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## Parents' Voices Supporting Music Therapy within Pediatric Palliative Care

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That was one good moment - the absolute extreme opposite of the horrendous memory of his last breaths. If I didn't have that good and precious moment to counter all the horrific moments, I don't know how I'd cope (Rees, 2005, p. 25).

 Kathryn  
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It has been my experience that parents are willing and open to express their voices to promote and advocate for music therapy services for their terminally ill children. By listening to parents' voices when providing care for terminally ill children, much can be done to ease the suffering of children and families at the end of life (Widger & Wilkins, 2004). My music therapy masters research at the University of Melbourne with Dr. Katrina McFerran will investigate bereaved parents' experiences of music therapy with their terminally ill child. This inquiry unfolded through my music therapy work with several children and families within hospice and palliative care. Parents have reflected that music therapy was a vital component in their child's care at the end of life. As one mom commented, "I don't care what anyone says, it has made a world of a difference." In order to further explore parents' experiences of music therapy, in-depth interviews will be conducted and transcripts will be analyzed using phenomenological strategies. It has been reported that parents find the interview process helpful in working through grief. They have also reported feeling an overall eagerness to share their child's story in order to provide input that might assist other families in the future (Widger & Wilkins, 2004). This article will describe pediatric palliative and hospice care, discuss parents as advocates for their terminally ill children, portray the use of music therapy within pediatrics, and share an example of music therapy with Jack.

### Defining Pediatric Palliative Care

Being a music therapist from Minnesota, USA and now studying my masters in Melbourne, Australia, I've realized that although the work we do as music therapists in the palliative and hospice field is similar, our terminology is somewhat different. For example, in Minnesota, palliative care is the provision of treatment for comfort acknowledging that a cure is not an option. Hospice, then, is a philosophy of care focusing on the physical, psychological, and spiritual comfort and support at the end of life when all treatments have ceased. Hospice care is generally a service provided in the home, or wherever the patient is dying. However in Australia, hospice is a facility where the terminally ill patient is cared for throughout various stages of their illness, including death. Palliative care is then the philosophy of care providing comfort and support in the home at the end of life. Overall, pediatric palliative or hospice care aims to improve children and families quality of life when faced with a terminal illness. "The goal of pediatric palliative care is to provide proactive, comprehensive, and holistic care to infants and children whose disease process is not amenable to cure-oriented interventions" (Carter, Feudtner, Rushton & Strong, 2004, p. 25). These goals aim to provide relief from pain and suffering, offer emotional and spiritual support, affirm life while acknowledging the dying process, and provide bereavement support for families (Cohen, Hain, Oleske, Orloff & Weinstein, 2004; Kane & Primomo, 2001; World Health Organization, 2005). The World Health

Organization defines palliative care for children as the active, total care of the child's body, mind and spirit, and also involves giving support to the family.

- It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.
- Health providers must evaluate and alleviate a child's physical, psychological, and social distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centres and even in children's homes.

This definition addresses the physical, psychosocial and spiritual care of children and their families that is encompassed within palliative care services. One of the differences between adult and children's palliative or hospice care is the involvement of the child's parents and family. Parents are usually the primary caregivers for their terminally ill child and so it is their voice that the health care team listens to when determining care and services for the child. Cohen and colleagues (Cohen et al., 2004) describe palliative care within this model as achieving holism, which recognizes that the care of children and families addresses physical, psychosocial, and spiritual needs. This holistic approach flexibly and responsively addresses these needs in order to provide care that is determined by the specific desires of the child and family. It is argued that by reducing pain and suffering of children, families also find relief (Martinson, 1996). Additionally, parents advocate for comfort and support on behalf of their child.

### **Parents as Advocates**

Parents are primary caregivers and advocates for their terminally ill child. By listening to parents' voices, health care providers, including music therapists, may provide more effective comfort and support. Through parent interviews, the need for improved pediatric palliative and hospice care has been identified (Cohen, Contro, Larson, Scofield & Sourkes, 2002). Parents suggest that one of the most important aspects of care is maintaining quality of life for their children at the end of life. I have heard numerous reports that music therapy services results in an improvement in quality of life for both the child and their family. Parents have shared stories with me that have reflected on the benefits of music therapy to reduce pain and discomfort, improve quality of life, create a supportive and bonding experience between family members, and improve communication and expression of feelings. It is necessary for our field to further investigate parents' experiences of music therapy in order to educate health care providers about the needs of families for music therapy services, and their obligation to provide funding for these services. Parents have an important voice in supporting music therapy within pediatric palliative care, as they are primary advocates for their child. After all, the first music therapy program within a children's hospice was advocated and funded by the parents of a terminally ill child.

### **Establishing Music Therapy at Martin House**

The family of a little girl named Jessie funded the first music therapy program within a children's hospice. According to the text *Music Therapy in Children's Hospices*, music therapy was established at Martin House Children's Hospice in the UK in 1994 through *Jessie's Fund* (Pavlicevic, 2005). *Jessie's Fund* was used to raise money to pay for her expensive cancer treatments. After Jessie died in 1994, her family decided to use the money to provide music therapy services at Martin House. Jessie and her family had found Martin House Children's Hospice to be full of love and support, but found one thing missing; music. Their family thought that music therapy could "offer children a uniquely valuable form of self-expression and enjoyment, however complex their medical needs" (Schatzberger, 2005, p. 30). Jessie's mom expressed that "music therapy can provide a vital escape from all this: a place for children to be themselves, to reinforce their identities, to regain an element of control in their lives, to be heard, and to be creative" (Schatzberger, 2005, p. 34). Music therapy provides unique opportunities for children and families within children's hospice and palliative care programs around the world, as told by parents, carers, children and professionals.

### **Music Therapy within Pediatric Palliative Care**

It is only within the last decade that music therapy has been acknowledged within pediatric palliative care. Research is lacking in the area of music therapy with children who are terminally

ill. Because of the dearth of evidence-based research in this area, most of the literature is portrayed through case examples (Aasgaard, 1999; Aasgaard, 2003; Daveson & Kennelly, 2000; Fagen, 1982; Froehlich, 1996; Hilliard, 2003; Ibberson, 1996; Lane, 1996; McFerran & Sheridan, 2004; Sweeney, 2003). Hilliard (2003) provided case studies from his work that depicted the pediatric palliative care patients' experiences with music therapy to decrease anxiety, improve emotional expression, quality of life, and family interactions. McFerran and Sheridan (2004) depicted the use of music therapy to provide opportunities for choice and control within a children's hospice environment. Aasgaard (2003, p. 6) provided case examples of children's song writing experiences that were "interplays of loveable acts between patients, parents and music therapist," and reflected that the moments shared in music therapy can be highly emotional and remembered throughout time. Although research is lacking in pediatric palliative and hospice care, there is a large quantity of literature supporting music therapy within the pediatric hospital setting which is relevant to music therapy practice in pediatric palliative care (Aasgaard, 2000, 2001; Barrickman, 1989; Daveson, 2001; Daveson & Kennelly, 2000; Dun, 1999; Edwards, 1999; Froehlich, 1984; Gowan, Smith & Pfaff, 1989; Hadley, 1996; Lane, 1991; Loewy, MacGregor, Richards & Rodriues, 1997; Loewy, 1997; McDonnell, 1983). This literature has indicated that music therapy may benefit pediatric patients by decreasing fear and anxiety, increasing expression, increasing immunity, decreasing pain, and supporting relationships.

Music therapy may help children and families face many of the issues they are to confront throughout terminal illnesses, such as separation from family and friends, misunderstandings regarding illness, disease and death, loss of control, hospital fears, pain management, coping with loss and disappointment, sensitivity with self-esteem, and the realities of a debilitating diagnosis (Aldridge, 1996). Music therapy sessions often allow children to explore their thoughts about death and facilitates increased communication within families (Fagen, 1982). Music therapy enables families to share "special times together to alleviate and accompany 'caring' tasks" (Everitt & Nall, 2005, p. 152). Everitt and Nall (2005) described the benefits of music therapy during palliative and hospice visits within the home. They noticed that music therapy services provided a vital means of communication and self-expression for children with terminal illnesses and their families (Everitt & Nall, 2005). Another example of this is provided by Sweeney (2003) who describes music therapy work with a 5-year old boy named Matthew. Matthew was an active boy who wanted control of the music therapy sessions and often directed the process. Symbolic play took place through the use of improvisations and the metallaphone was seen to represent his deteriorating self and illness. Although Matthew did not verbally process his experience with the music and instruments, it appeared that he was aware of the themes he was creating in the music, and that this resonated with his physical and emotional state. It is possible that Matthew came to acknowledge and accept his illness and impending death through the musical play with children's rhymes and improvisation (Sweeney, 2003).

### **Examples of Parents' Experiences of Music Therapy**

As depicted through some of the examples above, the benefits of music therapy often include the provision of comfort and support for both the terminally ill child and their family. Music therapy is frequently a shared experience between the child and parent to relieve stresses and to provide opportunities to support their emotional bond (McDonnell, 1983). Literature supporting parents' experiences of music therapy with their terminally ill child is sparingly provided through the brief case examples in the literature. In an example by Hilliard (2003, p. 130), "the music therapy provided opportunities for the family to feel as though they were making a difference in the quality of life for their daughter." Aasgaard (2001) reports that music therapy had meant something valuable to families and Lathom-Radocy (2002) notes that it provided a positive focus for both the child and family at a time when most aspects of life felt daunting. Parents perceptions of their child and their illness can be supported by participating in music therapy together according to Dun (1999). The musical memories and creations can be a gift left for the family after the child has died and may assist in coping for both the child and family members (Daveson & Kennelly, 2000; Froehlich, 1996).

### **Music Therapy with Jack - A personal Experience**

During music therapy hospice visits, Jack's face would light up. Although Jack had a rare Genetic Chromosomal Disorder, non-specified with daily petite mal seizures, he would smile, giggle, and work up enough strength to grasp a mallet to swing at the drum and play the maracas. Along with Jack's engagement in the music therapy, his mom, dad, baby brother Calvin, and other family members would join in the music to share some of Jack's 'happiest moments' at the end of his life. Some of Jack's favorite songs that continue to be shared and

remembered by his family are, "Baby Beluga," "Down by the Bay," and "Old McDonald." Some of the times when Jack had music therapy, his parents had a few moments for themselves knowing that Jack was doing something that he liked. At the very end of Jack's life, his parents requested music therapy knowing that it brought him joy and comfort. While Jack was dying, soft guitar and vocal music emphasized his family's love and gratitude for him. His mom reported many times that music was the only gift they could share with Jack to bring him comfort. "It was the only thing that made him happy," and was a positive experience in the midst of letting go and dying. Along with providing Jack comfort, she said it also brought her peace to know that he was happy and comfortable. The music provided an "incredible bonding experience." "It was something that we could all share together since music is a universal language and reaches all of us regardless of our age or cognitive level." The memories of music therapy with Jack continue in their family and they report holding on to those memories of sharing music with Jack as some of the happiest times at the end of his life. "I can't imagine not having had music therapy, and highly recommend it for other families." Reflecting on the significance of music therapy for their family, Jack's mom, Naomi, stated that she hoped other children were able to access music therapy at the end of life as well.

It is important for us to hear parents' voices. There is a lot to be learned from talking with bereaved parents in order to continue improving care for children at the end of life. In the depths of grief and bereavement, parents often have immense beauty to share while continuing their child's legacy. Legacy's can be created through engagement in music therapy, by creating memories that support and comfort the family after a child has died. Perhaps through these conversations, and caring investigation and analysis of these experiences, music therapy can continue to grow within pediatric palliative and hospice care. Losing a child is thought to be the most devastating experience, as it goes against all hopes, dreams, and expectations imagined for a child's life (Monahan & Worden, 2001). Any fragment of joy and beauty that can be shared is treasured. After listening to parents' voices, we may be better able to provide music therapy services in order to make the end of a child's life at least a bit more bearable.

"Your joy is your sorrow unmasked. And the selfsame well from which your laughter rises was oftentimes filled with your tears. And how else can it be? The deeper that sorrow carves into your being, the more joy you can contain. When you are sorrowful look again in your heart, and you shall see that in truth you are weeping for that which has been your delight" (Gibran, 1923).

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