



PEDIATRIC HOSPICE & PALLIATIVE CARE: CASE MANAGEMENT AND THE ROLE OF THE SOCIAL WORKER


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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
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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
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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.
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DIFFERENCES BETWEEN PEDIATRIC AND ADULT HOSPICE


○ 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.
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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
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DIFFERENCES BETWEEN PEDIATRIC AND ADULT HOSPICE

○ 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
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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
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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
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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
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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

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QUESTIONS OR COMMENTS?

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