Pediatric Palliative Care:
It May Not Be
What You Think It Is?

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Objectives

<table>
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<tr>
<th>Understand</th>
<th>• Understand what palliative care is and how it is similar yet different than hospice</th>
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<tbody>
<tr>
<td>Describe</td>
<td>• Describe common misconceptions associated with palliative care</td>
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<tr>
<td>Develop</td>
<td>• Develop primary palliative care skills that can be useful within your practice</td>
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3 Requests

Prepare Your Hearts For Something Different

LEAN IN

Ask Questions
A little about me

- Bayous
- Bama Land
- West Coast
- NOLA
- Nashville
- New England
- HOME SWEET HOME
- @drmoppc
What Comes To Mind When You Hear “Palliative Care?”
It Depends on the Audience
Beneficial at any stage of a serious illness, palliative care is an interdisciplinary care delivery system designed to anticipate, prevent, and manage physical, psychological, social, and spiritual suffering to optimize quality of life for patients, their families and caregivers.
Palliative Care

- Staff Support
- Meaningfulness
- Coordination
- Mitigate Suffering
- Continuity of Care in Different Settings
- Communication
- Social Worker
- Physician
- Nursing
- Research
- Education
- Integrative Therapies
- Psychology
- Spiritual Care
- Bereavement Services
- Optimize Quality of Life
- Patient Experience
- Increase length of life
- Increase length of life
- Education
- Research
- Staff Support
We help make EVERY day the very best day possible

Ultimate Goal

Have the honor to be invited into the world of serious illness and bear witness to our patients' Stories
Caring for the Sickest in the Hospital Requires a Trained, Present, Resilient Interdisciplinary Team Who are Experts in Stomping Out Suffering (in all its forms.)
What’s Going On in LA?

• CHNOLA, Women’s, Ochsner have pediatric pall care programs
• CHNOLA – 2 MDs, 1 NP, 1 SW, 1 RN
• ~180 consult requests in 10 months (16 in last 2 weeks)
• Inpatient only, Telemedicine
• Growing to be outpatient in 2020/2021
Let's talk numbers for a bit...
Why is PPC needed?

- 500,000-1 million children with complex, chronic illnesses
- 10,000+ Dx with Cancer per year
- 40,000+ Dx with Complex congenital heart disease
- 80,000+ with severe prematurity
- 50,000 children die/year (about 800 in LA)
- 75-85% children die in an institutional setting
Most common diagnoses:

Genetic syndromes

Congenital abnormalities

Neuromuscular disease

Cancer
... The demographics of a subspecialty service

<table>
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<th>Age distribution</th>
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<tr>
<td>5% less than 1 mo</td>
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<tr>
<td>13% 1-11 mos</td>
</tr>
<tr>
<td>37% 1-9 yrs</td>
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<tr>
<td>30% 10-18 yrs</td>
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<tr>
<td>16% 19+ yrs</td>
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What are other benefits of palliative care?

Other cool stuff...
- Decrease LOS
- Decrease readmission rates
- Decrease hospitalization costs especially with home-based pall care
- 9 points on USNWR

Education outreach to clinicians to improve primary palliative care skills

Gives a voice to parents and children in helping them identify goals (Wolf 2008)

Enhances well-being, strength and resilience of families (Hays et al 2006)

Increased patient and family satisfaction and experience with care

Families have more FUN! (Friedrichsdorf, Wolfe)

Improved staff satisfaction and retention
<table>
<thead>
<tr>
<th>Myth</th>
<th>Description</th>
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<td>Palliative care = hospice = giving up hope</td>
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<tr>
<td>Child must be terminally ill or at the end of life</td>
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<tr>
<td>Child must have a DNR to have hospice care</td>
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<tr>
<td>Only for children with cancer</td>
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<tr>
<td>Must abandon all disease-directed treatment</td>
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Myths in palliative care and hospice

- Must abandon primary treatment team
- Child must move to a different unit/location
- Child will die sooner/lose hope if PC introduced
- All families want end-of-life to be at home
- Administering opioids causes respiratory depression and quickens death
Early Palliative Care

Palliative care meets families where they are in their journeys and can be apart of the care plan whether families are pursuing intensive therapies or comfort directed care plans or anywhere in between

Agendas at the door!
• Any stage of serious illness

• Prevents disruptive transition

• Rapport building prior to serious decision nodes

• Preemptive symptom assessment and management

• Adult studies show it increases survival even in fatal diagnoses

Early Integration of Palliative Care
“But we will take away hope…”
Actually, not in pediatrics

Mack et al showed that prognostic information and involvement of palliative care does not take away hope

Families live better when they are receiving information in a meaningful way

HOPE for the best and PREPARE for the rest
More information allows families to live with less anxiety

Life-limiting illness – give a spectrum of what to expect in best case, worst case, most likely (time – days to weeks, months to years)

Our goal is not to steal hope (allow oscillation)
- Goal is to diversity hopes for realistic outcomes
- Regoaling

Mack et al showed that prognostic information and involvement of palliative care does not take away hope

Families live better when they are receiving information in a meaningful way

HOPE for the best and PREPARE for the rest
What does this all mean to families?

They don’t want to lose hope, help them find new hopes – “Regoaling”

They want to do everything in their power to be a Good Parent

No decisional regrets
"The good parent is adequately knowledgeable about the child’s medical situation to make informed and unselfish decisions, advocates for the child with staff, has sufficient strength to remain at the child’s side no matter how difficult the Circumstances, provides the basics of food, shelter, clothing and positive health, and teaches the child to make good choices, to respect and have sympathy for others, and to know a Greater Being. Of particular importance is to be certain that the ill child knows he or she is loved by the parent."

Pamela Hinds, PhD, RN, FAAN
“But Palliative Care Is **SO** Sad...”

• It’s actually what we all went to school to do (before we broke our patients into problems and checkboxes)
• Hanging out with sick super heroes all day
• Be a part of a special story
• HAVE FUN! (aquarium, outside, Prom)
We get one chance...
Skills Development Scaffolding

Access free online tools for clinicians and faculty at www.vitaltalk.org

CAPC's Communication Curriculum
https://www.capc.org/capc-central/courses/

The Conversation Project

PCEP