Pediatric Palliative Care In and Out of the PICU Setting: It Is Not Just for Death and Dying

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Disclosures

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Learning Objectives

• Define pediatric palliative care in the context of up-to-date and evidence-based practice standards
• Recognize situations for the utilization of palliative care outside of death and dying
• Identify barriers and facilitators to full utilization of palliative care services
• Name resources that can facilitate full utilization of palliative care in and out of the critical care setting

Pediatric Palliative Care: Q & A

• Who feels like their education and experience in regards to pediatric palliative care is lacking? Why?

• Who has a strong working knowledge of the theory and practice of pediatric palliative care? If so, where did you obtain this knowledge and experience?

Pediatric Palliative Care: Q & A

• When do you think it is appropriate to implement palliative care into your patient’s treatment course?

• What do you feel are facilitators to pediatric palliative care within your practice setting?

Pediatric Palliative Care: Case Example

Your patient is 16 year-old male with history of Crohn’s Disease who has required multiple operations for bowel resections and fistulas and is TPN dependent. He is now recovering from another surgery which has required an ileostomy. He reports that is feeling better than he ever has.

Does this patient qualify for palliative and/or hospice care?
Hospice and Palliative Care: Definitions and Basics
- Palliative vs Hospice Care
- History
- Current Practices

Organizational Views on Pediatric Palliative Care
What are the positions of national and government organizations?
- American Academy of Pediatrics
- American Nurses Association
- NAPNAP
- World Health Organization

Pediatric Palliative Care: Who and Why?
Why is pediatric palliative care needed?
- 50,000 children die every year
- 500,000 cope with life-limiting conditions
Benefits:
- Better outcomes
- Impact on families
- Lower costs
- Call for action

Pediatric Palliative Care: Where?
Where are areas that children receive palliative care?
- Hospice Center
- Hospital
- Nursing Facilities (LTAC)
- Home and Community

Pediatric Palliative Care: What?
- Hospital-based programs
- Free-standing facility
- Hospice-based programs
- Community agency or long-term care facility

Pediatric Palliative Care: Experiences During Major Illness, Dying, or Death of a Child
- Child
- Family
- Sibling
- Grandparents
- Community
- Schools
Pediatric Palliative Care: Barriers

**Patients, families, guardians, and caregivers:**
- Often invokes anxiety and fears when initially discussed
- Confused with term “hospice”
- Concern life-prolonging treatment will be denied
- Misconception that focus is on death and dying
- Fear it may hasten death
- Do not understand benefits
- Cultural and religious barriers

**Healthcare Clinicians:**
- Minimal to no educational exposure
- Lack of experience
- Unsure of when to initiate
- Uncertainty of prognosis
- Overtreatment
- Lack skill and comfort with difficult conversations

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Pediatric Palliative Care: Barriers

**Reimbursement:**
- Fragmented
- Affordable Care Act vs Private Insurance

**Perceived Costs:**
- Expenses of additional clinicians and support staff
- Increased interventions for patients

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Pediatric Palliative Care: Best Practices

- Initiated upon diagnosis of life threatening or life-limiting illness or injury
- Continue throughout illness or injury trajectory
- Set goals of care that follow the patient through the continuum of care
- Ongoing needs assessment for changes in goals
- Standardized plans of treatment with room for individualization as necessary

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Pediatric Palliative Care: Facilitators and Resources

**Patient and families:**
- Engage community organizations to improve public’s understanding of concepts of palliative and end of life care

**Healthcare clinicians:**
- Integrate concepts of palliative and end of life care into BSN, APRN, and Medical School curriculums
- Increased access to on-going training
- Develop protocols with triggers to implement palliative care within hospital and clinic setting
- Incorporate into standards of care
- Continued research to improve care
Pediatric Palliative Care: Facilitators and Resources

• Education for those already in practice
• Education for future APRNs and RNs
  – Integration into curriculum
  – Additional APRN specialty training programs
• Professional organizations
  – HPNA
  – ELNEC
  – Respecting Choices

Pediatric Palliative Care: Specialists

• Demand is growing
• Complex patient and family dynamics
• Fellowships

Pediatric Palliative Care: Generalists

• Educational needs
• Control of costs

Pediatric Palliative Care: Reimbursement:

• Address inconsistencies in reimbursements with state and national leaders

Pediatric Palliative Care: Tips for Success

• What can **you** do to succeed in your practice?
  
  • **Small** things that can make a **big** impact in any setting:
    – Obtain additional pediatric palliative care education
      – Continuing education sessions, webinars, courses, etc.
    – Know the triggers for palliative care consults or implementation
      – Create a document, EHR trigger, etc.

Pediatric Palliative Care: Tips for Success

• **Small** things that can make a **big** impact in any setting:
  – Utilize or create a screening tool appropriate to your practice setting
  – Obtain and maintain a baseline knowledge of palliative care models and resources in your practice setting and region
  – Standardize a process for utilization of all of the above when needed

Pediatric Palliative Care: Resource Examples

Source: Hassenfeld Children's Hospital of New York at NYU Langone Medical Center's Pediatric Palliative Care Team

Source: Lutmer, J. E., Humphry, L., Kempton, T. M., Moore-Clingenpeel, M., & Ayad, O. (2016). Screening criteria improve access to palliative care in the PICU. *Pediatric Critical Care Medicine, 17*(6), e335‐e342. doi:10.1097/PCC.0000000000000848
Pediatric Palliative Care: Q & A Recap

• When is it appropriate to implement palliative care into your patient’s treatment course?

• What can you do to be a facilitator of pediatric palliative care within your practice setting?

Pediatric Palliative Care: Case Recap

Your 16 year-old male patient with history of Crohn’s Disease which has required multiple operations, is TPN dependent. He is seen at his primary care clinic for a sinus infection and flu shot. He is being worked up for another operation to have an ileostomy placed. The PNP talks with the patient and his parents about their goals of care and what their expectations are in regards to the upcoming operation. The parents hope that this will cure their son’s Crohn’s Disease, but the patient does not want any further surgery since he feels better than he usually does.

Pediatric Palliative Care: Applying What We’ve Learned

• A 6 year old female patient presents to the Emergency Room with seizures. After unsuccessful attempts to control her seizures, the patient is admitted to the PICU in refractory status epilepticus. Her parents worry ventilator support is not allowed by their religion but want their daughter to live.

• What else do you want to know from a palliative care standpoint?

• How will you proceed from a palliative care standpoint?

References

Jones, B. M. (2011). The need for increased access to pediatric hospice and palliative care. Dimensions in Critical Care Nursing, 30, 235-235. doi:10.1097/DCC.0b013e31821e23de
References


