

# Pediatric Palliative Care in U.S. Hospitals, 2014-2015

The National Palliative Care Registry<sup>™</sup> is the only platform building a profile of palliative care programs, operations, and service delivery. The Registry provides actionable data that programs can use to measure and monitor impact to improve quality and support program expansion. The Registry is free and open to all palliative care programs.

Recognizing the importance of palliative care for infants and children, the Registry has expanded to address the growing need for national pediatric data. Participating programs receive pediatric-specific comparative reports. Registry participation supports the field by building a national profile of pediatric palliative care.

**38** hospital-based pediatric palliative care programs participated in the National Palliative Care Registry<sup>™</sup> in 2015 or 2014.



# **Hospital and Program Metrics**

Among pediatric palliative care programs participating in the Registry, the majority of programs were located in urban settings (89%), not-for-profit hospitals (79%), teaching hospitals (90%), children's hospitals (95%)—either free-standing or embedded in a larger hospital—and hospitals with fewer than 300 pediatric beds (53%).

All programs (100%) provided palliative care to neonates and infants, and nearly all programs (97%) provided care to children and adolescents. Additionally, 76% of programs provided perinatal palliative care, and 82% of programs also provided care to young adults over the age of 18. On average, 47% of the pediatric palliative care patients seen by these programs were less than one year old.

# **Patient Encounters**

Hospitals with fewer than 300 pediatric beds:

**152** palliative care consults provided, on average, annually (median: 122)

**2.4%** of annual pediatric hospital admissions received a consult

Hospitals with 300 or more pediatric beds:

**395** palliative care consults provided, on average, annually (median: 237)

**2.8%** of annual pediatric hospital admissions received a consult

# **Patient Referrals**

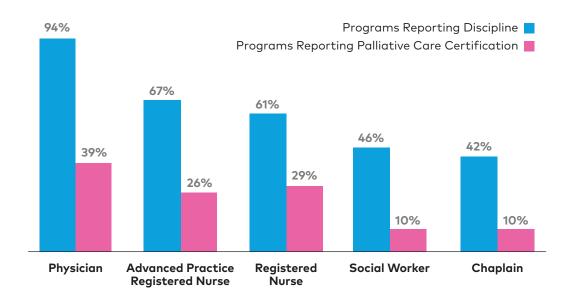
On average, 22% of pediatric palliative care patients had a diagnosis of cancer. 50% of all pediatric palliative care referrals came from an Intensive Care Unit (ICU), with an average of 21% of all referrals coming from pediatric ICU, 20% from neonatal ICU, 5% from medical/surgical ICU, and 4% from cardiac ICU.

### 21% 22% **Pediatric ICU** Cancer 20% 16% Neonatal ICU Neurologic 15% **General Pediatrics** Congenital 13% Medical/Surgical 12% 9% **Complex Chronic** Cardiac 9% Oncology 11%

# Top 5 Primary Diagnoses

# Program Staffing

The average pediatric palliative care program reported a staff of 4.9 full-time equivalents (FTEs), representing 7.7 staff members. Programs at hospitals with fewer than 300 beds had an average of 3.7 FTEs representing 6.0 staff members; whereas programs at hospitals with more than 300 beds had an average of 6.3 FTEs representing 9.7 staff members. 81% of pediatric programs reported having at least one team member certified in palliative care.



The National Palliative Care Registry<sup>™</sup> is a joint project of the Center to Advance Palliative Care (CAPC) and the National Palliative Care Research Center (NPCRC).

Learn more and participate at registry.capc.org.

# **Top 5 Referral Locations**