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November 2025

Background

Pediatric palliative care (PPC) should be available for children with complex health care needs

Children and Youth with Special Healthcare Needs (CYHSCN)

- ~14.1 million children in U.S. (19.4%)
- ~4x more likely to have unmet medical needs
- ~3x higher annual cost ($2,498 vs. $803)
- 35.9% Medicaid/CHIP[2]

PPC Known Benefits

- Improved quality of life[1]
- Decreased symptom burden[1]
- Improved caregiver satisfaction with care[2]
- Reduced caregiver distress[2]
- Greater likelihood to receive care at home[3,4]

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1. HRSA Maternal and Child Health: Children and Youth with Special Health Care Needs. NSCH Data Brief, June 2022. https://mchb.hrsa.gov/sites/default/files/mchb/programs-impact/nsch-data-brief-children-youth-special-health-care-needs.pdf
2. Casarett DS, Shreve C, Luhrs K, et al. Measuring families' perceptions of care across a health care system: preliminary experience with the family assessment of treatment at end-of-life short form (FATE-S). J Pain Sympt Manage 2010;40:801-809.
3. Ananth P, Melvin P, Berry JG, Wolfe J. Trends in Hospital Utilization and Costs among Pediatric Palliative Care Recipients. J Palliat Med. 2017.
4. Postier A, Chrastek J, Nugent S, Osenga K, Friedrichsdorf SJ. Exposure to home-based pediatric palliative and hospice care and its impact on hospital and emergency care charges at a single institution. J Palliat Med. 2014;17(2):183-188.
5. Weaver M, Wichman C, et al. Proxy-Reported Quality of Life and Family Impact for Children Followed Longitudinally by a Pediatric Palliative Care Team. J Palliat Med, 2018 Feb; 21(2):241 244.

Background

Pediatric palliative care (PPC) is under resourced and too scarcely available.

Fee-for-service (FFS) care models are vulnerable to "misaligned incentives" with PPC programs.

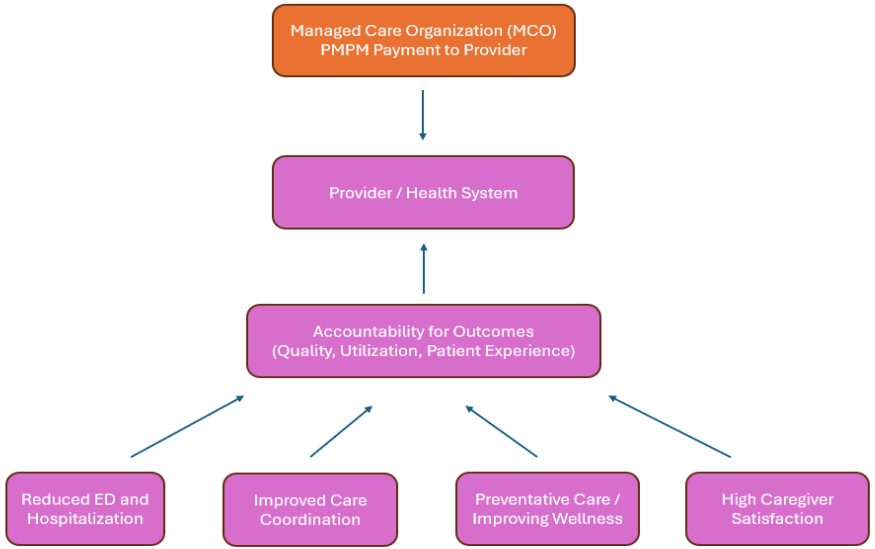
National scarcity of Pediatric Palliative Care

- 63% programs below minimum staffing thresholds [2]
- 60% "unable to meet clinical demand"[1]
- Many IP programs do not have outpatient PPC clinics
- ~0.57 FTE devoted to outpatient PPC clinics[3]

1. https://www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNProducts/html/medicare-payment-systems.html
2. Rogers MM, Friebert S, Williams CSP, Humphrey L, Thienprayoon R, Klick JC. Pediatric Palliative Care Programs in US Hospitals. Pediatrics. 2021 Jul;148(1):e2020021634
3. Autrey AK, James C, Sarvode Mothi S, Stafford C, Morvant A, Miller EG, Kaye EC. The Landscape of Outpatient Pediatric Palliative Care: A National Cross-Sectional Assessment. J Pain Symptom Manage. 2023 Jul;66(1):1-23..

Background

Value-based-care models may offer alignment of financial and clinical incentives, thereby justifying investment in PPC.



Palliative Medicine results in…

- Decreased ED and hospital utilization[1]
- Reduced hospital LOS and cost of admission[2,3]
- Decreased acute care costs[4]
- Decreased overall cost of care[5]

*Little research examines the need and feasibility of PPC in these models.

1. Ananth P, Melvin P, Berry JG, Wolfe J. Trends in Hospital Utilization and Costs among Pediatric Palliative Care Recipients. J Palliat Med. 2017.
2. Postier A, Chrastek J, Nugent S, Osenga K, Friedrichsdorf SJ. Exposure to home-based pediatric palliative and hospice care and its impact on hospital and emergency care charges at a single institution. J Palliat Med. 2014;17(2):183-188.
3. May P, Normand C, Cassel JB, et al. Economics of Palliative Care for Hospitalized Adults With Serious Illness: A Meta-analysis. JAMA Intern Med. 2018;178(6):820-829.
4. Costs: A Propensity-Matched Study. Am J Hosp Palliat Care, 2018 Jul; 35(7):966-971.
5. Starks H, Wang S, Farber S, Owens DA, Curtis JR. Cost savings vary by length of stay for inpatients receiving palliative care consultation services. J Palliat Med. 2013;16(10):1215-1220.

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Imagine Pediatrics was founded with a vision of creating a world where every child with special health care needs and their caregivers get the care and support they deserve.

Imagine Pediatrics is a tech-enabled, multidisciplinary, pediatrician-led medical group providing fully integrated and personalized medical, behavioral and social value-based care innovation for children with special health care needs.

We don’t replace a child’s existing care team. We work with them. We engage and coordinate with network providers, caregivers, and community partners to expand access to specialized pediatric care for children with special health care needs and their caregivers.

Quantifying the Need

Cross-reference of claims for CYSHCN attributed to Imagine Pediatrics against “Pediatric Palliative Care Referral” produced by Center to Advance Palliative Care (CAPC)[1]

Malignant Disease Criteria

Presence of malignant disease with any one of the following:

- Progressive metastatic cancer
- Bone marrow / stem cell transplant
- Diffuse intrinsic pontine glioma
- Stage IV neuroblastoma
- Relapsed malignant disease following stem cell / bone marrow transplant

→ **Automatic**

Gastrointestinal Criteria

Presence of chronic gastrointestinal dysfunction with one of the following:

- Multi-visceral organ transplant under consideration
- Biliary atresia
- Total ganglionosis of colon
- Progressive hepatic or uremic encephalopathy

→ **Automatic**

Genetic Criteria

Presence of malignant disease with any one of the following:

- Trisomy 18, 14, 15
- Asphyxiating thoracic dystrophy
- Severe forms of osteogenesis imperfecta (type 3 or 4)
- Potter Syndrome
- Epidermolysis Bullosa

→ **Automatic**

OR

- Rett’s Syndrome
- Other rare chromosomal anomalies with known poor neurologic prognosis

→ **Suggested**

Metabolic/Inclusion Disease Criteria

Presence of any one of the following:

- Krabbe’s disease
- Hunter’s / Hurler’s disease
- Niemann-Pick disease
- Menke’s disease
- Pompe disease
- Sanfilippo syndrome
- Tay Sachs disease
- Fabry’s disease
- Sandhoff's disease

→ **Automatic**

OR

- Severe mitochondrial disorder
- Severe metabolic disorders for which BMT is a therapeutic consideration

→ **Suggested**

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1. CAPC Pediatric Palliative Care Referral Criteria; Sara Friebert, MD and Kacei Osenga, MD

Quantifying the Need:

Results

- n = 20,872 patients included in cohort
- 3,994 (19%)
  - Patients with an ICD-10 code indicating a PPC-need billed in the last 3 years (08/2021 – 08/2024)

Snapshot of PPC-Need Population in cohort

Common diagnoses (# of pts)

- Malignancy: 510
- Home Vent/BiPAP Dependence: 730
- Tracheostomy: 548
- Severe HIE: 116
- Sickle Cell Disease: 288
- Anencephaly/PVS: 26
- Single Ventricle Physiology: 147
- Agitation: 533
- Chronic Pain: 53
- "Palliative Care Patient" (Z51.5): 264

Utilization over 6-mo period (03/2023-08/2023)

- 36% with ED visit (11% with 3+)
- 18% with IP stay (6.4% with 2+)

Cost of Healthcare Expenditure

- 14%: > $192,000/patient/year
- 5%: > $384,000/patient/year
- 1%: > $564,000/patient/year

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The PATH Team: Outpatient Pediatric Palliative Care

Pain Management, Advocacy, Trust, Hope

1 MD, 1 APP, 1 RN, 1 Pharmacist

131 patients since 11/2023

Filling systemic gaps in care

1. Collaborating with academic teams to provide outpatient palliative care
2. Collaborating with adult hospice agencies to provide services to children
3. Complex symptom management for children falling through the cracks
4. Full integration of behavioral health support
5. Home based palliative services including advances diagnostics (blood work, urinalysis, cultures) and therapeutics (IV medications, IV fluids, wound care, etc.)

Example Patient: J.P., 8 yo boy

PMHx: hypoplastic left heart syndrome, s/p Fontan; not transplant candidate; +atrial thrombus

Situation

- Admitted to large academic institution
- Single mother of 5, rural community
- Caregiver/patient want discharge to home for EOL, no pediatric hospice in area

Our involvement

- Contacted adult hospice agencies, offered 24/7 supplementary support to help facilitate hospice admission
- Biweekly visits for symptom assessment, anticipatory guidance, and caregiver support

Outcome

- **Still alive** s/p 15 months
- Discharged from hospice, receiving home-based palliative care
- Symptoms well controlled
- Memory making with family; Disney Make-A-Wish; etc.

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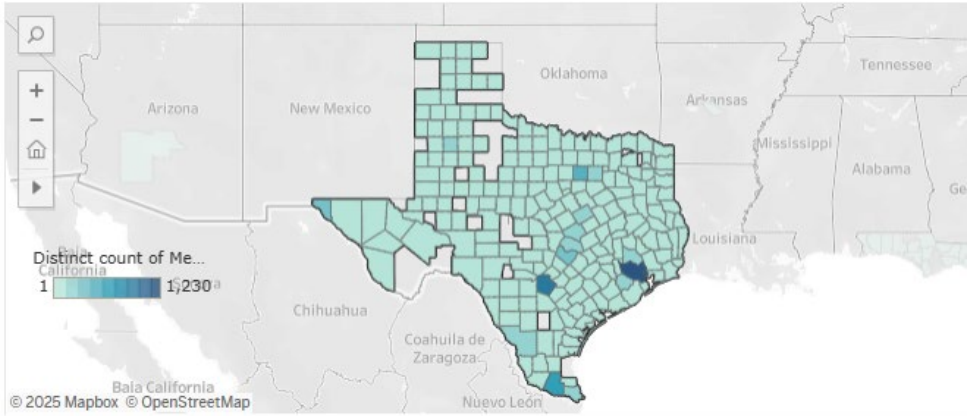
Triaging the Need

Population health via data analytics to triage the need for palliative care

“Palliative Readiness Index”

- Diagnoses (ICD-10 codes, claims data, etc)
- Healthcare utilization (frequency and severity)
- Presence of uncontrolled symptoms
- Prognosis
- Polypharmacy
- Social Determinants of Health
- Geography / availability of community PC resources



Condition	Attributed and not enrolled					
	1: < 1	2: 1-4	3: 5-9	4: 10-14	5: 15-18	6: >18
Grand Total	**463**	**1,394**	**835**	**756**	**879**	**68**
VLBW infants	348	825	228	65	39	
Complex congenital heart disease	109	397	222	175	147	13
Trisomy 18, 13, 15	14	146	174	151	108	12
Chronically ventilator dependent	22	160	135	104	81	15
Static encephalopathy	8	68	85	90	103	10
Severe schizencephaly	19	76	60	54	59	2
Agitation	13	35	38	81	131	13
New diagnosis with complex pain or symptom mana..		5	22	73	165	13
Respiratory_insufficiency	17	99	45	19	30	3
Palliative Care	7	50	33	30	33	10

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Thank you

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