Value Proposition

Pediatric Palliative Care's Value Proposition: Making the Case

Pediatric palliative care (PPC) differs from adult palliative care in fundamental ways. PPC teams care for patients ranging in age from prenatal to young adult (i.e., neonates, perinates, infants, children, adolescents, and young adults), follow families through wide-ranging diagnoses and disease trajectories that can span many years, and must involve parents in every decision while meeting children at their developmental stage. Perinatal palliative care has grown into its own area of practice, supporting families navigating a life-limiting diagnosis identified before birth.

The American Academy of Pediatrics recommends, by expert consensus, that PPC begin at diagnosis and continue throughout the course of illness to improve quality of life, reduce suffering, and support goals of care.[1] CAPC's 2024 Serious Illness Scorecard estimates that approximately 700,000 children in the United States are living with a serious illness[2] Because data stratifying pediatric age and disease categories remain limited, this figure is best understood as a floor, not a ceiling, on the true population who could benefit from PPC.

The Scope of Need Continues to Grow

The numbers behind pediatric serious illness are sizeable and trending upward:

- **Children with medical complexity are increasing in prevalence,** driven by higher survival rates among infants born prematurely, with congenital anomalies, or with chronic conditions, along with improved treatment for acute illness in fields such as intensive care and oncology.[3]
- **Chronic condition prevalence among youth has risen sharply.** The share of children ages 5–17 with a chronic condition or functional limitation grew from about 23% in 1999–2000 to more than 30% in 2017–2018, an increase of roughly 130,000 additional children per year. An estimated 25.7 million youth ages 5–25 now live with such a condition.[4]
- **More than half of childhood deaths occur in infancy,** most in the neonatal period and due to congenital or chromosomal anomalies and prematurity. In 2023, the U.S. infant mortality rate was 5.61 deaths per 1,000 live births, a total of just over 20,000 deaths in children under age 1, and a rate that has plateaued after decades of decline.[5]
- **Millions of family caregivers support children with serious illness.** The 2025 AARP/National Alliance for Caregiving report identifies roughly 4 million family caregivers providing ongoing, often complex, care to children under 18 with disabilities or serious medical conditions in the U.S.[6]

These statistics, and the stories behind them, underscore the priority of investing in PPC research, professional training, and program expansion to meet rising demand for high-quality palliative care that supports infants, children, and families across every care setting and transition.

Trends in Pediatric Serious Illness and Palliative Care Access

The National Alliance for Care at Home (formerly NHPCO) tracks the state of PPC in the U.S., identifies children who may need support, and documents gaps in service.[7]

Children with complex health care needs are living longer

- The overall prevalence of children with life-threatening conditions continues to rise as pediatric medical and surgical care advances, even as mortality among children with complex chronic conditions has declined over the longer term.[8]

PPC program growth has not kept pace with need

- As of 2019, national palliative care organizations identified specialty inpatient PPC programs in 48 freestanding children's hospitals in the U.S., growth from a decade earlier, but still well short of universal coverage across the roughly 220 freestanding and general hospitals that care for children.[9]
- Outpatient and community-based PPC is the fastest-growing frontier: a 2024 national survey found that 78% of responding hospitals with a PPC program now offer clinic-based outpatient services, up from a field that barely existed a decade ago.[9]
- Despite this growth, access gaps remain stark. A 2022 national survey found that 55% of hospitals with a PPC program had no access to hospice for children, and 79% had no access to respite care, meaning even families connected to specialty PPC often cannot access the full continuum of support.[10]

Bereavement and location-of-death preferences matter

- Growth in service capacity enables grief and bereavement support for families affected by trauma or sudden serious illness, a population PPC has traditionally served less consistently than deaths considered anticipated.
- Parents who can plan a location for their child's death report greater comfort with that setting and are less likely to have wished for a different one. This is a reminder that the place of death is not, by itself, a meaningful quality indicator for PPC: what matters is whether the outcome matched the family's preference.[11]

Even as pediatric palliative care programs have grown, most operate only during weekday business hours and only within hospital walls. Extending PPC into outpatient, home, and community settings, and to the general hospitals that lack any dedicated program at all, remains one of the field's most urgent priorities.

Messaging Matters

What's in a Name: Explaining Pediatric Palliative Care

Using consistent, clear language to explain PPC matters. CAPC's original 2011 consumer research found that roughly 7 in 10 Americans were “not at all knowledgeable” about palliative care, yet 92% said they would want it for themselves or a loved one and believed it should be available in every hospital, once it was explained using messages developed through focus groups and interviews with patients and caregivers:[12]

- Palliative care helps provide the best possible quality of life for patients and their families.
- Palliative care helps patients and families manage the pain, symptoms, and stress of serious illness.
- Palliative care is a partnership of the patient, all medical specialists, and family.
- Palliative care provides an extra layer of support for families and patients with serious illness.
- Palliative care is appropriate at any age and at any stage of a serious illness and can be provided alongside curative treatment.

CAPC's follow-up public opinion research in 2019 confirmed this awareness gap had persisted: palliative care remained poorly understood by the public, even as patients, family caregivers, and physicians surveyed separately agreed that consumer education is essential.[13]

The term “palliative care” remains unfamiliar to many laypeople, and some clinicians still equate it with a terminal prognosis or end-of-life care alone. This erroneous association with “giving up hope” or hospice remains one of the largest barriers preventing families from accessing PPC's benefits. Consistent use of the consumer-tested messages above helps the field address this identity problem.

Organizations including *Courageous Parents Networ*k, the *National Alliance for Care at Home*, the *American Childhood Cancer Organization*, and CAPC's own consumer-facing *Get Palliative Care* initiative maintain family-facing educational resources, provider directories, and clinician training materials that programs can point families and colleagues toward directly.

PPC Delivers Value That Warrants Focused Investment

Palliative care remains one of the fastest-growing medical specialties in the United States: CAPC's 2024 Serious Illness Scorecard found that 83.6% of U.S. hospitals with 50 or more beds now report specialty palliative care services (96.2% among hospitals with 300+ beds)[2], though availability still lags significantly in rural and for-profit hospitals, and pediatric-specific capacity lags further still. This growth is driven by palliative care's demonstrated ability to improve care quality and clinical outcomes while helping patients and families avoid unnecessary emergency visits and hospitalizations, advancing what health systems now frequently describe as the Quadruple Aim: better patient experience, better population health, lower per-capita cost, and improved clinician well-being.

With health systems increasingly focused on value-based care and payment reform, communicating PPC's benefits to administrators, policymakers, payers, and referring clinicians is becoming a core part of every interprofessional team member's job.

Philanthropic support remains the single largest funding stream for PPC, and it is neither sufficient nor sustainable on its own. Building and sustaining programs requires evidence-based talking points the field can use consistently to expand understanding of PPC's ability to improve quality and meet system-level goals in the care of infants, children, and families.

Pitch Points: PPC Helps Deliver the Best Care Possible

- **PPC provides an evidence-based solution supporting quality of life and improved clinical outcomes** for seriously ill infants, children, and families throughout the care continuum,[14,15] including improving the likelihood that children and families continue to enjoy and share experiences that add meaning to life.[16]
- **PPC improves patient and family experience and satisfaction,** reduces parent caregiver burden,[17] and reduces needless hospital admissions through effective care coordination and symptom management, and through these quality gains, also reduces costs.[18,19]
- **PPC programs are becoming more common in children's hospitals,** but most still offer inpatient-only services during standard business hours. A growing number are expanding into perinatal palliative care and outpatient clinics.[20,21]
- **Millions of infants and children in the U.S. still lack access to quality PPC** from the point of diagnosis throughout the course of illness, and PPC team staffing and capacity vary tremendously by hospital and region.[10]
- **Resources for program development and fellowship training of the next generation are essential** to build teams with the capacity to improve care quality for infants, children, and families.
- **Outpatient and community-based PPC services are still developing.** Continued investment in community-based PPC is essential to bridge the gap from hospital to home.[9,22]

- **PPC research funding continues to lag far behind adult palliative care investment.** Outside of pain, relatively few studies guide clinicians in treating common pediatric symptoms such as fatigue, nausea, breathlessness, anxiety, and depression.[23,24]
- **Educating and training all pediatric clinicians in pain and symptom management, communication, and care coordination is essential** so every clinician caring for a seriously ill child has a uniform set of core ("generalist") palliative care skills and knows when to refer to a PPC specialty team for more complex or nuanced situations.[25]

Building the Case: Action Steps for PPC Leaders

- Document your program's full value: quality outcomes, avoided hospitalizations, family experience, and clinician well-being, before a budget crisis forces the conversation.
- Build strategic relationships with key referring clinical teams and organizational leaders. Referring teams can be effective advocates for needs and growth and leaders can help ensure the PPC is aligned with organizational goals and resources.
- Use the consumer-tested messages above consistently across family materials, referral scripts, and administrator presentations to close the awareness gap.
- Prioritize expansion into outpatient and community-based care, and into hospice and respite access, where gaps are largest.
- Invest in fellowship training and generalist palliative care education so capacity grows alongside need.
- Track and share your own data, such as referral sources, patient trajectories, and outcomes, to make the case for sustained and expanded investment.

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