Advancing the Field of Pediatric Palliative Care

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Objectives:

→ Characterize the barriers and opportunities for growth in the field of pediatric palliative care (PPC)

→ Define the goals, structure, and activities of the National Pediatric Palliative Care Steering Committee

→ Synthesize the results of a national survey to the PPC field
Palliative care = Quality care

- Focused on quality of life for the patient and family that provides relief from the symptoms and stresses of serious illness

- Appropriate at any age and any stage

- Provided along with curative treatment as an added layer of support

Consumer-driven and tested description from CAPC 2011 public opinion research
The Need

➔ Child mortality: 45,000 per year (2% of US total), more than half under age 1
➔ Children living with serious illness: >500,000 (2.2% US total)
➔ Caregivers: 17 million adults
➔ Small numbers, huge diversity of need (and therefore approaches) across age groups, diseases, and settings

Challenges for strategy
Service Prevalence

➔ **Children’s hospitals:** 85.7% (48/56) report palliative care services

➔ **Community palliative care programs:** only 53 pediatric programs identified (6% of 890 total)

➔ **Hospices:** roughly 15% report services for kids
We have a long way to go – but PPC is making its mark.
Research and Quality

Pediatric Palliative Improvement Network (PPIN)

Quality Improvement Methods in Pediatric Palliative Care
Moving the Marbles
Challenges and Priorities for Pediatric Palliative Care Research in the U.S. and Similar Practice Settings: Report From a Pediatric Palliative Care Research Network Workshop

Chris Feudtner, MD, PhD, MPH, Abby R. Rosenberg, MD, MS, MA, Renee D. Boss, MD, Lori Wiener, PhD, DCSW, LCSW-C, Maureen E. Lyon, PhD, Pamela S. Hinds, PhD, RN, FAAN, Myra Bluebond-Langner, PhD, and Joanne Wolfe, MD, MPH

5 Challenges
- Patient Diversity & Small Population Size
- Interdependencies & Dynamic Interactions
- Outcomes & Measurement
- Workforce & Infrastructure
- Presumed Burden of PPC Research Upon Participants

7 Priorities
- Bolster Training & Development of PPC Investigators
- Develop Core Resources
- Advance Symptom Measurement (& Other Exposure & Outcomes Measurements)
- Improve Symptom Management & Quality of Life Interventions
- Improve Communication, Elicitation of Goals of Care, and Decision-Making
- Understand Family Impact and Facilitate or Improve Family Adaptation and Coping
- Analyze & Improve Systems of Care, Policy, & Education

Crucial Topics

Fig. 1. Pediatric palliative care research challenges and priorities. PPC = pediatric palliative care.
Payment for palliative care services

CMMI is launching a palliative care APM right now
A National Call to Action
AAP Guidelines - 2013

“All hospitals and large health care organizations that frequently provide care to children with life-threatening conditions and routinely provide end-of-life care should have dedicated interdisciplinary specialty PPC-PHC teams”

Teams with “sufficient collective expertise to address the physical, psychosocial, emotional, practical, and spiritual needs of the child and family” should:

– support decision-making
– provide timely and effective interventions to minimize suffering while maximizing quality of life
– manage and coordinate logistics to provide seamless transitions between settings

http://pediatrics.aappublications.org/content/early/2013/10/23/peds.2013-2731
National Mandates for Palliative Care

- AAP Policy Statement (2000; revision 2013)
- Joint Commission Advanced Certification
- National Quality Forum
- Magnet nursing status
- NINR public messaging campaign
- American Hospital Association: Circle of Life
- NHPCO Pediatric Standards
- POLST/MOLST paradigms
- US News & World Report
- PPACA Concurrent Care for Children Provision
- Medical Home legislation
- IOM
- Disease-specific orgs: ASCO, ACS, AHA/ASA, SCCM
- National Consensus Project (NCP) guidelines
…and in the words of children’s hospital leaders…

“If you want to care for children in a quality way today, pediatric palliative care has to be part of the standard of practice.”
National Pediatric Palliative Care Steering Committee
February 2019
Convening Participants

➜ Co-Chairs: Sarah Friebert, Diane Meier

➜ Executive Advisors: Chris Feudtner, Joanne Wolfe

➜ Steering Committee: Toluwalase Ajayi, Justin Baker, Bob Bergamini, Deborah Campbell, Jody Chrastek, Rick Goldstein, Tammy Kang, Kathie Kobler, Ron-Li Liaw, Jenni Linebarger, Debra Lotstein, Kathy Perko, Stacy Remke, Abby Rosenberg, Elisha Waldman
Goals of the Convening

→ **Mission**: Identify priority areas for strategic initiatives that will improve access to quality pediatric palliative care

→ **Anticipated outcomes**:
  - Consensus recommendations for action steps to improve access to PPC
  - Strategy for disseminating the action items and eliciting feedback from the field
  - Identification of key stakeholders to support dissemination and execution of action items
Barriers Identified During Pediatric Convening

Highest Impact Priority Rankings

➔ Payment + financing
➔ Demonstrating quality + value
➔ Workforce adequacy + training + ongoing education

Lower Impact (But Still Important)

➔ Public and professional awareness and demand
➔ Clinical and operational TA
➔ Standardization + accountability
We Asked, You Answered: October 2019 Field Survey

➔ 177 respondents

➔ Diversity among
  – Clinical disciplines
  – Years of experience in the field
  – Region of the country
Rank-Ordering Action Items to Grow the Field

1. Market research with parents
2. Training for non-specialists
3. Identify and sit at the right tables
4. Develop PPC-specific program development tools
5. Analyze payment mix of existing programs
6. Market research with referring clinicians
7. Assess specialty workforce trajectory
8. Consensus definition of PPC
9. Create alternate pathways to PPC certification
10. Develop fundraising toolkit for PPC programs
11. Develop standard PPC-specific messaging
Now What?

ID highest-priority, feasible action items

Recruit PPC leaders for 'action committee' working groups

Strengthen our capacity as a field
Questions?

Please type your question into the questions pane on your WebEx control panel.