INTRODUCTIONS

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UNDERSTANDING PEDIATRIC HOSPICE & PALLIATIVE CARE

- NHPCO Concurrent Care Update, 2016
  - Pediatric palliative and/or hospice care is both a philosophy and an organized method for delivering competent, compassionate and consistent care to children with chronic, complex and/or life-threatening conditions and their families.
- Studies show that a *very* small number of children die on palliative or hospice services
- Criteria for children being on hospice services is more inclusive than it is for adults
- Palliative vs Hospice services

CASE MANAGEMENT IN HOSPICE & PALLIATIVE CARE

- Primary agency team
  - Physician
  - Nurse case manager
  - Social worker
  - Chaplain
- Secondary support/systems
  - PCP, specialist team
  - Expressive therapies
  - PT/OT
  - Dietician
DIFFERENCES BETWEEN PEDIATRIC AND ADULT HOSPICE

THE CHILD
- “Children are not small adults.”
  - Developmental stages impact how we communicate with and support families.
  - Often lacks the verbal skills to describe needs, feelings, etc
- Patient vs Parent
  - How much do we tell them?
  - Children as minors do not have legal right to make decisions.
  - Hope
- Children are members of the community in many different ways like sports or church, and always in the education system.

THE FAMILY
- Childhood illness and EOL has an impact on family systems
  - Strain in relationships
  - Siblings Issues
    - Resentment/anger
    - Protecting parents
    - How much do we tell them?
- Children don’t die
  - How much is too much?
- Care at home vs hospital
- Anticipatory grief differs due to out-of-order loss.
DIFFERENCES BETWEEN PEDIATRIC AND ADULT HOSPICE

CARE TEAM
- Children’s physiological resilience complicates predictions about their future.
- Competency of various rare childhood diseases
- Lack of experience with pediatric EOL
  - Especially in the home setting
- Boundaries and fatigue working with families in the home setting
- Signs of imminent EOL are less discernible

INSTITUTIONAL
- Less reimbursement for pediatric care at home
- Balancing costs and family desires for child's care
- High staff competency required for pediatrics
  - High staff intensity
- Lack of qualified institutions and providers for care in the home
SOCIAL WORK RESPONSIBILITIES UNIQUE TO PEDIATRIC PATIENT-FAMILIES

- Provide developmentally appropriate education
- Assess for socioeconomic difficulties due to caring for a child in this kind of crisis
- Provide emotional/anticipatory grief support for siblings, parents etc due to out-of-order loss
- Provide opportunities for meaning making
  - Bucket list, hand molds
- Identify ethical issues that sometimes occur when caring for a minor child
- Assist the interdisciplinary team in accommodating care for child within its community ie. school

PATIENT A

- 17 yo
- Developmental Age
- Journey through decision making, palliative to hospice
- Concerns r/t turning to legal adult
- Dynamics of family system
- Team involvement
**Patient B**

- 7 yo
- Prognosis, physiological resilience
- Family system
- Financial burden
- Treatment course & hope
- Team involvement
- Transition to hospice
- End of Life experience

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**So how do you prepare yourself or your program in order to better serve pediatric patients?**

- Reassess your mission statement
- Identify areas lacking in your services
- Assess if services are available through another community agency
- Conduct a survey of past families – this voice isn’t captured any other way!
- Networking with other professionals that are doing this work for support and advice
Bereavement Services

- Solace House
- Support available to both palliative and hospice patients
- Make exception to accommodate unusual bereavement needs due to unique type of loss
- Refer out to other appropriate grief support options

Questions or Comments?
WORKS CITED

- Pediatric Palliative Care. Alexandria, VA: National Hospice and Palliative Care Organization, December 2012
- Pediatric Palliative Care. Alexandria, VA: National Hospice and Palliative Care Organization, December 2012
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