Addressing Workforce Development Needs and Current Gaps in the Evidence

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Disclosures

No conflicts of interest to disclose
Outline

• Model of Pediatric Palliative Care
• Primary and subspecialty workforce needs
• Current gaps in the evidence
  – A focus on suffering
• Opportunities
• Call to action
Model of Pediatric Palliative Care

Hope for cure, life extension, a miracle…

Individualized blending of care directed at underlying illness and physical, emotional, social, and spiritual needs of child and family with continuous reevaluation and adjustment

Hope for comfort, meaning…

End-of-life care

Bereavement care
Primary Palliative Care Workforce Needs

• All interdisciplinary clinicians who care for children with cancer should have basic PPC knowledge, skills, behaviors and attitudes. Yet,
  – Physicians:
    • Learn primarily through trial and error
    • 71% of training programs lack a PPC curriculum
  – Nurses: High need for specific PPC education at pre/post graduate levels
    Pearson HN "You've only got one chance to get it right": children's cancer nurses' experiences of providing palliative care in the acute hospital setting. Issues Compr Pediatr Nurs. 2013 Sep;36(3):188-211. Epub 2013 Jun 12.
  – Other disciplines: Unknown
Subspecialty Palliative Care Workforce Needs

- Contrary to AAP policy, only 58% of COG member institutions have access to a PPC service
  


- 69% of children’s hospitals have a PPC program, many are understaffed
  

- Yet, families want access to PPC
Only 3/15 valued elements of PPC are often accessible to families

Willingness and impact of meeting PPC at Diagnosis (N=130 pairs)

Would you like to meet the palliative care team around the time of diagnosis?

Would meeting the palliative care team affect your willingness to meet them?

Levine D et al, Manuscript in preparation
Clinician PPC training and education opportunities are increasing

• More textbooks of PPC and greater number of chapters in general textbooks
  Oxford Textbook of Palliative Care for Children, Textbook of Interdisciplinary Pediatric Palliative Care, Palliative Care for Infants, Children and Adolescents, etc…

• More curricula
  ELNEC-Pediatric Palliative Care, EPEC-Pediatrics, Program in Palliative Care Education and Practice, Smith College/Baystate End of Life Certificate Program, NYU Zelda Foster Studies in Palliative and End of Life Care, etc…

• Increasing fellowship training slots
  Over 25 PPC slots for physicians, 1 PNP and 1 SW
Pediatric Starter Kit:  
Having the Conversation with Your Seriously Ill Child
Emerging Data Suggest that Palliative Care Improves Outcomes

- Children who received PPC/Oncology more likely to have fun (70% versus 45%) and to experience events that added meaning to life (89% versus 63%)

- Families who received PPC/Oncology report improved communication
  Kassam A, Skiadaresis J, Alexander S et al Differences in End-of-Life Communication for Children with Advanced Cancer who were Referred to a Palliative Care Team. Ped Blood Cancer In Press

- Children receiving PPC experience shorter hospitalizations and fewer emergency department visits
  Ananth, manuscript In preparation
Speaking of evidence, what are the gaps in PPC?

- **Canadian Delphi Study** came consensus around 4 questions:
  
  What matters most for patients and parents receiving PPC?
  
  What are the best practices in pain and symptom management?
  
  What are effective strategies to alleviate suffering?
  
  What are the bereavement needs of families in PPC?


- **North American Delphi study** resulted in consensus of 20 PPC research priorities thematically grouped into decision-making, care coordination, symptom management and quality improvement

A Focus on Suffering

“Visible” threats
Life-threatening illness
Symptoms
Emotional Factors

Targeted Interventions
(e.g. symptom treatment trials)

“Invisible” threats
Disruptions from "normal life"
Emotional factors
Existential concerns
Socio-demographic concerns

Global Interventions
(e.g. communication, PediQUEST)

Family Integrity
PATIENT
SIBLINGS
PARENTS

NEW
Family Integrity
PATIENT
SIBLINGS
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Symptoms and suffering according to bereaved parent in children with cancer in last month of life

What would children say?

What is the most common response you get when you ask a child, “How are you feeling?”
I'M FINE.
Symptom prevalence and distress observed in children with advanced cancer

### Panel A
**Full Cohort PQ-Surveys**

<table>
<thead>
<tr>
<th>Symptom</th>
<th>High Distress</th>
<th>Low Distress</th>
</tr>
</thead>
<tbody>
<tr>
<td>Image issues</td>
<td>8%</td>
<td>7%</td>
</tr>
<tr>
<td>Difficulty concentrating</td>
<td>12%</td>
<td>6%</td>
</tr>
<tr>
<td>Worrying</td>
<td>18%</td>
<td>6%</td>
</tr>
<tr>
<td>Sadness</td>
<td>17%</td>
<td>7%</td>
</tr>
<tr>
<td>Nervousness</td>
<td>17%</td>
<td>8%</td>
</tr>
<tr>
<td>Sleep disturbance</td>
<td>22%</td>
<td>7%</td>
</tr>
<tr>
<td>Irritability</td>
<td>27%</td>
<td>10%</td>
</tr>
<tr>
<td>Dysuria</td>
<td>3%</td>
<td>2%</td>
</tr>
<tr>
<td>Dyspnea</td>
<td>8%</td>
<td>2%</td>
</tr>
<tr>
<td>Sweating</td>
<td>10%</td>
<td>6%</td>
</tr>
<tr>
<td>Numbness</td>
<td>10%</td>
<td>2%</td>
</tr>
<tr>
<td>Dry mouth</td>
<td>9%</td>
<td>4%</td>
</tr>
<tr>
<td>Dysphagia</td>
<td>11%</td>
<td>4%</td>
</tr>
<tr>
<td>Constipation</td>
<td>10%</td>
<td>6%</td>
</tr>
<tr>
<td>Skin issues</td>
<td>8%</td>
<td>8%</td>
</tr>
<tr>
<td>Itching</td>
<td>13%</td>
<td>5%</td>
</tr>
<tr>
<td>Vomiting</td>
<td>15%</td>
<td>10%</td>
</tr>
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<td>22%</td>
<td>5%</td>
</tr>
<tr>
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<td>9%</td>
</tr>
<tr>
<td>Anorexia</td>
<td>26%</td>
<td>6%</td>
</tr>
<tr>
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<td>24%</td>
<td>11%</td>
</tr>
<tr>
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<td>27%</td>
<td>12%</td>
</tr>
<tr>
<td>Fatigue</td>
<td>39%</td>
<td>7%</td>
</tr>
<tr>
<td>Pain</td>
<td>39%</td>
<td>9%</td>
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### Panel B
**Subgroup of end-of-life PQ-Surveys**

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<td>8%</td>
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<td>40%</td>
<td>10%</td>
</tr>
<tr>
<td>Fatigue</td>
<td>41%</td>
<td>8%</td>
</tr>
<tr>
<td>Pain</td>
<td>58%</td>
<td>8%</td>
</tr>
</tbody>
</table>

Child report of symptoms and suffering at diagnosis

Levine D et al, Manuscript in preparation
Results of a Randomized Controlled Supportive Care Trial in Pediatric Advanced Cancer

All Children Survivors Children ≥8 years old Survivors ≥8 years old

Average Change in Scores

MSAS Scores
Total Physical Psychological

PedsQL Scores
Total Physical Psychological

Sickness Scores

¥ 0.05 < p ≤ 0.10  * 0.01 < p ≤ 0.05 ** ≤ 0.01

Wolfe J, Orellana L, Cook, EF et al Improving the Care of Children with Advanced Cancer by Using an Electronic Patient-Reported Feedback Intervention: Results From the PediQUEST Randomized Controlled Trial J Clin Oncol 2014;32:1119-1126.
Family reasons for enrolling on a supportive care randomized controlled trial

Dussel V, Orellana L, Soto N et al  Feasibility of Conducting a Palliative Care Randomized Controlled Trial in Children with Advanced Cancer: Assessment of the PediQUEST Study J Pain Symptom manage 2015 Epub ahead of print
How will we get the work done?

**Evidence Base: QOL not a priority**

![Bar chart showing research publications from 2003-2005 and 2008-2010 for Oncology and Palliative Care.](chart)

(Gelfman & Morrison J Palliat Med 2008 & 2013)
Very few NIH Funded PPC Grants

Number of funded grants

- K25
- K01
- K07/23
- R01

Number of funded grants: 0, 1, 3, 8
Building the Evidence Base and Community

• National Palliative Care Research Center and American Cancer Society Partnership
  – Together **funding millions** in palliative care and symptom management research grants associated with Kathleen Foley Palliative Care Research Retreat
  – **Mentorship** to build the next generation of palliative care clinical researchers and support a collaborative community for this work, including expanding funding for **PPC research** and encouraging junior investigators to pursue the field
  – **Grantee engagement** in QOL agenda and activities
  – Extramural training grant program support
Emerging Opportunities for PPC Research

Children's Oncology Group's Cancer control and supportive care - the objective is to reduce overall morbidity and mortality by decreasing acute and delayed treatment-related toxicities in all children with cancer.

To foster multi-centered collaborative interdisciplinary research

To advance PPC research questions and methods

To enhance the cohort of highly qualified investigators

To enable an evidenced based practice of PPC

To promote a culture of inquiry in collaboration with patients and families in PPC
A Call to Action

• Enhance
  – PPC training of interdisciplinary primary oncology workforce
  – Subspecialty PPC training opportunities
  – PPC evidence base
  – Research funding
To provide children and families with what they are asking for including:

• Access to PPC
• PPC research opportunities
• Health, wellbeing, and quality of life

Let's make it **happen**!

Thank you!