A Decade of Data: Findings and Insights from the National Palliative Care Registry™

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Research Associate, CAPC

July 19, 2018 at 1:00 p.m. ET
About the Registry & Analyses
National Palliative Care Registry™

History

• Established a decade ago as a joint project between the Center to Advance Palliative Care and the National Palliative Care Research Center
National Palliative Care Registry™
Purpose

- Provide actionable data that programs can use to secure, expand and retain resources for delivery of high-quality palliative care
- Promote standardization of structure and process in palliative care programs
- Support the establishment of new palliative care programs where none exist
The estimated number of hospitals with palliative care has drastically increased in the past decade.
What is the Registry?

• Annual survey on palliative care program’s operations, service delivery, and processes
  – Programs enter data once per year
  – No patient-level data
  – No patient reported outcomes (PROs)
  – Questions aligned with national recommendations from the NCP

• **Free and open to all programs**
  – Hospital, home, office/clinic, nursing home

[registry.capc.org]
### Module 2  Patient Visits

Please select the module and enter the following fields below.

#### Module In-Progress

Questions marked with an asterisk (*) may require chart review and be more difficult for programs to answer. These questions may be relevant for quality improvement purposes for your program. However, due to the difficulty in answering these questions, they are optional.

<table>
<thead>
<tr>
<th>Question</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. How many initial patient visits (new consults) did your palliative care team see during the reporting period?</td>
<td>306</td>
</tr>
<tr>
<td>1a. Of the total initial patient visits, how many were unique patients?</td>
<td>Enter Number</td>
</tr>
<tr>
<td>2. What was the total number of physician and nurse practitioner-billed subsequent visits (i.e., follow-up visits) seen by your inpatient palliative care consultation service during the reporting period?</td>
<td>205</td>
</tr>
<tr>
<td>3. Are you able to report non-billable visits across all palliative care team members?</td>
<td>Yes</td>
</tr>
<tr>
<td>4. Considering all of your initial patient visits, indicate the percentage of the palliative care team's role in Consult only</td>
<td>0.0</td>
</tr>
<tr>
<td></td>
<td>Enter %</td>
</tr>
<tr>
<td></td>
<td>Enter %</td>
</tr>
</tbody>
</table>
Approximately 20% of hospitals with palliative care programs participate each year.

Circle size represents the size of the hospital (total beds).

+ a number of palliative care programs in settings outside of the hospital.
Answers questions for programs, such as:

- How has my reach into the hospital changed over time?
- How does my staffing compare to programs of a similar size?
- Has my program grown at the same rate as my peer programs?

Answers questions for the field, such as:

- How many programs meet national standards on structure and process?
- What are programmatic gaps for palliative care programs in hospitals?
- Are palliative care programs reaching all patients in need?
Over Time Reports

- Help palliative care programs measure their progress and track their operational capacity and reach over time
- Used to set internal program goals and targets based on historical performance
- Key metrics such as penetration (initial consults/annual admissions), staffing, hospital discharges
Peer Comparisons

- Help palliative care programs evaluate against similar peer programs
- Reports include averages, medians, and percentiles for comparison groups

ACME Adult Palliative Care at ACME
Report Date 03-29-2018

Palliative Care Service Penetration by Hospital Bed Size (2017)

Mean Penetration
- <150
  - Percentile
  - 99th Percentile
  - 75th Percentile
  - Mean
  - Median
- 150-299
  - Percentile
  - 99th Percentile
  - 75th Percentile
  - Mean
  - Median
- 300-499
  - Percentile
  - 99th Percentile
  - 75th Percentile
  - Mean
  - Median
- 500+
  - Percentile
  - 99th Percentile
  - 75th Percentile
  - Mean
  - Median
- Your Program

Penetration by Bed Count: <150 Beds, 150-299 Beds, 300-499 Beds, 500+ Beds

<table>
<thead>
<tr>
<th>Penetration by Bed Count</th>
<th>&lt;150 Beds</th>
<th>150-299 Beds</th>
<th>300-499 Beds</th>
<th>500+ Beds</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean</td>
<td>6.6</td>
<td>5.2</td>
<td>4.9</td>
<td>4.1</td>
</tr>
<tr>
<td>Median</td>
<td>5.6</td>
<td>4.3</td>
<td>4.4</td>
<td>3.9</td>
</tr>
<tr>
<td>99th Percentile</td>
<td>16.1</td>
<td>15.0</td>
<td>15.3</td>
<td>8.8</td>
</tr>
<tr>
<td>75th Percentile</td>
<td>8.2</td>
<td>6.7</td>
<td>5.6</td>
<td>5.3</td>
</tr>
<tr>
<td>25th Percentile</td>
<td>3.8</td>
<td>3.0</td>
<td>3.4</td>
<td>2.6</td>
</tr>
<tr>
<td>1st Percentile</td>
<td>0.2</td>
<td>0.6</td>
<td>1.5</td>
<td>0.6</td>
</tr>
<tr>
<td>Your Program</td>
<td>--</td>
<td>--</td>
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</tr>
</tbody>
</table>

Quick Facts
Palliative care service penetration is an estimate of how well programs are reaching patients in need. It is defined as the percentage of annual hospital admissions seen by the palliative care team.

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
Impact for Programs

• Make the case for more resources (i.e. staff), show that your program is understaffed
• Demonstrate value to the hospital’s C-Suite, Board of Directors, system leaders, and other leadership meetings
• Set program targets or internal benchmarks for the year and years to come
• Lead discussions in palliative care team meetings on process and effectiveness
• Plan for expansion into the community
Number of years of participating over the past decade

- 10 years: 32
- 9 years: 37
- 8 years: 42
- 7 years: 46
- 6 years: 77
- 5 years: 78
- 4 years: 105
- 3 years: 141
- 2 years: 175
- 1 year: 330

Thank you!!
Over the past decade, we’ve learned that palliative care programs…

• Need actionable data to advocate for more resources & seek out peer comparisons to see where their program stands
• Are often understaffed and overworked
• Are not always able to reach national recommendations
• Spreading beyond the hospital into community settings
About the Analysis

• 1,063 unique hospital palliative care programs over time
  – Of which, 79 are pediatric programs
• 396 unique hospital palliative care programs in the 2017 analysis
  – Of which, 31 are pediatric programs
• Findings are presented separately for pediatric palliative care programs
Palliative care service penetration is the percentage of annual hospital admissions seen by the palliative care team. Penetration is used to determine how well palliative care programs are reaching patients in need.

100 initial consults / 3,500 hospital admissions = 2.9% penetration
Penetration has more than doubled since 2008
### Palliative Care Programs, 2017

<table>
<thead>
<tr>
<th>5.3% Penetration</th>
<th>830 Initial Consults</th>
<th>3.2 Visits per Patient</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Varies depending on the type of hospital, including size</td>
<td>• Larger hospitals provide a larger number of initial consults</td>
<td>• 1 initial consult + 2.2 follow-up visits per patient during a single hospital stay</td>
</tr>
<tr>
<td>• Depends on the make-up of the patient population</td>
<td>• 1,302 for large hospitals with 300+ beds compared to 376 for small hospitals with &lt;150 beds</td>
<td></td>
</tr>
</tbody>
</table>
## Pediatric Programs, 2017

<table>
<thead>
<tr>
<th>Penalty</th>
<th>3.1% Penetration</th>
<th>326.5 Initial Consults</th>
<th>4.4 Visits per Patient</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Based on pediatric admissions</td>
<td>• Range: 70 – 1,309</td>
<td>• 1 initial consult + 3.4 follow-up visits during the hospital admission</td>
<td>• More visits per patient than adult programs</td>
</tr>
<tr>
<td>• Smaller hospitals reach a larger percentage of annual hospital admissions</td>
<td>• Larger hospitals provide a larger number of initial consults</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Smaller hospitals reach a larger % of annual hospital admissions

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;150 beds</td>
<td>6.7</td>
<td>5.5</td>
</tr>
<tr>
<td>150-299 beds</td>
<td>5.6</td>
<td>5.0</td>
</tr>
<tr>
<td>300 + beds</td>
<td>4.6</td>
<td>4.3</td>
</tr>
</tbody>
</table>
Penetration Differences, 2017

• **Teaching Status:** Teaching hospitals see an average of 4.9% compared to 5.9% for non-teaching hospitals (trend holds across all hospital sizes)

• **Pal Care Trigger:** Hospitals with automatic screening criteria see an average of 6.0% of admissions compared to 5.0% for hospitals without a trigger

• **Follow-ups:** Programs providing at least 1 follow-up visit per patient see a smaller penetration (4.9%) compared to programs that provide an initial consult without follow-up visits (5.6%)
Palliative Care Program Staffing
### Percent of Programs Reporting the following Staff Disciplines, 2017

<table>
<thead>
<tr>
<th>Staff Discipline</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physician</td>
<td>83.6%</td>
</tr>
<tr>
<td>APRN</td>
<td>80.1%</td>
</tr>
<tr>
<td>Social Worker</td>
<td>67.7%</td>
</tr>
<tr>
<td>Chaplain</td>
<td>55.6%</td>
</tr>
<tr>
<td>RN</td>
<td>48.1%</td>
</tr>
<tr>
<td>Support Staff</td>
<td>35.2%</td>
</tr>
<tr>
<td>Administrator</td>
<td>29.4%</td>
</tr>
<tr>
<td>Medical Director</td>
<td>27.4%</td>
</tr>
<tr>
<td>Pharmacist</td>
<td>9.5%</td>
</tr>
<tr>
<td>Fellow</td>
<td>8.4%</td>
</tr>
<tr>
<td>PA</td>
<td>6.1%</td>
</tr>
<tr>
<td>Hospice Liaison</td>
<td>4.9%</td>
</tr>
<tr>
<td>Nutritionist</td>
<td>4.3%</td>
</tr>
<tr>
<td>Music/Art Therapist</td>
<td>4.3%</td>
</tr>
<tr>
<td>Ethicist</td>
<td>4.0%</td>
</tr>
<tr>
<td>Childlife Specialist</td>
<td>4.0%</td>
</tr>
<tr>
<td>PT or OT</td>
<td>3.2%</td>
</tr>
<tr>
<td>Massage Therapist</td>
<td>2.9%</td>
</tr>
<tr>
<td>Resident</td>
<td>2.3%</td>
</tr>
<tr>
<td>LPN</td>
<td>1.4%</td>
</tr>
<tr>
<td>Psychologist</td>
<td>1.2%</td>
</tr>
<tr>
<td>Doula</td>
<td>0.9%</td>
</tr>
</tbody>
</table>

**Core Interdisciplinary Team**
Growth in Staffing Full-time Equivalent for the Interdisciplinary Team
(Physicians, APRNs, RNs, Social Workers, Chaplains)
Growth in Staffing FTEs limited to large hospitals and APRNs
# Pediatric Programs: Percent of Programs Reporting the following Staff Disciplines

<table>
<thead>
<tr>
<th>Staff Discipline</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physician</td>
<td>100.0</td>
</tr>
<tr>
<td>APRN</td>
<td>77.8</td>
</tr>
<tr>
<td>Social Worker</td>
<td>63.0</td>
</tr>
<tr>
<td>Chaplain</td>
<td>59.3</td>
</tr>
<tr>
<td>RN</td>
<td>44.4</td>
</tr>
<tr>
<td>Support Staff</td>
<td>55.6</td>
</tr>
<tr>
<td>Administrator</td>
<td>29.6</td>
</tr>
<tr>
<td>Medical Director</td>
<td>37.0</td>
</tr>
<tr>
<td>Fellow</td>
<td>48.1</td>
</tr>
<tr>
<td>Music/Art Therapist</td>
<td>18.5</td>
</tr>
<tr>
<td>Ethicist</td>
<td>3.7</td>
</tr>
<tr>
<td>Childlife Specialist</td>
<td>29.6</td>
</tr>
<tr>
<td>PT or OT</td>
<td>7.4</td>
</tr>
<tr>
<td>Massage Therapist</td>
<td>3.7</td>
</tr>
<tr>
<td>Resident</td>
<td>11.1</td>
</tr>
<tr>
<td>Psychologist</td>
<td>14.8</td>
</tr>
</tbody>
</table>

**Core Interdisciplinary Team**
Pediatric Programs: Staffing FTEs

- **2015**
  - Physician: 1.5
  - APRN: 0.6
  - RN: 0.8
  - Social Worker: 0.8
  - Chaplain: 0.2

- **2017**
  - Physician: 1.5
  - APRN: 0.6
  - RN: 0.7
  - Social Worker: 1.0

Not enough data to compare back to 2008.

Small increases since 2015 across all disciplines, with the largest growth also being in APRNs on teams.
• **Hospital Program Models:**
  – 81% of programs are internal to the hospital, where all team members are employed by the hospital
  – 3% are administered by an outside entity like a hospice
  – 16% are partially internal with additional contracted services

• **Staffing Models:**
  – 90% of Physicians, APRNs, RNs, and SWs are funded through the palliative care budget
  – Nearly 30% of chaplains are either in-kind (paid out of other budgets) or are volunteer
More adequately staffed programs see a larger percentage of annual hospital admissions.

Based on: Interdisciplinary Palliative Care Team FTE per 10,000 Hospital Admissions
Programs with higher penetration have higher billable workload

Number of Initial Consults per 1 FTE Billable Provider by Penetration

- Penetration: < 3% - 297
- Penetration: 3-4% - 411
- Penetration: 4-6% - 517
- Penetration: 6%+ - 706

Workload = Number of initial consults per 1 FTE of Physician or APRN or PA
Palliative Care Program Features
Top 4 Referrals (2017)

**Referring Sites**

- Oncology Unit: 8%
- Step-down Unit: 13%
- Intensive Care Unit: 24%
- Medical/Surgical Unit: 45%

**Referring Physician Specialties**

- Hospital Medicine: 53%
- Internal/Family Medicine: 22%
- Pulmonary/Critical Care: 14%
- Oncology: 9%
Pediatric: Top 4 Referrals (2017)

**Referring Sites**

- Pediatrics: 8%
- Medical/Surgical Unit: 12%
- Oncology Unit: 15%
- Intensive Care Unit: 40%

**Referring Physician Specialties**

- Cardiology: 7%
- Hospitalist: 12%
- Oncology: 20%
- Pulmonary/Critical Care: 26%

Mean % of Patients Referred from...
Top 5 Primary Diagnoses (2017)

- Cancer: 26%
- Cardiac: 15%
- Pulmonary: 14%
- Neurological: 9%
- Infectious: 7%
Pediatric: Top 5 Primary Diagnoses (2017)

- Cancer: 22%
- Neurological: 14%
- Congenital: 13%
- Cardiac: 13%
- Pulmonary: 6%
# Programs meeting NCP Guidelines

<table>
<thead>
<tr>
<th>Program Feature</th>
<th>Adult Programs</th>
<th>Pediatric Programs</th>
</tr>
</thead>
<tbody>
<tr>
<td>24/7 Availability</td>
<td>38.7%</td>
<td>81.5%</td>
</tr>
<tr>
<td>Team Wellness Plan</td>
<td>46.7%</td>
<td>61.5%</td>
</tr>
<tr>
<td>Bereavement Plan</td>
<td>48.7%</td>
<td>79.2%</td>
</tr>
<tr>
<td>Quality Improvement (QI) Plan</td>
<td>71.4%</td>
<td>54.2%</td>
</tr>
<tr>
<td>Education Plan</td>
<td>74.0%</td>
<td>87.5%</td>
</tr>
<tr>
<td>Physician on Team</td>
<td>83.6%</td>
<td>100.0%</td>
</tr>
<tr>
<td>Social Worker on Team</td>
<td>67.7%</td>
<td>63.0%</td>
</tr>
<tr>
<td>Chaplain on Team</td>
<td>55.6%</td>
<td>59.3%</td>
</tr>
<tr>
<td>At least one HPM Certified Clinician</td>
<td>83.6%</td>
<td>83.9%</td>
</tr>
<tr>
<td>Established Relationship with a Hospice</td>
<td>97.5%</td>
<td>96.6%</td>
</tr>
</tbody>
</table>
What’s New?

• 2 new reports on billable workload on the dashboard now for hospital programs
• Fall 2018: Gap report on where programs are not meeting national recommendations and the resources that can help get them there
• January 1st 2019
  – New and improved version of the hospital survey with pediatric module
  – New and improved version of the home and long-term care surveys
  – Reports for home and long-term care programs
Making the Case for More Resources

Case Study
St. Mary Medical Center

- Used Registry reports to show:
  - Palliative care program’s penetration was in the top 75% percentile for peer group and reaching patients in need appropriately
  - Team members are overworked compared to peer group average, top 75% for workload
  - Palliative care team is understaffed, staffing FTE fell below the 25% percentile for peer group

Workload above the 75th percentile for the peer group
St. Mary Medical Center

- Action: Leadership meeting with hospital staffing committee to request additional staffing resources
- Outcome: More staff!
  - +1.0 FTE palliative care nurse practitioner (APRN)
  - +1.0 FTE palliative care registered nurse (RN)
  - Palliative care recognized as its own service line in the hospital

Three-year project to map all palliative care programs serving community service sites nationwide

- Funded by the Gordon and Betty Moore Foundation
- To make it easier for patients and their families to find local resources
- To measure palliative care access and inform the field

mapping.capc.org
Preliminary Results: County Coverage
Preliminary Results: Office/Clinics and Long-term Care Facilities
Palliative Care Provider Directory
Search Results: 20 results found

The Palliative Care Provider Directory is a resource to help you or a loved one locate palliative care in your area. It includes all programs that have listed themselves with us. Please contact the palliative care program directly to confirm eligibility.

- Thomas Jefferson University Hospitals
  - Address: Philadelphia, PA 19104-4319
  - Distance: 0.41 mi
  - Phone: 267-426-5245
  - Serves: Pediatric patients, Young adult (aged 18-25) patients
  - Palliative care services provided in the: Hospital, Office/Clinic

- Pennsylvania Hospital
  - Address: Philadelphia, PA 19104-4319
  - Distance: 0.73 mi

- Hospital of the University of Pennsylvania
  - Address: Philadelphia, PA 19104-4319
  - Distance: 1.47 mi

- Children’s Hospital of Philadelphia
  - Address: Philadelphia, PA 19104-4319
  - Distance: 1.53 mi
  - Phone: 267-426-5245
  - Serves: Pediatric patients, Young adult (aged 18-25) patients
  - Palliative care services provided in the: Hospital, Office/Clinic

[Map with locations marked]
National Palliative Care Registry™

Website: registry.capc.org
Email: registryhelpdesk@capc.org
Phone: 212-201-2689

✓ The Registry is **FREE** and open to all palliative care programs.
✓ CAPC Membership is **NOT** required to participate.
Questions?