VCU Palliative Care ECHO*

April 11, 2019
Pediatric Palliative Care
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The following Planning Committee and Presenting Faculty Members report relevant financial relationships to disclose:

The following Planning Committee and Presenting Faculty Members report having no relevant financial relationships:

Danielle Noreika, MD
Kelly Lastrapes, MD

No commercial or in-kind support was provided for this activity

April 11, 2019 | 12:00 PM | teleECHO Conference
Helpful Reminders

- You are all on mute please unmute to talk
- If joining by telephone audio only, press *6 to mute and unmute

Unmute your microphone and start video
Helpful Reminders

Right click to your Zoom screen to rename your login; include your **name** and **organization**.
Helpful Reminders

Activate chat feature

Use the chat box to ask questions as they come to mind
What to Expect

I. Didactic Presentation
   20 minutes + Q&A

II. Case Discussions (x2)
   • Case Presentation
     5 min.
   • Clarifying questions from spokes, then hub
     2 min. each
   • Recommendations from spokes, then hub
     2 min. each
   • Summary (hub)
     5 min.

III. Closing and Questions

• Bi-weekly tele-ECHO sessions (1.5 hours)
• Didactic presentations developed by inter-professional experts in palliative care
• Website: www.vcuhealth.org/pcecho
• Email: pcecho@vcuhealth.org

Let’s get started!
## Hub Introductions

### VCU Team

<table>
<thead>
<tr>
<th>Role</th>
<th>Name</th>
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<tbody>
<tr>
<td><strong>Clinical Director</strong></td>
<td>Danielle Noreika, MD, FACP, FAAHPM</td>
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<td>Medical Director/Fellowship Director VCU Palliative Care</td>
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<td><strong>Clinical Experts</strong></td>
<td>Egidio Del Fabbro, MD – VCU Palliative Care Chair</td>
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<td></td>
<td>Jason Callahan, MDiv – Palliative Care Specialty Certified</td>
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<td></td>
<td>Tamara Orr, PhD, LCP – Clinical Psychologist</td>
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<td></td>
<td>Diane Kane, LCSW – Palliative Care Specialty Certified</td>
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<td></td>
<td>Felicia Hope Barner – RN</td>
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<td></td>
<td>Candace Blades, JD, RN – Advance Care Planning Coordinator</td>
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<td></td>
<td>Brian Cassel, PhD – Palliative Care Outcomes Researcher</td>
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<tr>
<td><strong>Support Staff</strong></td>
<td>Teri Dulong-Rae / Bhakti Dave, MPH</td>
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<td>David Collins, MHA</td>
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<td>Frank Green</td>
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Spoke Participant Introductions

Name and Institution
Pediatric Palliative Care

Kelly Lastrapes, MD
Assistant Professor, Division of Pediatric Hematology, Oncology and Stem Cell Transplant
CHoR Definition of PPC

• “PPC is an extra layer of support focused on identifying, preventing and treating suffering in children with serious illnesses, their families and the teams that care for them. Palliative care is appropriate at any stage of a serious illness and can be provided together with disease-directed treatment. Palliative care supports ongoing treatment of the patient’s underlying illness and at the same time strives for optimal quality of life.”
Our Team at CHOR!

• The Supportive Care Team
  – Medical providers
    • Jean Teasley, MD (medical director)
    • Kelly Lastrapes, MD
    • Amanda Gideon, CPNP
  – Social workers
    • Patty Roberts, LCSW
    • Ellen Hanson, LCSW
    • Robyn Dillon, LCSW
  – Pastoral Care
    • Josh Andrzejewski, BCC
The Numbers…

• In 2013
  – 2.6 million deaths
    • Children aged 0-19 accounted for 1.6% or 42,328 deaths
      – 55% in infancy
        » 66% in the neonatal period
### Table 3. Causes of Death, Children Birth – 19 years

<table>
<thead>
<tr>
<th>All Infants</th>
<th>Infants with CCC</th>
<th>All Children 1-19 Years</th>
<th>All Children 1-19 Years with CCC</th>
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</thead>
<tbody>
<tr>
<td>5. Accidents/unintentional injury</td>
<td></td>
<td>5. Congenital malformations, deformations and chromosomal abnormalities</td>
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<tr>
<td>6. Complications of placenta, cord, or membranes</td>
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<td>6. Heart disease</td>
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<tr>
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<td>7. Influenza and pneumonia</td>
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* Includes static neurologic and neurodegenerative conditions
NHPCO 2007 survey
- 78% serve pediatric patients
- 36.6% have a formal pediatric program
- 21.7% that did not have a formal pediatric program had a “specialized staff” for pediatric patients.
Concurrent Care

- Patient Protection and Affordable Care Act (ACA) 2010
  - Section 2302
    - Mandates that children in a state Medicaid or Children’s Health Insurance Program who are eligible for hospice care also be eligible to receive coverage for curative, disease-directed therapy
PEDIATRIC PALLIATIVE AND HOSPICE CARE COMMITMENTS
Palliative Care for Children

ABSTRACT. This statement presents an integrated model for providing palliative care for children living with a life-threatening or terminal condition. Advice on the development of a palliative care plan and on working with parents and children is also provided. Barriers to the provision of effective pediatric palliative care and potential solutions are identified. The American Academy of Pediatrics recommends the development and broad availability of pediatric palliative care services based on child-specific guidelines and standards. Such services will require widely distributed and effective palliative care education of pediatric health care professionals. The Academy offers guidance on responding to requests for hastening death, but does not support the practice of physician-assisted suicide or euthanasia for children.

Pediatric Palliative Care and Hospice Care

Commitments, Guidelines, and Recommendations
PPC-PHC Commitments

• Patient centered and family-engaged
• Respect and partnering
• Quality, access and equality
• Care across the age spectrum and life span
• Integration into the continuum of care
• Universal preparedness and consultation
• Research and continuous improvement
If I may...

SOME ANECDOTES
Differences between adult and PPC

• Diagnoses
  – CSHCN = children with special health care needs
  – CCC = chronic complex condition
  – LLC = life-limiting condition
  – LTC = life-threatening condition

• Prognostic uncertainty
  – Children are resilient, therefore unpredictable
Differences between adult and PPC

• Providing developmentally-appropriate PC
  – Lack of PROs (until PediQUEST study)

• Autonomy/Consent/Assent
  – That delicate balance between autonomy and parental protection
Where our paths intersect...

- COMMUNICATION
- Family members as barriers to care
- Medication abuse/addiction
- AYA population
Some motivation...

The end-of-life physician Evan had through Children’s National never met him before or after he started to receive hospice care at home. “The person who cared for my son at home when he needed it the most never met him and never spoke to him,” Lindberg stressed. In addition, he added, “The wonderful oncology nurses at Children’s National never had an opportunity to care for our son while he was at home. Instead we had nurses who came to see us from an adult hospital. Their experience and expertise was in caring for adults.”

Because the nurses were not comfortable administering intravenous pain medicines to pediatric patients, Evan was not given effective pain releasers and experienced extreme discomfort, distress, and anxiety. In addition, Evan had respiratory challenges that were not appropriately anticipated or addressed. When his end-of-life physician was called and asked to address these issues, the doctor said to expect Evan would live another week or two, but he died the next morning “after a horrific night that my wife and I will forever have seared in our memory,” Lindberg said.

“Unfortunately, there are a lot of kids like Evan and that is just simply unacceptable in this country. Home was the right place for my son to pass, but what was wrong was the type of care he received. We put our trust and faith in the providers and in the system and that was a mistake on our part. There was a lack of communication. There was a lack of transparency about what was happening and why. Children with cancer fight too hard every single day to be left with a fate like that. If we can’t get this right, then shame on us. The hospice system failed our son and as a result, we feel like we failed our son. Those thoughts stay with you. On your worst days, they haunt you.”
References

• American Academy of Pediatrics. Section on Hospice and Palliative Medicine and Committee on Hospital Care. Pediatric Palliative Care and Hospice Care Commitments, Guidelines and Recommendations. *Pediatrics* 2013;132;966; originally published online October 28, 2013; DOI: 10.1542/peds.2013-273


Case Presentation 1

Emily Rivet, MD
Kasia Trebska-McGowan, MD
Virginia Commonwealth University
Case 1: Question

Main question:
How to best communicate unforeseen events to patients and families

What is the nature of your question?
• Treatment options (goals of care)
• Communication
• Determining Prognosis
Case 1: History

Patient history

66-year-old female

Current medications and therapies
  • None

Patient social and spiritual history
  • Very involved son and brother

Pertinent findings
  • Delirium was a major symptom and significant factor in disease course.

Brief history of serious illness and other comorbid disorders:

Patient initially seen and underwent surgery for colovesical fistula. Surgical recovery complicated by anastomotic leak. Diagnosed with plasma cell leukemia post-operatively. Patient developed multi system organ failure and required dialysis, trach although weaned from ventilator.
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View previously recorded ECHOs for CME

Select the session you would like to view
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Click “Tests” to view video of the session and take a short quiz for continuing education credit.
THANK YOU!

We hope to see you at our next ECHO