Nurses and Pediatricians:

Powerful Partners in Challenging Times

July Webinar Series

New Jersey Chapter

INCORPORATED IN NEW JERSEY

American Academy of Pediatrics

DEDICATED TO THE HEALTH OF ALL CHILDREN®

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Pediatricians and Nurses: *Powerful Partners in Challenging Times*

EDU 2052-2: July 15, 16, 22, 23, 2020

(All four sessions required)

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To Obtain Your Certificate

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Attendees are required to complete the evaluation AND participate in at least 85% of each of the live webinars in order to receive a certificate.

Certificates will be emailed on or about July 31, 2020.

Thank you
Nancy E. Winter, MSN, RN, NE-BC
Director of Clinical Quality and Program Development
Primary Nurse Planner

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(EDU 1905)

Thank you for attending this informational series.

The NJAAP will donate $25.00
for each attendee to the
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Pediatric Palliative Care

The Unterberg Children's Hospital at Monmouth Medical Center

Monmouth Medical Center | RWJBarnabas HEALTH

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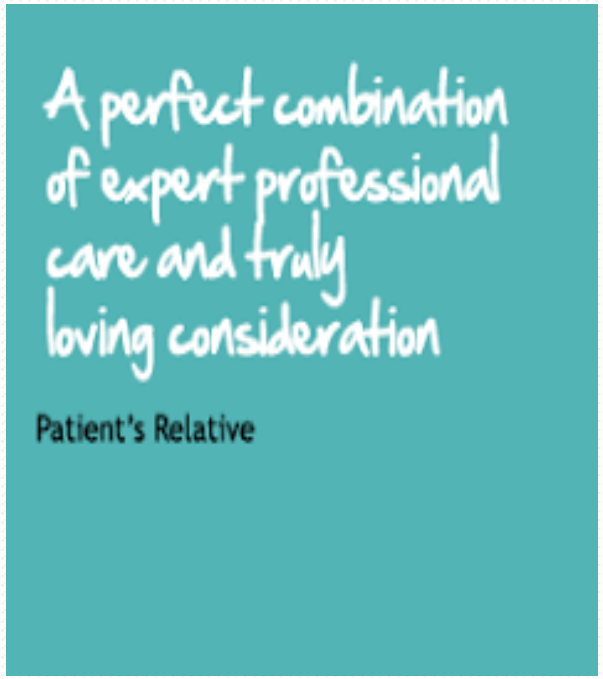
Disclosure

- I have no conflicts of interest to disclose.

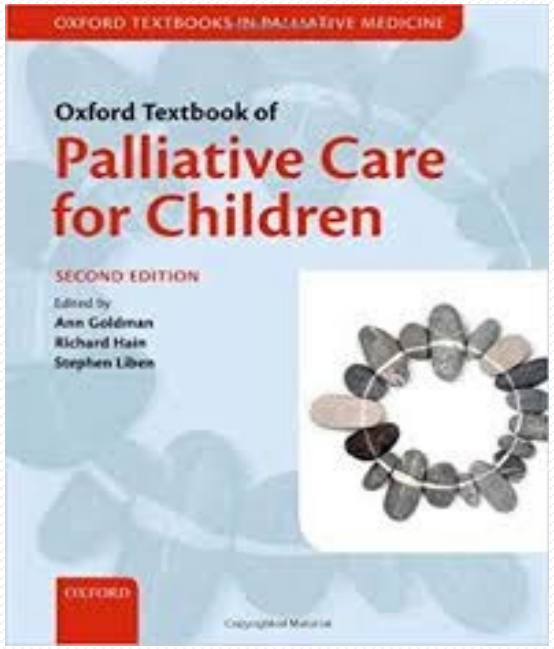
- The pictures and images contained within this presentation were obtained from Google Images or PowerPoint Online Pictures.
- ELNEC (End of Life Nursing Education Consortium)

Pediatric Palliative Care

- Palliative care is the active total care of the child's body, mind and spirit and focuses on providing relief from the symptoms and stress of the illness. (WHO)
- The goal is to improve quality of life for both the child and the family.



Pediatric Palliative Care



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Pediatric Palliative Care

- "We are in need of medicine with a heart …"

- **“Palliative Care adds life to years not years to life.”**

Patient Defining Palliative Care

- “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 then die gently.”

  Mattie Stepanek

  (1990 - 2007)

Why Palliative Care

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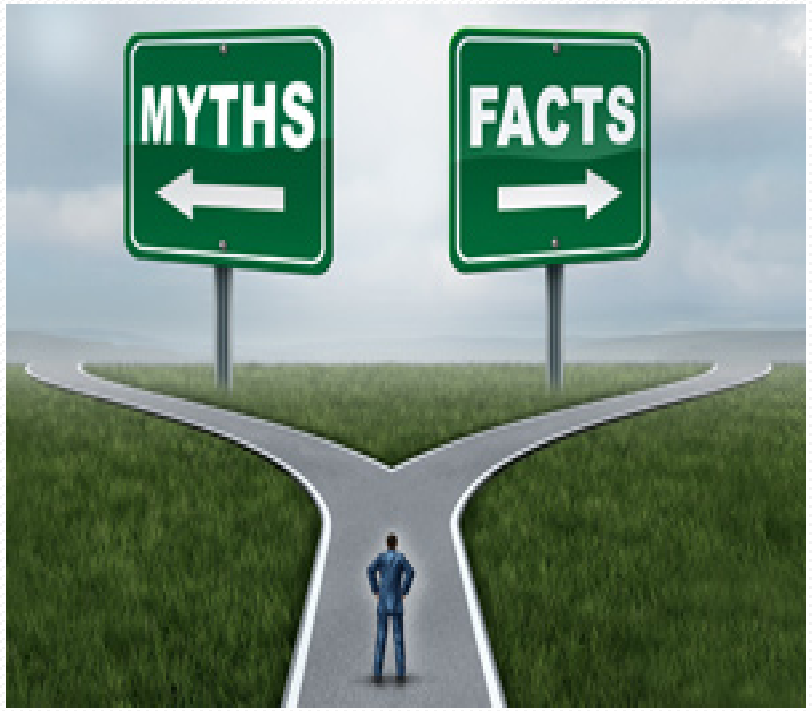
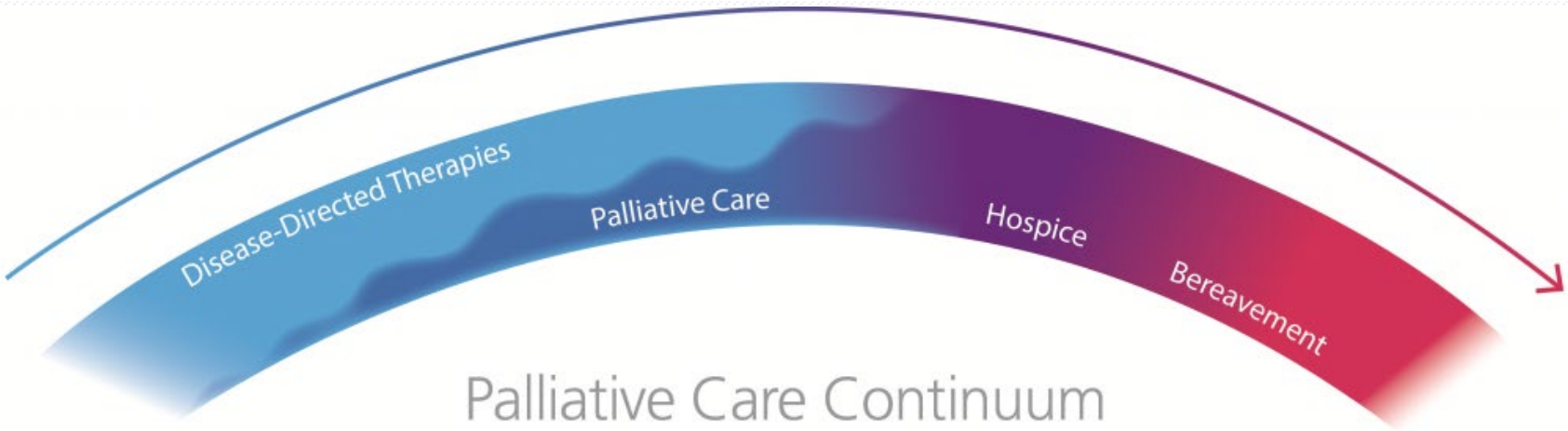
Palliative Care / Hospice Care



Pediatric Palliative Care



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Hallmark of Pediatric Palliative Care

Communication

Myths of Communication

- Communication is deliberate.
- Words mean the same to BOTH the speaker and listener.
- Verbal communication is primary.
- Communication is one way.
- Can't give too much information.
- Silence should always be filled.

ELNEC

Listen With Parents' Ears

What HCP Says	What Patient Hears
His creatinine is better.	He will get well.
She is stable today.	She is getting better.
We have an experimental treatment.	This new therapy will cure my child.
Do you want us to do CPR?	You think CPR will help.
Do you want us to "do everything" for your child?	Doing everything means you think my child will survive and get well.

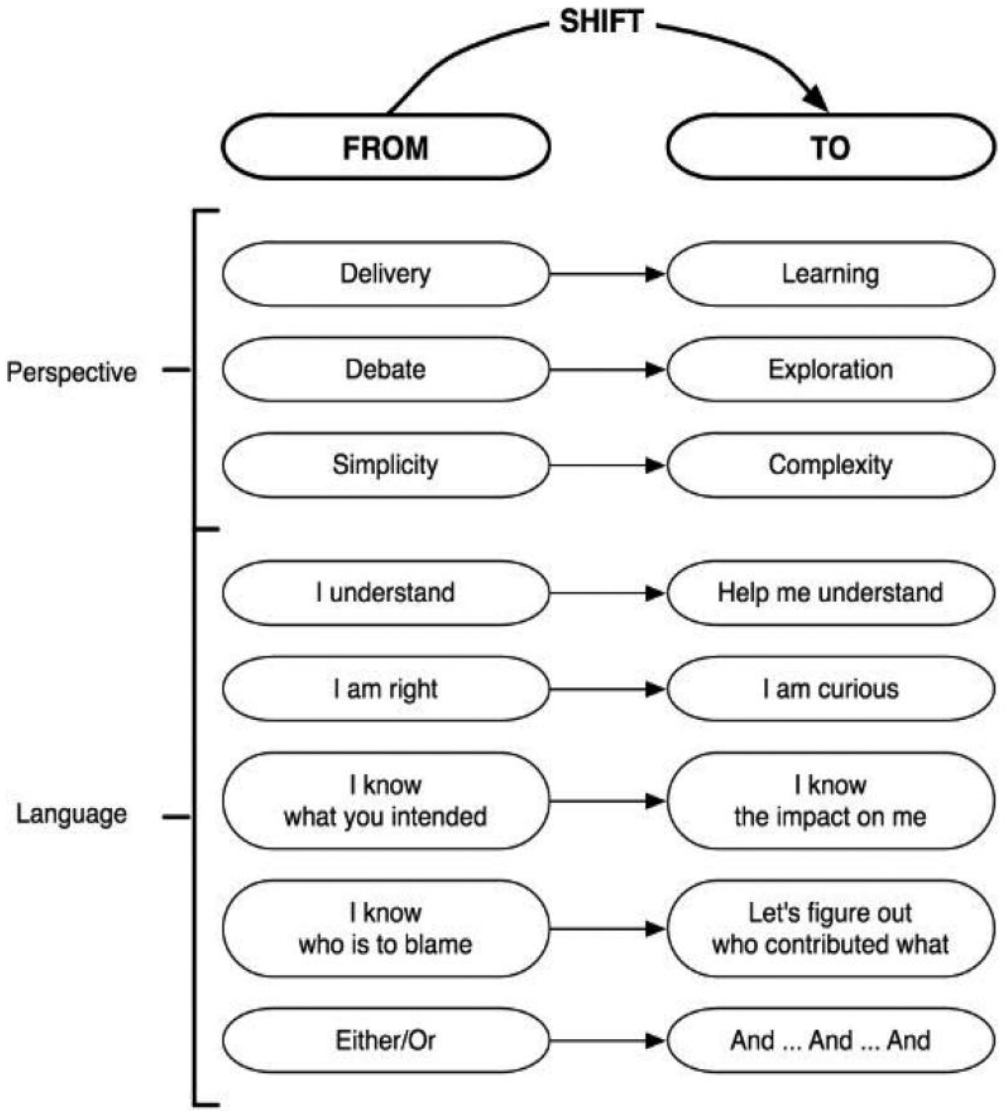
Why/How is Communication Important?

- Imparting necessary information for informed decision making
- Required interdisciplinary collaboration
- Dispels pre-conceived notions/myths
- Helps us connect with those around us

Interpersonal Skills for Good Communication

- Listening
- Clear, timely, relevant information
- Shared goal-setting/decision-making
- Conflict resolution skills
- Sensitivity
- Personal awareness
- Age appropriate communication
- Face to face if possible

Palliative Care



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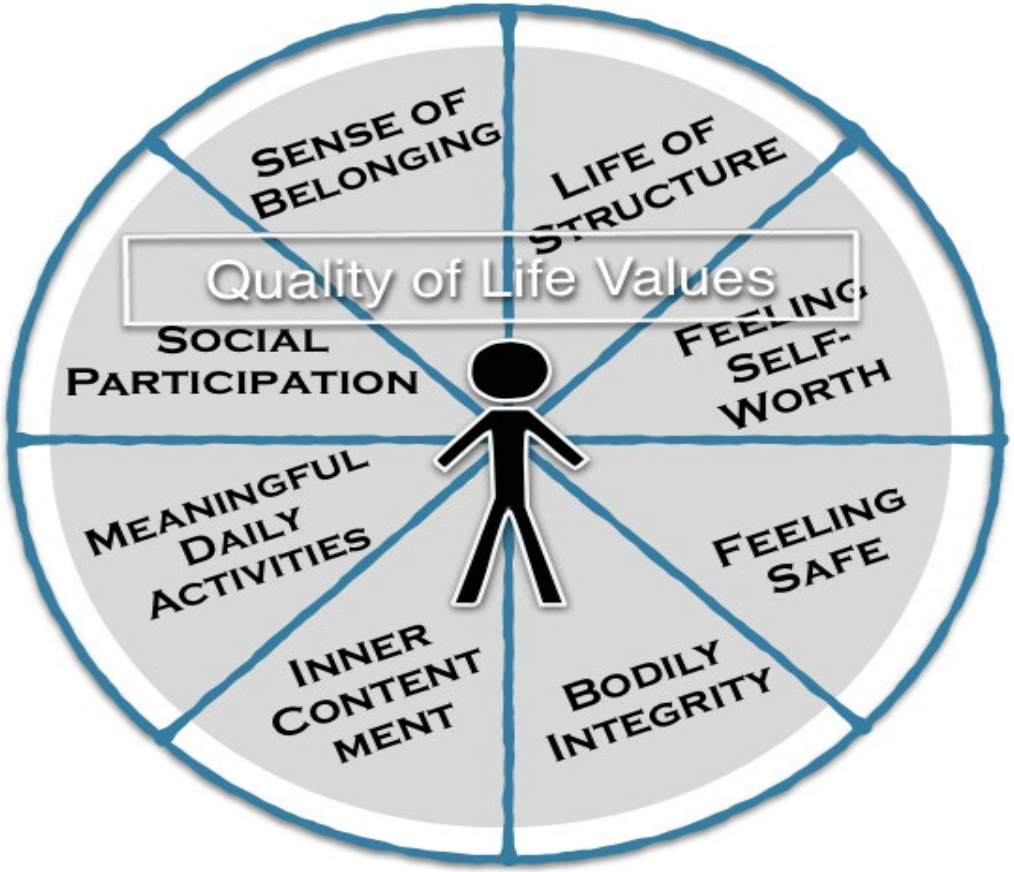
Pediatric Palliative Care the Standard of Practice

- World Health Organization(WHO)
- American Academy of Pediatrics
- Hospital Administrators
- The Center to Advance Palliative Care (CAPC)
- American Academy of Hospice and Palliative Medicine

American Academy of Pediatrics

- Respect for Dignity of Patients and Families
- Access to Competent and Compassionate Palliative Care
- Support for Care givers
- Improved Professional and Social Support for Pediatric Palliative Care
- Research and Education

Quality of Life



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Pediatric Palliative Care

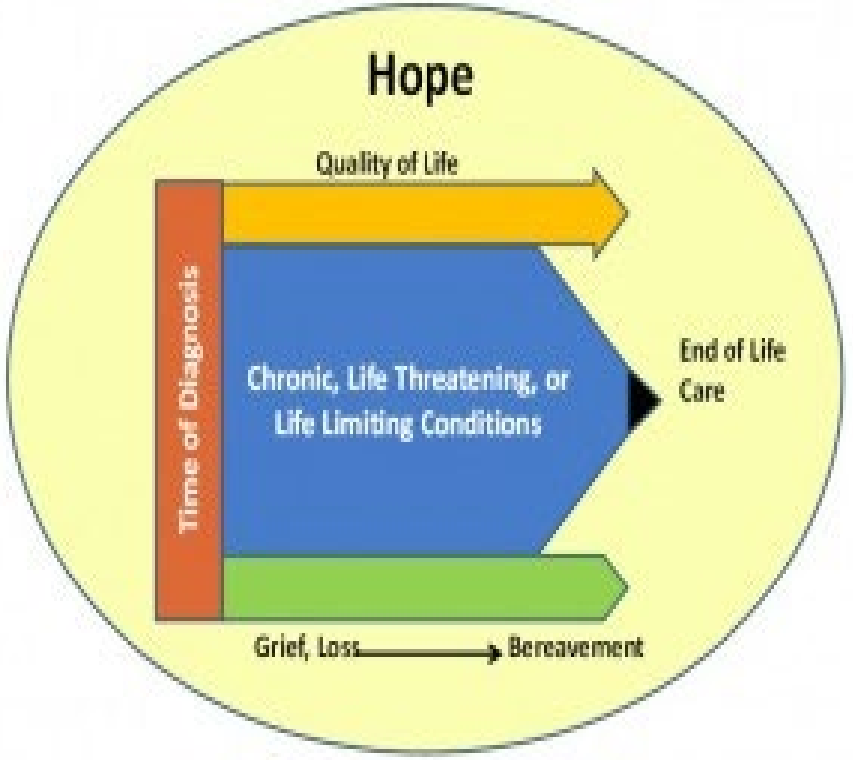
- Anticipate
- Prevent
- Treat
- Promote
- Advocate

- Be Present
- Maintain a realistic perspective
- Become the safety net for patients and families

Pediatric Palliative Care Team

- Interdisciplinary team approach
- Combines caring, communication, knowledge and skill
- On going Communication and Collaboration with the Primary Care Provider

Optimal Model of Pediatric Palliative Care



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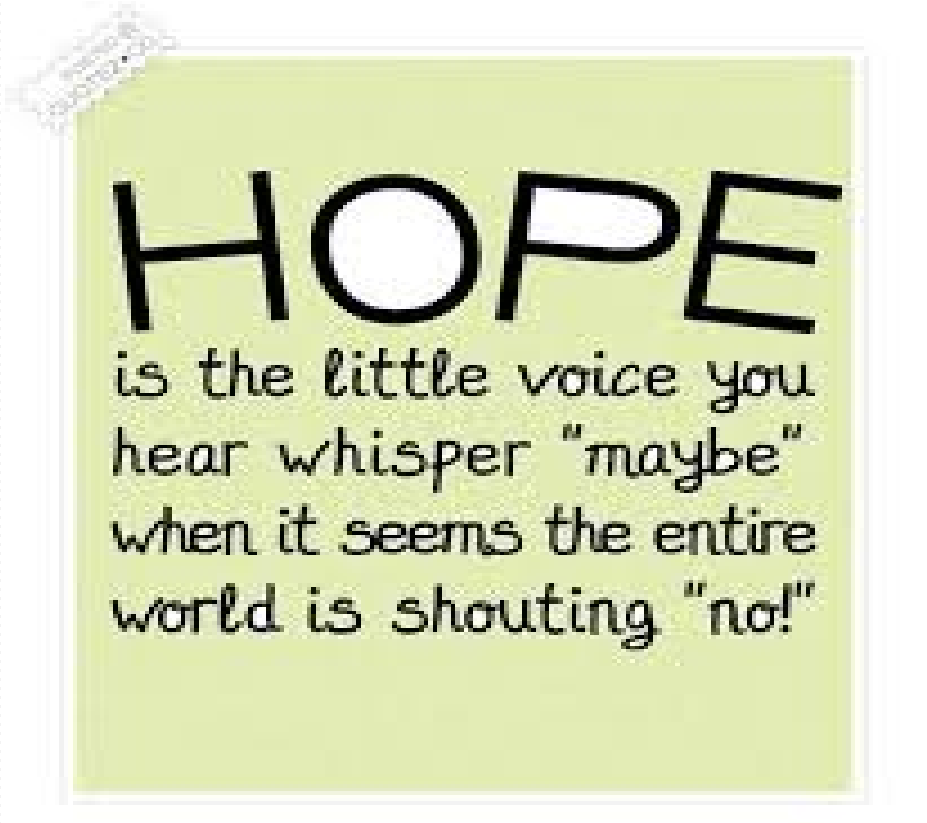
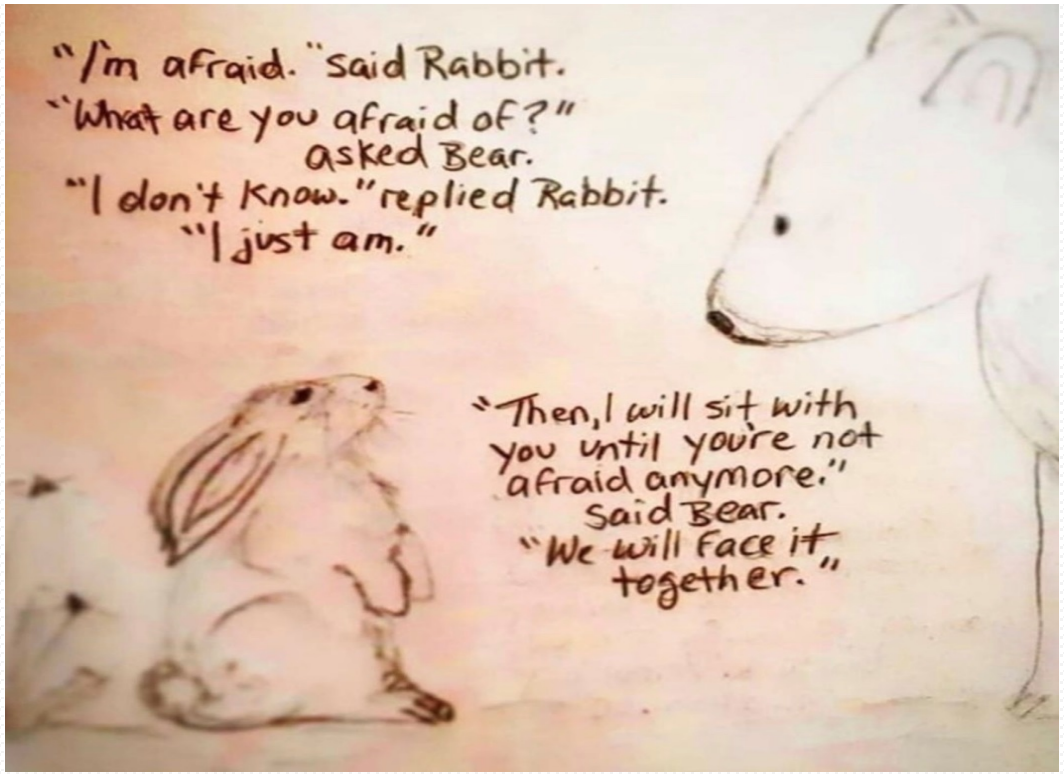
Hope within Pediatric Palliative Care

- Meaning of hope
- Hope vs. despair
- Role of hope


HOPE
is the little voice you
hear whisper "maybe"
when it seems the entire
world is shouting "no!"

What are you afraid of ?



AMEN

Affirm

Meet

Educate

No Matter What

"There is no keener revelation of a society's soul than the way in which it treats its children."

Nelson Mandela

Pediatric Palliative Care

Pediatric Palliative Care

- One of our goals is to help promote a balance of hope for cure with hope for comfort, dignity, and integrity for every child and family.

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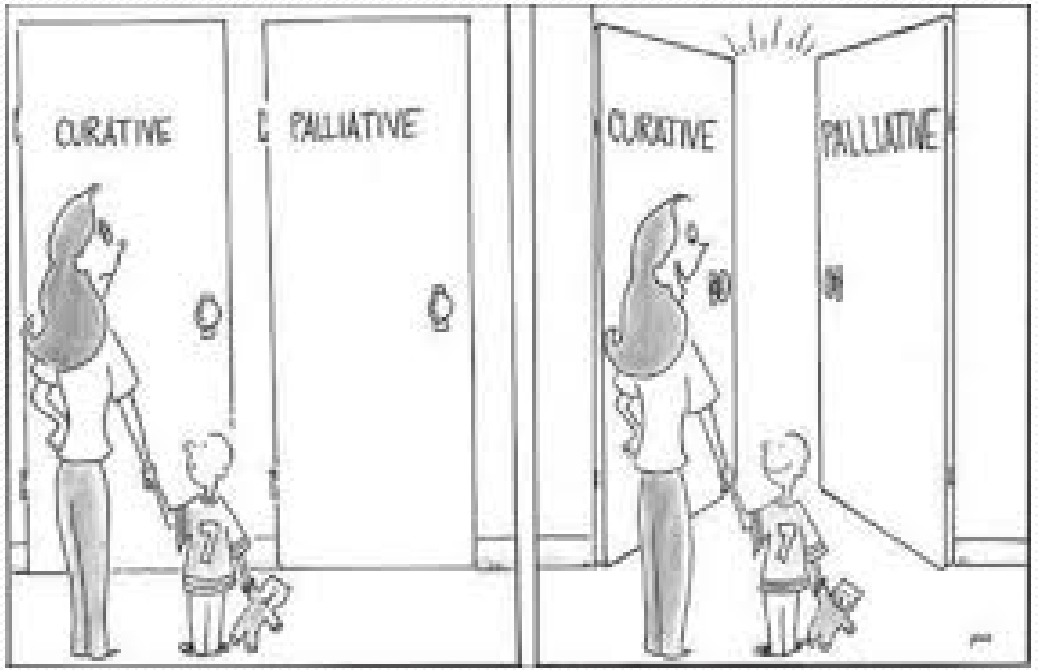
Identity Crisis



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What Gets in the Way

- Uncertainty of prognosis
- Overtreatment
- Insensitivities to cultural concerns
- Communication breakdown
- Other Limitations:
  - -Financial
  - -Geographical
- Lack of adequate training of professionals
- Delayed access to hospice/palliative care
  - -Death denial

Unconscious Bias

Areas of Opportunity

- Work force investment
- Philanthropy
- Education / Training
- Evidence based research
- Funding
- Insurance reform
- Self Care

- **“You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, <u>but also to live until you die</u>.”**
- ***Dame Cicely Saunders*, nurse, physician and writer, and founder of hospice movement (1918 – 2005)**

Pediatric Palliative Care

- MMC initiative to involve RWJ system in Palliative Care
- January 31 – February 1, 2018 – system ELNEC course
- Overwhelming positive feed back
- Dr Debbie Lafond expert in PPC - how to incorporate Primary Pediatric Palliative Care concept at MMC and RWJBH System
- Met with MMC Administration to introduce Primary Pediatric Palliative Care
- Met with physician and nursing leaders

  OVERWHELMING

  SUPPORT

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- COHORT

1

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Thank you

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Integrating Primary Palliative Care Into Pediatric Practice

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Objectives

* To define primary palliative care across settings from the pediatrician's office, to the hospital, to community partners.
* To identify and discuss patients appropriate for integration of primary palliative care in the community-based setting.
* To discuss the primary care provider's role in palliative care discussions with patients and families.

Case study from the literature

* *Imagine 2 parents, Amy and Todd, sitting in the waiting room in their pediatrician for a follow up appointment after a recent hospitalization. Their formerly healthy 2-month-old son, Jack, was recently diagnosed at the local hospital with spinal muscular atrophy (SMA) type 1 during an admission for respiratory failure secondary to respiratory syncytial virus. He is now off respiratory support and pain free, and back at home. His parents met with the hospitalist, neurologist, and pulmonologist regarding what SMA is and how Jack's life will be affected. For the parents, many questions remain: How will we cope with the changes that are happening in our life? How will we afford the specialized care Jack will require? How will we be able to juggle work and other responsibilities to go to multiple medical appointments? Will this affect our marriage? Will this exacerbate our own medical conditions? How will we obtain the supplies we need to care for all of Jack's medical needs? How do we tell his siblings what is happening?*

Hirsch & Friebert, 2014

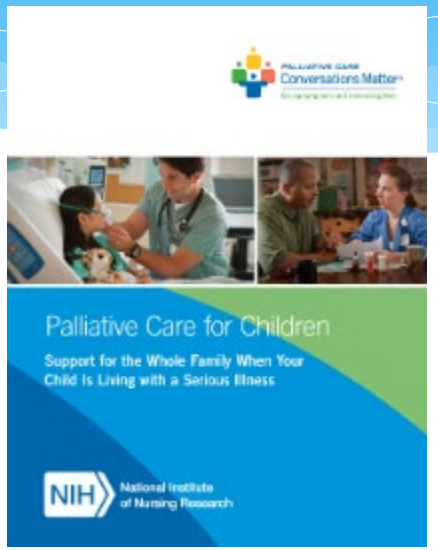
The pediatrician was the key to holding it all together…

Primary versus Sub-Specialty Pediatric Palliative Care

* **Primary PPC**
  * Palliative care competencies required of all primary care clinicians. Included in these competencies is the ability to assist patients and their families in establishing appropriate goals of care. (Ahia & Blais, 2014)

* **Sub-Specialty PPC**
  * Specialized medical care provided by interdisciplinary medical specialists boarded in hospice and palliative medicine, concurrently with the primary medical team, to address advanced physical, psychosocial, spiritual and environmental needs of children with serious illness and their families. (WHO, 2008; Kaye et al, 2016)

You are an excellent PCP!
You got this!



* How do you respond?
  * Punt them to the hospital teams?
  * Punt them to the palliative care team?
  * Avoid the conversation?

* What in the world is palliative care anyway?
  * https://www.ninr.nih.gov/sites/files/docs/NINR_508cBrochure_2015-7-7.pdf
  * Anticipate difficult conversations

Primary PC Assessment Components

Assessment	Question(s)
Pain/symptom assessment	Are there distressing physical or psychological symptoms?
Social/spiritual assessment	Are there significant social or spiritual concerns affecting daily life?
Illness/prognosis understanding	Does the patient/family/surrogate understand the current illness and prognostic trajectory?
Treatment options understanding	Does the patient/family/surrogate understand the treatment options, their risks, and their benefits individually and relatively?
Identification of patient-centered goals of care	What are the expected outcomes of treatment (goals of care), as identified by the patient/family/surrogate? Are the treatment options matched to the identified patient-centered goals? Has the patient participated in an advance care planning process? Has the patient completed an advance care planning document?
Transition of care postdischarge	What are the key considerations for a safe and sustainable transition from one healthcare setting to another or to home with a structured care plan?

[a]Information derived from Weissman and Meier.[1]

Ahia & Blais, 2014

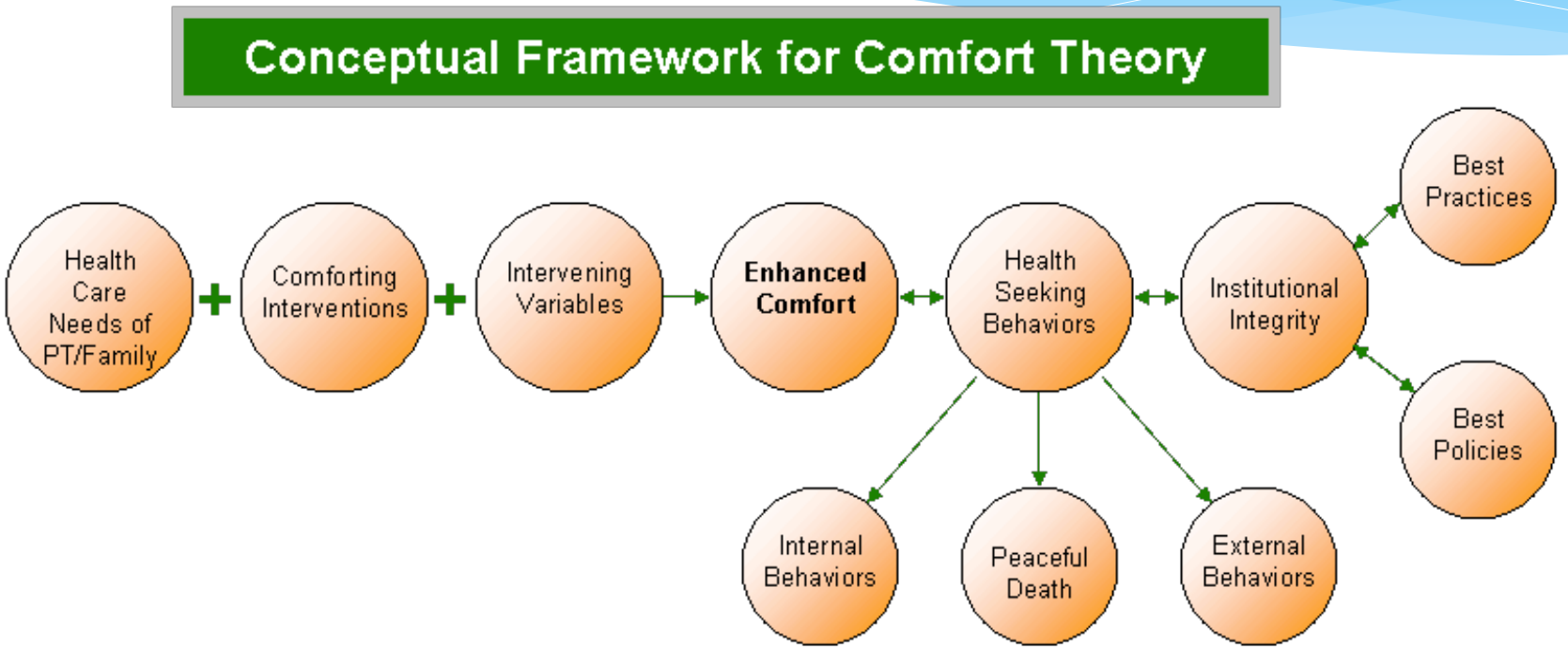
BACKGROUND

* Children with serious illness have significant morbidities related to their diagnosis and treatment.
* Palliative care (PC) mitigates symptom distress.
* Providers express being uncomfortable and unprepared to have difficult conversations about goals of care.
* Bedside clinicians lack confidence in EOL care.

Common Barriers to Primary PPC

* Time
  * Busy clinical practice
  * Not enough time in a regular visit to have in-depth discussions
  * Lack of specialty PPC services 24/7
* Education
  * Lack of formal education in medical, nursing, SW, etc. schools
  * Lack of understanding of what PPC really is
* Skills
  * Lack of feeling confident to provide PPC

What we do and say matters!



Exemplar PPC Project

* Innovative models are needed to provide access to care and continuity across the spectrum of services, and support bedside clinicians providing primary palliative care (PC).

* Evidence demonstrates PC improves satisfaction, symptom control, quality of life, eases burdens, and decreases health care utilization.

* Primary PC improves access to care while decreasing moral distress for clinicians and improving clinical skills to assist families in transcending the experience of a life-threatening illness.

Hospital Needs Assessment

* Initiative for Pediatric Palliative Care (IPPC) – 2002
  * PEDIATRIC PALLIATIVE CARE INSTITUTIONAL SELF-ASSESSMENT TOOL (ISAT) for Enhancing Family-Centered Care for Children Living With Life-Threatening Conditions
    * Administrative Form (Hospital wide)
    * Unit Form
    * http://www.ippcweb.org/quality.htm
* PANDA Needs Assessment
  * Community hospice surveys
  * Unit based focus groups
  * Patients and family focus groups

PANDA Cubs Primary Palliative Care

* Intensive interdisciplinary educational and leadership program
  * 4 cohorts to date and the 5th began 11/18/2019
  * Based upon EPEC-Pediatric and ELNEC-Pediatric Palliative Care curriculums

PANDA Cubs Demographics

N = 268 [7.1% left institution; 1.9% attrition]

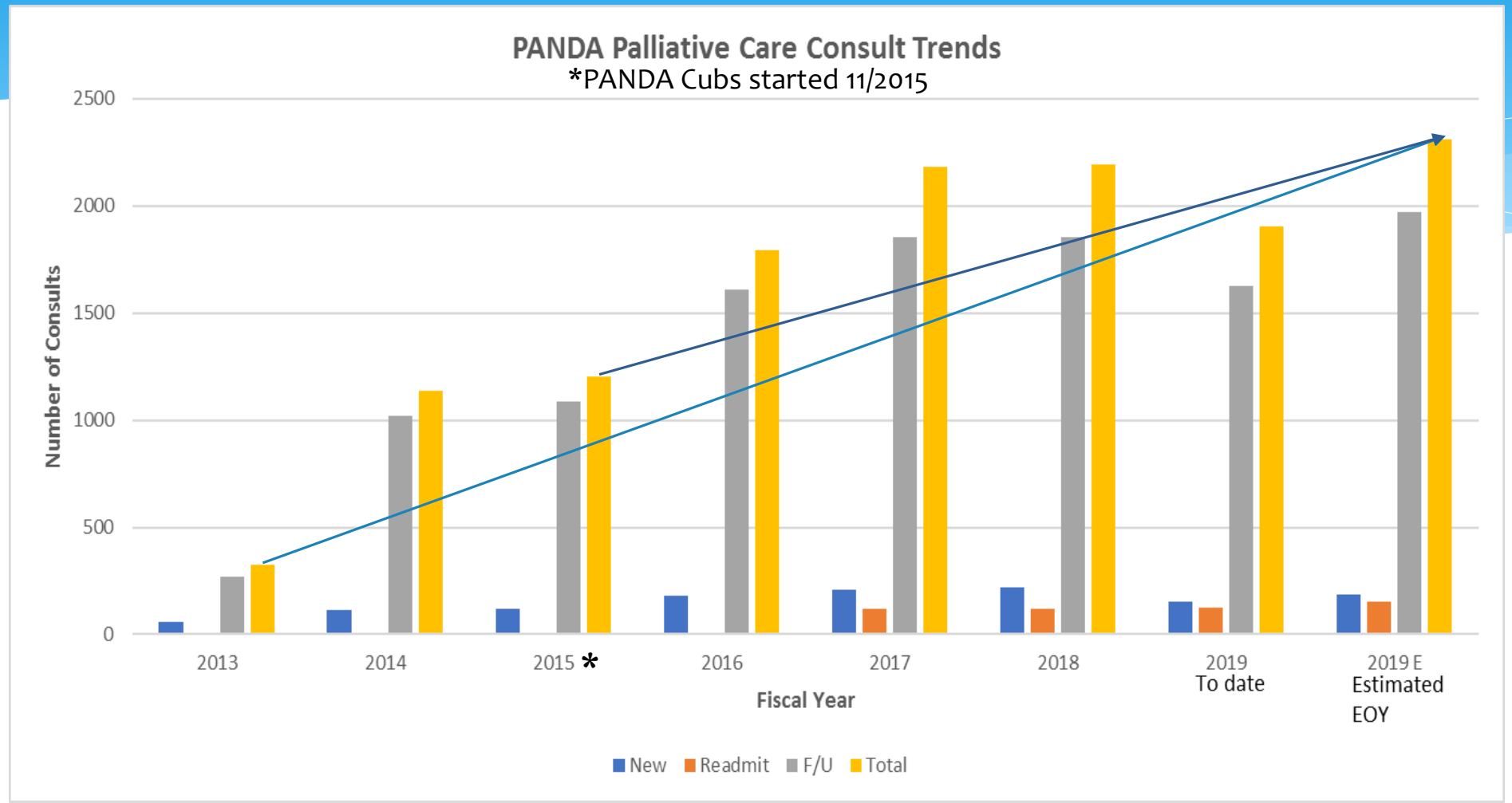
* Cohort 1, N = 44 (5 have since left the institution)
  * Bedside clinicians including RNs, Social Work, Child Life Specialist, Chaplain, Volunteers
* Cohort 2, N = 41 (6 have since left the institution)
  * Physicians, APRNs, PAs
* Cohort 3, N = 65 (4 have since left the institution, 2 dropped out)
  * Physicians, APRNs, RNs, Social Work, Child Life Specialists, Chaplains, Volunteers, including community hospice colleagues
* Cohort 4, N = 60 (5 have since left the institution, 3 dropped out)
  * Physicians, APRNs, RNs, Social Work, Child Life Specialists, Ethics, Volunteers, and community hospice colleagues
* Cohort 5, N = 58
  * Physicians, APRNs, RNs, Social Work, Child Life Specialists, and community hospice colleagues

Current Project METRICS

* Numbers of visits, deaths, hospice referrals
* PC involvement greater than 30 days prior to death
* Assessment of family satisfaction with palliative care involvement
* Followed 1 year pre-implementation and 4 years post
* Clinician moral distress
* Clinician self-reported confidence in PPC

INTERIM RESULTS

* Specialty PPC consults have increased with higher acuity
* Integration of PC in high risk cancers increased to 95% (for FY20= 98%!)
* PC is now standard for all patients with heart failure, bone marrow transplant, high risk brain tumors and solid tumors, and cystic fibrosis
* Self-reported moral distress decreased by 31%.



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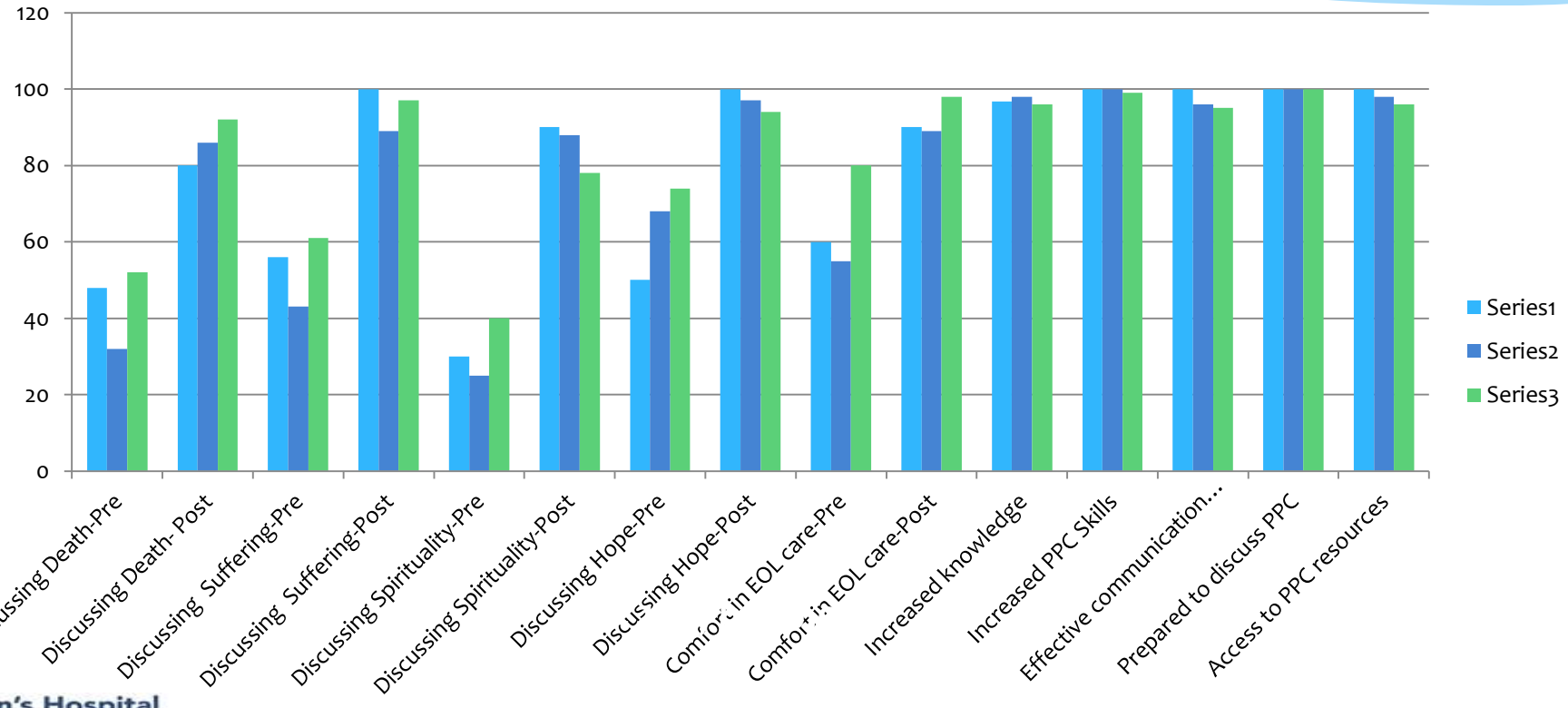
Evaluations and Outcomes of Cohorts 1-3

% who report comfort in…



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Key Outcomes

* Primary pediatric palliative care has changed the culture of palliative care at our institution
* Penetration has increased across the institution reaching every unit with the exception of the ED
  * 2015 = 0.86%
  * 2018 = 2.3%
  * 2019 = 2.8%
* Self-reported moral distress decreased by 31%

How do families become prepared for EOL?

* Recent study of 110 parents of children with complex chronic conditions (63% had congenital or CNS progressive conditions)
* Followed for median of 7.5 years
* 71% (N-78) had palliative care involvement
* 65% (N=69) had completed ACP

* **Most of these parents reported feeling unprepared for their child's EOL.**

Bogetz et al, 2020

What contributed to unpreparedness?

* Chronic illness experience
* Pretense of preparedness
* Circumstances and emotions surrounding their child's death

Bogetz et al, 2020

Benefits of Primary PPC by the Primary Care Provider for the Family

* Family centered approach
  * Longstanding relationship with family
  * Often caring for siblings as well as ill child
* Medically fragile child
  * Often with a lot of medical technology
  * Changing goals of care over time
* Knowing the ill child well
  * Able to see subtle changes over time to guide family in decision making
  * Consistent communication

Benefits of Primary PPC by the Primary Care Provider - continued

* Care coordination
  * Reduces medical errors
  * Avoids unnecessary testing
  * Protects PHI and missing information
* Anticipatory guidance to potentially avoid crisis
* Anticipatory symptom management
* Prompt access to care, often closer to home

Tripathi et al, 2012

Benefits of PPPC for the Provider

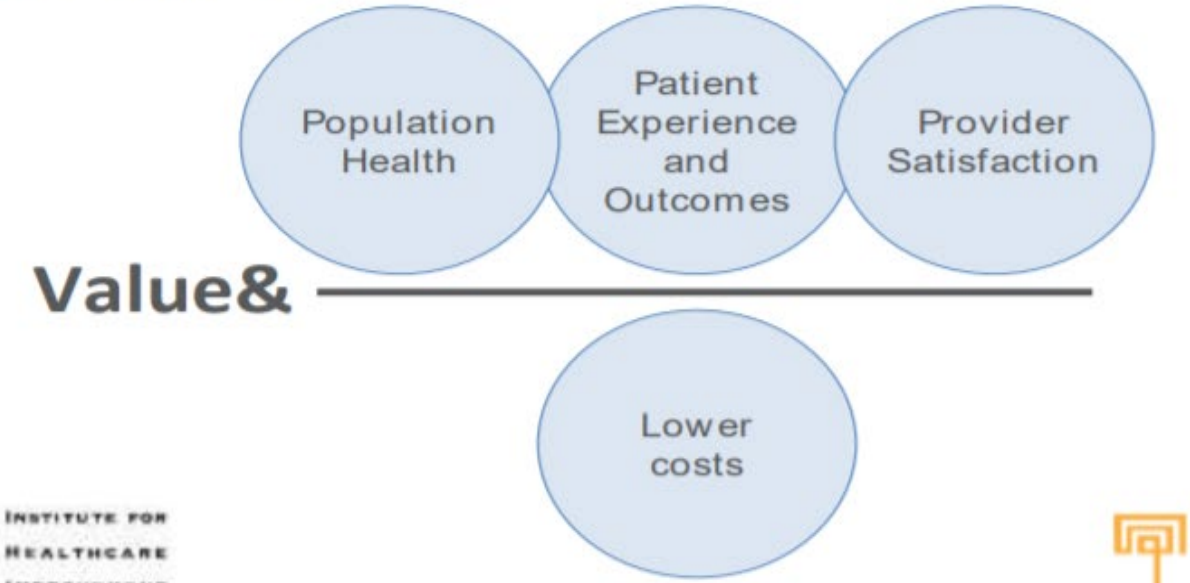
* Many of the same as for the family
* Reduction of medical errors
* Shared responsibility in care
* Improved communication across settings of care
* Long term relationship building

Supported by the AAP

* The American Academy of Pediatrics (AAP) supports this concept of PPC, affirming that "components of palliative care should be offered at diagnosis and continued through the course of illness, whether the outcome ends in cure or death."

Value in *more, better,* and *earlier* conversations

The Quadruple Aim



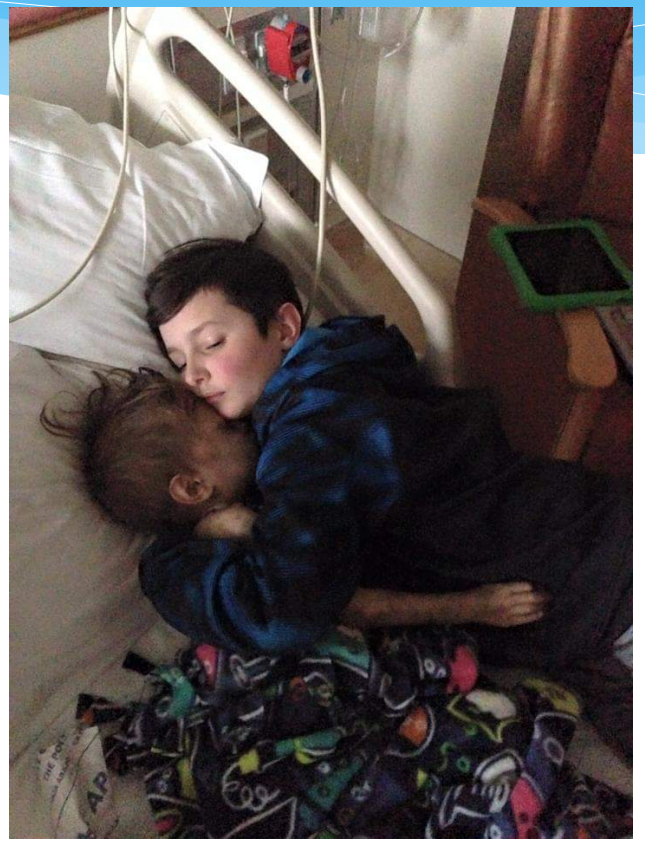
INSTITUTE FOR HEALTHCARE IMPROVEMENT

6

AMERICAN ACADEMY OF FAMILY PHYSICIANS

So where do we go from here?

* Which of your patients may benefit from integrating palliative care?
* Optimize community partnerships
* RWJBH pediatric palliative care system wide initiatives
* Primary palliative care education initiatives



So what about Amy, Todd and Jack

* *Jack is now 2 ½ years old. He has had 5 admissions since his initial diagnosis of SMA. Jack's older sibling is now 6 years old and is beginning 1st grade. His parents have noted more acting out behaviors as the frequency of Jack's hospitalizations increase. Amy and Todd are also now expecting their 3rd child in a few months. Amy shares with you that during the last hospitalization, the PICU doctor told them that Jack may need a tracheostomy. She wonders if that is the right thing for Jack?*


Sometimes we need someone to simply be there not to fix anything, or to do anything in particular, but just to let us feel that we are cared for and supported.
— Bipratik Saha
HEALTHYPLACE.COM
YourQuote.in

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Thank you for listening!

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