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The State of Pediatric Concurrent Hospice Care in the United States

Weaver M, Smith S, Torkildonson C, et al

The Patient Protection and Affordable Care Act (ACA) required all state Medicaid programs to pay for both curative and hospice services for children and adolescents. The purpose of this Special Article report is to quantify and describe the use of concurrent care for children, including a depiction of the barriers and benefits according to community-based hospice organizations in the United States. A total of 295 hospice organizations from 50 states and Washington, DC responded to the National Alliance for Care at Home call for engagement. Almost three-quarters of responding organizations admit children under concurrent care. An average of 38% (median 10%) of admitted pediatric patients are cared for under concurrent care. There was a notable lack of uptake of diverse reimbursement models relevant to concurrent care. Definitions of concurrent care focused on location of care and access to ongoing treatments without defining services. Responses tended toward an emphasis on regulatory/compliance language rather than goals of care or partnership focus. Challenges and barriers to concurrent care were quantitatively and qualitatively described as confusion, complexities, lack of consistency, cumbersomeness, and poor cross-partner communication. Policy and reimbursement model clarification is warranted to improve the potential benefits of this coverage for children and their families. As the ACA is currently at risk of discontinuation and Medicaid is at risk of decreased funding, the pediatric community should leverage advocacy for improved concurrent care coverage approaches that are clear, consistent, and compassionately attuned to the needs of children and their families. Pediatrics 2025;156(3):e2025071610

Improving Intensive End-of-Life Care for Infants and Children: A Scoping Review of Intervention Elements

Acriprete E, Ouyang N, Wawrzynski S, et al

High-quality pediatric critical care includes supporting children nearing the end-of-life (EOL) and their families. Cataloging existing interventions for children dying in the neonatal or pediatric intensive care unit (NICU, PICU) establishes critical areas for future research. In this scoping review, we evaluated characteristics of PICU EOL interventions. **Methods**: A librarian guided a search of OVID Medline, CINAHL, OVID PsycINFO, OVID Embase, Cochrane Central, and Web of Science, plus backwards and forwards reference searching. We included interprofessional interventions, defined as any systematic change (e.g., educational programs, symptom management, electronic medical record, etc.), for children dying from any cause. Studies were independently screened by two reviewers. Data were extracted by one team member and reviewed by a second. We extracted intervention elements, contextual factors, implementation barriers/facilitators, and generated frequencies from qualitative coding. **Results**: Of 11,643 screened articles, 44 met the inclusion criteria. Most were in neonatal ICUs (n = 28/44, 64%) and general PICUs (n = 10/44, 23%). Most interventions aimed to improve clinician knowledge (25/44, 57%), augment clinical structures and processes (n = 11/44, 25%), or enhance communication (n = 8/44, 18%). Common delivery methods included clinical practice changes (n = 25/44, 57%; e.g., protocols, order sets [n = 12]), and educational sessions (n = 20/44, 45%). Outcomes included clinician knowledge (n = 17/44, 39%), qualitative feedback (n = 18/44, 41%), feasibility/acceptability (n = 12/44, 27%), or treatment utilization (n = 11/44, 25%). Few examined families' mental health (n = 3, 7%) or bereavement (n = 2, 5%). Few reported implementation facilitators or barriers. **Conclusions**: Most included studies targeted clinician outcomes through education. Designing, testing, and implementing interventions focused on family outcomes is a critical next step. Children (Basel). 2025;12(11):1485

Full text is freely available at https://pmc.ncbi.nlm.nih.gov/articles/PMC12651015/

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Pulse Check: Status Update on Pediatric Palliative and Hospice Community-Based Coverage

Weaver M, Ware A, Fisher D, et al

The pediatric literature describes reliance on community-based palliative and hospice organizations in extending the reach of care for children. **Objective**: To provide an updated post-pandemic snapshot of pediatric palliative and hospice services and staffing offered by community-based organizations in the United States. **Design and Subjects**: This study utilized an online survey distributed to organizational members of the National Alliance for Care at Home in the United States. **Results**: A total of 295 palliative and hospice organizations from 50 states and Washington, DC, responded. Half (49%) of organizations reported increasing the number of pediatric patients accepted into their care over the past five years. A total of 6% of responding programs newly started to accept pediatric patients between 2020 and the current survey completion. Programs are less likely to include perinatal (61%) patients compared to infants through young adults (94%). Trauma increased as a reason for pediatric enrollment. Nonmetro geographies are less likely to provide services for children. The pediatric palliative average annual census was 271, and the pediatric hospice average annual census was 74. The pediatric patient's average length of stay for palliative care was 154 days and for hospice was 96 days. Medicaid (47%) is the most common form of reimbursement. Lack of trained personnel, low referrals, and funding were depicted as the most common barriers. **Conclusions**: Children remain underrepresented in the extension of care offered through community-based hospice organizations, with the gap widening in nonmetro settings. Further research into training, staffing, and funding models may improve care reach. J Palliat Med. 2025;28(12):1568-1575

Hospice Enrollment in Young Adult LGBTQ+ Decedents with Cancer: A Multi-Site Single Healthcare System Study

Rajput S, Suleiman R, Kimball B, et al

Hospice is specialized medical care that strives to provide comfort to dying patients. To our knowledge, no study has examined the percentage of young adult LGBTQ + patients with cancer who enrolled in hospice and circumstances that surround enrollment/non-enrollment. **Methods**: A single healthcare system, 4000 + self-reported LGBTQ + database of patients with cancer identified young adult decedents (18-39 years old at death) to report the percentage who died with hospice, the conversations that preceded hospice enrollment, time-on-hospice, and circumstances that surrounded the deaths of those not enrolled. **Results**: From the database, 43 decedents were identified with a median age at death (range) of 33 years old (20, 39 years). Twenty had self-identified as gay/lesbian, and 23 as bisexual. Twenty-nine decedents (67% (95% CI: 51, 81%)) were enrolled in hospice (3 not enrolled and died unexpectedly; 11 with unknown hospice outcome). Conversations that preceded enrollment discussed (1) limited cancer therapeutic options with worsening end-of-life symptoms and how hospice could help ("discussed... decline and how patient would not want to die hooked up to machines"); (2) medical staff's acknowledgement of same sex spouse/life partners ("[She] is here with her wife"); (3) the inclusion of the birth family in end-of-life discussions, especially if the decedent had been single ("Her father met us... this was difficult news for him to hear."). Four of 18 decedents with known date of hospice enrollment died 3 or fewer days after enrollment. **Conclusions**: Most young adult LGBTQ + decedents with cancer receive hospice services with thoughtful and inclusive conversations that precede enrollment. For some, time-on-hospice appears limited. BMC Palliat Care. 2025;epub ahead of print

Full text is freely available at https://pubmed.ncbi.nlm.nih.gov/41275242/

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Pediatric Home-Based Palliative Care and Hospice: Characterizing and Comparing the Populations

Reader B, Kitio S, Smith S

Home-based palliative care (HBPC) and hospice programs offer support for children with complex life-shortening conditions. However, there is little comparison of the characteristics and care trajectories of children and young adults enrolled in HBPC versus hospice, particularly across different age groups. **Objectives** To compare the characteristics of children and young adults who received HBPC and/or hospice and identify differences and similarities between these populations. **Methods** A retrospective cohort study of children birth-21 years of age who received HBPC and/or hospice in their home between 1/2019-12/2022 at a single site. Data were manually extracted from the electronic health record. Statistical analyses included descriptive statistics, chi-square or Fisher's exacts tests for categorical variables, and Mann-Whitney U tests for non-normally distributed continuous variables. Subgroup analyses excluded children <1 year of age due to differences unique to population including utilization of perinatal palliative care or palliative care in the neonatal intensive care unit. **Results** Of 113 participants, hospice recipients were younger (median 2 vs. 7 years; P = 0.033), more likely to have an oncologic diagnosis, and had a higher mortality during the study period (69.6% vs. 22.1%; P < 0.001). HBPC participants had more hospital admissions, longer inpatient stays, and more outpatient visits. Subgroup analyses of children ≥1 year revealed diagnosis and code status differences, with hospice participants more likely to have 'allow natural death' orders and experience a code status change. **Conclusion** Among children and young adults, significant differences exist between those receiving HBPC and those receiving hospice care, particularly in age, diagnosis, and healthcare utilization. J Pain Symptom Manage. 2025;70(60):672-678

Beyond the Label: How Naming and Framing Impact Pediatric Palliative Care Acceptance

Brasuel D, Johnson M, Ritchie K, et al

Pediatric palliative care (PPC) underutilization persists despite proven benefits. Some barriers stem from the misconception that PPC is exclusively for end-of-life, causing parental distress and reticence to engage. This study explores the origins of these misconceptions to enable smoother introduction of this helpful service line. **Objectives**: This study examines how program naming and the framing of PPC services impacts perceptions of, and receptiveness to, PPC services among community-dwelling parents in the United States. **Methods**: A national sample of 363 U.S. parents recruited via Amazon Mechanical Turk (MTurk). Participants were randomly assigned to one of four vignettes introducing a PPC team. Introductions varied team name ("palliative care" vs. "Pediatric Advanced Care Team [PACT]") and frame (with/without explicit end-of-life mention). Questions assessed demographics, perceptions of, and willingness to engage with, PPC. Analyses included inferential statistics and Exploratory Factor Analysis (EFA). **Results**: There were no significant differences in the reception of PPC based on team name or the inclusion of end-of-life language. EFA identified two latent factors accounting for 76.46% of the variance: 1) Best Interest (parent's perception that the services were beneficial) and 2) Parental Distress (parent's perception of being overwhelmed when considering the service). **Conclusion**: Parental perceptions of PPC are predicated on underlying factors that may constitute referral barriers. In this study, neither renaming the team nor excluding the mention of end-of-life impacted participants' enthusiasm. Future interventions should look beyond name changes to characterize and directly address the latent factors of parental distress and the perceived best interests of the child. J Pain Symptom Manage; 2025; epub ahead of print

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