

Pediatric Considerations in Hospice Care

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Disclosures

- All presenters have no significant financial conflicts of interest to disclose.

Objectives

- 1) Review national data on pediatric hospice and palliative care.
- 2) Brainstorm challenges to providing pediatric hospice in your community.
- 3) Investigate resources for local pediatric hospice availability and expertise.
- 4) Review sample curriculum to train and empower hospice personnel to care for pediatric patients and families.

Pediatric Palliative & Hospice Care is Unique

- Epidemiology of Death in USA (2013)
 - Nearly 2.6 million total death (all ages)
 - Only 42 thousand (1.6%) were children aged 0-19 years
 - 55% of pediatric deaths occurred <1 year of age
- Causes of Death, Children Birth – 19 years

Infants (<1 Year) with CCC	Children 1-19 Years with CCC
1. Cardiovascular	1. Malignancy
2. Congenital/Genetic	2. Neuromuscular*
3. Respiratory	3. Cardiovascular
4. Neuromuscular*	<i>*includes static neurologic and neuro-degenerative conditions</i>

Osterman MJ, et al. Annual summary of vital statistics. 2012-2013. *Pediatrics* 2015; 135(6).

NHPCO Facts and Figures: Pediatric Palliative and Hospice Care in America, September 2014.

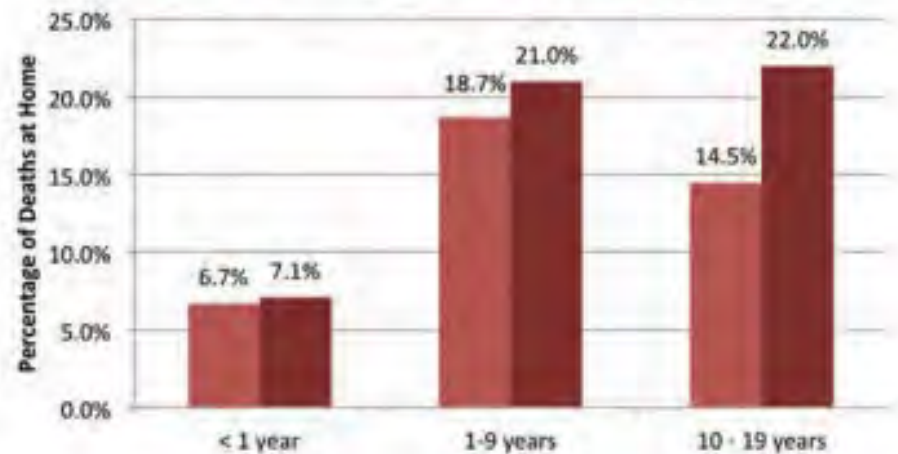
Pediatric Palliative & Hospice Care is Unique

- Children with palliative care/hospice needs range from prenatal to young adult.
 - Most have complex chronic conditions (CCC)
 - Some >21 years are still considered in this category if they have conditions followed by pediatric subspecialists.
 - Ex: congenital heart disease, genetic syndromes, cerebral palsy

Location of Pediatric Death in America

- Majority of children (62%) still die in the hospital, most in an ICU setting; only ~10% of pediatric deaths received hospice services.
- Increasing number are dying at home
 - Changes in technology and reimbursement structures have created more complex medical regimens managed in the home.

Figure 1. Deaths at home, by age group??



Feudtner, et. al. PPC patients: a prospective multicenter cohort study. *Pediatrics* 2011; 127: 1094-1101.

NHPCO Facts and Figures: Pediatric Palliative and Hospice Care in America, September 2014.

● 1999
● 2013

Location of Pediatric Death in America


- Are children dying at their (family's) preferred location?
 - Death at home is not always preferable.
 - Hospital is often a 2nd home for children with CCC
 - Added complexity with siblings
 - Advanced care planning for location of death was associated with:
 - Increased deaths at home (especially if home services provided).
 - Decreased hospital admissions in last month of life.
 - For those who died in the hospital, they were more likely to be on a general ward rather than ICU during their last admission.
 - Parents were more likely to be comfortable with setting of death.

Dussel V, et al. Looking beyond where children die. *J Pain Symptom Manage* 2009; 37(1): 33-42.

NHPCO Facts and Figures: Pediatric Palliative and Hospice Care in America, September 2014.

Our Challenges?

Barriers to Pediatric Hospice

- 
- Lack of Education
 - Lack of Resources
 - Lack of Comfort

Barriers to Pediatric Hospice

Lack of Education

- Referring physicians
- Patients and Parents
- Hospice Staff

Barriers to Pediatric Hospice

Lack of Resources

- Limited pediatrics-trained hospice personnel
- Large geographic area
- Rural and immigrant families
- Higher rates of uninsured (at least 15%)

Barriers to Pediatric Hospice

Lack of Comfort

- Advanced Care Plan discussions
- Fear
- Self-care

Pediatric Hospice Concurrent Care Benefit



ALABAMA

MEDICAID

EFFICIENCY
INNOVATION
QUALITY

News

Concurrent Care for Children Under the Hospice Election

Meet Jay!

7/19/2010

To: All Hospice Providers

Effective immediately, Medicaid will **no longer require parents with children under the age of 21 receiving hospice care, to waive all rights to Medicaid services covered under Medicaid for the duration of hospice care.** Based on the *Patient Protection and Affordable Care Act*, a voluntary election to receive hospice care for a child shall not constitute a waiver of any rights of the child to be provided with, or to have payments made for services that are related to the treatment of the child's condition for which a diagnosis of terminal illness has been made. **Children can now receive services related to the treatment of the condition for which a diagnosis of terminal illness was made.**

For additional information or further clarification, please contact Samantha McLeod at (334)242-5584 or Samantha.McLeod@medicaid.alabama.gov.

Remembering Brendan

Brendan was a 13 year old with end-stage hepatoblastoma, no longer responding to chemotherapy and with known intra-abdominal, pulmonary and brain metastases.

He lived with his parents in rural Alabama, about three hours from his Children's of Alabama specialists.

Given progression of his illness, his primary oncologist arranged hospice services at discharge.



Remembering Brendan

Despite hospice care, Brendan was readmitted two weeks after discharge with uncontrolled pain and seizures.

Parents were reluctant to return home with hospice as “they didn’t know what they were doing.”

Sound familiar?

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Our Story

- Problem: We had no local hospices willing/able to care for pediatric patients (2010).
- Investigation:
 - Surveyed COA SW to see hospices used in past
 - Expanded internet search for other hospices providing pediatric services (www.nhpco.org/directory/)
 - Called to verify level of services
 - Needs assessment for interest in providing pediatric hospice and barriers to service

Our Solution: Hospice Day of Learning (HDOL)

- Solution: Developed interdisciplinary interactive curriculum
- Objectives of HDOL:
 - Introduce community hospices to our Pediatric Palliative Care team as a resource
 - Reinforce baseline skillset (most of palliative knowledge translates)
 - Expand and adapt skillset to aid in unique aspects of care for the pediatric patient and family
 - Flexible modules tailored to community needs and to troubleshoot unique challenges
- Incentives:
 - CEUs for nursing and interdisciplinary participants
 - Partnership as clinical back-up for pediatric patients

HDOL Exchangeable Learning Modules

Education Modules

Kids are NOT Just Little Adults
How to Talk with Children
Medication Challenges in Pediatrics
Self-Care in Pediatric Palliative Care
Experience of the Child at the End of Life
Experience of the Adolescent at the End of Life
Pain and Symptom Management
Families “Living an Uncomfortable Life”
Spiritual Care for Pediatric Patients/Families
Truth-Telling and Decision-Making
Giving Bad News

Nursing Skills

Caring for a Child with a:
Feeding Tube
Tracheostomy
Ventriculostomy
Central Line
Neuro-oncology Tumor

Break-out Sessions

Pain Management
Social Work
Pastoral Care

Remembering Brendan

After help of Palliative Care with symptom management and understanding of hospice, Brendan returned to his home in rural Alabama with hospice.

Hospice
disc
that

Because
he le



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l goals:

More Resources: National Hospice & Palliative Care Organization (NHPCO)

- Concurrent Care

- <https://www.nhpc.org/resources/concurrent-care-children>
- https://www.nhpc.org/sites/default/files/public/ChiPPS/Continuum_Briefing.pdf

- Resources for Families

- Talking to children about their serious illness, Coping with Loss
<https://www.nhpc.org/childrenspediatricschipp/brochures-families>

- Member benefits:

- Palliative Care Resource Series
<https://www.nhpc.org/palliative-care-resource-series>



More Resources:

- Center to Advance Palliative Care (CAPC)

- Building, Financing a Program

<https://www.capc.org/>



- Courageous Parents Network

- Making Informed Decisions
- Keeping Your Family Strong, Self-Care Guides
- Learning from Providers and Other Parents

<https://courageousparentsnetwork.org/>



COURAGEOUS
PARENTS
NETWORK



Jay was a 12 year-old boy who was born to a mother with an ongoing substance abuse disorder and had no prenatal care.

He had cardiomyopathy complicated by multiple strokes and developmental delay.

Given his complexity, he was adopted by a nurse; his adoptive family included his mom, dad, brother and two sisters.

Lessons from the field...

- Unique considerations for Jay:
 - End-stage cardiomyopathy on milrinone infusion
 - Inability to characterize/localize pain
 - Difficulty with impulse control
 - Special seizure regimen, often titrated at home



Lessons from the field...

- Unique considerations:
 - Navigating multiple care providers (at the hospital and home)
 - Partnering with the expert parent
 - Dual goals for quality and quantity of life
 - Communicating with community partners
 - Out of hospital DNRs in pediatrics
 - Coordination with the funeral home
 - Care for siblings
 - Navigating complex grief



Questions???

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