



Pediatric Palliative Care in the Community

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Pediatrics



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Learning objectives

- At the conclusion of this activity, the participant should be able to:
 - Describe pediatric palliative care
 - Explain how to think like a palliative care doctor
 - Identify strategies to improve communication surrounding severe illness
 - Discuss strategies to implement or improve delivery of palliative care in community hospital settings
- Time for questions at the end

What is pediatric palliative care (PPC)?

- The active, total care of the child's body, mind, and spirit
- Involves giving support to the family
- Begins when the illness is diagnosed and continues regardless of whether a child receives disease-directed treatment

World Health Organization

What is pediatric palliative care (PPC)?

- Requires a broad multidisciplinary approach that is appropriate and feasible even if resources are limited; this approach includes family and the community
- Can be provided wherever the child is located, including home, acute care institutions, long-term care facilities, or community health centers
- Is life affirming and can positively influence course of disease

World Health Organization

Who is pediatric palliative care for?

- Any child with a serious or life-threatening condition
 - Genetic disorders
 - Cancer
 - Prematurity
 - Neurologic disorders
 - Cardiopulmonary disease
- It's rarely too early to provide palliative care

Getpalliativecare.org

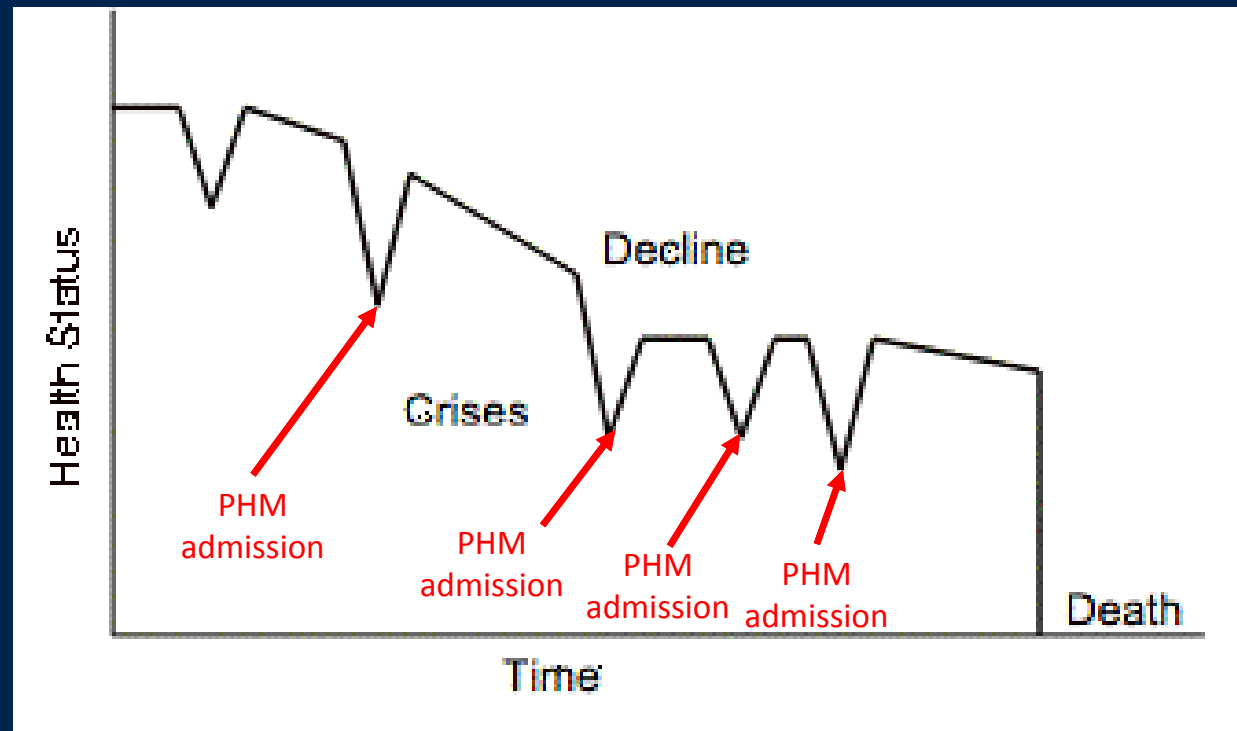
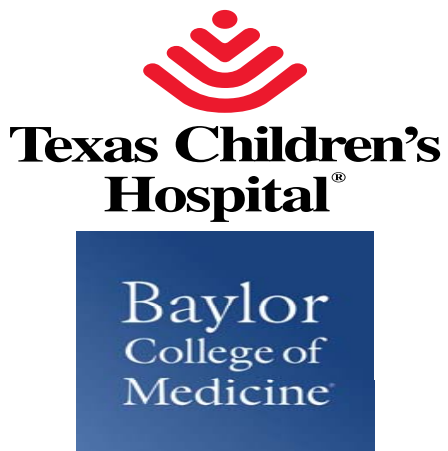
Benefits of early palliative care

- Adults with non-small-cell lung cancer.
- Randomized to early palliative care along with oncology or oncology care alone
- Patients with palliative care had better quality of life, less depression
- Fewer in palliative group received aggressive end-of-life care
- **And palliative care patients lived 2 months longer on average!**

Temel, 2010

Primary vs. Subspecialty Palliative Care

- Primary: Some basic level of palliative care knowledge and skills that all healthcare providers should possess
- Subspecialty: Advanced training and certification in palliative care required to care for the most complex patients and families



Pediatrics

PPC in Practice

- Goals of care discussions
- Medical decision-making
- Pain and non-pain symptom management
- Psychosocial and spiritual support
- Care coordination
- Advance care planning

PPC in Practice: Goals of care

- Patient/family values
- “What is most important to you?” or “What are your priorities?”
- Concept of “regoaling”



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PPC in Practice: Medical Decision-Making

- Facilitating decision-making with patients and families
- “Some decisions are too big to make alone”
- Enhanced autonomy
-Quill, 1996



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PPC in Practice: Psychosocial and spiritual support

- Total pain
 - Physical + Psychological
 - + Social + Spiritual
- Utilize your team



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PPC in Practice: Care coordination

- You get it



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PPC in Practice: Advance care planning

- “Hope for the best, plan for everything else.”
- Use goals of care as a guide
- Documents
 - Voicing My Choices
 - Five Wishes/My Wishes



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PPC in Practice: Advance care planning

- Do not resuscitate (DNR)
- Out-of-hospital DNR
- Medical/Physician Orders for Life-Sustaining Treatment (MOLST/POLST)



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Communication pearls

- “I’m worried”
- “I wish”
- “Tell me more”
- Use hope as a verb, not a noun
- Allow family to talk
- Silence



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Communication: Talking to children about death

- “We can’t tell her she’s dying”
 - Parents protect their children
 - Cues not to talk about it
 - Children protect their parents too
- Goals:
 - Establish trust between patient, family, and team
 - Protect children from misconceptions about death



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Communication: Talking to children about death

- Kreicbergs, 2004
 - Study of parents after death of a child
 - No parent who spoke to child about death regretted it
 - 27% of parents who didn't speak to child regretted it
 - More likely to regret if child seemed aware of impending death



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Staff support

- For an individual
- In a group setting

Table 1.
Format and Structure of Bereavement Debriefing Sessions

Format	Structure
Welcome and Introductions	<ul style="list-style-type: none">• Review purpose of bereavement debriefing sessions• Invite participants to give names and answer• “How were you involved in care for this patient and family?”
Factual Information	<ul style="list-style-type: none">• Review time of death circumstances
Case Review	<ul style="list-style-type: none">• “What was it like taking care of this patient?”• “What was the most distressing aspect of the case?”• “What was the most satisfying aspect of the case?”
Grief Responses	<ul style="list-style-type: none">• “What have you experienced since the death?” (Elicit physical, emotional, behavioral, cognitive, or spiritual responses)
Emotional	<ul style="list-style-type: none">• “What will you remember most about this patient/family?”
Strategies for Coping with Grief	<ul style="list-style-type: none">• “How are you taking care of yourself so you can continue to provide care for other patients and families?”• Review grief coping strategies• Review available resources
Lessons Learned	<ul style="list-style-type: none">• “What lessons did we learn from caring for this patient/family?”
Conclusion	<ul style="list-style-type: none">• Acknowledge care provided• Review bereavement support available for families and staff

Pediatric Palliative Care in the Community

- Building infrastructure at your institution
 - Palliative care training for yourself and other interested colleagues
 - Utilizing existing psychosocial support
 - Work toward administrative buy in

Pediatric Palliative Care in the Community

- Finding palliative care support outside your institution
 - Pediatric colleagues at other institutions
 - Local adult palliative care colleagues
 - The AAP palliative care listserv: ppcaap@listserv.aap.org

Pediatric Palliative Care in the Community

- Pearls of wisdom on potential barriers and facilitators
- Be realistic about what you can take on and don't burn yourself out!

Hospice

- A model for quality compassionate care for people with life-limiting illness
- Certified by 2 physicians (often primary and hospice physician) to have prognosis <6 months
 - Prognostic uncertainty is OK
 - “Surprise” question
- Care managers and Social Workers can assist with making referrals

Hospice 4 Levels of Care

- Home care – 80%
- Respite care – when the caregiver needs a break
- Continuous/Crisis care – hospice provides in-home 24 hour care for short period
 - Actively dying patient
 - Difficult symptom management
- In-patient care – symptom control, transition from hospital to home, actively dying patient

The ACA and concurrent care model

- Insurance hospice benefit takes place of other coverage, so opting for hospice has historically meant deciding to forgo further disease directed therapy
- But now, children under 21 who qualify for Medicaid or CHIP can receive hospice AND disease directed therapy (covered by insurance outside of hospice benefit)
- Many commercial insurance companies now willing to negotiate concurrent care options

UNIPAC, 4th edition, AAHPM

Resources

- The Center to Advance Palliative Care (CAPC) at www.capc.org
 - Resource for palliative care knowledge and skills, focused training opportunities
- American Academy of Hospice and Palliative Medicine
www.aahpm.org
 - Organization providing education, resources, and training opportunities
- AAP section on Hospice and Palliative Medicine
 - Pediatric-specific information and resources
- Hospice and Palliative Medicine Fellowships – Only 1 year long!!!

Resources

- Feel free to email us!
- Jared Rubenstein jerubens@texaschildrens.org
- Taryn Schuelke tsschuel@texaschildrens.org
- Ellie Crow ecrow@phs.org

References

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Questions?