Evidence as a Tactic to Advance Pediatric Palliative Care

Richard Goldstein, MD, Boston Children’s Hospital-Harvard Medical School

Maggie Rogers, MPH, Senior Research Associate, CAPC

August 28, 2017
2017 SEMINAR THEMES

➔ Program design for all care settings
➔ High-functioning teams
➔ Health equity in palliative care
➔ Quality measurement

HIGHLIGHTS

➔ Interactive sessions on cutting edge topics
➔ Networking events to connect and share ideas
➔ Office Hours with Seminar faculty for deep dive Q&A
➔ Poster session and reception

KEYNOTE LINEUP

Diane E. Meier, MD, FACP
Director, Center to Advance Palliative Care

Eric Widera, MD
Co-founder, Geri-Pal

Kimberly Sherell Johnson, MD
National Health Disparities Expert

Ira Byock, MD
Founder, Providence Institute for Human Caring

Lauren Taylor, MDiv, PhD(c)
Co-author, The American Health Care Paradox

Matthew Gonzalez, MD
Associate Medical Director, Providence Institute for Human Caring

Lynn Hill Spragens, MBA
Leading National Palliative Care Consultant

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capc.org/seminar
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August 28, 2017
PPC as a moral, humanistic, and emotionally charged enterprise

- Addresses suffering in vulnerable children
- Emotionally compelling cases
- The complexity of it all
- The injustice of it all
- The insensitivity of a system
When we advocate in our teams, among our colleagues, or at an administration level…
Some sizing up

Take it away from their deficiencies and an emotional plea
Leverage work we are already doing in favor of shared goals

We add something of value that makes us all better
Objectives

➔ Discuss needs for evidence in different settings
➔ Propose ways to frame advocacy and development
➔ Present findings from the National Palliative Care Registry™ for pediatric programs
➔ Discuss some examples of using the data
Caveats

- Existing research
- Efforts of other organizations
- Work in progress
  - Registry isn’t a CAPC thing, it’s a you thing
  - Earnest attempt to develop useful tools to promote the field
A palliative care program can provide services at **one or more service settings** including: hospitals, long-term care facilities, outpatient clinics, patient homes, and doctors’ offices.
Different settings, different needs

Referring Services

Institution

Community

Team
Within a Team

Team (system) improvement: How are we doing?

- Benchmarks
- Best practices
- QI metrics
- Team support
With referring services

Who we are and how can we help you with your patients (institutional and comparative):

- Shared patients
- Overall referral patterns
- More seamless collaboration
How we operate within our institution to strengthen the delivery of care:

- Imprint of our patients on the institution
- Composition of the team
- Reimbursement and funding data
- How this compares to comparable institutions
Where can we find this data?
The National Palliative Care Registry™ is the only platform tracking the nation’s palliative care programs and operational features.
About the Registry

➔ Annual survey collecting aggregate data (not patient-level) on palliative care program’s operations, patient encounters, staffing, program features, and referrals.

➔ The Registry is free and open to all palliative care programs, including PPC, across service delivery sites.
Now:

➔ Pediatric guidance & answer categories added to select questions
➔ Comparative reports limited to comparisons with other PPC programs

Future:

➔ Tailored questions and answer categories for PPC programs
➔ More relevant reports for PPC programs
Dashboard Reports

ACME Pediatric Palliative Care at ACME

Report Date 08-07-2017

Total Palliative Care Consults and Hospital Service Penetration

<table>
<thead>
<tr>
<th>Year</th>
<th>Total Admissions</th>
<th>Initial Visits</th>
<th>Subsequent Visits</th>
<th>Total Encounters</th>
<th>Penetration</th>
</tr>
</thead>
<tbody>
<tr>
<td>2016</td>
<td>1,311</td>
<td>175</td>
<td>220</td>
<td>395</td>
<td>13.3%</td>
</tr>
<tr>
<td>2015</td>
<td>1,311</td>
<td>120</td>
<td>200</td>
<td>320</td>
<td>9.2%</td>
</tr>
<tr>
<td>2014</td>
<td>1,311</td>
<td>100</td>
<td>165</td>
<td>265</td>
<td>7.6%</td>
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<tr>
<td>2013</td>
<td>1,323</td>
<td>114</td>
<td>170</td>
<td>284</td>
<td>8.6%</td>
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<tr>
<td>2012</td>
<td>1,316</td>
<td>95</td>
<td>100</td>
<td>195</td>
<td>7.2%</td>
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<tr>
<td>2011</td>
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Quick Facts

Palliative care service penetration refers to the percent of annual hospital admissions treated by a palliative care team.

Palliative care service penetration is an estimate of how well programs are reaching patients in need.

ACME Pediatric Palliative Care at ACME

Report Date 08-07-2017

Palliative Care Staff per 10,000 Admissions by Hospital Bed Size (2016)

<table>
<thead>
<tr>
<th>Hospital Bed Size Categories</th>
<th>FTE per 10K Admissions</th>
</tr>
</thead>
<tbody>
<tr>
<td>150 Beds</td>
<td>7.1</td>
</tr>
<tr>
<td>150-299 Beds</td>
<td>5.2</td>
</tr>
<tr>
<td>300-499 Beds</td>
<td>4.6</td>
</tr>
<tr>
<td>500+ Beds</td>
<td>3.0</td>
</tr>
</tbody>
</table>

Legend

- 99th Percentile
- 75th Percentile
- Mean
- Median
- 25th Percentile
- 1st Percentile
- Your Program

Quick Facts

Staff per 10,000 admissions standardizes data, allowing for easier comparisons across programs. This graph reports includes all full-time equivalent (FTE) staff. For comparison, programs are divided by relative size, defined by total hospital beds.

The National Palliative Care Registry™ is a project of the Center to Advance Palliative Care and the National Palliative Care Research Center
Dashboard Reports

➔ Make the case for more resources
➔ Bring it to the C-Suite and Board of Directors
➔ Set program targets or internal benchmarks
➔ Use in fundraising materials
➔ Understand what other PPC programs look like and how they operate
Participation/Representation

➔ 52 programs participated in 2015/2016
➔ 90% were in free-standing children’s hospitals
➔ This represents:
  – 42% of the estimated 112 children’s hospitals with palliative care programs in the U.S.
  – 21% of the estimated 220 children’s hospitals in the U.S. Children’s Hospital Association
PPC Registry Reach

Pediatric Palliative Care Program Participation in the National Palliative Care Registry, 2015/2016
Pediatric palliative care programs provide care to patients of all ages and stages of development.

Percentage of PPC Patients by Age Group

- 1 year or younger: 13.4%
- 2 to 17 years: 41.0%
- Over 18 years: 45.6%
Pediatric palliative care programs see patients frequently throughout a hospitalization

2.6% of annual pediatric admissions/newborns received an initial palliative care consult

During the course of 1 year, an average palliative care program:

- Provided 235 initial consults
- Saw 141 individual patients
- Provided 1,000 billable subsequent visits
This translates to...

Nearly **5** billable subsequent visits per initial PPC consult

Over **8** billable subsequent visits per unique patient
Pediatric palliative care programs treat patients with diverse primary diagnoses.

**Top Five Primary Diagnosis Categories**

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Average Percentage of PPC Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer</td>
<td>24.5</td>
</tr>
<tr>
<td>Prematurity</td>
<td>14.3</td>
</tr>
<tr>
<td>Neurological</td>
<td>12.0</td>
</tr>
<tr>
<td>Congenital</td>
<td>11.7</td>
</tr>
<tr>
<td>Chronic</td>
<td>9.6</td>
</tr>
</tbody>
</table>
Pediatric palliative care programs receive referrals from throughout the hospital, but the majority come from the ICU.

Top Five Referring Sites

- Oncology: 13.0%
- Pediatrics: 14.7%
- Med/Surg: 17.2%
- Neonatal ICU: 25.9%
- Pediatric ICU: 26.5%
Pediatric palliative care programs report a variety of staffing models

<table>
<thead>
<tr>
<th>Title</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physician (MD/DO)</td>
<td>93%</td>
</tr>
<tr>
<td>Advanced Practice Registered Nurse</td>
<td>76%</td>
</tr>
<tr>
<td>Social Worker</td>
<td>54%</td>
</tr>
<tr>
<td>Chaplain</td>
<td>53%</td>
</tr>
<tr>
<td>Registered Nurse</td>
<td>51%</td>
</tr>
<tr>
<td>Administrative Support Staff</td>
<td>49%</td>
</tr>
<tr>
<td>Administrator (non-clinical)</td>
<td>38%</td>
</tr>
<tr>
<td>Child Life Specialist</td>
<td>33%</td>
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<tr>
<td>Fellow</td>
<td>27%</td>
</tr>
<tr>
<td>Music &amp; Art Therapist</td>
<td>13%</td>
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</tbody>
</table>
Pediatric palliative care programs report a variety of staffing models

**Average Full-time Equivalent (FTE)**

- **Physician (MD/DO)**: 1.4
- **Advanced Practice Registered Nurse**: 1.0
- **Registered Nurse**: 0.7
- **Social Worker**: 0.5
- **Fellow**: 0.3
- **Administrative Support Staff**: 0.3
- **Music & Art Therapist**: 0.2
- **Child Life Specialist**: 0.2
- **Administrator (non-clinical)**: 0.2
- **Chaplain**: 0.2
Most pediatric palliative care teams include staff with board certification in hospice and palliative medicine

➔ 87% reported having at least one team member certified in palliative care on their staff

➔ Half reported a physician or APRN certified in palliative care on their team
Pediatric palliative care patients go home after being discharged from the hospital.

21% of PPC patients discharged home received hospice.
Evidence As A Tactic
What is available

➢ Access to your data
➢ Access to 21 standardized reports showing your program over time
  • 8 reports show your program over time
  • 13 reports compare your program to others, including sub-analysis by hospital size, by penetration, and by staffing.
➢ Comparison reports show de-identified means, medians, and percentiles for comparison group
➢ Programs do not have the option of accessing other program’s answers or data and do not have the option of using the entire database for research purposes at this time
➢ Your data is private
Within a Team - Benchmarks, Best Practices, QI

Advocacy framing: smarter not harder

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<tr>
<td>Patient satisfaction</td>
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<table>
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<tr>
<th>Time to consult</th>
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<td>Psychosocial screening</td>
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<td>Spirituality screening</td>
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<th>Documentation of DNR status</th>
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<td>Pain screening</td>
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<td>Dyspnea screening</td>
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Within a Team - Team Support

Advocacy framing: sustainable program, healthy workplace

Wellness policies and procedures
Meetings as a team
With referring services

Advocacy framing: Working together with resource-intense, high stakes patients

Distribution of referrals by location and referring clinician
- ER and ICU patterns
- LOS
- Continuity/discharge settings
- Alive/deceased/length of relationship

Triggers
Institutional Leadership

Advocacy framing: The are important patients. We can contribute to institution-wide performance.

Patient profile
- Case mix
- Billable visits
  - Non-billable visits
- LOS
- Re-admissions within 30 days

Staffing Profile
- Staffing
- Funding
- Certification by Joint Commission
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Engagement

➔ Comprehensive ascertainment and reliable data
  • 52 programs participated in 2015/2016
  • 90% were in free-standing children’s hospitals
    (~20% Children’s Hospitals but ~40% have PPC programs)

➔ Experiences using the data in your settings

➔ Feedback about perceived needs
Utility for the field

- Characteristics of successful programs
- Context of program niche/directly comparable programs
  - Children’s Hospital or not
  - NP led vs. Physician led
  - New vs. old
  - Medicine-based vs. pain/anesthesia-based
Please participate!!

All that’s missing is your data!
Registry Contact Information

→ **Website:** Registry.capc.org
→ **Email:** registryhelpdesk@capc.org
→ **Phone:** 212-201-2689

→ **Pediatric Blog on Registry Findings:**

*Spotlight on Pediatric Palliative Care: National Landscape of Hospital-Based Programs, 2015-16*

→ **Available at:** palliativeinpractice.org