GULF STATES PEDIATRIC PALLIATIVE CARE CONSORTIUM

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ASSISTANT PROFESSOR OF CLINICAL PEDIATRICS, LSUHSC

LA PEDIATRIC PALLIATIVE CARE CONSORTIUM, CHAIR
WHO DAT?

- Bayous
- Alabama
- California
- Louisiana
- Mississippi
- Tennessee
- Boston
- HOME SWEET HOME
- @DrMoPPC (Twitter)
- amorva@lsuhsc.edu
NO DISCLOSURES
WHAT IS PEDIATRIC PALLIATIVE CARE?

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.
Why is PPC needed?

- 500,000-1 million children with complex, chronic illnesses – LIVING LONGER AND LONGER
- 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 (~700-800 deaths in LA)
- 75-85% children die in an institutional setting = need inpatient programs!
Laurel Kitto, RN (Woman’s BR), Lori Naquin, RN (Ochsner), Cori Morrison MD (CHNOLA), Sonia Malhotra MD (UMC)

Paved the Way, please stand

Summit last year

Many phone-calls for collaboration

I wanted to meet people

Partnered with LMHPCO (Jamey Boudreaux and Nancy Dunn)

Dinner at my home in January – what is going well and where are our growth opportunities discussion

The rest is history

STORY OF PEDIATRIC PALLIATIVE CARE IN LOUISIANA/MISSISSIPPI

AND

OUR CONSORTIUM
VISION
All children and families in the gulf state region facing serious illness will have access to comprehensive support through the entire duration of serious illness both in the hospital and the home with the goal to prevent, anticipate and mitigate suffering in all its forms.
We will achieve our vision through an interdisciplinary workforce advocating for every child and family to have access to the support necessary to live as well as possible with serious illness.

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<tr>
<th>Our interdisciplinary workforce will:</th>
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<td>Provide quality clinical care both in our hospitals and in the home</td>
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<td>Collaborate with our Gulf Coast community to advance education</td>
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<td>Engage in advocacy</td>
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<td>Provide leadership and expertise in the region</td>
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<td>Identify utilization and gaps within hospice and palliative care in Louisiana</td>
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WHO IS PARTICIPATING?

- 50 MEMBERS
- 5 HOSPITALS
- MANY HOSPICE COMPANIES
- 9 DISCIPLINES
HOW DO WE HOPE TO EFFECT CHANGE?

Bring a voice to children and families living with serious illness

Dividing and Conquering

6 Subcommittees, led by incredible humans
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<th>Area</th>
<th>Contact</th>
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<tr>
<td>LA Pediatric Hospice and Palliative Care Professional Education and Community Outreach</td>
<td>Christy Heitmeier, RN and Sonia Malhotra, MD</td>
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<tr>
<td>LA Pediatric Hospice and Palliative Care Literature and LMHPCO Newsletter Updates</td>
<td>Judy Zeringue, RN</td>
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<tr>
<td>LA Pediatric Hospice and Palliative Care Utilization, Outreach and Resources</td>
<td>Ben Rothwell, MD, Annie Vaden, LCSW</td>
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<tr>
<td>LA Pediatric Palliative Care Consortium Social Media, Website and Networking</td>
<td>Thad Hicks, RN</td>
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<tr>
<td>LA Pediatric Hospice and Palliative Care Data Collection</td>
<td>Haritha Vellanki, MD, Catherine Buckingham, RNP, Kimberly Stewart, MD</td>
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<td>LA Concurrent Care Benefit</td>
<td>Melissa Salus, RN and Jamey Boudreaux, SW</td>
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WHAT’S HAPPENING IN PEDIATRIC PALLIATIVE CARE WITHIN LOUISIANA?

- Survey created by Drs. Vellanki and Stewart and Catherine Buckingham
- CHNOLA, Ochsner Baptist NICU, Women’s Baton Rouge NICU, OLOL – replied to our survey
- UMC’s adult palliative care program sees pediatric trauma cases
  - led by Dr. Sonia Malhotra who is med/peds trained and board certified in HPM
- Disclosure: If there are other programs who exist! Please let us know!
WHAT DID WE LEARN?

- Programs are between 1-8 years old
- ~8000 pediatric admissions with about ~320 consults per year = 4% penetration rate (~750 peds deaths/year)
- All programs are inpatient only at this time, no 24/7 availability
- 1 joint commission certification
- 1 program has formal relationship with hospice and the others informally collaborate
- 1 program sees all ages and diagnoses of pediatric patients
- 100% of programs worry about burnout for their team
- 100% hope for expansion of a formal team
SUPER TRAINED!

- **EPEC-PEDS** (train the trainer certified)
- **Vital Talk**
- Nursing and social work *certification* in palliative care
- **ELNEC-PEDS** certification (train the trainer certified)
- 2 completing **PCEP** this year
- By 2020, 3 **HPM board certified** pediatricians who completed pediatric HPM fellowships and will be 100% dedicated to pediatrics

WOO HOO
**LA PEDIATRIC PALLIATIVE CARE PROVIDERS**

**Formal versus Informal Providers**

- **Formal**: 15
- **Informal**: 4

**Disciplines Represented**
- Social Work*
- Physician*
- Nursing*
- Child Life
- Psychology
- Spiritual Care
- Respiratory Therapy
- Integrative Therapies
- No formal bereavement coordinators
GOOD NEWS!

Ochsner Main Campus - palliative care Medical Director who completed a pediatric HPM fellowship at the world-renowned Children's Minnesota.

CHNOLA - HPM pediatrician Dr. Ashley Kiefer who completed a pediatric HPM fellowship at St. Jude – interest is outpatient palliative care, parental bereavement and hospice.

CHNOLA - full-time nurse practitioner, Catherine Buckingham, NP who completed NP school at UAB. Her interest are education and program development.
GOALS TO CONSIDER

- Expand infrastructure – every hospital who admits high number of pediatrics = formal IDT
- We have dynamite trained folks – spread the love! EDUCATION OVERHAUL
  - Including our elected representation
  - Burnout and concern of burnout is real and we need to take care of one another and ourselves – selfcare
- Improve transitions from hospital to home with hospice support
- Home Based Pediatric Palliative Care
- Protect concurrent care
CONCURRENT CARE

What is Concurrent Care?

How is it going in LA?

Are there any concerns?

WE CAN HELP!
WHAT IS
“CONCURRENT CARE FOR CHILDREN REQUIREMENT?”

- March 2010 Affordable Care Act:
  - Makes hospice services available without forgoing any curative or life-prolonging services for which the child is eligible.
- Infants, children, adolescents and young adults who are <21 years of age
- Prognosis of <6 months
- Entitled to curative/life-prolonging treatments AND hospice benefit
- For any child who is supported by Medicaid (private insurances – case by case basis, very helpful)
- States would continue to pay providers of curative services AND hospices for services within the hospice benefit.
HOW IS CONCURRENT CARE GOING IN LA & MS?

Excellent! Barrett Leonhard

No hospices or hospitals have reported any challenges with reimbursement for concurrent care
Individuals who are under age 21 and who are approved for hospice may continue to receive curative treatments for their terminal illness; however, the hospice provider is responsible to coordinate all curative treatments related to the terminal illness, including:

1. Curative treatment shall be defined as medical treatment and therapies provided to a patient with the intent to improve symptoms and cure the patient’s medical problem.

2. Curative care has its focus on the curing of an underlying disease and the provisions of medical treatments to prolong or sustain life.

3. The hospice provider is responsible to provide durable medical equipment or contract for the provision of durable medical equipment. Personal care services, extended home health, and pediatric day health care must be coordinated with hospice services.

4. Individuals who elect hospice services may also receive EPSDT personal care services concurrently. The hospice provider and the PCS provider must coordinate services and develop the patient’s plan of care.

ARE THERE ANY CONCERNS WITH LA CONCURRENT CARE BENEFIT?

- LMHPCO and AAP are working with LA Medicaid to ensure that concurrent care language is adequate in providing the best care possible.
HOW WILL WE KNOW IF WE ARE SUCCESSFUL?

- **Community Based Palliative Care** funded by LA in all areas of LA & MS within 10-12 years

- Formal pediatric hospice and palliative care **education** offered quarterly throughout LA & MS regions within 5 years
  - Goal- improve hospice comfort with pediatrics and improve primary palliative care skills with community pediatricians

- Hospice checklist for hospitals to utilize as kids **transition** home to have clear communication within 5 years

- **Website** with State specific and national pediatric resources and accessible **networking** ability within 3 years

- Yearly **pediatric palliative care conference** within 7 years
  - Utilize our EPEC-PEDS and ELNEC trainers in LA
WE GET ONLY ONE CHANCE...
LEAN IN and Join our consortium!

Pediatric palliative care is rockin` and rollin` in LA & MS!

Pediatric palliative care and hospice is going to be utilized more and more because kiddos are living longer with chronic illnesses.

And as our palliative care programs grow, hospice will be utilized more.

Concurrent Care is working well for our patients – please continue to educate us on your experiences.

Let’s do this!
THE BEGINNING!!!!
SKILLS DEVELOPMENT SCAFFOLDING

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