PEDIATRIC PALLIATIVE CARE (PPC): STATE OF THE SCIENCE UTILIZATION IN INTENSIVE CARE UNITS

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OBJECTIVES

• Review the most important articles of Pediatric Palliative Care in 2018 related to intensive care units

• Review articles published and to be published from Primary Children’s Hospital and PPC
PPC UTILIZATION IN THE ICUS
OUTLINE

• Integration of PPC in the ICU
• Benefits
• Challenges
• End-of-life Care
• Primary Children’s Hospital (PCH) and PPC experience
INTEGRATION OF PPC IN INTENSIVE CARE SETTINGS
The American Academy of Pediatrics (AAP) recommends involvement early in the disease course for children with complex chronic health issues, life-threatening, or terminal conditions.

The AAP released a statement in 2013 outlying core commitments to the discipline.

AAP encourages integration of palliative care delivery into ICUs (2014)


PPC INTEGRATION IN THE ICU-AAP

• Improve the quality of life of patients and families who face life-threatening illness

• Facilitate goals of care discussions while assisting with symptom management throughout the duration of illness as well as the end of life

PPC INTEGRATION IN THE ICU-AAP

- Continuity of care
- Emotional support to families, patients and staff
- PPC coordinates multidisciplinary care
- PPC provides end-of-life care and bereavement support
- “Standard for high quality care of critically ill children”

BENEFITS OF PPC
BENEFITS OF PPC—PROVIDERS PERSPECTIVE

- Semi-structured interviews of 22 attending physicians from neonatal, pediatric and cardiac intensive care units in a single children’s hospital in the USA

BENEFITS OF PPC—PROVIDERS PERSPECTIVE

• Support to families
  – Nonjudgmental approach
  – Emotional, spiritual and informational support
  – Transitions from curative to comfort-focused care or from critical to chronic disease management
  – “One physician said that the longer the stay, the more the family needed, but the less support the clinical team provided”

BENEFITS OF PPC—PROVIDERS PERSPECTIVE

• Bridging communication
  – Physicians reported they lack the capacity to explore family goals
  – Disagreement between the clinical team and the family about expectations

• Competing priorities
  – Physicians in the ICU are responsible to address the physiological needs of their patients
  • Acute management decisions instead of big-picture discussions with families
  • Lack of time for in-depth conversations with families

BENEFITS OF PPC—PROVIDERS PERSPECTIVE

• Fragmentation of care
  – Each subspecialty views the child through their discipline-specific perspective
  – Issues with continuity
    • Weeklong rotations for ICU and subspecialist physicians

– PPC indicated for patients with greater medical complexity, long ICU/hospital stays, anticipated readmissions, uncertainty in prognosis or “right” course of action

BENEFITS OF PPC - MATERNAL STRESS

• Randomized trial of early palliative care

• Mothers diagnosed prenatally with single ventricle planned to undergo first stage palliation

• Impact of early palliative care on maternal stress in infants prenatally diagnosed with single ventricle disease

• Early palliative care consultation defined as a consult when patient admitted for planned surgery following birth but before first stage palliation

BENEFITS OF PPC-MATERNAL STRESS

• April 2013 to August 2015
• 18 mothers randomized to early palliative care
• 20 mothers randomized to standard of care
• Early palliative care resulted in decreased maternal anxiety, improve maternal positive reframing, and communication and family relationships

BENEFITS OF PPC-SINGAPORE’S EXPERIENCE

- Singapore’s first specialist home-based palliative care service
- PPC group had:
  - 2.46 fewer mean hospital admissions than control group
  - 52 day shorter mean 1-year cumulative length of stay (LOS) in hospital
  - No significant difference in mean number of ED visits between PPC group and control group
- PPC group ~5 times more likely to have an advance care plan (ACP), or to have discussed ACP with a healthcare professional, compared to the control group

Chong PH et al *Paediatric palliative care improves patient outcomes and reduces healthcare costs: evaluation of a home-based program*. BMC Palliative care 2018
BENEFITS OF PPC- A DIFFERENT LANGUAGE

• Retrospective cohort review of ICU family conferences with and without the PC team

• Meetings without PC team – “instrumental support”
  – giving medical information, discussing medical options
  – statements included hopelessness, insensitivity, “health-care provider challenges”

• Meetings with PC team – “emotional support”
  – Supportive statements, open-ended questions, discuss quality of life

CHALLENGES OF PPC IN ICU CARE
CHALLENGES OF PPC-UNEXPECTED SURVIVORS

- Retrospective single institution large tertiary children’s hospital
- 349 children enrolled in PPC from March 2008 to October 2012 followed until September 2015 or death
- 5% (n=18) “unexpected survivors”

CHALLENGES OF PPC-UNEXPECTED SURVIVORS

• Unexpected survivors are small group of children with life-limiting conditions

• Highlights that prognostication of survival is difficult in children with life-limiting illnesses due rarity of these conditions and technological advances

CHALLENGES OF PPC- RELIGION AND SPIRITUALITY

- Parents consider R&S fundamental to decision-making
- Application of R&S concepts is vague
- R&S impact how decisions are made more than what decisions are made
- R&S can be applied to decision-making in both functional and dysfunctional ways

Superdock AK et al. Exploring the vagueness of Religion & Spirituality in complex pediatric decision making: a qualitative study. BMC Palliat Care 2018
Perceptions regarding PPC:

- PPC only assists with end-of-life issues and is only appropriate for children who are dying or are expected to die.
- Primary providers perceive themselves competent in caring for patients at the end of life without PPC involvement.


CHALLENGES OF PPC-CARDIOLOGIST PERSPECTIVE

- Lack of PPC benefit
- Involvement of new teams
- Fear of undermining parental hope
- Concerns that PPC will be poorly accepted by parents
- Concerns that philosophy of the palliative care team is inconsistent with provider therapeutic approach


END OF LIFE CARE AND PPC INVOLVEMENT
UK data from 2004-2025

Children with LLC accounted for:
- 58% of all PICU admissions
- 73% PICU deaths
- 87% PICU stays >28 days

Similar to US results of children with CCCs

“There is an opportunity, given the recent growth in specialist paediatric palliative care services, to have integration of these services to enable choice around place of care and place of death for these children and families”

END OF LIFE CARE AND PPC INVOLVEMENT

• Children who died in a large USA children hospital from July 2011 to June 2014
• 579 patients deceased
• 61% were less than 1 year of age

END OF LIFE CARE AND PPC INVOLVEMENT

• 74.1% died in an ICU setting (NICU, PICU, or CICU)

• Five modes of death were identified:
  – Withdrawal of life-sustaining technologies (40.2%)
  – Nonescalation (25.6%)
  – Failed resuscitation (22.8%)
  – Code-then-withdrawal (6%)
  – Death by neurologic criteria (5.4%)

END OF LIFE CARE AND PPC INVOLVEMENT

• PPC for 32% (n=187) of the patients who died

• When controlling for patient age, race, and LOS, patients with code death were less likely to have had palliative care consultation (OR 0.31; 95% CI: 0.13–0.75)

• Patients who had nonescalation death were more likely to have had palliative care consultation (OR 5.02; 95% CI: 2.77–9.10)

PPC AND PRIMARY CHILDREN’S HOSPITAL (PCH)
PPC AND PCH

- Patients 0 to 25 years old, died inpatient stay at PCH ≥48 hours after admission from July 2012 to December 2015
- No complex chronic conditions (CCCs) before admission
- 167 patients met the eligibility criteria
- 89% (n=149) died in intensive care settings
- 80% (n=133) (-) PPC
- 20% (n=34) (+) PPC

Spraker-Perlman HL, Tam Reena P, Bardsley T et al. The Impact of Pediatric Palliative Care Involvement in the Care of Critically Ill Patients without Complex Chronic Conditions. J Palliative Medicine 2019
PPC AND PCH

• Patients (+) PPC vs. (-) PPC were more likely to:
  – Multidisciplinary care conference
    (70.5% vs. 39.9%; p = 0.001)
  – Earlier multidisciplinary care
    (7 days vs. 2 days before death; p = 0.04)
  – Documentation of end-of-life planning in medical records
    (9.5 days before death vs 2 days before death; p < 0.0001)
  – DNR order before death
    (67.7% vs. 39.9%; p = 0.004)
PPC AND PCH

- Retrospective
- Descriptive
- Single Center
- Children (0-21y) admitted to a cardiac intensive care unit (CICU) from January 2014 to June 2017
PPC AND CHILDREN WITH HEART DISEASE TREATED IN CICU

1. Describe rates of PPC consultation during study period and retrospectively apply CAPC criteria for potential consults

2. Describe the demographic and clinical characteristics of children admitted to the CICU and compare by PPC consultation

3. Evaluate the impact of PPC consult on end of life care
PPC AND CHILDREN WITH HEART DISEASE TREATED IN CICU

- 1389 children were admitted to the CICU during study period

- 112 (8%) children received PPC consultation
FIGURE 1. OBSERVED VS. POTENTIAL PEDIATRIC PALLIATIVE CARE CONSULTATIONS BASED ON CRITERIA FROM THE CENTER TO ADVANCE PALLIATIVE CARE

Delgado-Corcoran et al. Manuscript submitted to PCCM.
# PPC AND CHILDREN WITH HEART DISEASE TREATED IN CICU

### Table 1: Demographics of Children Compared by Pediatric Palliative Care Consultation (n=1389)

<table>
<thead>
<tr>
<th></th>
<th>(+) PPC (n=112)</th>
<th>(-)PPC (n=1,277)</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age in days at first hospital admission, median (IQR)</td>
<td>63 (0 – 1,954)</td>
<td>239 (3 – 2695)</td>
<td>0.003</td>
</tr>
<tr>
<td>CCCs at end first hospital admission, median (IQR)</td>
<td>3 (2-5)</td>
<td>1 (1-2)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Lifetime CCCs, median (IQR)</td>
<td>4 (3-6)</td>
<td>2 (1-3)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Total CICU days, median (IQR)</td>
<td>11 (5-30)</td>
<td>2 (1 - 7)</td>
<td>&lt; 0.001</td>
</tr>
<tr>
<td>Total hospital days, median (IQR)</td>
<td>60 (22-100)</td>
<td>7 (3-19)</td>
<td>&lt; 0.001</td>
</tr>
<tr>
<td>Mortality, n (%)</td>
<td>42 (38)</td>
<td>43 (3)</td>
<td>&lt; 0.001</td>
</tr>
</tbody>
</table>

PPC= Pediatric Palliative Care,  IQR=Interquartile range, CCC= complex chronic conditions
## LOCATION AND MODES OF DEATH IN THE CICU COMPARED BY PPC

**Table 3: Location and Modes of Death Compared by Pediatric Palliative Care Consultation (n=85)**

<table>
<thead>
<tr>
<th>Patients Who Died</th>
<th>PPC (+) (n = 42)</th>
<th>PPC (-) (n = 43)</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Location of Death, n (%)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intensive Care Unit</td>
<td>28 (67)</td>
<td>31 (74)</td>
<td>0.474</td>
</tr>
<tr>
<td>Home on Hospice</td>
<td>10 (24)</td>
<td>1 (2)</td>
<td>*0.004</td>
</tr>
<tr>
<td>Home unexpected</td>
<td>1 (2)</td>
<td>2 (5)</td>
<td>0.500</td>
</tr>
<tr>
<td>Hospital, not ICU</td>
<td>2 (5)</td>
<td>8 (19)</td>
<td>*0.044</td>
</tr>
<tr>
<td>Chronic care facility</td>
<td>1 (2)</td>
<td>0 (0)</td>
<td>1.000</td>
</tr>
<tr>
<td>Unknown</td>
<td>0 (0)</td>
<td>1 (2)</td>
<td>1.000</td>
</tr>
<tr>
<td><strong>Modes of Death, n (%)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Withdrawal of life support measures</td>
<td>21 (50)</td>
<td>28 (67)</td>
<td>0.184</td>
</tr>
<tr>
<td>Comfort care</td>
<td>15 (36)</td>
<td>1 (2)</td>
<td>*&lt; 0.001</td>
</tr>
<tr>
<td>Died during resuscitation</td>
<td>5 (12)</td>
<td>11 (27)</td>
<td>0.164</td>
</tr>
<tr>
<td>Unexpected</td>
<td>1 (2)</td>
<td>2 (5)</td>
<td>0.500</td>
</tr>
<tr>
<td>Unknown</td>
<td>0 (0)</td>
<td>1 (2)</td>
<td>1.000</td>
</tr>
</tbody>
</table>
PPC AND CHILDREN WITH HEART DISEASE TREATED IN CICU

- PPC consultation occurred rarely in the CICU
- Applying CAPC guidelines there were missed referrals
- Children who received PPC were different to those who did not
PPC AND CHILDREN WITH HEART DISEASE TREATED IN CICU

- PPC was associated with high disease burden, complexity and lower survival
- PPC was associated with more frequent use of comfort care at the end of life and death at home
PPC AND PCH

• **Aim:** Understand patterns of PPC consultation and timing of consultation in relation to heart disease diagnosis.

• **Inclusion:** Patients with heart disease and a new PPC consultation from January 2014 to June 2017.

• **Exclusion:** PPC consult occurred prenatally but patient was never admitted to the hospital.

• **N=113**

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### PPC AND PCH

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>N=113</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age at first admission (days), median (IQR)</td>
<td>8 (0-522)</td>
</tr>
<tr>
<td>Age at time of palliative care consult (days), median (IQR)</td>
<td>72 (17-590)</td>
</tr>
<tr>
<td>Congenital heart disease, n (%)</td>
<td>96 (85)</td>
</tr>
<tr>
<td>Two ventricle, n (%)</td>
<td>59 (61)</td>
</tr>
<tr>
<td>Single ventricle, n (%)</td>
<td>37 (39)</td>
</tr>
<tr>
<td>Prenatal diagnosis of congenital heart disease</td>
<td>51 (53)</td>
</tr>
</tbody>
</table>

Greene D et al.
FIGURE 2: PROVIDERS AND PPC REFERRAL

- Neonatologists
- Pediatric or Cardiac Intensivists
- Hospitalists
- Cardiologists

NUMBER OF PPC REFERRALS
PPC AND PCH

• PPC referral occurs late for children with heart disease

• Despite of a high percentage of prenatal CHD diagnoses, most PPC referrals occurred early infancy

• A high proportion of infants and newborns died in the intensive care unit after a prolonged hospitalization and withdrawal of life-sustaining therapies.

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• The rate of PPC referral varied by subspecialty but was particularly low among cardiologists.
CONCLUSIONS

• Pediatric palliative care involvement in the ICUs has many benefits for providers, families and patients

• Pediatric palliative care faces unique challenges

• Pediatric palliative care involvement impacts modes and location of death
CONCLUSIONS

• Overall, Intensivists see the potential benefits of PPC. However, there is still misperceptions and barriers by providers

• The rates of PPC utilization in the CICU and children with heart disease are low at PCH despite benefits and recommendations by the AAP and CAPC guidelines
THANK YOU
REFERENCES


