Current Practices for Providing Pediatric Palliative and Psychosocial Care for Children and Adolescents with Cancer

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Comprehensive Care for Pediatric Cancer Patients and their Families Workshop
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Objectives

1) Review historical information
1) Describe critical components of Pediatric Palliative Care
1) Address barriers to Pediatric Palliative Care integration
1) Describe current initiatives and action steps
Before the 1970’s

Secrecy surrounded cancer diagnosis and prognosis

Researchers reported that until the age of 10, fatally ill children were not aware of what was happening to them, and did not experience anxiety about death.
Total anxiety scores of the children with fatal illness were twice as high as the scores of the other hospitalized children.

In projective testing, they discussed loneliness, separation, and death much more frequently in their fantasy stories, although none of them did so directly.

Eugenia H. Waechter
"It’s not an issue of to tell or not to tell, but rather how to tell, when to tell and who should do the telling"
Palliative/Hospice Care in the U.S.

- In 1974, the first home hospice program based in New Haven, CT
- In 1975, St. Luke’s Hospital in New York had the first hospice incorporated into an existing medical center

Concept of palliative care, “the science and art of lessening physical, psychosocial, emotional, and existential suffering”, evolved from the hospice philosophy
Combination chemotherapies offered new hope

“...A high percentage of the survivors, their parents, and siblings felt that the cancer diagnosis should be shared with the child early on.”
Do Children with Cancer Suffer?

• A team at Dana Farber sought to evaluate the care and suffering at the end of life of children who died of cancer.

• 103 parents of children who had died of cancer, 1990-1997.

Findings

• 89% of children who died of cancer experienced substantial suffering in the last month of life.
  – Significant discordance between parent and physician report of child’s suffering.

(Wolfe et al., 2000)
Do Children Suffer Not at EoL?

- The National Cancer Institute and the National Institute of Mental Health validated an adapted Pediatric Distress Thermometer and Problem Checklist (Patel et al, 2011) with 280 outpatient child/caregiver dyads (ages 7-21) – standardized measures of anxiety, depression, pain & fatigue.

“When we say DISTRESS, we are referring to a range of feelings that can include sadness, being anxious, fearful, worried, or upset.”
## Most endorsed items on the Distress Thermometer

<table>
<thead>
<tr>
<th>Checklist Item</th>
<th>All Diagnoses</th>
<th>Cancer Only</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>% 13-17 n=133</td>
<td>% 18+ n=68</td>
</tr>
<tr>
<td><strong>Physical</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fatigue</td>
<td>32.3</td>
<td>45.6</td>
</tr>
<tr>
<td>Pain</td>
<td>39.8</td>
<td>35.3</td>
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<tr>
<td><strong>Emotional</strong></td>
<td></td>
<td></td>
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<tr>
<td>Worried</td>
<td>41.4</td>
<td>61.8</td>
</tr>
<tr>
<td>Nervous</td>
<td>34.6</td>
<td>50.0</td>
</tr>
<tr>
<td>Bored</td>
<td>38.3</td>
<td>51.5</td>
</tr>
<tr>
<td><strong>Social</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>School</td>
<td>48.9</td>
<td>33.8</td>
</tr>
<tr>
<td>Dealing with parents</td>
<td>24.1</td>
<td>20.6</td>
</tr>
<tr>
<td><strong>Spiritual</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Distanced from God/faith</td>
<td>7.5</td>
<td>13.2</td>
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</table>
43% of Parent-Child dyads place the child’s distress in a DIFFERENT category
What lessons have been learned about ‘suffering’ from listening to the caregivers’ and child’s voices?

- Children and families at all stages of the cancer trajectory experience distress and suffering.
  - Family life disruption, rigorous treatments, unpredictable setbacks, repeated invasive procedures, burdensome symptoms (Remke, 2015)

- Parents and providers are not always aware of their suffering
Calls to Action

- Benefits of palliative care when offered concurrently with curative (Joint Committees-AAP, 2000)

- (ChiPPS) white paper - recommendations to improve the care of children living with life-threatening conditions (NHPCO, 2001)


All calling for provision of high-quality, palliative and bereavement care
Concept of **palliative care**, “the science and art of lessening **physical, psychosocial, emotional, and existential suffering**”

Health care professionals have been **slow to implement** recommendations for pediatric palliative care integration.
Recent Progress

✓ NHPCO in conjunction with ChiPPS developed its first national pediatric standards for Pediatric Hospice and Palliative Care Programs (Friebert & Huff, nhpco.org/pediatrics)

✓ WHO defined palliative care as a human right (WHO, 2014)

✓ IOM Report (2014) – “Palliative care can begin early ... for any serious illness that requires excellent management of pain or other distressing symptoms...”
Addressing Barriers to Effective Delivery of PPC

1. Ineffective communication between HCP and families

2. Resources not aligning with patient and family needs

(Kassam ....Wolfe., 2013)
1. Ineffective communication between HCP and families

- Education
- Response to the word “palliative”
- Timing of ACP discussion
Addressing Barriers to Incorporating PPC: Education

• Majority of health care providers lack formal education in palliative and end-of-life care for children

  – Communication, developmental techniques, pain and symptom management, sensitivity to cultural and spiritual beliefs, grief and bereavement care (Wiener, Weaver, et al, 2015)
Education: Recommendation

• Core competencies
  – Implemented in schools of medicine, nursing, social work, psychology, and counseling (Contro et al, 2004; Davies et al, 2008; Hilden et al, 2001; Schiffman et al, 2008; Shea et al, 2010).

Good news!

• Within the past 10 years, rapid expansion of pediatric Hospice and Palliative Medicine (HPM) programs (Feudtner et al, 2013); HPM has become an official medical subspecialty (Klick et al, 2014).
Does it matter what you call it?
Misconceptions miss the essence of palliative care

The Power of Perception

- Changes in terminology ("palliative care," to "supportive care") led to increased and earlier referrals (Dalai et al, 2011), more favorable impressions and intended use of future services (Maciasz et al, 2013).
Caregivers’ Understanding about pediatric palliative care?

What is your understanding of the term ‘palliative care’? (N=244)

- Comfort care that is provided during the child's last few days or weeks of life when curative treatment is no longer possible. (45%)

- Comprehensive care of the child physically, emotionally and spiritually including pain and symptom management to improve quality of life from the time of diagnosis onward throughout the child's treatment. (50%)

- Not sure what the term means (5%)
Defining Pediatric Palliative Care for Caregivers

“Pediatric palliative care ... focused on providing relief from symptoms, pain and stress for the child and his/her family, as an extra layer of support with the goal to improve quality of life.....”

Considering this definition, how likely, if at all, would you be to consider pediatric palliative care for your child during cancer treatment?

Not too likely: 2%
Somewhat likely: 14%
Undecided: 7%
Very likely: 73%
Misconception: Recommendation

Continuum, PC has a role to play at each particular moment of the patient’s cancer journey (Tsai, 2008)

Palliative concepts introduced simultaneously with potential curative treatments

On/Off-switch
Dimmer switch
Shared Decision-Making and Advance Care Planning

• Rates of advance care planning are low, often initiated late in the illness trajectory.

• Advance care planning and palliative care are associated with positive outcomes (e.g. care consistent with patient preferences, better quality of life, less distress, and longer survival).

Limited data about how much youth understand about their role in decision-making, palliative or end of life care.
We asked adolescents and young adults living with advanced cancer or vertically acquired HIV infection if they would want to be more involved with advance care planning.

*Development of an Advance Care Planning Guide (2007-2012)*
Key Developmental Issues

- Spiritual Thoughts
- Identity
- Finding Meaning
- Family & Friends
- Legacy
- Autonomy/Control
Voicing My CHOICES
A Planning Guide for Adolescents & Young Adults
Integration/Conversations Remains Challenging Recommendation

- 20,000+ copies requested, 4 languages

- IOM (2014) proposes a life-cycle model, in which advance care planning occurs at key developmental milestones, including diagnosis of a life-limiting illness
  - Can be revisited periodically, becoming more specific as changing health status warrants

- Funding for Future Research – Understand how choices may change, ensure the preferences are heard, understood, and honored

Advance care planning
2. Resources not aligning with patient and family needs

- Pediatric inpatient hospice homes
- Bereavement
Children Die in Different Locations

- Most of the over 3,000 hospices in the U.S. will now consider accepting children.

- In the US, there are a dearth of freestanding pediatric inpatient hospice programs.
Further research needs to be directed towards understanding need, patient and family preferences, cost and psychosocial benefit for location of EOL care. (Kassam...Wolfe, 2014)
The death of a child has a profound, lasting impact on the family. Bereaved parents are at increased risk of prolonged grief, isolation, economic/health decline and behavioral health concerns (Rosenberg et al., 2012; Vegal et al., 2014).

Recent multicenter study, 120 parents (Lichtenthal, under review)
- 40% of parents with expressed need not receiving services
- 36% dropped out of treatment (not helping, therapist couldn’t understand)
- Emotional & logistical barriers (difficult to find help, lack of time, finances)
  - telemedicine
- 47% expressed need 2 to 4 years post loss - screening
Recommendation

Our healthcare delivery system needs **financially sustainable, continuity of care models** (offered prior to and following the death of a child), interventions for the "**whole family**", extending at least **through the 2nd year** post-loss (*Donovan et al, 2014*).
What do we know?

• Substantial evidence of the physical, psychosocial and existential impact of cancer on children and families

• While many services are provided to children and their families, care is inconsistent across and even within centers

  • Lack of established evidence-based standards is an impediment
Psychosocial Standards of Care (PSCPCC) Project

Develop evidence-based standards and guidelines for the psychosocial care of children with cancer and their families.
Congressional Briefing
March 2012, Capitol Hill, Washington, DC

• Presentations by psychosocial experts and parent advocates
  highlighting psychosocial needs in pediatric oncology

Where is the evidence?
Monthly Phone Calls

Search the literature
Identify key evidence
Consider barriers to implementation

Evidenced based when possible, expert opinion, consensus based when not
Standard: Palliative and End of Life Care Recommendation

“Youth and their families should be introduced to palliative care concepts to reduce suffering throughout the disease process regardless of disease status.”

Evidence from 36 Research Articles Support this Standard

Successful implementation of Pediatric Standards requires systematic, intentional application and reimbursement

Lead authors: Meaghann Weaver; Bob Casey, CNMC Palliative Care SIG (Weaver et al, under review)
Summary: How to Integrate?

- **Frame Goals of Care for Concurrent Care: Inclusive Approach**
  - If there is a palliative care service, integrate into the existing care with attention to symptom management, personal goals and values, and QOL throughout care; extend beyond the hospital (ambulatory, community, home settings) (*Pizzo, 2014*)
  - “I want to make sure your child gets the best care possible….no stone unturned”

- **Adopt a Team Approach**
  - There are psychosocial oncology professionals (social workers, psychologists, psychiatrists, child life specialists) trained in providing care and palliative care concepts throughout the disease trajectory, into survivorship. Plenty of work, transitions, we’re better together

- **Set priorities**
  - Resources will never be able to meet all health needs. Consider urgency of needs, societal impact, choose the type of palliative care strategy according to: affordability, sustainability
Rigorous Prospective Research & Quality Improvement Projects

- Education & Training
- Interdisciplinary Care Initiatives, Interventions
- Advance Care Planning Models
- Palliative Care Programs
- Implementation of Standards
Take Home Action Steps

- Raise the bar
- Access, Integrate
- Communication, Align resources
- Standards
- Policies, Implementation
- Funding