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2013

## Luba's Theme

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### Recommended Citation

Clements-Cortés, A. (2013). Luba's theme. *Imagine*, 40(1), 70-73.

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## **Luba's Theme**

**Amy Clements-Cortes, PhD, MTA, MT-BC, FAMI**

The following case study is of Luba, a 4 year old girl diagnosed with Tay-Sachs disease and her music therapy process. Foundational information on Tay-Sachs disease is provided alongside a discussion of anticipatory grieving, and the death of a child.

### **Foundational Concepts**

#### **Tay Sachs Disease**

Tay Sachs Disease is a rare genetic disorder that destroys nerve cells in the brain and spinal cord. It is caused by mutations in the HEXA gene that prevent the substance GM2 Ganglioside from breaking down. In turn, this causes an accumulation of this substance which leads to progressive neuron damage. In infancy, a child with Tay-Sachs Disease appears healthy. At age 3-6 months, their development slows down and their muscles weaken, causing them to lose motor skills like crawling or turning over. Seizures, vision and hearing losses, intellectual disabilities, and paralysis may be experienced as the child ages. Children with Tay Sachs Disease generally only live until early childhood (U.S. National Library of Medicine, 2013).

#### **Anticipatory Grieving**

Anticipatory grief was first defined by Lindemann (1944) as feelings or symptoms of grief in someone who has not experienced actual bereavement, but instead is threatened by a possible upcoming death. Friedman (1967) suggests that anticipatory grief looks similar to general grief but takes place over a longer span of time. In parents of a dying child, anticipatory grief may show itself as a renewed interest in other children and past hobbies, limited hope, (Friedman, 1967) discussing the possibility of the child's death, grieving in anticipation of the loss, thinking what the future would be like without the child, acknowledging that the child is going to die,

discussing the child's death with the child, planning the type of death they want, making funeral preparations, and beginning to disengage themselves emotionally from the child (Rando, 1983).

Friedman (1967) further suggests that anticipatory grieving is a positive experience that can help a parent control their feelings of grief when the death finally occurs. Specific behaviours may help parents experience a positive amount of anticipatory grief, including receiving detailed information from health care professionals and being able to take care of and hold their child before death (Rini & Loriz, 2007).

### **Death of a Child**

The death of a child can provoke feelings of depression, anger, vulnerability, hopelessness, and fear with almost all parents experiencing intense loss (Arnold, Gemma, & Cushman, 2005). In addition the death may affect parents' relationship with remaining children causing them to be overly cautious, anxious, and guarded with other children; or experience a better relationship (Arnold, Gemma, & Cushman, 2005). Spouses may also experience marital strain (Arnold, & Gemma, 2008). On the other hand, bereaved parents reported feeling stronger, more sensitive, more courageous (Arnold, Gemma, & Cushman, 2005), and more compassionate (Arnold & Gemma, 2008). Some factors that were helpful to parents processing their grief included inner strength, family support, friendship, spirituality or religion, support groups and individual counseling (Arnold, Gemma, & Cushman, 2005).

### **Introducing Luba**

Luba was a 4 year old girl of Romanian descent. She was diagnosed with Tay–Sachs disease at 18 months. Luba and her parents, Luis and Anna were referred to music therapy by the social worker at the pediatric hospital as part of the out-patient package of services to be provided to the family. The interdisciplinary team believed that music therapy could be useful in helping the

parents in their grieving process, as they were in denial regarding Luba's prognosis. All music therapy sessions were provided in the family's home, two times per week for a total of 18 sessions.

Luis immigrated to Canada and began working in the 90's. After two years he returned to Romania and married Anna and the couple relocated to Ontario, Canada. They had no family in Canada but a small supportive circle of friends. Luis and Anna had struggled to conceive for several years and were overjoyed when they learned Anna was pregnant with Luba. Luba was born 6 weeks premature and began her life with health issues attributed to premature birth. It only surfaced around the six month mark that Luba was suffering from advanced symptoms that could be attributed to Tay-Sachs disease.

### **The Therapeutic Process**

Luba's therapeutic process consisted of 18 sessions that can be divided into 4 phases:

"Assessment", "Creating an Environment of Love" (Sessions 2-6), "Luba's Theme (Sessions 7-14), and "Saying Goodbye" (Sessions 15-18) which included planning funeral music and assisting the grieving process with Luis and Anna.

#### **Assessment**

During the assessment session it surfaced that Luis and Anna were greatly in denial about Luba's prognosis. They explained that the doctor had told them that Luba would die soon, but they believed that God would answer their prayers.

Luba had flaccid muscle tone and was no longer able to sit up. She was confined to her bed and no longer able to speak. Luba had limited head movement but appeared very much aware of her surroundings and maintained long stretches of eye contact during the music

interactions. Luba's parents were invited and encouraged to participate in the sessions but only Anna accepted in this stage and sat at Luba's bedside.

The assessment session was used as a way to determine Luba's responses to a variety of musical instruments, timbres and musical styles. She tracked the sources of the music with her eyes and engaged in extended eye contact with her mother and therapist when they sang.

In collaboration with Anna, the following goals were established for music therapy sessions.

1. To provide opportunities for: a) sensory stimulation, b) cognitive stimulation and c) social interaction.
2. To provide distraction from pain
3. To provide and enhance opportunities for relaxation
4. To provide alternative methods for Luba and her parents to interact.

Music therapy was implemented to promote a family-centered approach to medical care. Henneman & Cardin (2002) and Kardis, Modell, & Peyser's (2003) studies have shown the benefit of this approach for patients and their families. This model takes into account the patients' psychosocial states and how that impacts their physical health while also placing significance on the needs of the family who form the patients' support system.

### **Sessions 2-6 "Creating an Environment of Love"**

Sessions 2-6 focused on engaging Luba in music, and creating an environment in the home where love was conveyed to Luba. Luba's favourite songs were the primary focus and the lyrics of several songs were changed to personalize them for Luba. I encouraged Anna to sing with me, and at times she did but would become labile and held Luba's hand as I sang. Luis would peek into sessions but was not yet able to participate. It appeared that perhaps Luis had begun the

anticipatory grieving process in terms of disengaging from interaction with Luba as described above by Rando (1983).

I created a CD of the songs used in sessions for Luis and Anna to play for Luba and provide further opportunities for them to interact with her.

### **Sessions 7-14 “Luba’s Theme”**

During these sessions a focus continued to be on using Luba’s favourite songs. Additionally several hymns also became a part of the receptive music interventions. Slowly, Luis began to join in the music therapy sessions with the amount of time he stayed in sessions increasing from 10 minutes to the full length of the sessions by week 11. Hymns were important for Luis and Anna, and singing them for Luba provided a supportive platform for them to begin to understand Luba’s prognosis and essentially begin the anticipatory grieving process.

It was also during this period that songwriting was introduced and together with the therapist, Anna and Luis composed several songs for Luba. These songs were recorded and given to Luis and Anna by the therapist. “Luba’s Theme” became her signature song played at the beginning and end of each session commencing in session 10. Bailey (1984) avers that music therapy can stimulate cognitive function, improve communication between family members and enhance relationships and was introduced into the therapeutic process for these reasons.

In these sessions the iso-principle was implemented and was used to ease Luba’s labored breathing and pain. The iso-principle is defined as matching music to the client’s current emotional or physical state using the elements of music such as tempo, rhythm, volume, and mood (Altschuler, 2001). Clinical improvisation was also a central part of the work at this stage. These sessions ended with a musical relaxation and Luba’s theme.

*Luba’s Theme*

You are a shining star  
Always bright and warm  
Your smile lights up our hearts  
And fills them up with love

We loved you Luba before you were born  
And we love you more each day  
That love will always be there  
And grows stronger everyday

Your eyes are large and beautiful  
Your hair is golden sun  
You are our sunshine  
Our ever bright rays of light!

### **Sessions 15-18 “Saying Goodbye”**

Luba died after session 15. During the last three sessions with this family, music therapy involved planning music for Luba’s funeral and supporting Anna and Luis in the grieving process. Luba’s parents requested that I provide the music at Luba’s funeral and together we selected the important hymns for the service. In addition to these hymns, Anna and Luis confirmed they wanted “Luba’s Theme” to be a prominent part of the funeral service music. After the funeral, the last two sessions were held with Anna and Luis to help facilitate and initiate their grieving process. In these sessions songwriting and improvisation were the primary

tools that led to emotional expression and discussion between Anna and Luis. Wolfe and Waldon (2009) assert “music serves as a carrier wave on which troubling feelings may ride. In other words, [music] becomes a concrete representation of that which was previously difficult to put into words” (p.48). The words that Anna and Luis could not speak to each other they were able to put into a song and we used this song as a springboard for discussing those difficult questions and emotions that were raised in their lyrics.

### **Conclusion**

McDonnell (1984) acknowledges that “In family sessions, child and parent often have pleasure together for the first time” (p. 55) and that songwriting, moving to music and singing are effective interventions in supporting children and their families in reducing anxiety, alleviating emotional strain and increasing verbalization. This was reflective of the experience of Luba and her parents. Music therapy sessions provided the family with a new way of interacting through songwriting, moving to music and singing. These interventions were successful in enhancing and facilitating communication between Luis and Anna while reducing emotional angst and providing a way of communicating with Luba. Improvisation and song writing were also central interventions in facilitate the grieving process for Luis and Anna.



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