the young people at Very Special Kids. The case vignettes describe ways in which the participants were able to experience or perceive control through (a) creative story telling, (b) improvised piano and drum playing, (c) movement directed and controlled by the client’s musical input, (d) and song writing. The young
people appeared to be empowered by this work, as seen in the ways that they chose their levels of participation and engagement, response and decision making, and duration. The vignettes illustrated the sense of personal satisfaction and happiness that resulted from participation, in the way that each individual communicated musically and verbally through the creative opportunities, and expressed and released emotions through the music. It is hoped that this acquired sense of control, and these opportunities for personal expression, may result in enhancing the quality of life of young people with life threatening illnesses.

References


