PEDIATRIC PALLIATIVE CARE: CONCURRENT CARE FROM THE BEDSIDE TO THE COMMUNITY

Deborah Lafond, DNP, PPCNP-BC, CPON, CHPPN
Kathy Perko, MS, CPNP-PC, CPON, CHPPN, CPLC

Objectives

- To define pediatric palliative care and differences from adult palliative care.
- To define concurrent care benefits and challenges, including barriers to access to care.
- To discuss two successful care delivery models of primary palliative care from the acute care setting to the community.
- To identify opportunities for changes in policy to improve access to pediatric palliative care services for the preborn, infants, children, adolescents and young adults.

Establishing the Need

- 43,328 deaths in children ages 0 to 19 years in 2013
  - Accounting for 1.6% of all total deaths in U.S. [1]
- 55% of these deaths were infants

- Over 5,000 more children are living in the last 6 months of their lives with complex chronic conditions (CCC)[2]

- **Over 400,000 children in the U.S. are living with CCC**
  - Accounting for as much as 1/3 of health care spending on children[3]
  - ~ $100 billion[4]

Causes of Death in Children

2015, NHPCO, Facts and Figures

All infants	Infants with CCC	All Children 1-19 Years	All Children 1-19 Years with CCC
1. Congenital malformations	1. Cardiovascular	1. Accidents	1. Malignancy
2. Short gestation/ LBW	2. Congenital/ Genetic	2. Suicide	2. Neuromuscular*
3. Maternal complications	3. Respiratory	3. Assaults	3. Cardiovascular
4. SIDS	4. Neuromuscular*	4. Malignancy	
5. Accidents/ unintentional injury		5. Congenital malformations, deformations and chromosomal abnormalities	

* Includes static neurologic and neurodegenerative disorders

Definitions

Coming to a common framework

Global definition of PPC

- Pediatric Palliative Care (PPC) requires an ***interdisciplinary*** approach and is most beneficial when provided ***together with curative, restorative and life prolonging treatment*.**

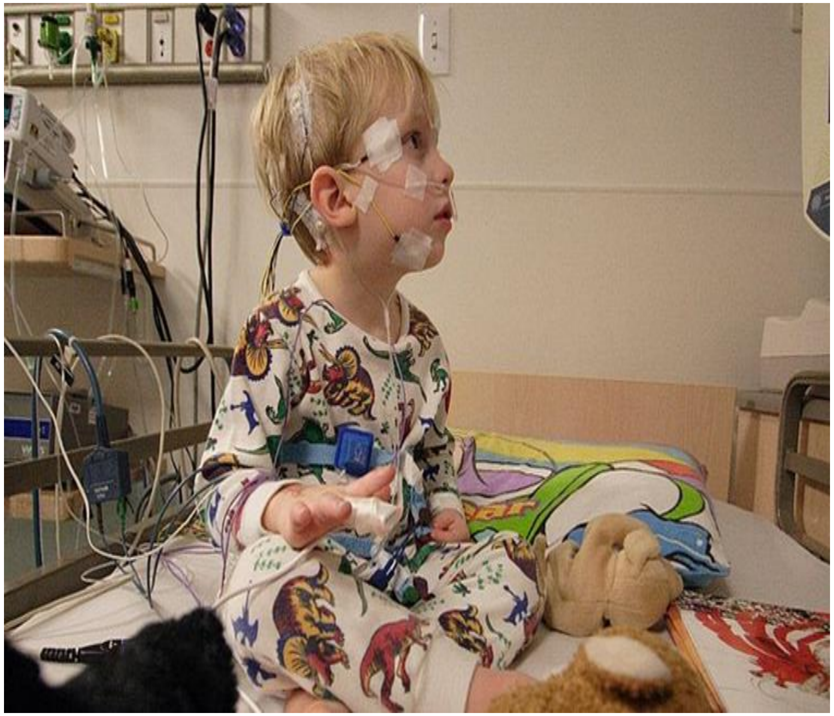
- PPC interventions focus mainly on:
  - Relieving suffering,
  - Slowing the progression of the disease, and
  - Improving the quality of the child's life at all stages of the disease.

Adult versus Pediatric Palliative Care

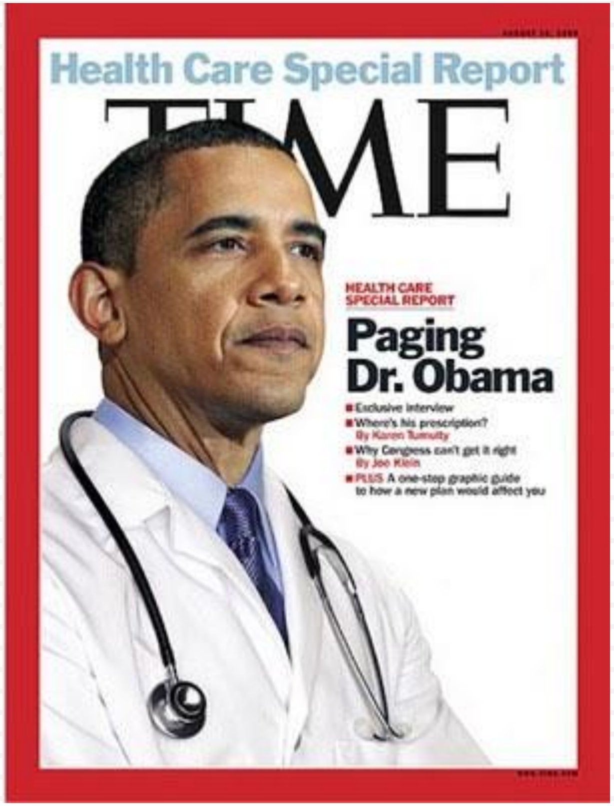
Adult PC	Pediatric PC
Patient is primary decision maker	Parents/Guardians are primary decision makers
Advance care planning theoretically required by law for adults ≥ 18 years	Often no formal ACP
Less aggressive life-prolonging therapies	Increased use of technology in pediatrics
Cognitive considerations with dementia/Alzheimer's	Developmental considerations

Pediatric Palliative Care

- Caring for patients and families across the lifespan
  - Perinatal
  - Infants
  - Children
  - Adolescents
  - Young adults

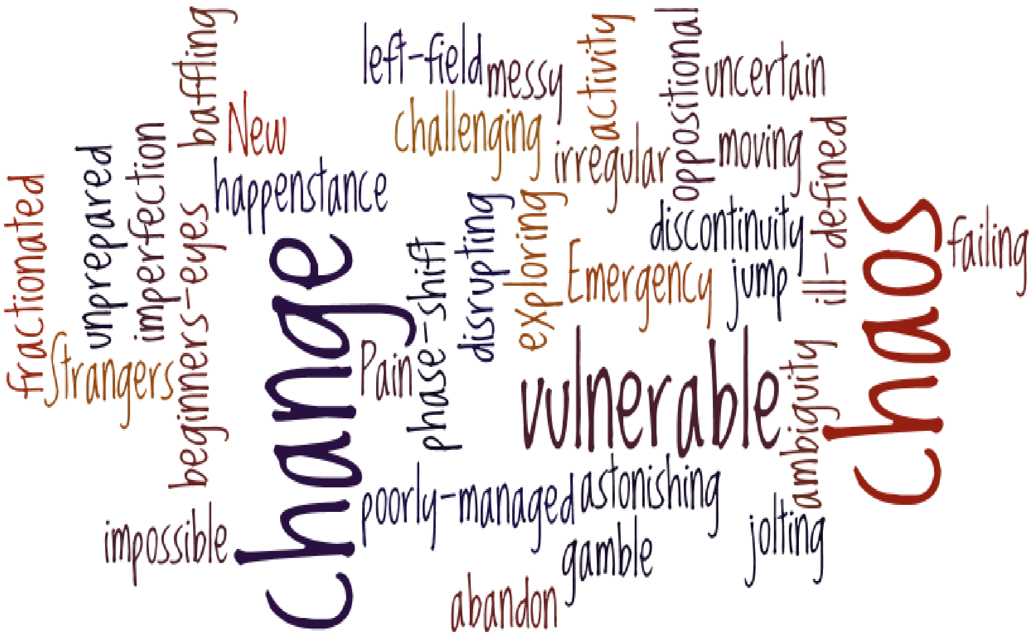


Patient Protection and Affordable Care Act



The landscape prior to 2010…

- Very few families enrolled children into hospice care
- If elected to enroll, child often at end-of-life
  - Pain/symptoms poorly managed
  - New caregivers in home
  - Emergency enrollment



Created using http://www.wordle.net/create

Changes in 2010

- Affordable Care Act
  - Section 2302: Concurrent Care for Children Requirement (CCCR)
  - Removed the prohibition of receiving curative treatment for any eligible child with Medicaid or Children's Health Insurance Program (CHIP).
  - To be eligible:
    - < 21 years of age
    - Physician certifies the child is within the last 6 months of life
    - Entitled to any other service to which the child is entitled under Medicaid for treatment of the terminal condition

Benefits of concurrent care

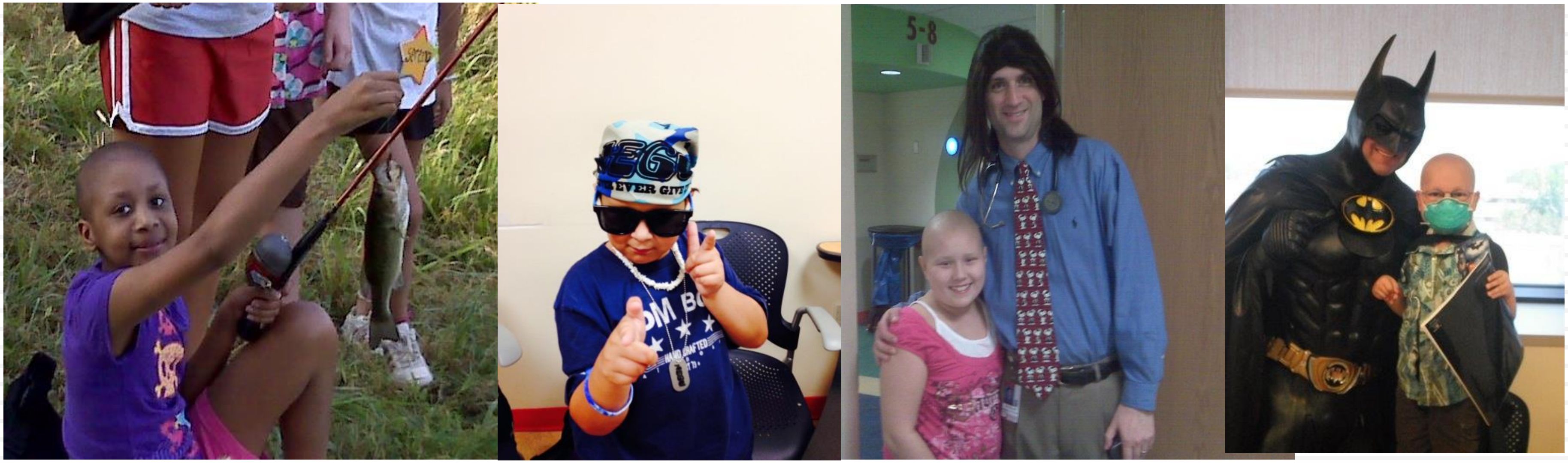
- Lower health care costs
  - 11-27% cost reductions when allowed to access hospice benefits without being required to first discontinue curative therapy (Gans, et al, 2012; Forlini & Goldberg, 2014)
- Continuity of care
  - Time to build rapport with new team prior to death
    - National median LOS: 17 days (NHPCO, 2016)
    - Children's National Health System
      - LOS 2015: 57 days

Patient Age Category	2014
Less than 24 years	0.5%
25-34 years	0.3%
35-64 years	15.3%
65-74 years	16.8%
75-84 years	26.0%
85+ years	41.1%

Innovative Programs in Action

Bridges Palliative Care Program

PANDA Cubs Primary Palliative Care



Bridges Palliative Care Program

- 2003 survey to hospices in Oregon and SW Washington
- Barriers
- Education
- Clinical expertise
- Support

Bridges Palliative Care Program

- Sustainability
  - Continue weekly support for nurses
  - Family phone calls
  - Less webinars
  - Less Telehealth
  - Yearly conference
  - Feedback from parents, hospice and referring teams

PANDA Cubs Primary Palliative Care

- Intensive year long interdisciplinary educational and mentorship program
  - 3 cohorts to date (N = 149)
  - All disciplines
  - Hospital and community hospice partners
- Based upon the well established ELNEC-PPC and EPEC-Pediatrics curricula
- Includes individual and unit based mentoring, as well as didactic education

PANDA Cubs Sustainability

- Unit/organizational based pediatric palliative care resource teams
  - Continued palliative care education sessions

- Expanded access for community based hospices
  - In person trainings
  - Telehealth collaborative visits for shared patients
    - Mentoring of adult hospice teams in caring for pediatric patients and families
    - Ensure consistency in communication with families and primary acute care teams

Conclusions

Pediatric Palliative Care: Why does it matter?

Desired Outcomes

- Better ***understanding*** of pediatric palliative care
- Family in the ***setting of choice***
- ***Decreased LOS & readmissions*** to acute care settings
- Improved ***advance care planning***, including ***reimbursement*** for non-physician team members
- Improved ***patient and family satisfaction*** through ***continuity of care***
- Increased ***family autonomy/empowerment***
- Decreased medical errors through ***education and optimal communication***
- Improved ***pain and symptom management***
- Improved ***EOL care***, including ***crisis care*** and ***bereavement care***

Supporting the IOM Recommendations

- These approaches to serious illness in children:
  - Support seamless, high-quality, integrated, patient-centered, family-oriented care of children with CCC;
  - Can be competently delivered by professionals with appropriate expertise and training;
  - Include coordinated, efficient, and interoperable information transfer across all providers and all settings;
  - Equip clinicians to initiate high-quality conversations about advance care planning, integrate the results of these conversations into the ongoing care plans of patients, and communicate with other clinicians;
  - Encourage clinician engagement in the development and implementation of policies and procedures to promote institutional excellence in palliative and end of life care.

References

1. Osterman MJ, et al. Annual summary of vital statistics: 2012-2013. *Pediatrics* 2015; 135(6).
2. Feudtner C et al. Deaths attributed to pediatric complex chronic conditions: National trends and implications for supportive care services. *Pediatrics 2001*, 107(6).
3. Kuo DZ, Cohen E, Agrawal R, Berry JG, Casey PH. A national profile of caregiver challenges among more medically complex children with special health care needs. *Arch Pediatr Adolesc Med*. 2011;165(11):1020-1026.
4. Berry JG, Hall M, Neff J, et al. Children with medical complexity and Medicaid: spending and cost savings. *Health Aff (Millwood)*. 2014;33(12):2199-2206.

Thank you!

- Debbie Lafond, DNP, PPCNP-BC, CPON, CHPPN
  PANDA Palliative Care Team
  Children's National Health System
  Office: (202) 476-2194
  Email: dlafond@childrensnational.org

- Kathy Perko, MS, CPNP, CHPPN, CPLC
  Program Director Bridges Palliative Care
  OHSU Doernbecher Children's Hospital
  Office: (503) 418-5172
  Email: Perkok@ohsu.edu