CHILD LIFE AND MUSIC THERAPY IN
PEDIATRIC HOSPICE AND PALLIATIVE CARE:
A PROGRAM MODEL

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OBJECTIVES

Participants will be able to...

• Describe Child Life and Music Therapy roles in a pediatric hospice setting

• Identify the unique needs of patients and families in a pediatric hospice and palliative care setting

• Describe the use of Child Life and Music Therapy in an End-of-Life Care Setting
WHO, WHAT, WHY, AND HOW

CASE EXAMPLE - N

- 8 y/o with Interstitial Lung Disease, B & T Cell immunodeficiency, Arthropathy
- 7 siblings
  - 3 have milder form of illness
- Goals
  - Family Support
  - Memory making
  - Expression
STARSHINE HOSPICE AND PALLIATIVE CARE PROGRAMS

- Hospice
- Transitions
- Perinatal
- Bereavement

WHO COMPRISSES STARSHINE?

- Psychosocial and Spiritual care
- Child Life and Music Therapy for pt. and sibling support
- Nursing visits
- Pain and symptom management
- Physical, Occupational, and Speech Therapies
- Massage/Holistic Health
- Volunteer Services
- Bereavement follow-up for two years
WHAT EXACTLY IS CHILD LIFE AND MUSIC THERAPY?

CHILD LIFE
- Definition
- A brief history
- Overview of current practice and role
WHAT IS A CHILD LIFE SPECIALIST?

Child life specialists are trained professionals with expertise in helping children and their families cope with health care experiences. Child life specialists:

- Have a strong background in child development and family systems.
- Promote effective coping through play, preparation, education, and self-expression activities.
- Provide emotional support for families, and encourage optimum development of children facing a broad range of challenging experiences, particularly those related to healthcare and hospitalization.
- Provide information, support and guidance to parents, siblings, and other family members.
- Educate caregivers, administrators, and the general public about the needs of children under stress.

CHILD LIFE BEGINNINGS...

- Began to flourish in the United States and Canada in the early 1960s
- Emma Plank was the pioneer who is credited with starting the profession
- She used principles of child development to promote appropriate care for this special population in the hospital.
CURRENT PRACTICE AND ROLE OF A CHILD LIFE SPECIALIST IN A HOME HOSPICE AND PALLIATIVE CARE SETTING

- Developmentally appropriate activities for siblings of the patient, to allow them to speak freely about their feelings and ask questions in a non-threatening and open environment

- Age-appropriate explanations and conversation about life-threatening disease and/or death for the child and his/her siblings

- School talks to the child’s classmates to explain his/her condition and/or death

- Implementation of legacy and memory activities for the entire family

- Preparation and suggestions for inclusion of the siblings in the funeral and/or memorial services for the child

PLAY

You can discover more about a person in an hour of play than in a year of conversation.

-Plato
MUSIC THERAPY

- Definition
- A brief history
- Overview of current practice and role

WHAT IS MUSIC THERAPY

Music Therapy is the clinical and evidence-based use of music interventions to accomplish individualized goals within a therapeutic relationship by a credentialed professional who has completed an approved music therapy program (AMTA, 2005).

- Music Therapy uses music therapeutically to address physical, psychological, cognitive and/or social functioning for patients of all ages.

- Training consists of coursework in music, music therapy, biology, psychology, social and behavioral sciences, and general studies.

- Clinical skills are developed through 1200 hours of required fieldwork, including an internship in healthcare and/or education facilities.
**HISTORY**

- Music as a healing influence referenced in writings of Aristotle and Plato
- Current profession rooted in work with WWI and WWII veterans with physical and emotional trauma
- First formalized educational program formed in 1944 at Michigan State University
- National Association for Music Therapy (1950) and American Association for Music Therapy (1971) merged to form American Music Therapy Association (1998)
- Board Certified Music Therapist (MT-BC) credential since 1983

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**CURRENT PRACTICE AND ROLE OF A MUSIC THERAPIST IN A HOME HOSPICE AND PALLIATIVE CARE SETTING**

- The primary aim of music therapy in this context is to improve a person's quality of life by helping
  - relieve symptoms (e.g., pain, agitation),
  - addressing psychological needs (e.g., anxiety, fear, need for expression/processing),
  - offering support and comfort (through validation, opportunities for expression, decreasing isolation, relaxation),
  - facilitating communication (through discussion, songwriting, life-review), and
  - meeting spiritual needs (e.g., legacy, funeral/memorial planning)
- In addition, music therapists assist family and caregivers with coping, memory-making, communication, and grief/bereavement.
- Music is adaptable and flexible – intervention can change based on in-the-moment assessment of pt
WHY CL AND MT IN PEDIATRIC HOSPICE AND PALLIATIVE CARE

- What are the unique needs of pediatric hospice and palliative care patients

- “Children aren’t supposed to die before adults”
- Barriers/taboo’s around talking to kids about death
- Varying diagnoses and illness trajectories
- Parents/caregivers not on same page
- Traditional vs. today’s family
- Sibling involvement and support
- Life in hospital vs. home
- Pt. often a minor, yet has opinions that need to be considered
- Transition to young adult
- Openness to outside support
- Classmates, community involvement
CL AND MT CAN HELP BY...

- Empowering patients and families
- Facilitating conversation and ways to cope
- Encouraging expression of feelings
- Providing support
- Listening
- Creating opportunities for legacy work and memory making

HOW DOES IT ALL COME TOGETHER?
ASSESSING NEEDS

- Child Life Risk Assessment
  - Communication
  - Family system
  - Anxiety and Coping
  - Medical Factors
  - Community Support
- Ongoing assessment as pt. declines or stabilizes
- Adapt interventions across the spectrum from anticipatory grief into bereavement

SUPPORTING THE FAMILY SYSTEM

- Collaboration with other team members
- Collaboration with community
  - school, peers, extended family
- Providing resources
OVERVIEW OF GOALS ADDRESSED

- Pt and/or sibling will...
  - Verbalize understanding of health status/ disease process on an age-appropriate level
  - Communicate their feelings (verbally or expressively) through music, art, and activities
  - Engage/Participate in expressive and memory making activities
  - Verbalize understanding of procedure and reasons for treatment on age-appropriate level
  - Establish/maintain functional support systems
  - Have access to appropriate resources to support students/staff in sharing/coping with EOL status
  - Effectively cope through play, music, preparation, education, and self-expression
  - Exhibit improved physical comfort
  - Decrease fatigue/increase energy
  - Elevate mood/diminish depression
  - Have opportunities to engage socially, cognitively
  - Decrease anxiety, agitation/increase relaxation

- Parent/caregiver will...
  - Have knowledge and access to appropriate resources

POSSIBLE INTERVENTIONS USED

- CL interventions
  - Provide resources
  - School visits, letters, support
  - Expressive activities
  - Encourage Family interaction
  - Legacy/memory making
  - Procedural support
  - Medical play
  - Engage siblings to determine understanding
  - Photos/videos

- MT interventions
  - Active
    - Songwriting
    - Improvisation
    - Audio/visual Recording
    - Active music engagement
    - Singing and/or song choice
    - Music-facilitated movement
    - Lyric analysis
    - Developmental music play
  - Receptive
    - Receptive music listening
    - Respiratory entrainment
    - Music assisted relaxation/guided imagery
    - Vibroacoustic therapy
CASE EXAMPLES

CASE EXAMPLE – B

- Infant with Encephalocele
  - Involved with perinatal program, then hospice
  - Bereavement support continues
- 2 siblings actively involved
  - one previous child loss (SIDS)
- Goals:
  - Family support
  - memory making
  - expression
B WITH HIS FAMILY

CASE EXAMPLE - T
- 22 y/o with Neurofibromatosis
- Family involvement
  - Pt.’s mother, siblings and children often present
  - Psychosocial stressors
    - Housing
    - Transportation
- Goals:
  - Support
  - Legacy leaving
  - Self-expression
T WITH FAMILY AND FRIENDS

T’S LIFE STORY

[Drawing of faces and a brain]
T'S LIFE STORY AND PSALM OF LAMENT

CASE EXAMPLE - M

- 16 y/o with Pompe Disease
  - Rare genetic disorder, involves skeletal and heart muscles, respiratory difficulties
  - Baby J
- 3 siblings, one niece
- Goals:
  - Self-expression
  - Legacy leaving
  - Memory making
  - Family support
  - Relaxation (MT co-treat with Holistic Health)
I LOVE YOU – A SONG FOR MY FAMILY

This is a song for my family
I want to say how much I love you
And how much you mean to me

When I'm gone I hope you will remember me for those times when I was happy
And for all those good times we had together.
I wish we could do them over again. I Love you.

P – When we were young we were inseparable, but as we grow up, we began to go different ways. But always know that I'm still very close to you. I Love You.

R – You are my little helper. I can count on you to be there. You are very special to me. I Love You.

A – We were best of friends when we were young, but as time went on we drifted. But I just want to let you know that you're the greatest big sister and I look up to you. I Love You.

P – from the first time we've met, I knew you were kind and gentle. Thank you for being like a big brother. I Love You.

M – You have brought sunshine into my dark world. Even when I don't feel like it, you can make me smile. You are very close to my heart. I Love You.

Mom and Dad - Thank you for being patient and for always being there with me. I know it's been hard and I'm grateful for having you help me. I Love You.

**note from M – I hope this song helps you remember all our family time.**

M’S SISTER
M WITH HER MOM AND SISTER

REFERENCES

- www.musictherapy.org
- www.childlife.org
- http://www.cincinnatichildrens.org/service/s/stars
  hine/default/