Pediatric Project ECHO-Palliative Care
Core Competency Session:
What is Pediatric Palliative Care?

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CHEO and Roger Neilson House
April 12, 2023
Land Acknowledgement

• I live in Ottawa, which is built on unceded Algonquin Anishinabe territory
• The peoples of the Algonquin Anishinabe Nation have lived on that territory for millennia and I honour them and the land
• Their culture and presence have nurtured and continue to nurture our land
• I also honour all First Nations, Inuit and Métis peoples and their valuable past and present contributions to our land
• I invite you to consider the peoples who have lived on your territory in order to honour them as well.
Speaker Disclosure

- I have no conflicts of interest to declare
Objectives

At the end of the session, attendees will be able to:

- Define pediatric palliative care (PPC)
- Identify predictable opportunities for palliative care intervention
- Describe when and how to utilize a subspecialty palliative care team
- Evaluate myths and assumptions about PPC
What is Pediatric Palliative Care?

Palliative care aims to prevent and relieve health related suffering of adults, children and their families facing problems associated with life-threatening illness.

(World Health Organization)
Other Definitions of PPC

- An active, holistic approach to care which focuses on relieving the physical, social, psychological and spiritual suffering experienced by children and families who face a progressive, life-threatening condition, and helping them fulfil their physical, psychological, social and spiritual goals.

Canadian Hospice Palliative Care Association
Hospice palliative care is holistic care – comfort, meaning and support for people facing the end of life, and their families.

Hospice Palliative Care Ontario
Hospice

- Historically was care, services and resources centered on end-of-life issues
- In the US, it is an insurance benefit associated with a terminal prognosis
- In Canada it is a building, a place where palliative care is provided
Aspects Particular to Pediatric Palliative Care

- Trajectory of illness
- Different diagnosis
- Focus on developmental stage
- Resilience
- Family responsibility and involvement
Questions?
Tasks of Palliative Care: Mitigating Suffering

- Communication
- Care Coordination
- Intervention
Sam’s Suffering

Health/Functional Status Over Time
Predictable Opportunities to Initiate PPC Tasks

Health/Functional Status Over Time
Acute Decompensation and Hearing Bad News (Point A)

- symptom management
- Coping with new diagnosis
- Collaboration and communication with new team members
- Distress re siblings
Opportunities to Treat Suffering

- Identify problems & challenges
- Facilitate understanding
- Explore hopes & worries/ set goals
- Aid in making decisions
Opportunities to Treat Suffering

- Physical Suffering
- Spiritual Suffering
- Family, sibling support
- Facilitate collaboration with specialists
Recovery and Accommodating to a New Life (Point B)

Health/Functional Status Over Time

Lingering symptoms
Coping with new normal
Coordinating care
Grieving loss of “well” child
Anticipatory grief over change in family, suffering for child
Sibling issues
Opportunities to Treat Suffering

- Facilitate understanding of disease
- Explore hopes and worries/ set goals for physical and psychosocial suffering
- Support family
Opportunities to Treat Suffering

- Facilitate collaboration with specialists
- Opportunity to build therapeutic relationships that will be essential later
Acute Decompensations and Unexpected Recoveries (Point C)

Health/Functional Status Over Time

Pain and symptom management
Assistance with decision making
Goal setting
Comfort care initiatives
Opportunities to Treat Suffering

- Identify problems and challenges
- Facilitate understanding
- Explore hopes, worries/ set goals
- Advanced care planning
- Aid in decision making
- Physical suffering
Opportunities to Treat Suffering

- Spiritual suffering
- Anticipatory grief and bereavement
- Family, sibling support
- Team support
- Facilitate Collaboration with specialists, primary care providers
Slow or Precipitous Decline Preceding End-of-Life (Point D)

Coping with declining condition
Decisions regarding invasive technology
Self-determination for child-patient
Pain and symptom management
Increasing sibling distress
Bereavement
Opportunity to Treat Suffering

- Identify problems and challenges
- Facilitate understanding of disease
- Explore hopes/worries, Set goals
- Advanced care planning
- Aid in making decisions
Suffering Requiring Interventions

- Physical Suffering
- Psychosocial suffering
- Spiritual suffering
- Bereavement
- Family and Sibling support
- Team support
- Community Support
Suffering Requiring Care Coordination

- Facilitate collaboration with specialists
- Partner with community programs to transition
- Identify community resources to support additional care and requirements
End-of-Life (Point E)

Planning for death
Decisions regarding resuscitation
Intensive symptom management
Increasing family and sibling distress
Care of the imminently dying patient
Bereavement
Opportunity to Treat Suffering

- Tasks more specific to EOL care
  - Establishing goals of treatment decisions
  - Discussing dying process: anticipatory guidance
  - Identifying barriers to care in all settings
  - Proactive planning to manage symptoms
  - Establishing partnerships with PC resource
Opportunity to Treat Suffering

Tasks more specific to EOL care

- Collaboration with PC to work on symptom management and likely specific cause of death
- Partner with community programs to prepare for EOL
- Planning for rituals, memorial assisted by PPC team
The Family Experience as Context

- From moment of diagnosis, coping with fear and hope for the best
  - Stress and anxiety
  - Multiple demands
  - High degrees of uncertainty
The Family Experience as Context

- From moment of diagnosis, coping with fear and hope for the best
  - Balancing hopes for a good outcome with fears of a bad one: death
  - Pressures last months to years and can erode resilience
Bereavement Support

- Offered as early as dx of a life-limiting illness
- Offered to those who have lost a child
- Depends on needs
Bereavement Support

- May include individual, couple’s and group counselling
  - Anticipatory Bereavement - siblings, parents
    - decrease the sense of isolation
    - reduce fear of unknown
  - Grandparent group
  - Perinatal Palliative Care group
Impact of Pediatric Palliative Care

- Children with serious illnesses and their families benefit from PPC
- Earlier initiation improves symptom management & quality of life
- May lead to prolonged life, less distress and less ineffective treatments
Questions?
8 Pediatric Palliative Care Programs
- 7 based in tertiary care hospitals
- 1 based in a free-standing Hospice

Estimated 5% of all children who might benefit from PPC were receiving it

Widger et al., 2007
Hospices and Dedicated PPC - Canada V.2012

- 3247 children ≤ 19 died in Canada
- 2317 children may have benefitted from PPC
- 1401 children (60%) received specialized PPC services
  - 517 in 3 free-standing hospices
  - 884 cared for by 10 programs based in hospitals

Widger et al 2012
Estimates - 9.8/10,000 children might benefit from PPC services

# children who received specialized PPC services quadrupled in 10 years but
  - more children died in critical care
  - more had delayed referrals to PPC
Other

- 60% with access to pediatric hospice in 2012 had access for over a year
  - Availability of respite likely a factor
- 41.9% of children with access died in hospice
  - Alternative to hospital or home
- Increasing #s of children <1 yr of age at time of referral received care
  - > % of children die in first year of life
  - Reflected in increased referrals in perinatal period.
<table>
<thead>
<tr>
<th>Condition</th>
<th>n</th>
<th>%</th>
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<tr>
<td>Cong malfns, deform, chromosomal abn</td>
<td>402</td>
<td>(28.7)</td>
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<td>Disease of Nervous system</td>
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<td>(26.8)</td>
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<tr>
<td>Neoplasms</td>
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<td>(15.8)</td>
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<td>Endo., nutritional, metabolic disease</td>
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<td>(10.6)</td>
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<td>Conditions originating in prenatal period</td>
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<td>(7.3)</td>
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Primary Dx of Children Receiving PPC - Canada 2012

- Mental & behavioural disorders: 26 (1.9)
- Infectious and parasitic diseases: 25 (1.8)
- External causes of morbidity/mortality: 25 (1.8)
- Other: 76 (5.4)
- Unknown: 1 (0.1)
Location of Death

- Critical Care/emergency dept.  105  (24.4)
- Home                      92
- General Hospital unit      85
- Hospice/palliative care bed 66
- Labour and delivery        41
- Community hospital         26
- Other/unknown              16

158 (36.7%) died in non-acute care settings
## Age at Referral to PPC

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<td>&lt;1</td>
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<tr>
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<td>5-9</td>
<td>247</td>
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<td>10-14</td>
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<td>15-25</td>
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<tr>
<td>Unknown</td>
<td>7</td>
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<tr>
<td>50 +% &lt; 4</td>
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## Time from DNR order to Death

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<th>n</th>
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<td>181-365</td>
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<tr>
<td>( &gt; 365 )</td>
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<tr>
<td>No DNR order</td>
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<tr>
<td>DNR status unknown</td>
<td>48</td>
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Only 24% of children cared for by PPC teams had DNRs.
Signs and symptoms of patients receiving PPC services

* Other symptoms include paralysis, edema, sepsis, sweating, and dry mouth.

Feudtner et al, Pediatrics 2011
Common Baseline Signs and Symptoms

- Cognitive impairment
- Speech impairment
- Fatigue and sleep problems
- Enteral intake
- Seizures
Common Baseline Signs and Symptoms

- Somatic pain
- Dyspnea
- Excessive secretions
- Spasticity
- Swallowing difficulties
Meds Received by Children Receiving PPC

Feudtner et al, Pediatrics 2011
The Interdisciplinary Palliative Care Team
The Interdisciplinary Team

- Majority of Canadian PPC teams consist of a physician, a nurse, a bereavement coordinator, social worker or psychologist.
- Key additions: spiritual support, recreation or child life therapists
- Collaborative services: oncology or neurology, hospice teams and community care providers.
Tasks of a Subspecialty PPC Service

Symptom management (58%)

- Cognitive impairment (47%)
- Seizures (25%)
- Dyspnea (22%)
- Pain (31%)
  - Somatic (22%)
  - Visceral (12%)
  - Neuropathic (10%)
Tasks of a Subspecialty PPC Service

Other tasks (42%)

- Communication (48%)
- Decision making (42%)
- Care coordination (35%)
- Transition to home (14%)
- Limiting interventions – DNR/DNAR (12%)
- Bereavement (11%)
- Recommendations at end-of-life (9%)
Primary vs. Subspecialty Palliative Care

Primary Palliative Care includes primary care teams such as oncology, etc.

Subspecialty Palliative Care is provided by interdisciplinary teams trained, certified, and experienced in the tasks of PPC.

Health/Functional Status Over Time

Risk of Suffering Threshold
Myths in Palliative Care, Hospice

- Palliative care = hospice = giving up hope
- Child must be terminally ill or at the end of life
- Child must have a DNR to have hospice care
Myths in Palliative Care, Hospice

- Only for children with cancer
- Must abandon all disease-directed treatment
- Must abandon primary treatment team
- Child must move to a different unit/location
Myths in Palliative Care, Hospice

- Child will die sooner/lose hope if PC introduced
- All families want end-of-life to be at home
- Administering opioids causes respiratory depression and quickens death
Early Integration

- Care integrated at diagnosis
  - Provides focus of disease and suffering in all stages
  - Provides necessary supports to help families cope
  - Prevents perception of transition in care or abandonment
Early Integration

- Subspecialty care integrated with primary team
  - Keep PMD or primary specialist in control
Early Integration

- Synergism of disease modifying and palliative care strategies
  - Better symptom and psychosocial management may improve tolerance of treatments and outcomes
  - Palliation and restorative strategies both aim to improve function
Introducing Palliative Care to Families

- As close to diagnosis as possible
- “The part of care for kids with serious illness that focuses on:”
  - Help manage symptoms, stress of serious illness
  - Provide extra layer of psychosocial support
  - Spend time with patients, families to help them understand disease and treatment
Integrating Subspecialists Early

- Prevents disruptive transition to new care team at worst possible time
  - Decreases feelings of abandonment
- Minimizes fragmentation of care
- Umbrella of support through process
  - Support for primary team too (time, resources, self-care, prevention of compassion fatigue)
Integrating Subspecialists Early

- Allows patient, family self-determination about treatment options
- Empowers parents to be capable of maintaining dual goals of care concurrently
- Health care justice: access to emerging best practice
Integration Strategies

- Automatic consultation
- Prioritize symptom management & find a symptom to invite the PPC team to treat
- Consider PC as adjunct medical specialty, part of package, not an optional service
Integration Strategies

- Forget prognosis entirely:
  - Resource management for complex needs of family and community
  - Preventive and anticipatory guidance for children with life-threatening conditions
Integration Strategies

- Honest appraisal of “doing to” vs. “doing for”

- Think about list of applicable diagnoses
  - Acknowledge likelihood of cure
  - Acknowledge burdensome treatment course
Integration Strategies

- Think about appropriate time points
  - Bad news/overwhelmed at diagnosis
  - Phase I enrollment
  - Relapse/recurrence
  - Serious complications
  - ICU admissions/transfers
  - Change in technology (new trach)
  - Listing for transplant
The Language of PPC

- Interdisciplinary
- Life-threatening, not just life-limiting, progressive
- Children range in age from prenatal to young adult
- Family (biological, adoptive, foster, etc) core to decisions
The Language of PPC

- Surrogate decision making
- Benefits/Burdens
- Goals of care
- AVOID: Withdrawal of support/care/treatment
- Transition to focus on quality and comfort
Summary
Pearls

- Refer to PPC early
- Focus on the relief of suffering
- Consider careful use of language
Pearls

- Additional referral points
  - Complex, higher risks situations
  - Conflicts
  - Communication challenges
- PPC works with the primary care team to enhance care
- Define goals for care
Pitfalls

- Confusing PPC with hospice or end of life care
- Asking families to choose PPC when they may not understand what it is or when it is considered standard of care
- Using language that suggests “giving up” or loss of hope
Pitfalls

- Waiting so long to refer that suffering increases
- Using terms like “withdrawing” or “withholding” care
Comments or Questions???
EPEC - Pediatrics

The Education in Palliative and End of Life Care: EPEC-Pediatrics
2010 – 2016

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Funded by the National Institute of Health / National Cancer Institute
[1 R25 CA151000-01]

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