OBJECTIVES

- Define pediatric palliative care (PPC) as a set of tasks with impact
- Identify predictable opportunities for palliative care intervention
- Describe when and how to utilize a subspecialty palliative care team
- Evaluate myths and assumptions about PPC
500,000 children live with complex chronic conditions
55,000 patients ages 0 to 19 years die annually

IOM report 2013

Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer


(11.6 months vs. 8.9 months, P=0.02)

THAT’S THE PATIENT. . . WHAT ABOUT THE CAREGIVER?


IMPACT OF PEDIATRIC PALLIATIVE CARE

- Children with serious illnesses and their families benefit from PPC
- Earlier initiation of PPC improves symptom management & quality of life
- May lead to prolonged life

IMPACT OF PEDIATRIC PALLIATIVE CARE

• Symptom improvement: peds-specific PPC literature — uh, too many to cite!


• Children who received PPC home care were more likely to have fun (70% versus 45%) and to experience events that added meaning to life (89% versus 63%). — Friedrichsdorf SJ, Postier A, Dreyfus J, Osenga K, Sencer S, Wolfe J. Improved quality of life at end of life related to home-based palliative care in children with cancer. Journal of palliative medicine. 2015; 18(2): 143-50.


WHAT IS PEDIATRIC PALLIATIVE CARE?

Hint: More than hospice.
DEFINITIONS – World Health Organization

“Pediatric Palliative Care prevents, identifies and treats suffering in children with serious illnesses, their families, and the teams that care for them.

It is appropriate at any stage of the illness, and can be provided together with disease-directed treatment.”

DEFINED BY A PEDIATRIC PATIENT. . .

"Palliative care no longer means helping children die well, it means helping children and their families to live well, and then, when the time is certain, to help them die gently.”

DEFINITIONS — Center to Advance Palliative Care (CAPC)

- Entails active, total, longitudinal care of the child’s body, mind, and spirit
- Involves giving support to the family via a team
- Begins when the illness is diagnosed and continues regardless of whether a child receives disease-directed treatment
- Incorporates evaluation and alleviation of not just physical distress but also psychological and social distress
- Requires a broad multidisciplinary approach that is appropriate and feasible even if resources are limited; this approach includes the family and the community
- Can be provided wherever the child is located, including home, acute care institutions, long-term care facility, or community health centers.

THE BIGGEST SECRET IN PALLIATIVE CARE?

We are all palliative providers!
Palliative care is a team-based specialty devoted to improving quality of life for seriously ill patients and families through:

- Attentive pain and symptom management
- Skilled communication about what matters most to patients and their families
- Well-coordinated care over the course of illness — longitudinal presence
PALLIATIVE CARE STANDARDS UPHOLD

<table>
<thead>
<tr>
<th>Table 1. Palliative care standards, statements, and recommendations</th>
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<tbody>
<tr>
<td>Organization</td>
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<td>The Joint Commission</td>
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<td>National Hospice and Palliative Care Organization</td>
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<td>National Priority Partnership</td>
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Note: Validated metrics, please!


DOMAINS WITHIN PALLIATIVE CARE STANDARDS

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<th>Table 2. Palliative Care Domains and Recommendations from the National Consensus Panel Guidelines.</th>
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<td>Domain</td>
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<td>Structure and processes of care</td>
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<td>Physical aspects of care</td>
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<td>Psychological and psychiatric aspects of care</td>
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<td>Spiritual, religious, and existential aspects of care</td>
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<td>Cultural aspects of care</td>
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<td>Care of the imminently dying patient</td>
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<tr>
<td>Ethical and legal aspects of care</td>
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* Adapted from the National Consensus Project for Quality Palliative Care.
**MYTH BUSTER MOMENT...**

1. Must be a code word for hospice
2. Must be terminally ill or at the end of life (life-limiting or life-threatening)
3. Must “be ready” for a DNR
4. Must be an alternative to life prolonging care (“____” versus palliative care)
5. Must abandon disease-directed treatment
6. Must transition away from primary treatment team
7. Must want end-of-life to be at home – (location, location, location)
8. Must be a costly service for the hospital to carry
9. Must be more likely to die sooner/lose hope
10. Must only consult Friday at 5:30 PM

Friedrichsdorf SJ. Contemporary Pediatric Palliative Care: Myths and Barriers to Integration into Clinical Care. Curr Pediatr Rev. 2016. PMID: 27848889

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**WHAT IS HOSPICE?**

Component of palliative care centered on end of life

An insurance benefit associated with a terminal prognosis

Defined as having potential for death in 6 months or less – “surprise question”

Services and resources centered on end-of-life issues

* In-home assessment for pain & symptom management – but, **NOT** 24/7 home nursing!
* Ongoing psychosocial & decision-making support
* Grief & bereavement support

WHAT TASKS ARE INVOLVED IN PPC?

- Symptom Management
- Communication
- Needs Assessments & Interventions
- Longitudinal Care
- Contextualization

SYMPTOM MANAGEMENT — 58%

Feudtner et al, Pediatrics 2011
CASE STUDY

Patient:

13 year old female with metastatic osteosarcoma
Consulted for pain and nausea
Disease progression on curative-directed therapy

Bio-Psycho-Social-Spiritual Approach

Physical Issues

Disease Management

Psychological & Cognitive Issues
• Loss, Grief

Patient/Family Characteristics

Practical Issues

Social Issues
• Ethical aspect of care

Spiritual Issues
• Life meaning, connectedness

Interdisciplinary Team Approach

Adapted from Frank Ferris- EPEC-O
CONTINUE THE CARE! (longitudinal value)

Healthy/Functional Status Over Time

Predictable opportunities to initiate PPC tasks

Needs Assessment!!!
FORMALIZED NEEDS ASSESSMENT

Reviewed with Hand in Hand team the past 3 years of Needs Assessment data for palliative care patients (70 patients)

Journal of Palliative Medicine: “Pediatric Palliative Care Needs Assessments: From Paper Forms to Actionable Patient Care”

- Urie Bronfenbrenner

NEEDS: CHILD AND PARENT VOICE
ACUTE DECOMPENSATION AND HEARING BAD NEWS (POINT A)

Healthy/Functional Status Over Time

Pain and symptom management
Coping with new diagnosis
Collaboration and communication
Sibling distress

SYMPTOM MANAGEMENT — N/V
SYMPTOM MANAGEMENT - PAIN

RELATIONSHIP BETWEEN SYMPTOMS AND SUFFERING
RECOVERY AND ACCOMMODATING TO A NEW LIFE (POINT B)

Healthy/Functional Status Over Time

Lingering symptoms
Coping with new normal
Coordinating care
Grieving loss of “well” child
Anticipatory grief over change in family, suffering for child
Sibling issues

COMMUNICATION

- Eliciting family and patient’s understanding of prognosis
- Identifying problems and challenges from child and family perspective
- Learning about family’s preferences for communication
- Defining family’s approach to decisions prior to decision-making
- Exploring hopes and the many domains of hopes
- Setting goals
- Clarifying what makes a “good” day
- Defining comforts and strengths
- Advanced care planning
**CARE COORDINATION**

- Defining the team; personally for patient and inclusively
- Collaborating with other providers/specialists
- Facilitating logistics of medical and social needs
- Partnering with community programs
- Identifying community resources

**ACUTE DECOMPENSATIONS AND UNEXPECTED RECOVERIES (POINT C)**

- Healthy/Functional Status Over Time

  - Pain and symptom management
  - Assistance with decision making
  - Goal setting
  - Comfort care initiatives
ASK-TELL-ASK APPROACH (ATA)

- What is your understanding of your (or, your child’s) prognosis?
- Would it be helpful for me to explain what is going on with your cancer?
- Some patients (or families) benefit from knowing medical details such as expected timelines or details of what to expect, are you the type of person (or family) who prefers to hear these details?
- What is your preference for receiving communication?

COMMUNICATING WITH THE CHILD . . .

Explore what the child currently knows and understands
Assess what the parents think their child know
Assess what the parents want their child to know
Educate the parents that not talking to their dying child about his/her death may be regretted later
Consider use of bibliotherapy
Open, but non-forced conversation – foster questions/goodbyes
SLOW OR PRECIPITOUS DECLINE PRECEDING END-OF-LIFE (POINT D)

Healthy/Functional Status Over Time

- Coping with declining condition
- Decisions regarding invasive technology
- Self-determination for child-patient
- Pain and symptom management
- Increasing sibling distress
- Bereavement

COMMUNICATION - (ideally mostly listening)

Ground with goals and values!
PHRASES TO AVOID

What would you like us to do?
Would you like us to do everything? Do nothing?
Do you want your child to:
Be intubated?
Get chest compressions?
Be defibrillated?
The parents “signed” the DNR
“Withdrawal”

END OF LIFE (POINT E)

Healthy/Functional Status Over Time

Planning for death
Decisions regarding resuscitation
Intensive symptom management
Increasing family and sibling distress
Care of the imminently dying patient
Bereavement
ANTICIPATORY GUIDANCE IS ESSENTIAL!!

- In the days/weeks prior to death:
  - Respiratory changes
  - Increasing somnolence
  - Fatigue (less walking/speaking)
  - Not eating

- In the days/hours prior to death:
  - Labored, slow or fast, or loud breathing
  - Seizures or changes in movement
  - Less urine
  - Skin changes – mottling, coolness

PARENTAL GUIDANCE

- Continue to bathe child gently (sponge)
- Change the position of his/her body – less focus on monitors
- Watch for signs of discomfort
- Provide child with the familiar voices, sounds, and touch
  - Favorite books, gentle music, soothing smells - aromatherapy
- Consider massage, Healing Touch, and reflexology
- Power of permission!! We are all “protecting” each other.
RECOVERY (POINT F)

Healthy/Functional Status Over Time

Maximizing recovery and optimizing function
Monitoring for and managing late effects

CONTEXTUALIZED ROLE: THE FAMILY EXPERIENCE

- Stress and anxiety
- Multiple demands
- High degrees of uncertainty
- Balancing hopes for a good outcome with fears of a bad one
- Pressures last months to years can erode resilience

WHEN AND HOW TO UTILIZE SUBSPECIALTY PPC?

Hint: Early integration.

HAD TO START SOMEWHERE...

Think about appropriate start points:
- Bad news/overwhelmed at diagnosis
- Phase I enrollment
- Relapse/recurrence
- Serious complications
- ICU admissions/transfers
- Change in technology (new trach)
- Listing for transplant
EVOLUTION OF PALLIATIVE CARE MODEL

Care should be integrated at diagnosis
- Provides focus of disease and suffering in all stages
- Provides necessary supports to help families cope
- Prevents perception of transition in care or abandonment

Subspecialty care is integrated with primary team
- Keeping PMD or primary specialist in control

Disease modifying and palliative care strategies work together synergistically
- Better symptom and psychosocial management may improve tolerance of treatments and outcomes
- Palliation and restorative strategies both aim to improve function

REASONS FOR INTEGRATING PALLIATIVE CARE EARLY

- Gives opportunity for child and family to be known fully not just “illy”
- Provides umbrella of support throughout entire process
  - Additional support for primary team too (time, resources, self-care, prevention of compassion fatigue)
- Empowers parents to be capable of maintaining dual goals of care concurrently
- Allows patient and family self-determination about treatment options
- Minimizes fragmentation of care
- Health care justice: access to emerging best practice

THE LANGUAGE OF PPC . . .

Interdisciplinary – team, team, team

Family (biological, adoptive, foster, etc) core to decisions

Patient-reported outcomes and PATIENT VOICE!!!

Surrogate decision making by proxy

Layers of hope

Benefits/burdens

AVOID: “Withdrawal of support/care”

AVOID: “Nothing more we can do”

AVOID: The word “narcotics”

AVOID: “Crazy family” (it’s a crazy situation!)

ACT LOCAL, THINK GLOBAL

PCC GROUP: 144 FROM 52 COUNTRIES (32 JOINED 2016)
IN SUMMARY

PEARLS

- Refer to PPC early
- Focus on the relief of suffering
- Consider careful use of language
- Work synergistically to enhance care
- Define goals for care

SAND

- Confusing PPC with hospice or only end of life care
- Asking families to choose PPC when they may not understand what it is
- Using language that suggests “giving up” or loss of hope
- Waiting so long to refer that suffering increases
- Using terms like “withdrawing” or “withholding” care

Hint: Pearls and sand.
GRATITUDE — to the Hand in Hand team!